

Agnes Rosemarie

H.J. Cummins



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It was not until my mother's funeral that I found out her real name. I'd always thought it was Rosemarie Agnes Cummins. It wasn't. It was Agnes Rosemarie Cummins. She'd flipped them when she immigrated after World War II.

How did I not know that? Damn. Isn't that just like us.

I wonder if she ever told me that little piece of personal information and I wasn't listening. Or maybe it stayed hidden because she never saw much sense in talking about her life.

"Oh, I don't remember," she'd say sometimes when I was a girl and I'd ask about Hitler and her mother who died, and how she got the scar on the left side of her throat.

Or, "That was a long time ago. Why would you want to know about that?"

She'd sound so hard, I was always left feeling that I'd said the wrong thing.

When I look in the family photo albums, I see my young mother with happy, red-lipstick smiles holding her babies and later, posing with my sisters and me in our matching corduroy pants and polka dot dresses and crocheted sweaters—all of which she had sewn or stitched for us. Yet, the single strongest emotion that I remember through all those growing up years was that she didn't like me.

I became a journalist, and a mother. There were times when Mom and I would circle close to one another. I moved around a lot, and she'd always come to sew curtains or crochet a lap cover. Lots of times it would start her talking about all our Army moves with Dad, and we'd feel close, connecting over the commonalities. Then something would happen, like she'd

see I was reading a book about parenting, and she'd make fun of me, and I'd get my feelings hurt. I hate to think how temperamental and ungrateful I must have looked to her.

She died of lung cancer when she was seventy-five, on September 26, 2000. And in a second jolt of mortality, I spent most of her last month hospitalized with a life-threatening intestinal problem of my own.

It took me a long time after that to think of something other than death. When I closed my eyes in prayer at church, it was always my mother's face—in old age, with silver hair and set jaw—that rose in the blackness.

So, I decided to go to Germany to find out more about Agnes Rosemarie Cummins. I became convinced that to survive any exceptionally hard circumstance—war, poverty, abuse, neglect—children commonly learn to entomb their emotions. I came to believe this creates a terrible legacy, when these girls are called on by their own children to be warm and soft and sensitive. To respond would mean excavating their own feelings, their old pain.

I discovered that researchers in both the United States and Germany have a name for the particular brand of bonding that goes on between these women and their children. It's called "avoidant attachment," as in "avoid" feelings.

Finally, I could begin to understand the scratchy relationship my mother and I had had.

Mom was an unapologetic two-pack-a-day smoker most of her life. Ever the pragmatist, she did cut way back in my dad's

last years, as his smoker's cough got worse.

"Pretty soon we'll have to have an oxygen tank in here and then I won't be able to smoke, anyway," she told me.

But then after he died she smoked more than ever. Mornings, she'd sit in her recliner quilting and smoking and watching TV and doing the newspaper crossword puzzle all at once. Because she used a pencil, she considered herself a dabbler. She had no problem erasing her first or second guesses. Still, she did so well it was easy to forget that English was her second language.

She was a morning person, so over the years when my phone would ring before eight in the morning I was pretty sure it was Mom. That's why the call early one summer morning in 2000 didn't alarm me until she said, "You better sit down."

She delivered the bad news fast: She'd gone in for a routine chest x-ray yesterday before her hip replacement surgery and they saw a spot on one lung. She was going in for a CT scan today. The hip surgery was called off.

"Telling you girls this is the hardest thing I've ever done," she finished, and took a breath.

Then I sat down.

My words stumbled over my thoughts. They don't know what it is yet, right? So, maybe it's cancer and maybe not? In any case, I said, one of us three girls would be with her for the next six weeks—time we had scheduled to care for her through the hip surgery convalescence. Now we'll deal with this instead.

She was sorry to be such a bother, she said, and that was the first of many times I wanted to cry for her sake. But I didn't cry then, and I didn't ever—if she could see me. Mom was especially impatient with tears. I never saw her cry in my whole life.

Maybe because nothing seemed bad enough to rate tears, after her young life in Germany. After a father who practiced the philosophy that good parents beat sense into their children—literally and until his only child finally left home at seventeen. And after the Allied bombs and stomach-cramping hunger she'd survived through World War II. And after her mother's suicide—Else threw herself out an attic window rather than face rape by Russian soldiers breaking into the house.

Now, home for my mother was the small town of Seward, in Nebraska. My little sister, Trisch, came from Phoenix to take the first two-week shift with Mom. Our older sister, Barb, came from Oklahoma City for the second. We stayed in close touch by phone. It took the entirety of their two stays for all the specialists to finish their diagnosis.

Some days were hard, like when Trisch called to say the fist-sized tumor led one of the techs to take her aside and caution her, "You girls should prepare yourself for the worst."

But by the end of Barb's visit, the doctors were telling Mom that the chemotherapy and radiation treatment she chose could give her another four years of life.

I came from my home in Minneapolis just as the six-week course of chemotherapy and radiation treatment started.

Her schedule of appointments and medications was so complicated I thought I may as well turn my many notes into a full-fledged journal. I asked Mom if it would be okay for me maybe to write about this episode in her life.

She looked at me with a slight smile and that powerful determination that always settled in her jaw. She wanted to be clear that she planned to claim those promised four years.

“Okay,” she told me, “but your story has no ending.”

“That’s the good part,” I said.

The plan was for my sisters and me to get her through the next six weeks and buy her those years. My journal would record her treatment and recovery. Instead, two weeks later I would leave her, and my journal entries would end abruptly because of my own illness.

MONDAY, JULY 31, 2000

I see that Monet is big in the cancer world. Those water lilies of his are in every waiting room we sit in today.

This is Mom’s first of three straight days of chemotherapy at an oncology clinic in nearby Lincoln. One round is now, the other in three weeks. Her six weeks of radiation are through a Lincoln hospital, at eleven in the morning. Monday through Friday for the next six weeks.

In the half-hour drive, I tell Mom that I hope she’s not beating herself up about smoking. She’s not, she says. She has always enjoyed smoking, it’s the only thing she ever found that stimulates her and calms her at the same time. She knew the risks, she says, and I admire her for telling me that.

She will continue to smoke through all her treatments. No doctor ever asks her if she has quit.

Our first appointment is eight thirty in the morning at the oncology center. A nurse takes her into a treatment room with nine chairs, chemical-drip poles and cabinets with pillows and blankets. The drip can be chilly, she says. Then the nurse asks Mom to choose from among the free chairs. I wonder if it's something they're trained to do, something that's supposed to subliminally give cancer patients the feeling they have some control over what's happening to them. Mom and I sit together through a two and a half hour drip of chemo drugs and an energizing antidote—a steroid.

I hear a young woman at the other end of the room. She looks to be in her twenties. She's clearly on the phone with her insurance company, talking about her liver and pancreatic cancer. She recites her call-back number, explaining that it's her sister's cell phone, which she borrows on her "chemo days."

There's also an older guy, his blue jeans held up around his wide paunch by some bright red suspenders. He wears a billed cap over his bald head. He starts telling the nurse about how his dog keeps jumping up on his lap at home. At first he sounds cross, but an affection quickly takes over. The nurse listens.

We go to Perkins for a late breakfast, and Mom eats two scrambled eggs, two sausages and a slice of toast. This is the beginning of my obsession with logging every piece of food Mom eats every day. She is a big-boned woman, five feet and

eight inches tall, and only 122 pounds now. She is certain to lose more weight through the treatments, and that scares me.

For the next two weeks, we don't go anywhere without a satchel of medical files, x-rays, CT scans, and cancer publications. There's: "Radiation Therapy and You," and "Chemotherapy and You," and "Taking Time: Support for People with Cancer and the People Who Care About Them."

At the hospital, Mom gets called to her radiology. While I wait, a skeleton of a man comes in and sits down beside me. "I keep wishing I'd be in the wrong place at the wrong time and take a bullet in my head, instead of dying slow for six years," he tells me.

He makes a joke about how he lost five pounds in one day—that was how much the tumor weighed. He has three children, and begins to recite their birthdays to me, except he forgets the youngest. He has memory problems, he says.

I don't even want to think of all the ways cancer may diminish my mother.

TUESDAY, AUGUST 1

Mom wakes up at three in the morning, and hearing her I get up. We know that it's because of the steroid, a painkiller and speed rolled into one drug.

The oncology appointment takes a strange turn, when Mom's doctor asks her what she has decided about surgery. My understanding is that she wasn't a candidate for surgery. Mom looks confused, too.

Mom's first expressed preference for treatment had been:

“To do nothing.” I thought the chemo/radiation had been her second choice, after the doctor told her that if she did nothing, he couldn’t promise her even another two months.

“That was like signing my own death warrant and I’m not ready to do that,” she had told me.

Now the doctor is saying that if she wants to consider surgery we’ll have to stop the chemo now. Then, under anesthesia, there’d have to be some biopsies of lymph nodes between the lungs. If those are clear, the doctor could open her chest and try to remove the whole tumor plus a “margin” around it—a formidable task given its size. The surgery would be risky, blah, blah, blah....

What’s becoming obvious to me is that surgery is a bad option and that’s why Mom didn’t choose it. But somehow that wasn’t clear in her records, which led to today’s confusion and emotional second-guessing.

After all that, we go ahead with the day’s chemo. And radiation. Then, home again.

I’m already looking ahead to the four weeks of treatment facing Mom after I leave. My cousin Nancy volunteers to drive Mom to her treatments in Week Three. Mom and I will line up some of her friends to drive her in Week Four. Then I’ll come back for Weeks Five and Six. I’m trying to convince Mom to fly to Trisch’s in Phoenix for a couple of weeks after her treatments end. Mom’s not ready to plan that far ahead.

WEDNESDAY, AUGUST 2

Mom wakes up at three in the morning again. The steroid

makes her feel “wired and tired at the same time,” she says. This is the first morning that she dozes through part of the chemotherapy, her last of three doses.

She’s so tired that today she will make some rare mistakes with her English. When someone asks how her treatment is going she says, “I’m waiting for the other foot to drop.” Another time she mentions something is “a bone of discontent” with her.

Today, like others to come, we talk about Dad, who had died almost eight years earlier of throat cancer. He was seventy-five.

They had met in Germany after World War II. Hal Cummins was a tall, skinny Army sergeant who’d suffered through most of his war duty in a German prisoner-of-war camp. Then he was one of the amazing U.S. soldiers who stayed—or even returned, in his case—to be part of the Marshall Plan to rebuild Europe. Rosemarie Näther was a raven-haired secretary and translator in a series of U.S. Army offices. People who knew her then said she looked like Judy Garland.

Rosemarie was on her own, her mother dead and her father now in a Russian prison. Hal brought her cans of Spam and olives. He endeared himself to her landlady by giving her some fresh onions. He was smart and funny, Mom said. And he was taller than she. That was her number one requirement.

They married in Frankfurt, and Rosemarie followed him to postings in Oklahoma, where Barbara and I were born, then Louisiana, where Patricia was born, and then Alaska,

Kentucky and South Carolina, where he finished his twenty-year military career. In 1961, they moved with us three girls to Seward, where Hal had grown up and his family still lived. He became the County Veterans' Service Officer.

Dad was a four-pack-a-day smoker. He had also been an alcoholic who quietly drank himself to sleep every night with beer and peach schnapps, until about the time I left home for college. He sobered up, after Mom finally threatened that he'd lose us otherwise. Then he retired from his job early, and switched his addiction to golf, which gave him great pleasure for years.

Now Mom is talking about his last months, when they'd take drives through the countryside and how he just loved to look at those Nebraska farm fields. I feel bad I'd forgotten that about him, about all the "pheasant hunting" we girls had done with Dad, when he never once reached for his shotgun.

THURSDAY, AUGUST 3

My journal is accumulating recipes, from all the food family and neighbors are bringing—a sweet noodle pudding is one, and there's apricot-glazed chicken and a corn casserole.

Mom and I both sleep until five in the morning. "Maybe this is a sign the steroid is wearing off and you'll start catching up on sleep," I suggest.

She's testy. "No. I had the sweats all night. That's a sign that the steroid is wearing off," she says. Then she jumps down my throat for buying too many Q-tips.

It's our first morning without chemotherapy, so we pre-

pare leisurely for our trip into Lincoln. She's in and out of radiation in minutes, and then we drive back to Seward to see the family doctor, Dr. Van Vahle. Mom has known him for decades. He came to the Seward Clinic fresh from medical school, when Mom was the receptionist there. He delivered my daughter, Leah. And he had cared for Dad until his death. That kind of continuity is rare in medicine these days.

Mom starts to fill him in, direct as ever. That it took the specialists five weeks from the time he'd found the spot in her lung to get her into treatment. And that when the doctors asked her first choice, she'd told them it was to do nothing. "Well, you know my sense of humor," she says.

She tells him she had felt fine the first three days of treatment, "and now I want to ask you to play God and tell me how I'm going to feel for the next six weeks."

So far, the only answers we've gotten are an evasive, "Well, everybody's different," from nurses and technicians, or the exhaustive lists of side effects in the cancer publications that scare us so much we stop reading.

Dr. Vahle gives Mom some idea of what to expect. "Radiation kind of beats you up," he says. And because it scatters, it may reach beyond the tumor into her lungs, and maybe her stomach. Mom might feel short of breath, and lots of small meals a day are best for the stomach. He recommends plenty of fortified drinks—instant breakfasts and pump-up drinks.

He tells Mom she doesn't have to deal with nausea. She has Compazine from the chemo doctors, but he can also give it to her in a shot if she needs it, he says.

I can see that Mom feels better as we leave. I realize the word “cancer” was never spoken.

Mom sleeps from noon to one thirty and then four to five that afternoon. She would have gone to bed about seven, except her neighbor Cheryl pays a visit. She animates Mom with local news. They think one of the cooks was involved in that rash of thefts at the retirement home, she says. And they airlifted one person from a crash on I-80 west of Lincoln—one semi and three cars involved. “That’s our turnoff to the hospital,” Mom tells her. “We drove there just this morning.”

I make Mom a chocolate instant breakfast as an afternoon snack and bulk it up with ice cream. She has some pan-fried potatoes and a dill pickle for supper. I try giving her a glass of wine to take the edge off her discomfort while she watches “Who Wants to Be a Millionaire?” Instead it nauseates her, so we retreat to Sprite.

About nine, Mom goes to the back deck to smoke. She had taken Extra Strength Tylenol, but it wasn’t having any effect. She goes to bed, but gets up again about midnight with a hard pain in her right back—about where the tumor should be, she says. She has me get a couple of shoeboxes of old medicine out of the hall closet, and she takes two pills from a 1998 prescription marked Acetaminophen #3. Within minutes, she’s throwing that up, gagging into a hand towel. So, we try more Compazine.

She’s exhausted. “I knew it couldn’t be that easy,” she says, thinking back on those first few days. Her head drops forward to doze every few minutes, until the pain sticks her side again

and startles her upright.

We talk about Dad's cancer.

He had followed the oncologists' recommendation for radiation to treat his throat cancer. The protocol delivers two years of life, on average. But my old, frail Dad was not average, and the treatments hit him hard, burning and blistering his neck. He never rebounded and died about a year later.

Mom thinks the problem was that he was just as burned inside, which made it hard for him to eat. "Or maybe he would have died that fast, anyway," she says. "Who knows?"

I tell Mom that I expect she faces the same hard time as Dad did, as the treatments assault the body, but that unlike him I really expect her to recover.

I hope it's okay to tell her that. I mean it to be encouraging.

What I don't say is that I think she's tougher and fiercer than he.

FRIDAY, AUGUST 4

It's another day of naps and pain. Mom calls Dr. Vahle at nine in the morning and gets a prescription of Ultram for pain and a Compazine suppository. "Throw all your old pills down the toilet," he tells her. She does, and I'm surprised by her compliance.

At radiation she tells the technician, "Don't do anything that hurts. I had a rough night."

"That's not from the radiation," he says. So I wonder if it's the chemo.

We've made a hairdresser's appointment to have Mom fitted for a wig this afternoon, but that's not for an hour. I suggest lunch at Burger King. We can eat in her car, more comfortable seating than in a restaurant.

She wants a malt and fries, but she sips the malt slowly and loses interest in the fries after eating just a couple.

"I'm pretty much going to be a bitch about you finishing that malt," I tell her.

She grins and says something like, "Oh yeah, like that's anything new," her voice carrying irony and love and humor, and we both laugh, happy that she can still be sassy.

Mom is so spent that she dozes in the hairdresser's chair. She picks out a wig that comes closest to her own short, no-fuss haircut. There are also catalogs of hair nets and hats and caps and scarves for people losing their hair to chemotherapy. The hairdresser suggests Mom buy a nightcap, because a lot of her customers say their bare heads get cold while they sleep. Mom picks a white one, with black lace.

I don't know if Mom ever wore her wig. I do know she liked knowing it was there if she wanted it.

At supper, she squirms with pain, still that right side. Mom says she has decided to try to get by on Extra Strength Tylenol during the day, and use the pain medicine only at night. "There's no honor in suffering," I tell her. Dr. Vahle said the same thing, I add, remembering his clout on the old-pills issue this morning.

So, she decides to take the pain pill. Only later does it occur to me that she's supposed to take it only once a day, and

I can't remember if she'd taken some already today. I'm not doing well at keeping all this straight.

SATURDAY, AUGUST 5

Naps and pain, again.

And more of my obsessive notes on her eating: a third of a cinnamon roll for breakfast; cereal and a banana for lunch—most of the banana snuck under the table to her Schnauzer, Sammi.

I think her body is functioning like that of an anorexic, that she really doesn't see how little she's eating. I also think the cigarettes sate her, in the way food would.

Trisch calls in the afternoon and asks about the wig fitting. "Mom opted for the green spiked look," I say into the phone knowing that Mom can hear. She laughs.

Her friend Millie calls to see how she is and Mom learns that Millie has just had bladder surgery. They catch up on one another's medical conditions. Cheryl #1—next door—stops by to say Cheryl #2—down the block—has signed on to drive Mom to radiation one day in Week Four.

In the evening, Mom goes to watch the movie *Michael* on the TV in her room, so she can stretch out on the bed. I take a quilt and sit on the floor beside her. She reaches and takes my hand, saying, "This is so boring to you." I cry silently, because I can't remember my tough German mother ever holding my hand like that before.

SUNDAY, AUGUST 6

More naps and pain.

Mom wakes up at three in the morning, and smokes a cigarette on the back deck. Then exhaustion shoves her back to bed and sleep, until about six. Another third of a roll for breakfast.

When she sits, she babies the pain in her right side by putting all her weight on her left hip, the arthritic hip that was to have been replaced.

“The body’s a funny thing,” she said. “This hip hasn’t spoken up lately. It’s like all the pain moved to the other spot.”

Her friend Norma becomes ride #3 for the open week. Norma works at the hospital, and she came to see Mom the day the x-ray with the spot showed up.

“You saw my film?” Mom said, when she saw who was at the door.

“What are you going to do?” Norma asked.

“I don’t know yet,” Mom said.

“I’ll help you sort it out,” Norma offered.

Mom’s friend Gladys signs on for ride #4. And her girlfriend, Teddy, calls to say if her leg problem goes away, she’ll handle the fifth ride.

Longtime friendships are so precious.

Somebody in the family checks in every day. My cousin, Dave, and his wife, Jean, stop by before church. Mom is cheered. She tells us that she’s happy family and friends went with her to all the doctors’ visits, because she realizes she was in denial and doesn’t remember half of what was said.

When it's just the two of us, again, I ask her how long she was in denial. It's the kind of touchy-feely question Mom hates.

"I just thought I'd sail through this," she says, with finality.

Later I ask if she'd like to talk about moving into one of the apartments at the new retirement home north of town, when her treatments are finished.

"Not yet," she says, in the same tone.

It occurs to me that Mom chooses to grit this out one day at a time, as her hard early years had trained her to do. She spent most of the war in Czechoslovakia, working for a kind of a Nazi youth services agency first in Prague and later in Budweis. Then, as the Russians came from the east she walked or caught all manner of rides back, deep enough into Germany to reach American-held land. She had survived strafings and random attacks on rail cars. She had slept in ditches or barns to avoid any Czechs, virulently angry over German atrocities. She went to sleep every night, silently pleading, Please let me wake up tomorrow. And she woke every day, pleading, Please let me find one potato or one apple today.

That's how she survived her first death threat. It makes sense to go with it again, now.

I think that's what convinced my mother that emotions are of little consequence in life.

"If you stopped for feelings, you'd be dead," she told me.

MONDAY, AUGUST 7

We've been up most of the night because of the pain in Mom's side. She can't get comfortable any way she tries to sit. I see her fold over in pain, her hands on her knees and her head in her hands. In the morning, she takes some Tylenol and she's in and out of bed for a couple of hours. She is supposed to meet with her radiation doctor this morning, anyway, and we hope he'll have some answer for the pain in her side.

She can't bear the chairs there, so she stretches out on the examination table while we wait. The nurse asks about her side: "On a scale of one to ten, how would you rate the pain?"

"Nine and a half," Mom answers. "It's not quite childbirth, but it's close."

The nurse introduces a new worry: The pain could be a kidney stone or a bladder infection.

When the doctor comes, he orders a CT scan, but Mom shakes her head. She's so fed up with tests. She gives me a look like, Make them stop, but I'm afraid the doctor might be right, so I don't. It's the first time Mom has ever asked me to protect her, but I can't. She closes her eyes, and the only thing I can think to do is take her hand.

"I feel like a mouse lost in a maze with no idea what's coming," she says.

We go to the waiting room for the CT scan. The earliest she can get in is two hours away, and Mom's upset. "He just wants to use his fancy machine," Mom says. "He just wants to protect himself from any malpractice charges," I say.

I start noticing the wigs on women around the room. One

is a kind of long, Sophia Loren look. Another is gray and tightly curled, with bangs a single tube across her forehead. A young woman's is short, sleek and blond. I look at Mom's hair, but I see no sign of it falling out. It is, in fact, a shiny gray and quite lovely. I had never paid attention.

A young woman comes in for an appointment. In a touching show of support, her husband and daughter come along, wearing sunbonnets to match the one that hides her bald head.

Another young woman has her radiation "target" painted on her cheek and forehead. That means the tumor is in her head, and I take that as a bad sign. She sits with her family, silent and tired, thin except for a distended stomach. Her son—I'd guess he's about eight—keeps asking his dad, "Is Mom still sick? Is Mom really sick since she's not in the hospital anymore?"

"Stop asking stupid questions," she finally snaps.

Mom and I have our last fight about food, right there in the waiting room. Mom weighed in today at only 119 pounds. She lost three pounds in a week.

"You've got to eat more," I tell her. "You don't want to go through all this shit"—I motion around the hospital meaning radiation and chemotherapy and pain—"and then get in trouble because you didn't eat enough."

I'm pushing too hard, and she reasserts herself as my elder. "It's hard for me to think fondly of food right now. Look, I'll do the best I can and if that's not enough and I have to go in the hospital, then I'll go in the hospital."

The nurse comes to tell Mom that she's going to get her some pain medication. Mom, clearly touched by the care, says, "I'm sorry I'm giving you such a rough time."

"You're giving me a rough time, too," I poke at Mom, in mock anger.

"That's the power of blood," she tells me. Then she laughs: "Sometimes blood is *bad* blood!"

The humor gets us through the tense wait, and we start talking about us three girls—our various relationships with Dad, our marriages, our divorces, our children.

TUESDAY, AUGUST 8

I'm up at about five thirty, and the dog wakes Mom at about six. She slept through the night for the first time since treatments started.

She's in good spirits. She eats two eggs and a slice of toast. She even takes a power bar, and eats it in the car coming home from radiation. It's such a relief to have only that, the one-minute treatment this morning, and no other doctors' visits or tests or hair appointments.

No CT scan results yet, the nurse tells us. She'll call if anything startling comes up.

We're home in about an hour.

I do some errands in the afternoon, and pick up a couple of shorts and blouses for Mom. Now she'll have something new to wear, for fun, and she looks happy. In some ways she is so easy to please. Any caring gesture touches her.

WEDNESDAY, AUGUST 9

Mom sleeps all night again, thanks to Ambien.

At the hospital, the doctor says there's no evidence of a kidney stone. He says the pain is too severe to be related to the radiation, so he makes an appointment for Mom with her oncologist for next Monday. She receives the news stretched out on the examining table. She's so small. Even her skin is too big for her, like a coat that needs taking in.

Later Mom tells me that next time she has a pain, she'll just keep it to herself.

Still, I notice something about the nurses and doctors in the radiation clinic. They let you talk. They don't interrupt you or cut you off. It sounds like a small thing, but it's not.

More than anything, Mom's exhausted. Everything takes hard effort. She sleeps during most of our daily drives to treatment. She naps much of each day.

"I'm pretty worthless these days," she tells me.

"You get total slack these six weeks, and you should take advantage of it," I tell her. "I may never be this nice to you again."

She picks up on the humor: "Yes, it's a rare pleasure to have daughters be so nice to their mothers."

"That's why I'm keeping a journal," I say, "so I'll have documentation."

Mom does complain about itching skin, which sends me back to the radiation and chemo booklets we have, to take another look at the possible side effects: Fatigue, loss of appetite, skin burn, mouth sores, cough, fever, headaches, muscle and

stomach pains, anemia, dizziness, diarrhea, infection, blood clots, confusion, depression.

Talk about depression, I can see why we stopped reading the discouraging list. Still, it reminds me of all that Mom's poor body is going through, and again her strength amazes me.

This is where my journal ends, as the days took on a sameness until I left, the next Monday.

I never brought it up with Mom, but I wondered what it feels like to be told you have a terminal illness. This is just the kind of question she would hate.

I remember finding out just a few years earlier that she had a fiancé and he was killed in the war. He was a young man in her hometown, and I asked her how upset she got.

"I wasn't ever an emotional cripple, that I know," she told me.

"Well, I don't think you'd have to be an emotional cripple to be upset," I said.

"Don't pull that psychology on me," she said. "I don't have any idea how I felt. Nobody ever asked me how I felt about anything."

That was the end of that. I took her comments to mean that she considered me an emotional cripple, her middle daughter who was forever talking about feelings. All our conversations like this made me feel weak, by comparison. Only later did I realize that all our conversations like this left her feeling accused, too.

My mother was smart, my mother was funny, and above all my mother was strong. I hadn't known how much I counted on that strength until I heard worry in her voice for the first time. I was in college, I was going to Germany, and I wanted to go to her hometown in what was then Communist East Germany. She made me promise I wouldn't. She made me swear I wouldn't. I remember thinking, Wow, there is something out there that can scare my mother.

The only other time I heard worry in her voice was when I got sick. Her worried tone in one particular phone call created this reaction in me: She loves me. Now I hear that she loves me.

I got sick three days after I got home to Minneapolis. I was up all night, throwing up. The next day the doctors diagnosed a small bowel obstruction, the result of scar tissue left from earlier surgeries that twisted and finally blocked my intestines. Scars, the body's natural mending material, can sometimes backfire on you. The only treatment is more surgery, which of course makes more scarring, but there's really no choice. You just hope the new scars won't turn on you again. And the odds are more than eighty percent in your favor.

But this was already my second episode. The first blockage had happened just as suddenly four years earlier. Then, I'd had surgery to cut away the obstructive scars, and after three or four days my system kicked in again, and I went home.

I expected the same this time. My bigger concern was Mom. This was Friday, August 18, and I had planned to go back to Seward the next Friday, to cover her last two weeks

of treatments.

My even bigger concern was my daughter, Leah, who was visiting me at the time. I had moved to Minneapolis from New York only after she'd gone off to college. And now, here she was in a strange town calling cabs to get her vomiting mother to the doctor's office and then the hospital. I hated giving her such a scare.

Doctors operated that evening. The surgical records noted "multiple adhesions" that took awhile to clear, and then the surgeon put my intestines back in me and stitched me up. The final note was: "The patient tolerated it well and left the operating room in good condition."

Leah called my mother and my sisters, to tell them what was happening. The next day she had to fly to Washington, D.C., where she was starting graduate school.

I was sent to a room. A tube ran through my nose, down my throat and into my stomach. It would drain my stomach fluids into a jar hanging beside the bed, because even that bit of fluid cannot pass through a non-functioning intestine.

Thus began my obsessive monitoring of this jar. As long as muck continued to fill it, that meant my system was closed down. The end of muck was to be my signal of recovery.

I can't recount the passage of the next few weeks as accurately as I can my weeks with Mom. I kept no journal, at first because of fatigue and nausea, and that annoying tube. Then, as the days passed and I began to realize I was really in trouble, it was fear and inability to focus—and that annoying tube—that stopped me from writing.

My intestines refused to open up. I remember getting wheeled to CT scans of my intestines, looking for bubbles or bulges that could explain the continued clog. Even with the tube down my throat I vomited on the metal table, and the tech looked really disgusted.

I marked the passing days by the many roommates who came and went.

One was a young woman with adhesions from a sexually transmitted disease years earlier. She was hoping that they were the reason she was having trouble getting pregnant, and that surgery could fix things.

Then there was a woman who had an abdominal incision that got infected. She'd been a Medicaid patient somewhere else, and she suspected she hadn't gotten the kind of follow-up care better-paying patients do.

Another was an elderly woman who'd had a medical emergency at home, and now her children and a hospital social worker were trying to find some kind of care center where she could live.

One other old woman was taken quickly from the room one night. I think I overheard nurses saying that she had died.

One roommate was a beautiful, blond young mother who came in with her husband and their pastor. She'd had stomach cancer a few years ago, and now she had nausea and vomiting. It looked like the cancer had come back. "But I'm hoping I have what you have," she told me. A single room opened up and she took it, so her family could visit more easily.

I couldn't will my body to function, and the nurses said the only thing that might help was movement. So probably eight or ten times a day I'd pad up and down the hallways, pulling the stand with my drainage jar along. In one hallway hung a print of a vase full with a spring bouquet. I thought of Mom, because my assignment when I left her was to find something new to hang over her living room couch. It had been one of the many ways we'd expressed our optimism. "Let's buy some new things to enjoy when the treatments are over," we'd said.

I couldn't talk because of the tube down my throat. My friend David, now my husband, came every night. He was the person who stayed in touch with my family. Trisch and Barb each took a turn back with Mom, and he spoke with them and with Leah almost every day. There wasn't much to say, except that I seemed to be doing okay, and that I was walking every day.

Twice, the nurses pulled the tube out, thinking maybe they'd seen some improvement. Both times the vomiting started almost immediately. Then they'd have to put it back in, while I gagged.

Ten days passed. My condition was unchanged, except that I'd lost about fifteen pounds. And I was getting more and more worried. I'd lie awake until four in the morning, pleading, Please let me sleep. I'd wake up, pleading, Please let my body recover today. A little like Mom, I guess.

On the tenth day, the surgeon talked to me about my lack of improvement. I wondered if the first operation hadn't cleared all the problem scars, and so did he. So we decided on

another operation, that evening.

The surgery took seven hours. The doctor told David that he'd started cutting with a scissors, but the scars were so hard and thick he had to go to a heavier scalpel. He had cut until he could massage a bubble of fluid through my entire intestines, as they lay outside my body. He said now we'd just have to wait. He also said it was a good thing I was so healthy in every other way, that a weaker person probably wouldn't have survived the surgery.

I think it was two or three the next morning when I came to, and David was there. The nurse asked, "Do you know where you are?" I said, "Burger King?" a lame joke to suggest how hungry I was by now. She looked alarmed, but David smiled.

I woke the next day, hopeful, partly because the doctor had also inserted a drainage tube into my stomach to replace the one down my throat. My first disappointment came fast, though, because the stomach tube didn't work, so they stuck the old kind down my throat again. I also had another new tube inserted near my heart that somehow fed me, so now I had two tube systems to roll along with me when I went walking.

Two of my best friends came to see me that day, unfortunate timing for them. They'd gone online to get me more information on adhesions, and in a lighthearted gesture, they included some articles speculating on a connection between human abdominal problems and aliens coming to earth. They had no way of knowing how sick I was, or even that I'd

had a second operation. Their good humor only reminded me that the world was going on just fine without me. I felt alone, afraid, and with absolutely no control over my predicament—three of the feelings I hate the most.

I went through a series of despondent thoughts, wondering if they were fair or over-dramatic. It occurred to me that I was hooked to machines that were keeping me alive, so that essentially meant I was on life support.

Also, the stomach tube continued to confound me. Fluid would stop filling the jar, so then nurses optimistically took out my tube. Then I'd vomit and they'd put it back in—always trying to say something hopeful while they did. After a while, I lost track of what was real hopeful and what was made-up hopeful. Once, about four in the morning as I headed into sleep, I remember thinking, "This is what it feels like to die. You've lost track of reality, your body has stopped, and you're not pulling off one of those great, spunky efforts to save the day."

Mom would occasionally call my hospital room, for a short, one-sided conversation because I couldn't talk, and I loved her gesture to stay connected. Most of the time, she sounded groggy and I assumed it was all the pain medicine. One day, Trisch said Mom had had her photograph her after all her hair had gone, with a shiny, bald head. "It's for my story that H.J.'s writing," she told her.

David struggled to know what to tell people about me, because there were no developments. I wasn't getting worse, I just wasn't getting better. So, he relayed any detail he could

think of. That I'd gotten some nice flowers that day from my boss. Or we'd taken a walk through the hallways together at night. Or he'd brought me a change of clothes.

I think that's why Leah was stunned by news of the second surgery. She felt she'd had no clue that I wasn't recovering. So far away, she started to imagine the worst instead of the best.

I kept up with Mom's developments as much as I could, through what I suspect were shielded accounts from David. By now, he said, I looked so full-time afraid and lonely that he wanted to tell me only good things.

Then, almost two weeks after the second surgery, my intestines started to work. Unpredictably and painfully at first, but at last bile was coming out of the appropriate orifice. I was reluctant to trust in my recovery, especially because I threw up everything I ate for the next two days. But it didn't seem to worry the doctors, who sent me home on September 14—twenty-seven days after I'd gone into the hospital.

I threw up most of my food at home, too, for a while. I held off telling anyone, for fear I'd have to go back into the hospital. Then, gradually the yogurt and chicken broth started to stay down. My throat was so sore, but at least I could talk again. Mom's last radiation treatment was September 11.

I couldn't stop thinking about death. I obsessed over the news that an eighteen-year-old sailor on the USS Cole was killed in the terrorist bombing in Yemen. I tried to turn mortality into a question of math. Is it fair to die at eighteen? No way, I decided. What about forty-nine—my age? No, but lots of people do. That's probably the life expectancy in some

countries, I told myself. What about seventy-five—Mom's age? Eighty would be better.

On Friday, September 22, Mom asked to be checked into the local hospital. She was down to 106 pounds. Dr. Vahle put her on IVs of potassium and, I think, glucose. The next Monday, about four thirty in the morning, Mom couldn't catch her breath. Dr. Vahle tried a series of drugs to regulate her heart-beat, and steady her breathing, with only limited success.

I talked to Mom on the phone that night. "I'm always out of breath," she said. "Well," I told her, "the doctors will have to figure that out for you."

Those were my last words to her, and I will always wonder if I said the right thing. I was still colluding with her expressed conviction that she would recover. Did she now want someone brave enough to talk to her about death?

Barb drove to Seward the next day to be with Mom. She got to the hospital just before noon. Mom was in a restless sleep, agitated and uncomfortable, waking to pull a sheet up one minute, then kick it off the next.

Dr. Vahle came to Mom's room to tell Barb the results of a new x-ray. Mom's heart was compromised, and the tumor was unfazed by all the treatments. Mom then became alert, and in a characteristic move that still makes me smile, she again asserted herself: "Van, you're mumbling. Come closer so I can hear you." He leaned to tell her, "I'm sorry, Rose, but the treatments didn't do what we'd hoped. I think we should start thinking about hospice arrangements."

It may just be a daughter's futile effort to comprehend

death, but all three of us think that's when Mom decided to give up the fight. On the bedside monitor, her heartbeats spread farther and farther apart until they stopped. Her breaths followed.

My big sister was with her the whole while, telling her how much we loved her, and holding her hand.

Barb called me that night. It had fallen to her to carry out Mom's wishes to donate her eyes, and to be cremated. I got clearance from my surgeon the next day to fly, and went down to Seward the following day. Trisch came about the same time. It was good to be together. We laughed as much as we cried, telling Mom stories.

We buried her in a bright purple cloisonné urn, in honor of her love for exuberant color, next to our father, in a family plot north of Seward.

I came home for another month's recuperation. One day, David's pastor, Russell Rathbun, visited me. We'd never met. I remember my part of the conversation as basically: "Come in. Would you like some tea? What is the meaning of life? And excuse me while I cry through this entire conversation."

When he gave me his view on life after death, I realized it was the only answer I could have accepted. He said no one really knows for sure what happens when you die. But he finds life, basically, to be a good thing. So he figures that whatever the great force behind the universe has in store for us next, it will be basically good, too. I appreciate the logic in his answer. And it dodges uncertainty, something I handle badly. His answer is uncertainty, but not quite.

Over the next few weeks, I felt better. Each day my naps got shorter and my walks got longer. I spent some time looking for any possible way to avoid getting sick again. There is none. It may happen again, it may not. It is as simple and as hard as that. I keep checking with my surgeon, to see if medical science has found anything new. So far, nothing. I've gotten copies of my medical records. The notes after my last surgery say "re-exploration for a bowel obstruction would be a horrendous undertaking." I find it hard to believe I would survive another episode.

I try to think what Mom would say. What comes to mind is a story she told me about a woodpile falling on her neighbor's truck in Seward. Cheryl didn't know what to do, but Mom just started in on the logs.

"You gotta start at the top," Mom told her.

"How do you know that?" Cheryl asked.

"I've dug people out of bomb shelters," Mom said. "You can't work any other way. You just have to start with the top rocks and work down until you're finished."

That was my mother's matter-of-fact way. You do what you have to do.

So, about my illness I think she'd tell me, "Stop feeling sorry for yourself."

That's that gasp of hurt she could always give me.

She'd also say, "Stop thinking about it. There's nothing you can do about it, anyway."

And I think: That turns out to be good advice, Mom. You're right. I'll try.