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Death in the Desert: A Love Story

James Francis*

Abstract


Key Words: Creative nonfiction. Cancer literature

Out of the clear blue sky, the clearest of crystal blue skies in the bright Southwestern desert, a spot appears: tiny, nearly imperceptible, but growing larger and larger until its shadow blots everything formerly in sight. Or: like a plane coming down, out of control, with a girl’s face in a window. We can speak with her but there is nothing we can do. Sputtering, failing, and falling into a spin... How do you describe the impact of a death sentence? How to describe a loss, a negative-- something, someone who is no longer there?

A hole in the shape of a human being.

The end: how does it start?

Maybe like a line from a horror movie, her hoarsely whispered “It’s back.” (Pause, reflect.) “The tumor is back.” New Year’s Day. (“Back-story” is important, material Prefatory to the Finale: there was the “original” cancer, ten years gone, “beaten,” into remission. She was a “survivor.” A hero, a victim no more! That’s what we like. Inspirational, with pink “ribbon” pins and yellow plastic “Live Strong” bracelets. Popular current symbols of not-dying. Amulets.) At Thanksgiving, the false hope of a false negative on an MRI. Around Halloween, a tingling, then a simple numbness in the hand. But still, no, it was earlier... Late summer. Out of the clear blue sky, she tumbled down a flight of concrete steps, and a year later she was gone...

So this is all Epilogue, all post-script. “You should keep a journal,” she said, when things were getting interesting. She was shooting video, and put some online, some streaming live.

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Is this a Tragedy in the classical sense, death from some fatal inner flaw, something in-born, intrinsic, and inexorable? Unexorcizable, inoperable, fatal; a woman in the very prime of her life, stricken down. Perhaps. And all the attendant comedy notwithstanding, classical Comedy, (the other mask, the slightly less hideous symbol of the Thespian) simply means that the heroine doesn’t die at the end, so that wouldn’t apply here, with so fresh a corpse just offstage, just off page, as it were. (In Drama, of course, in the Theater, in theatres, ghosts may ascend through trap-doors, or be flown in on wires, or emote from backstage as disembodied spirits. Morte ex machina.) But this is no fiction, just echoes from a sad report. Something like 70 percent of people experience hallucinations, visual or auditory, after such a loss. I would like that, but it hasn’t happened.

Are these scenes of Pathos, the sufferings of an innocent? Possibly, partially. Bathos, per chance. To continue the Greek, “Thanatos” is death, which most certainly obtains. Whither Eros? Not far behind, in a cute mini-skirt. And the love story has some appeal… But love stories are all blissfully the same, with soft-focus flowers and candles, and the compelling thing here is death, not sex. It’s the “Tale of Two Tumors,” a life-affirming, heart-warming true life story of strength and dignity in the face of certain death, (in italics, capitals, a florid Gothic or Teutonic font. Spare no seraphs—order more umlauts. Good title, that.) A storybook, fairy-tale romance. “Once upon a deathbed, once upon a time running out…”

Spew it out as “true confessions,” a “tell all.” Monologue, memoir in the modern style. (Depravity and Desperation! Afflicted and Abused, Abandoned and Forsaken! A light shone into the deepest corners of the darkest closets. Skeletons rattling!) Print a lurid lobby card, a Technicolor-boasting movie poster, in the style of the torn-bodice exploitation sensationalism of a simpler time. Stamp it like an old postcard: Greetings from, Grieving from, Sunny Riverside County! Wish you were here, wish it were you here rather than...

Self-help literature could be the angle; a therapeutic piece, a treatise on Grief the topic, something that might help others in similar situations. Light for the benighted, a raft for the bereft, catharsis for suffering survivors: “The Anatomy of A Grieving.” Because it’s sharing, not caring. Healing, not dealing. All of those empty feel-good phrases, lots of laughs there… Hugs n’ drugs. Print it up in offset litho, do a stapled pastel cardstock cover, mint green or powder blue, with a poorly-executed “inspirational” picture— a lighthouse or butterflies, or clumsy clouds pierced by rays of sunshine, rainbows and doves, anything but skulls and bones. Clip art. It’s the thought that counts. Neither a memento mori nor a memorial. (“In Memoriam:” we use the dead language for the dead, understanding neither, and Death comes hauling a coffin-full of euphemisms, covered with bouquets of platitudes.) Just an experience, a memory. A death, which is also a life, both now gone. Both still here. The writing in the journal ends, the last letter of the last word continued as a scrawl where she swooned…

Life is not a story-- would that it were, because it would be on better paper. Perfect-bound, even, with some coherent design. Life is the scraps, notes on matchbooks and napkins, maybe especially the ones you lose. That exact angle or perfect line, the number you should have called. Memos, memoranda, memoirs. Where are those two perfect prints of her lips, one on restaurant napkin and the other on watercolor
fantasy “What would you do if you only had this long to live?” never reflects the possibility that you may already be compromised.

Before the operation, a conversation: “...anywhere... anything... some holiday?” She considered different places, but because she was optimistic she thought she would wait. She said “Every day has been a holiday for us.”

Maybe good to do it like Miller or Burroughs, cut it in pieces and let it arrange itself. Cut and paste. Cut and paste and waste away. Absinthe and opium: appropriate for a real-life experience both surreal and Dadaist… (Black narcotic sap, pale green hallucinogenic distillate—swirl them together into psychedelic art nouveau curlicues.) Linear doesn’t seem to be an option. This isn’t a work of art: it’s a scream of pain, the printed echo of a howl… Stress fractures from the aftershock of the blast, continuing toxic fallout… Things I never wanted to see or know, things I don’t want to remember… But this pain is my story, as routine as erotica. If you’re condemned it’s your party.

I can’t separate the situation from the scene, pastoral and bucolic: the clear skies and vast distances, California Impressionism mountains ranging ochre and violet, the Santa Rosas, the San Bernardinos, and the San Jacintos, dusted with snow, the higher peaks, Jacinto in the foreground and Gorgonio in the distance, “Big Bear,” streaked with brilliant white. Expansive sprays, spreading showers of bougainvillea, no other word but riot really of fuschia flowering everywhere. The tan stucco walls and red terra cotta tile squiggles of roofs. Old haciendas and ranch-houses, trailer parks, country clubs, condominium complexes and golf courses, golf courses, golf courses. Transplants all, preternaturally bright against the native bleach.

That first year was a “bloom,” one of the rare years when there is rain and everything comes
to life with a verdance verging on vengeance. The usually bare, baked hills are luxuriant with a furze of lime green grass, and the sands are alive with patches of purple violets and pink verbena and blowzy white sand-lilies. Barrel cactus are blooming with pale yellow petals against their shiny crimson barbs. The common brittlebush is covered with fresh leaves and yellow flowers, as is the larger creosote tree, with tiny, brighter yellow blossoms. The spiked pikes of ocotillos are aflame with lipstick-red blossoms, and Indian paintbrush is red, orange, or purple, depending on the altitude. The yuccas, in their special places, send up a shaft covered with white flowers. Higher up, and especially through the Pass coming into this valley, there are great swaths of orange, the golden smaze of poppies.

A river of butterflies, a seemingly endless yellow band fluttering down Indian Canyon. Lenticular clouds, perfectly formed ovoids of vapor floating like flying saucers, not fluffy but flat, titanium white, and radiant. The canyons riddling the sheer mountains hereabouts are a delight to explore. Tahquitz Canyon was still open. This is where “Lost Horizon” was filmed and a “homeless community,” a non-sequiter, had just been cleared out. (Careful there, though, because there’s a curse, involving a demon and a beautiful maiden. Land of Kokopelli, the grasshopper god.) We hiked them all, and also the trails above town, leading to the great Pacific Crest Trail, which runs from Mexico to Canada. Flowers to press and lichens to inspect—possibly my favorite life-form, after cute girls—and I remember coming across a field of garnet in just the right light, the mineral glowing red beneath our feet, near where we found some Cahuilla pottery shards.

Look toward sunset, where the neutral sand is flushing, blushing pink, below the huge boulders thrown down the canyons from the mountains, rocks that are not rust colored, or granite colored, but things like flesh that are their own color. Stars appear in the aquamarine vault...

There was a comet in the sky when we met. Palm Springs was beautiful, then, with lots of wide open space straight to those mountains. A sleepy, sun-baked resort community, and largely a retirement community— the land of purple and blue and strawberry orange hair, bleached teeth, and luxury cars. There were the golfers, of course, in their colorful togs, the pastel-tinted cream of the economic crop in this country, the “winners,” pursuing an “active adult community lifestyle.” (I am reminded of Aldous Huxley’s description of Southern California as a place where people come to die, of Man Ray’s characterization of the place as a “golden cage,” and of Nathanael West’s apocalyptic prose painting “Day of the Locusts.”) There is an annual “Blessing of the Golf Carts.” Truth is goofier than fiction. West died in a car crash not so far down the road.

At the top of the mountain, Mount San Jacinto, there is a light. When I came here I was never sure whether it was an artificial light or a planet or star, perched there on the jagged, high horizon. It’s the light at the top of the Tram, the “Palm Springs Aerial Tramway,” cable cars strung from the low desert to the high sierra, complete with a restaurant and bar and hiking trails. It’s a mid-century modern masterpiece by Albert Frey, although it’s been messed up with new, larger revolving cars and twenty-first century post-post-modern gift shops. “Upgrades.”

There is an optical trick with mountains. We see them as planes, flat, without depth, as walls, flat on each side. A stretch is required to imagine their depth, unless there are clouds or snow—only then is their horizontal size appar-
Make the nicest place you can. I remember her pleasure at finding a green wooden oval fruit bowl.

This was all great fun, notwithstanding the imminent surgery, set for six weeks later, and the immediate heartbreak of the fact that her hand would never work again, whatever else might happen. She started wearing a sling because the arm was being affected, due to the position of the tumor on what is called the "motor strip" in the brain. Pile-up on the motor strip. A limb that has ceased to function is a liability, in terms of circulation and sheer mechanics: dead weight. There is a process referred to as "shunning" whereby the body "ignores" the immobile part, leading to other problems...

She remained optimistic, the paralysis remained localized, and she found a physical therapist who explained, as her doctors hadn’t, why there was no hope for the hand, and what she could do to function as normally as possible, techniques and exercises. (This was at her own expense—Medical and Medicaid, let us say Welfare, does not cover such frivolous treatments.)

In that place that had always been so dry and warm, it was cold, and the rain just kept pouring down, and when the deluge of weeks, of months, finally ended, there was an earthquake which cracked our bathroom in half, from the tile in our tub to the ceiling. The telephone and Internet went out. A dog across the street howled continuously for three days. A litter of completely black kittens was born in our little courtyard. One night, unearthly shrieks and howls came from the nearby wash—a group of coyotes killing a cat, not quickly. So much for good omens. (Omens. Superstition, magical thinking. Making up stories to make sense. Signs are everywhere; everything is always everywhere, but when you are looking for signs, and desperate may be exactly not the word, co-

ent. This sounds like philosophy but it’s physiology, an optical effect. The way we see things. I could look at mountains forever.

That winter had begun as another wet one. Dour black cumulous clouds had risen behind the mountains as the days had grown shorter, and they came rolling up and over that normally protective massif, bringing record-breaking rains. There were flash floods and freestanding floods, and the great, wide flashes were now flowing rivers. For months, every single road out of town was submerged save one, and that down to one lane in parts.

Fascinating, meteorologically speaking, and exciting to anticipate another bloom, before the "news."

From our patio we could see both the peak of Jacinto and Bob Hope’s modern spaceship/doughnut house. Hope himself had only recently ceased to survive.

One of our games with our place was to keep it “period”—’64 or before. Finding just the right flame-shaped bulbs for the incongruous but original chandelier was a challenge. When you need peace lighting is important. Noise is a major issue, too. Even the faint clicking tick of a plastic quartz clock or the grinding of an electric clock... Important to avoid upset and harsh words. Continuity and stability. Easy for us, natural, and if it was no longer a laugh a minute, it was still every other minute. The professionals say “Live in the moment.” Is there some other place? Really, I’d rather not relocate.

Maybe the best game was trying to eliminate the sight of plastic. Hard to do in this injection-molded world, but worth the trouble. It was impossible to find a decent telephone. Before long we needed an intercom, so we were stuck with the awful noise that is the “ring” of modern phones. Such were the "preparations" for something that you can barely prepare for.
term. That would be the case if the tumor were to be removed “radically.” Unacceptable.

She remained, to this point, “normal,” but then there was a slight change. She exhibited some slight, uncharacteristic paranoia, and became, one night, argumentative. Then she was “back to normal,” and I remember her looking around and saying “This is all?” It wasn’t a question and she wasn’t talking about the place. Lament.

That was the last really “normal” evening. Maybe we had some wine or hot chocolate. After that, she locked herself in the bathroom for hours, and only came out after I insisted. She seemed OK. I was embarrassed that I had been so adamant.

She woke up around midnight, raving. It started with “Who are you, get out of my bed!” She didn’t recognize me, and began a rant… She screamed and tore her clothes. She knew some people, some friends, some details, but the salient feature was the rejection of many of the things she loved, things around the place— her own tools, the chairs she had made, even her clothing. “What is this hippy shit?” She freaked out on a box of medicine. “Whose is that? That’s not mine!” This continued through the night, and by dawn I had calmed her down enough to sleep a little. I didn’t know what to do, and I hoped she would wake up “normal.” Wishful thinking. She was worse, and becoming a little violent.

What to do? Back to the emergency room, and they didn’t want to deal with her, or couldn’t. Said it would be better to send her to her “primary” physician out of town, not that she had a “primary” physician. (She was on some list to get a doctor in two or three years.) Sedated, strapped into a gurney, and loaded into a paramedic truck. She was awake, but in and out, and still “psychotic.”
hospital and unstrapped and transferred to a bed in the emergency ward, with her limp arm bent under her. Screaming at that, then raging again. I tried to hold her down, to keep her from hurting herself on the metal rails of the bed, but she was too much for one person. An orderly and a nurse came in and waved me away, and by this time she was sitting up, screaming and flailing. She kept squirming and fighting and banging on the metal rails... Metal rails, no padding. Medieval. Then there was a security guard in uniform manhandling her, and she knocked out a front tooth on the rail and started bleeding everywhere. They muscled her over on her back and fixed unpadded nylon straps to her ankles and wrists and pulled them tight on the rails while she kept bucking and straining and even trying to bite them. The straps cut into her wrists and ankles. More injections to put her to sleep, and finally she was out, still breathing raggedly. Bruised, scraped, cut, and bleeding. She was transferred to a regular room and I saw her tooth lying on the bed. I went to the nurse’s station to get something to put it in and a passing doctor, maybe an intern, saw me and got an emergency container for it, kind man. (She got it fixed a few weeks later. A little bonus “procedure.”)

The next day she was simply in and out, almost coherent at one point, almost raving again at another. I felt sick. What could I “take,” what are my limits and boundaries? I don’t know, but insanity is over the line. Lose your mind and it’s no longer you.

But this was not really incoherent, and had more than dream-logic to it. It was in fact entirely “sensible,” looked at in a just-slightly different light. Only hours before, she had seemed “gone,” but now she seemed closer, and the next day she was almost normal—still persisting in parts of her “fantasy,” but obviously coming around, coming back. Seemingly miraculous, but how much of it was due to the heavy sedatives? Hard to say, too, how much of the “breakdown” itself was due to psychological pressure, how much to drugs, or how much to the tumor itself. These confusions and hallucinations, were they from stress or the growth or the drugs or not? The answers are yes, and no, and maybe, and all, or none, of the above.

More tests: another MRI and extensive X-rays. Here, too, was the kindest nurse of all, who understood just how sensitive she was to the touch, and was very careful and slow and gentle with her. The only one, the whole time. (Her skin had become so sensitive that she had to cut out the neckband of a t-shirt to sleep in.) Think of that old expression “on pins and needles.” Think of the Sonny Bono song “Needles and Pins,” the Ramones’ version. Think of a sandpaper blanket and a bed of nails.

Her surgeon came in to see how she was. No changes, apparently, although she was completely exhausted by that ordeal. The doctors recommended that she think about some counseling, which isn’t really easily available. No money? Get on the waiting list. No one suggested that this situation was anything other than psychological, either, anything like a common reaction to steroids or to a mass growing inside the brain. Blame the victim.

In any event, she was out of that particular nightmare, and psychologically “better,” and I took her home. Back to “normal.” She told me a few days later that this had been a suicide attempt. She laughed and said “I don’t have the guts to kill myself.” I said “Good!” and she kind of smirked, cocking her head, “I don’t know...”

She was weaker, and thin, but still determined to do what she could to survive.

Hunter S. Thompson shot himself dead that week, apparently sick of being sick. He had just
been in town, too, appearing with Sonny Barger of the Hell’s Angels.

There was an ‘interview’ at the famous Cedars Sinai for some possible something, some low-impact chemotherapy. She had almost died on chemo the first time, and this time it wasn’t an option: it would surely kill her, as would the higher-tech “gamma knife.” Too much pre-existing damage. She was against any clinical trials because they kill too many people, but maybe there was something here... There wasn’t, but it was nice to slip into L.A. for the day. Interview, shopping for Indian food, then out to a Thai place she always liked. Nearly normal. I recall driving out of town into a glowing double rainbow. I think that auditions are always open for guinea pigs.

She was generally positive, and what she worried most about was her general condition: “I’m older now...” She also said “I could accept this last time. Why can’t I now?” She also took care of me. “This is driving you crazy!” she said at one point. At that point, she was right, but it passed. I remember her “catching” me feeling bad for her, bummed out when she was feeling bad about the possibility of just another month or so to live. (Surgery, of course, sometimes kills.) She said “Don’t...” and I said I thought I could put a number on it, roughly, that whatever pain I felt was probably something like one ten-thousandth of what she was feeling. That would be a good poem, she said. I guess it was the delivery. I guess you had to be there. But, really, you wouldn’t want to. You had to have to be there.

Weaker and weaker still, and the doctor delayed the surgery a week. During that final week one leg stopped working. Wheelchair. And all too soon, all too late, it was time... The last night before the operation she whispered “I’m so scared.” Is there a response to that?

“Processed” again and waiting, waiting, waiting; sitting up in yet another curtain-ringed bed, waiting and waiting to go under the knife... She said “Get out of here,” or something like that... Good advice. “Good Luck.” Did I say something like that? “See you soon.” Nothing to say. Words evaporate.

Nothing to do but go home.

Glioblastoma. Astroblast. A mutation or scrap genetic material or aliens? Environmental or intrinsic? Think of it as a mole in a really bad place. Think of it statistically-- two people in a million will grow these things; scant comfort from statistics if you’re left holding the short statistic. Not just “regular” cancer, but a growth, a body, a thick-sheathed thing that grows its own veins, would grow its own brain if it didn’t kill you first. Nasty purple things with tentacles. “Glio” means “egg,” “Astro” means “star.” For what that’s worth. I always avoided too many specifics in this. General outlines only, please. Some people get all into “research,” learning all about this stuff. Maybe I’d be different if the tumor was in my head. I never wanted too much detail, just the range of possibilities and the worst-case scenario, which was, I guess, uncontrollable seizures leading to death. (That wasn’t the worst-case scenario, actually-- left alone, these things will push your brain out of your eye-sockets and ears.)

On the main road here there’s a “Cancer Survivor” “park.” A “happy” family in bronze, frolicking. There’s a series of arches, I guess “symbolic.” These should be emitting X-rays. The theme is cancer, but there’s no hospital bed! No slings, no prosthetics, no walker, no wheelchair? Why not an ambulance in marble? It’s hard to tell which of the figures had the cancer, really. The bird-shit on business-casual Dad’s forehead resembles melanoma, and that’s a drip in the right direction. Is that the bulge of
hallucinations. She spoke of “the girl,” the dreams she was having of “the girl...” She had double vision for days. This was kind of a big deal, a “bad sign,” until she herself insisted on lowering her dose of Ativan, and she was back to normal, just like that. Not her nurses, not her neurologist, not the other doctors, not clever me, but her. You’d think you’d get a little professional advice in a situation like that, but you’d be wrong. You’re on your own. Sink or whatever. Swim.

She still didn’t have an official “doctor,” just the neurosurgeon. Not that he should have been there—surgeons are mechanics, specialists, and if they do their job, who cares to ever see them again? (Interesting to note that neurosurgeons are always “top neurosurgeons.” By the way.) No physician assigned to her? Maybe that’s how it’s always done. I don’t know. And interns did look in on her. But when I say look in, I mean exactly that, often from the door. Peek-a-boo!

It was clear that she needed to be watched as often as possible. It’s not worth listing all of the mistakes the orderlies made, the minor injuries they caused. Nobody ever saw that she ate. They just left plates of food, and then, on their schedule, took them away, untouched. She was literally wasting away.

A bronze colostomy bag on Grandpa? A cancer memorial park should be cast blastomas, maybe blown glass. (Her opinion: “Gross.”) Radioactive would be a nice touch, as well. Perhaps a fountain of toxic water. Nothing above the recommended daily allowance, mind you. Just a touch, for verisimilitude. Worth thinking about, because the future will hold more of these. We are the Cancer Generation. Generations. Cancer culture.

The surgery, eight hours, or twelve, was a success—the doctor got everything out that he went in to get. She was loopy, drug loopy, but seemed “good.” Which is to say she seemed like “herself.” Smiling. When she lifted her head off of the pillow it was pink because the back of her head was bleeding. She was stuck in intensive care because they didn’t have room anywhere else: lots of moaning and too much excitement, electronic beeps and blips, and no privacy at all. Privacy. Why even mention it? First thing to go.

Looking back at the e-mails, I see that I forget that she didn’t want to see anybody during the days after the operation—this doesn’t fit with my romanticizing, but there it is. So, a few more days of waiting and seeing, or waiting and not seeing, which was fine. People need space, for, you know, their heads.

After two or three days, she was moved to the “rehab” hospital there, a longer-term “care facility.” Can’t we just say “hospital?” Call it a Therapeutic Discotheque or a Spa of Life Everlasting, and people will still be coming in on carts and leaving in bags with tags on their toes. Was it a “Wellness Center?” Memory spares me.

For her, at the moment, though, things didn’t look so bad. Not great, but not bad. And most of the tumor was out.

Then she started seeing people. Visions,
from flip out completely to go into massive seizures to die... I could see the fear in some of the nurses and assistants. Doctors, by and large, don’t give a dissected rat’s ass. They’re like homicide detectives-- they’ve seen too much to be shocked by anything. Maybe this is as it should be. I don’t know. I’m not a “doctor-basher.” A lot of people get into that. Kill the messenger.

It’s siege mentality at hospitals, and there’s always someone in worse shape. Just keep shoveling in the drugs, keep the inmates quiet. The perfect patient is sleeping, or dead. Takes the pressure off. The current California standard ratio for nurses to patients is one to six. At exactly this time, Schwarzenegger, the celebrity Governor, was trying to increase the number for “efficiency.” That was the word. Unfortunately, a lot of people don’t operate so “efficiently,” health-wise. One of the problems with “care” as a business.

Just a lot of stuff we’d rather not think about. Somebody must be taking care of these people, right? Right? Are you looking away because you don’t want to stare or you don’t want to see? Get too close and you might catch it! This is instinctive behavior, as natural as a cat hacking up a hairball.

Driving and driving and driving, and the mountains burning, ragged lines of fire, beautiful at night, advancing over the Badlands and Oak Valley between Palm Springs and Loma Linda, and everywhere else, as far as I could tell. In the daylight the firefighting chemicals looked like giant pink and sulphur-yellow scabs on the charred mountainsides.

I called every cancer-related organization in the country, looking for help of any kind. “Begging” is the word. Nothing there but pamphlets and tribute ribbons and workshops, and advice to try some local churches. Always the churches. No “Make a Wish Foundation” for adults. Fine fund-raised offices, and slick, expensive brochures. Money for research is great but what about suffering at this exact second? “Educating” the “public?” “Raising Awareness?” Good luck. Hope those seminars work out. Need a speaker?

This was also the time of Shiavo, the brain-dead woman who was America’s Sweetheart, her case the most important “issue” in the country, and every morning she was on the front pages, in a most stable condition. (On television, too, which is never turned off in the institutions. A kind of torture.) But the media is a circus, and politics is show business, and this is nothing new.

The Pope died at this time, too. Spirituality is part of our make-up, but churches are clubs, social groups, which is different. No avoiding the superstition, though, in cancer season. I recall a magic picture of the Virgin materializing, which she had taken down. Get sick and people want to decorate your room, like a baby’s room. Infantilizing.

The rehab hospital had a circus element on Sundays. Empty as a tomb during the week, it was busy on the weekends, crowded with families and friends, some of whom even wanted to be there. “Entertainers” would come. Magicians, jugglers, mimes. Felliniesque. There was a Labrador Retriever that a woman would bring in and march from room to room, bed to bed, week after week. The dog was bored, dutifully offering his head to be petted, then looking away.

Sick people never get touched enough, in the right ways. A touch on the hand, the shoulder, the face. We are so afraid.

She had stabilized, but she wasn’t getting any better. She started having some trouble; difficulty chewing, sometimes swallowing, possibly the tumor or the drugs, drugs, drugs.
There was no particular improvement, so, after about six weeks, she was sent home to die.

There was still some “hope.” Glimmery. I was taking my cues from her, and we had a real open line of communication on this, shall we say, critical point. I would often say when I left the hospital “You’re gonna be here tomorrow, right?” It wasn’t a joke, although it sounded like it, and sometimes we would laugh, even though it wasn’t funny. At this point she was psychologically strong and physically weak, and ready to come home, come what may.

There was, immediately, a frenzy of activity, with different nurses and organizations to be dealt with and various arrangements... Almost everything was taken care of by the all-volunteer Visiting Nurses Association Hospice program. All of these people working for free, doing it out of the kindness in their hearts.

Amazingly, once she got home she began to improve perceptibly, so much so that a few weeks later, when she had a “final” consultation with her surgeon, he asked if she were going to stay on hospice care. He wasn’t just being nice, either-- it was a total change. Like, maybe she might possibly pull through...

The hopefulness attending any improvement was guarded, for everybody. No “false” hopes, except the big one, I guess. All of the nurses and counselors were very careful and very tactful and very specific: anything can change anytime. Enjoy every moment. Still, improvement is better than decline, and we were curious about who had been in hospice care the longest-- some guy who’d been on it for twelve years. Not bad!

In the refrigerator we had an “emergency pack,” filled with drugs, most especially a hypodermic needle with adrenaline, and another with morphine. Those were the ones that mattered. She laughed at the other “anti-seizure” stuff-- “I’m already taking stronger stuff than that!” The morphine made me nervous, because it was a potentially lethal dose. Practice on a grapefruit.

But there it was: improvement, like a miracle! She did as much physical therapy as she could, and we got out most days. Hassle with the wheelchair and the heaving and the impossible world, but worth the trouble. Freedom!

She thought about getting a gun-- not a real one, a toy-- as a possible way of commanding some respect. The help was slipping now that she was a little better! But she figured that if we were filming, the gun might be a kind of negative image. (And her whole idea of the webcam wasn’t so much to make some “statement” about Death or privacy issues, although that was part of it. She mainly wanted to show how well she was being cared for. She loved the lady who came every day to bathe her, liked a lot of the people around.)

The big issue at this point was how to take care of her full-time. The state, Medicare or Medical or whatever, would only supply eight hours of nursing at home. (The other option was a nursing home, and that was the one thing that she didn’t want.) They would send people over for interviews, but even the director of that program admitted that the quality of their care was spotty.

Eight hours. Twenty-four in a day. What that gets down to, really, is that, unless you have some other resources, you will be left lying in your own shit for sixteen hours. And it does get down to that for the disabled, the simple fact of leaving somebody lying in their own shit. Or sitting, if you have a wheelchair. They do provide those. You might say it’s better than nothing, which it is.

At that moment it all looked manageable. It was possible to get some money to use for care
rather than taking the state’s choice, so we started looking around for someone.

A few good weeks, a few short, pleasant days, and then something happened. An “event” that left her stricken, unable to speak. Stroke? A “mini”-stroke? No telling, and no telling the cause. The same old possible suspects, although now there were issues of intracranial pressure. Coughing, sneezing, shitting, and even anger were all potentially dangerous.

She had been, on and off, having trouble speaking. The roughest thing of all for me. If we could communicate, then the important thing (to me) was still there. Her mind was always sound. There were too many times that no-one else could understand what she was trying to say. Always such simple things, too. Water. Peace.

She seemed on the verge of death, then rallied again. A good day, a bad day. One particularly good day she told me I should quit. She was right. This was just before Memorial Day, and I called the Hospice people and I left.

When I came home two days later she was gone. Her parents had taken her to the County nursing home. (Had wheeled her out, kicking and screaming, our lovely nosy neighbor informed me, even after the customary sedation.)

It was impossible to judge her condition. She’d been heavily dosed, with everything. Everything. They gave her drugs she’d tried already, drugs she’d had trouble with, drugs that didn’t make any sense at all. (One of her nurses gave me the list because I knew her “drug history.” Funny term.) There was some phantom doctor associated with this, a character who never appeared. “Consulting Physician” or something.


The staff people there were totally overburdened, but they really went out of their way for her. They didn’t understand why she was even there, in her condition. This place was for the destitute, not the nearly-dead. “Why is she here?” they asked. “Unprofessional,” but welcome. “She doesn’t belong here.”

More ups and downs, coupled with her depression at her situation. She was stable, though, and her mind remained strong, even as it became harder for her to speak. She declined there. Still sharp, but physically in decline. I was reading to her, Richard Brautigan’s “In Watermelon Sugar.” She was laughing at the funny parts, and that’s something. I hadn’t remembered that there was a suicide in that book, and she liked that part, too.

I was always asking how she was, and there came a day when she said “Not so good.” After that, with difficulty, “I don’t want to die here.”

I was ready to take her, but the “equipment” was gone (property of the State,) and we would need that back. “Now?” She shrugged, with her eyebrows and her head. She usually knew what was going on. I said “OK. How about a couple of days? Two. Is that alright?” It was.

Who knows how these things work? The next day when I went in I found that her parents had taken her to their place. Good. Better. Best. I was OK, acceptable, and maybe at some points invaluable to her, but her vision of the best situation was to be tended by women. Her mother, mainly. That was what she wanted, and that was what she got.

Going and going, though not yet gone, and we got through Gogol’s “Terrible Vengeance,” but we didn’t make it back to Brautigan, to
“Trout Fishing in America,” which was next. (Her choice— I wanted to read “The Abortion: An Historical Romance, 1966.”)

Fading, fading, fading. She could hardly swallow, so she wasn’t eating. Her breathing was labored so she was sometimes on oxygen. She could’ve been killed with a kiss. She could only occasionally barely whisper, but she remained expressive to the end. That last late afternoon she was so kind, and labored so hard, to simply move her head closer, tighter to my hand. That breaks me up.

I see her always making things, especially with a straight edge and an exacto knife. She had good tools, and she took care of them. Smart and professional— she was a great sharpener of kitchen cutlery, as well. Pointless to try to describe her work. Art is what you can’t say otherwise. Pointless to catalog the breadth of her interests, or those things that were “special” to me… A girl who wrote a love song to an amplifier, the inventor of urban camouflage, who always had a copy of “Exile on Main Street” at hand. “The Shroud of Santa” Christmas card. Who knows what things charm us? Baker of scones and graham crackers, great lover of Gaudi and shadow plaid. Fake wood on cars. Pinhole cameras. Her thumb piano.

“That,” she would point out, “can be tuned.”

I’m reaching for the light and the switch is gone. The door’s still there but the knob has disappeared. We use other people as crutches and I am stumbling. They are maps. I am lost. Sleepwalking. Haze. Smaze. Fog. Balance; im-. Derangement. Disarrangement. Recovery is a spiral. You only notice the aphasia as it fades… Is this normal? These reactions, yes. Is it common? This experience? No. Post dramatic. Symptoms, syndromes, disorders.

Pain is a corrosive streaking everything like a rain of acid and shit. Pigments fade and shapes are indistinct. Untreated stress can lead to depression, paranoia, and suicide. As can treated stress. The famous “stages” of grieving are another attempt to rationalize the ir-. Some people never adjust. Grief can be fatal.

This was an amputation. This is the phantom limb effect. Labor of love, this labor of love lost. But “Better to have than never…” Isn’t that what people say? People are always saying things. Death, where is thy quote?

Here’s a life in a presentation case. Do you like the frame? I think the red matte really sets it off nicely. Be careful, it’s still wet. How about the pins, the placement? The near-imperceptible whiff of the killing ether? She loved bugs, and told me a story about watching a dying cranefly motioning to her where it had been and what it had done and where it was born, communicating with its final motions. I’m sure she was right, too. She had that kind of patient intelligence, the ability to tease out hidden patterns. Not hidden. Subtle.

This makes a fine cameo, too, don’t you think? Picture it in sepia, as a rotogravure from an old Sunday paper, brown ink on ivory stock. Fix the negative, dodge the trouble spots— we’ll get a decent print out of this mess yet.

What is this emptiness? This nothing that is something palpable? Not blank like a page or a sun-bleached bone, but a blackening blankness like a fresh hole. A penumbra of dust and dirt, the severed roots and rocks displaced by the blast still hanging in the outraged air. Shards of skeleton, skeins of viscera, globules of blood, glistening bits of tissue. Frozen. A cloud that begins to spin like a tornado. The cloud is not moving. A violation, still a vacuum. I think of a black page in an old book. I think of noth-
grind from lapis lazuli, after the manner of the Old Masters, and the stars will be diamond dust, as on Warhol’s “American Myths.” At the very top, in profile, in serene repose, lit if you like by silver-sliver moonlight, picked out in portrait pink oil and a few glimmers of gold-leaf, radiant as Life itself, sits the idealized figure of a woman from another time.

Susan.

Let it all become a piece:

Here’s your perfect dusk, and we’ll do this as a hand-tinted lithograph, in a limited edition: the jagged mountain a dark chocolate and ochre silhouette against that Maxfield Parrish blue gradient sky where a few precocious stars are just beginning to shine. The firmament we will


Nothing to say, and what to do?