



The late Mary Daubenspeck was many things—a dog lover, a sailor, an antique-car collector. And, above all, a writer. When she died in March of 2001, she left behind 17 volumes of personal journals. They contain descriptions of nature’s unfolding glories, mundane but telling details of her daily life, and philosophical musings. And the last two chroni-

Daubenspeck’s byline has appeared in these pages many times—including on a Winter 1999 feature about Dartmouth’s palliative-care program. This feature is condensed from the last two volumes of the personal journals she kept her whole adult life.

cle her final struggle, physically and psychologically, with cancer. She had been successfully treated for cervical cancer in 1976 and breast cancer in 1991. In 1997, she was diagnosed with colon cancer and had an ileostomy—an operation in which the large intestine is removed and an artificial outlet for the bowel is created in the abdominal wall. Then, in March of 2000, her colon cancer recurred. In July of that year, she wrote in her journal:

“I am told it is useful for one to draft one’s own obituary, at some point in one’s

later life. The admonition has been nagging at me, so here goes with this egotistical and presumptuous exercise:

“Mary E. Daubenspeck, 5?, died yesterday at her hillside aerie in Lyme Center, N.H. To the last, she was buoyed by the unfailing support of her five brothers and her mother and strove—as a Bryn Mawr English major—to leaven life in her engineering-oriented family. . . .

“She counted among her treasures her strong faith and her many friends, not to mention her collection of boats and antique



One more byline

By Mary E. Daubenspeck

Nauset Light, a beacon for sailors, and Daubenspeck's beloved Keeper's House.

wheeled vehicles. She was a staunch protector of the 1875 Keeper's House at Nauset Light Beach on Cape Cod, which she'd owned since 1982. An enthusiastic and inquisitive freelance writer, she wrote frequently for Dartmouth's graduate school publications, deriving great pleasure from making complex subjects entertaining to ordinary folk like herself. . . .

"She is survived by her mother, Eleanor; five brothers—Josef, Andrew, Timothy, Peter, and Stephen; many nieces and nephews; and her loyal Labrador retrievers, Clipper and Polly, and adopted stray cat, Toby. They grounded her independent life in

simplicity and love and taught Mary the precious art of living in the present.'

"There. I did it."

Daubenspeck's brother Andrew is a professor of physiology at DMS. A year before Daubenspeck wrote the passage above, her brother's wife, Sarah, was dying of pancreatic cancer. It was July of 1999 . . .

Tuesday, July 20, 1999: I drove back from the family reunion in Pennsylvania with the pups and arrived home to a wonderful welcome from Toby. I phoned Andy and Sarah and learned they'd spent much of the weekend at DHMC, trying

In which a writer chronicles her final struggle with cancer—illuminating a stormy course but elucidating what really matters in the human condition.



Daubenspeck is pictured above in July of 1999, at the time these journal excerpts begin, and below with her canine companions Clipper (left) and Polly on the steps of Nauset Light.



to sort out the toxic effects of accumulating morphine metabolites, which Sarah's failing liver can no longer process. They are focusing now wholly on getting Sarah in good enough shape to make it to Cape Cod for her daughter Gillian's wedding on August 5. Mother said, "Remember when Dad's liver began to fail; it all went quickly from that time on." It certainly did. I hope Dad is on call to guide Sarah out the other side of this final tunnel.

Thursday, July 22, 1999: I am appalled by my dear sister-in-law's slide down the slippery slope that separates the quick from the dead. Sarah asked me to help her decide how to finish the two granny quilts she has cro-

cheted for her kids, each containing 80-some lovely painterly hued squares. One was already pieced, but the other was several squares short. What to do about it was the question. Drop the "extra" squares, I said. Enough is enough. But I sensed the root of this opinion: I knew it meant "Hurry up and finish them while you can."

Outside, a mist hangs over my hill and valley view. I cannot make out anything past the pine tree at the patio, although a bird warbles its watery songs from the middle distance and a car's tires sing along the Dorchester Road.

Wednesday, July 28, 1999: It seems so incredibly, incongruously ordinary to be sitting here at the service station, awaiting a minor repair to my 240Z, on a day when life and death are being equally entertained at Andy's. It is, after all, just another summer day to almost everyone except us.

Last night, Pete and Mary, Tim and Alice, several of their kids, and I took dinner over to Andy and Sarah's. I have a feeling we'll be gathering together again very soon. I hope we'll make it to the wedding first, but it may not unfold (or is it unravel?) that way.

Tuesday, August 3, 1999: This is my third day as a member of the vigil team encircling Sarah's bed as she awaits her turn to cross the divide between this world and the next. The visiting nurse called to our attention the far less frequent frowning of Sarah's brow, indicating acceptance. Yesterday, Sarah told Gillian she was "ready to die now."

Saturday, August 14, 1999: (Cape Cod) On Thursday, Andy organized us for a deep-night trek to the beach to gently return some of his dear wife's ashes to the ocean she wanted so much to return to while yet alive. Then we walked wordlessly back to the Keeper's Cottage and went quietly to bed. Ten days ago, there was to have been a wedding here. Instead, nine days ago there was a death.

Tuesday, November 2, 1999: I'm sitting on 3 West at DHMC, quaffing Tang-flavored contrast medium. It's time for another CT scan of everything but my limbs. Just entering this end of the building brings back so many memories of Sarah's ordeal that it evokes another emotion: anger. I didn't know it was there, but I'm angry—mostly because Sarah

lost her life to this thing. And partly because I have a sneaking suspicion I'm going to be walking that same road soon.

The monstrously long article I wrote for DARTMOUTH MEDICINE is done. I look forward to the upcoming season as one of constructive hibernation. I have decided to take on no new writing assignments, but instead to spend the winter reading and writing for my own self.

Monday, February 14, 2000: It has been an age since I wrote in this book, it seems. January was spent trying to get the Trophy 250 motorcycle I allowed myself to buy, over the Web, north from Florida; it finally arrived and now resides—handlebar-less, battery-less, speedometer-less—in my frigid garage till the weather permits work out there without gloves. For at least a fortnight, the mercury hardly rose above single digits before quickly plunging back below zero.

Thursday, March 9, 2000: In the space of a single day, everything changed. *Everything*. A week ago, on March 2, I headed out at 10:00 a.m. to visit Mom. My next stop was the copy shop. Thence to the P.O., the River Valley Club Nautilus room, the Co-op sandwich counter, and the Lyme firehouse.

I skipped dinner for lack of time and appetite and picked up Anne Harms at 6:30 for choir practice. I noticed a localized discomfort on the left side of my abdomen, but it had occurred before and not disrupted my activities. On this night, the pain worsened. As I dropped Anne off at 9:30 I wanted only to hie myself home to bed with a couple of gas tablets—which did nothing. By 11:30 I was in pretty bad pain, and at 12:30 I watched my lunch go down the drain. The situation deteriorated until 3:30, when I knew I was not going to make it till 8:00 a.m. to call Rick Barth, who did the 1997 ileostomy. I was going to have to drive myself to the emergency room while I still could. I let the pups out and in, rewarded them with biskies, and left for the ER.

Just placing myself in professional care relaxed the agony a notch, and it was soon clear I was where I ought to be—suffering a near-complete obstruction of my small (and only!) intestine. It seemed likely to be a postop adhesion, but only surgery would tell.

Andy reported to the ER as soon as he could. They had pushed my whole damn bed

over to the ER wall phone to let me call him, and a neighbor to pacify the pets till he could—bless his heart—fetch those of the canine persuasion to his house. By noon I had been assigned a room and was on the surgery schedule for 9:30 Saturday morning, ruining any number of people's weekends, in addition to my own.

I also was introduced to a urologist and her entourage who'd been added to my medical team to address a slight ballooning of the right ureter, probably in reaction to some constriction downstream—perhaps some scar tissue from Rick Barth's Great Evisceration of '97.

I remember little more from before the surgery, except that it seemed depressingly easy to banter with the orderlies and anesthesiologists and, at last, Rick himself as I was dispatched into oblivion. Barth's face gathered size and seriousness as I heard his voice enter my postop consciousness. I don't remember his words exactly, just the grayness, disappointment, apology in them: the bowel was obstructed by having been looped and tacked to the lining of the abdominal cavity (the omentum?) by one of many one-eighth-inch diameter pellets of recurrent colorectal cancer now peppering said lining. Not only were they too small to have been seen on a CT scan, they were also too numerous to remove. This was not the recurrence I had hoped for—a nice, neat tumor sitting up off the surrounding tissue like a golf ball waiting to be dispatched. This would be a case for chemotherapy, one of the cancer treatments I've not yet had the pleasure of experiencing. Barth said he'd confer with oncologist Marc Pipas ASAP.

I heard everything that Barth said, and I didn't. For the next 48 hours, I heard the same things again—sometimes in my memory, sometimes written in balloons over doctors' or nurses' heads. Sometimes I would awake from a deep sleep in which I would, for several moments, sustain the illusion that I had only dreamed them.

My poor middle felt as if my body had been hung by my abdominal muscles, like a jacket from a locker loop. Could it be that just three noons earlier I had been at the River Valley Club exercising these muscles at a personal-best level of 55 pounds?

"Your general good health, strength level, positive attitude, and will will serve you well in this," I was told by many people. Pipas said



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on Tuesday that these factors practically assured me (not his word—he's too circum-spect) better-than-average results from the protocol he has chosen for me: six once-weekly injections of the two standard chemicals used in this kind of recurrent colorectal cancer, followed by a two-week rest and then a CT scan and a CEA (carcinoembryonic antigen) test. As wacky as CEA numbers can be in tracking recurrence, for the individual they are useful reference points. Mine have always risen—from 3.9 one year out to 7—something to 17 to 45 to 123 to today's 313! The CT scan won't show diminution of treated tumors but will assure us of no new or enlarged tumors.

On Sunday afternoon, several friends visited, hymnbooks in hand, to sing for me two of the hymns from that day's service.

Monday, March 13, 2000: (1:45 a.m.) I think I heard Dr. Pipas say that my odds without treatment—including failed treatment—are to last six months before these evil BBs paste my innards together for good and/or proceed to some other site. I think he said that with treatment—successful treatment, that is—we can knock my CEA back to normal (from 313 to 3.5) and halt progress elsewhere. And that the odds of this with the chemo he's prescribed are 35% to 40%.

At 1:45 in the morning, this sounds awfully slim. I know Pipas said if the first barrage doesn't work, we have other matériel to bring to bear—though presumably we'll be starting out with our best shot. But each person's cancer is different. Each person's response is different.

Here are the things I have against me: (1) The cancer has recurred. (2) It's nonoperable because it's small and scattered. (3) It's likely to recur again, even if the first round of treatment is successful.

But here are the things I have going for me: (1) The cancer took two and a half years to come back. (2) It was caught early and is

small. (3) It finds me in generally very good health. (4) There is well-tolerated chemo, proven effective in some double-digit percentage of patients, that we can throw at it. (5) I needn't leave my home base and all my support systems to follow the most promising course of therapy. (6) My oncologist has a national reputation and can provide for me any agents or protocols possibly useful in this war. (7) My personal will is limitless. (8) I have enviable support on all fronts, not just the medical one; so many friends and family are praying for me, God may tire of hearing my name! (9) There are some known cases of remission of this disease. (10) I am going through this in springtime.

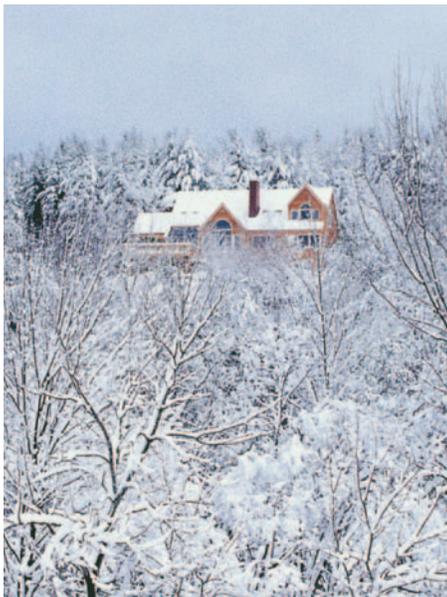
Tuesday, March 14, 2000: I feel like I have a sharp stick in my side. It is, however, only a rubber tube attached to my stomach and exiting my abdomen at a place where the stomach has been stitched to the abdominal wall. The idea is to leave it there for a few weeks while the body grows a "collar" of tissue that defines a pathway for the easy installation of a gastric tube, in case one is needed again. If I experience another intestinal blockage, between now and whenever chemotherapy renders those evil BBs harmless, a handy port will mean I needn't have a nasogastric tube—something to be avoided at all costs, even a few weeks of spear-in-the-side pain.

Wednesday, March 15, 2000: I am home at last. It feels right to return to the room where this diversion began with such an agonizing night some 13 days ago. How I survived nearly two weeks without Toby and the pups is a mystery to me.

Stephanie Carney, who was Toby's caretaker in my absence, stopped in for tea and promised to return tomorrow with a foot-massage kit. Touch, she says, is key to healing! Who can argue with that? I mustn't dwell on the power this disease has over me,



Pictured here in wintertime are the two places Daubenspeck loved most—above, the Keeper's House and Nauset Light on Cape Cod, and below her "aerie" on Acorn Hill in Lyme Center, N.H.



or I feel myself quailing in its path like some poor, dumb night-blind animal.

Thursday, March 16, 2000: This morning, I tapped my reserves early and did not find them lacking. Sufficient were they, in fact, to enable me to shower, shampoo, change my ileostomy apparatus (as I do weekly), do two loads of laundry, tend to the g-tube, and fix a smoothie—all between 7:00 and 9:00.

Against a tired old backdrop of snow and mud-melt, the birds are hinting—in numbers and in new, brighter songs—that spring's official arrival next week is not a figment of our collective imagination.

Now if only I weren't putting out a bright red ileostomy product. Maybe I pulled an in-

ner stitch. Or maybe it was caused by my overactivity (did the laundry really need doing, or was it the attendant illusion of being fine that I was intent upon?).

Friday, March 17, 2000: I told brother Steve how neither Andy nor I can remember the name of the second chemotherapy agent I'll be getting, but how we've decided it's better not to try to micromanage my program. When your job is to get through an unlit tunnel with a beast breathing down your neck, I think you'd best just put your head down and run—instead of trying to find out why the lights are off or the tunnel's so long.

It astounds me how many viewpoints about this recurrence I can have simultaneously. The opposites mock each other in a self-canceling feat. How can I consider both the possibility of hiring a painter for the Keeper's Cottage and the possibility of never enjoying the place again?

Tuesday, March 21, 2000: Now sustained above only minor pain by a middling dose of ibuprofen, I feel on my way out of this pit. And just in time for my oncology planning session with Marc Pipas and his assistant, Louise Meyer. Andy was by my side again today, "because four ears are sometimes better than two" when a lot of info is being transferred. Here's what of it I can remember. (I feel like a phony, with everyone seeming so awed by my attitude, when underneath I am a five-year-old injured child sitting bawling my head off on the toilet seat, asking Dad to "kiss it and blow it and make it better.")

There's less than two ounces of tumor material, scattered like mold on bread, on the peritoneal lining of the abdomen. It can paste itself to the intestinal tissue and cause blockages by scarring the intestinal wall or instigating other tissue reactions that narrow the passageway.

The agents against this infestation will be 5-fluouracil (5-Fu) and leucovorin, given in infusions once a week (on Tuesdays) for six weeks, after which I get two weeks' rest and a CEA test. Then we'll repeat the cycle, and after a two-week rest do a CT scan. We'll follow this 16-week schedule twice and see where we are. This protocol has been successful in 20% to 40% of the cases of this rather unusual kind of colorectal cancer recurrence. Andy cautions me to remember that in these seemingly not tremendous odds

are people who had far more tumor mass than I do, who did not catch the recurrence early, whose health was not good—in other words, who did not have everything I have going for them. Marc even has a patient whose cancer has vanished with this treatment, not just been knocked down.

The main side-effect is mouth ulcers, because the rapidly proliferating cells in the mouth and throat will also be targeted by the chemo-agents. I won't lose my hair (though that's not important to me; I'm funny-looking enough as it is, why not be bald, too). I gather n+v (nausea and vomiting) isn't a huge problem, though there may be some diarrhea. Lucky me to have an ileostomy to neatly manage that eventuality. (See how quickly a blight becomes a blessing?)

Marc will be glad to discuss my case with anyone I want him to or to have me seek a second opinion. He also said he'll keep his antennae out for anything new that he thinks would help. I mentioned our Philadelphia friend John Glick, head of oncology at UPenn, whom I've been thinking of asking to review my case; Marc said he'd welcome that. Andy feels no one would offer such broad consultative service if he weren't at the top of his field. So this evening I called John Glick; he thinks I'm steering the right course and is happy to call Marc. He did mention a third chemo agent that could be added later on—oxaliplatin—and a new one coming along soon—CPT-11. None are curative, he said, but they may give me more time. I felt better for making the connection.

Wednesday, March 22, 2000: I called my wonderful support person, Alison Scully, this morning to complain about my stomach drain—how sore it is and how disgusting the exudations from the hole in my belly: I look like a biology experiment, for heaven's sake! But in complaining about the g-tube, I may be confusing a detail with the overall sentence. Perhaps I am only expressing my despair at the sad immutability of what I'm facing. I let the shower water run over the irritated site. Then, drying my belly, I move from ileostomy to incision to gastric tube and wonder if I ever showed enough appreciation for my once-pristine abdomen—unscarred, untapped, undrained.

Tuesday, March 28, 2000: (First Chemotherapy Session) After the past few days' glo-

rious sunshine, this morning was a rude awakening: 30- to 40-mph winds and torrential downpours. But I chose to see the *Sturm und Drang* as external and transient. Step one in orienting my attitude toward this somewhat ominous day was completed.

Then, at the point in my shower when I wore maximum suds, the lights flickered, threatening to put a kibosh on my “best foot forward” effort. Wouldn’t I have been in a sad situation if the power had not immediately returned! A second omen, thought I, gratefully rinsing.

Judy Russell came for me right at 8:30 and we headed to the Norris Cotton Cancer Center, I fortified with Percocet to prepare for the removal of the torturous g-tube. But Rick gave a hearty tug and out it came. Then it was on to the Main Event: the infusion of the chosen poisons. I was given a seat in an alcove fitted with four recliner chairs and IV poles, plus big windows to the outdoors and strings of colorful origami birds streaming from the ceiling.

When my two hypodermic syringes arrived, nurse Jean Namois handed me a cup of ice chips to suck on—to slow the blood flow to the mouth, where the more potent agent can cause ulcers. Starting with the leucovorin, she slowly pushed the syringe contents into a vein in the back of my hand.

“Leucovorin, leucovorin,” I wondered, “what could that connote?” Then it was obvious: Saint Luke, the Great Physician, whom I welcomed into my corpus with everything I had.

As I crunched on the ice chips, it occurred to me to visualize the icy-cold rivulets that jump off the hillside by my driveway at this time of year, rinsing down from the deep woods above. I imagined that cold, clear water swirling around in my abdomen and bathing the spots of cancer in poison, loosening their grip and shortening their stay.

The second syringe contained the 5-Fu. Funny: from St. Luke to this, the sacred to the profane. As I watched the fluid begin to enter my hand, I said to myself, “Well, FU, too! In fact, FU5!”

Wednesday, March 29, 2000: I feel so weary. Who knows if it’s physical or emotional, postchemo or postsurgical—and who cares. Only time will tell what the pattern of this chemo-anchored calendar will be. I feel like a prisoner in a Third World country, vis-



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ited and momentarily cheered by American envoys, then left to serve my sentence.

Monday, April 3, 2000: Yesterday I was delighted to have four simultaneous African iris blossom openings (and closings, alas—they last but one day). And a geranium on the porch decided not just to bloom, but to explode with blossoms: 22 of them. In this season of renewal, how can I not see promise?

Old pal John Glick called today to say he had spoken with Marc Pipas and the two of them have decided, on the basis of yet unpublished studies, to add CPT-11 to my weekly infusion, starting tomorrow. This, I thought, was an agent we were going to hold in abeyance for use in the future. Is my case so desperate that we can’t wait? Or does it show such promise that we don’t want to wait? And must I know the answer?

Wednesday, April 5, 2000: Judy Russell delivered me again to the Cancer Center yesterday. I can’t imagine how many Samaritan points she earned. When I got home, I took the pups on our daily walk for the mail. At the top of the driveway, I noticed that my daffodils are up: more good-omen material.

Wednesday, April 12, 2000: Yesterday, I drove myself in for chemotherapy. As the infusion began, the sky began to lower. Where is my dream of a healing spring?

Monday, May 1, 2000: The weather outside vacillates from late winter to early spring—stalling at times in one camp or the other.

Inside, it is a similar story: I was admitted to the hospital on April 17 after a near-fatal reaction to my second treatment with 5-Fu, leucovorin, and the wickedly strong CPT-11. The night before, neighbors—nay, angels—Stephanie Carney and Lynn McRae had sat by my bedside till very late, forcing me to drink small bits of fluid and monitoring my temperature. When Steph came by

the next morning, she pretty much plucked me out of my bed like a dry leaf and drove me to the heme-onc clinic. We were ushered right into the infusion room to begin rehydration. It sounded like a simple task, but I’m still here 13 days later!

Wednesday, May 3, 2000: I’ve been held captive by data points that wander randomly back and forth across lines meaning this or that, good or bad, possibility of release or not. I’m now off antibiotics and IV morphine—a lulling drip that sustained me for two weeks. Instead, I swig a half-ounce of morphine elixir every eight hours; the horse that planted its hoof on my sternum each time I swallowed has lost weight. So I’ve talked them into letting me escape to Andy’s this afternoon. Providing my temperature and electrolyte balances remain normal, I needn’t come back here till Tuesday, at which time Marc Pipas and Andy and I will review the game so far and plot the next innings.

Wednesday, May 10, 2000: The plan is to set aside the benefits of the CPT-11 because of its risks for this battered and sensitive corpus and to continue with 5-Fu and leucovorin. Perhaps later we can try a course of just CPT-11, as it is reportedly better tolerated on its own. I hope that won’t be necessary. CPT-11 scares the bejesus out of me, as wondrous as it may be. I seem to have devolved from a fairly acute, purposeful human being into a pawn of a patient—slewing from pillar to post in response to physiological prompts randomly bestowed by some distant power. Will my life ever be mine again? Yes, it surely will.

Wednesday, May 17, 2000: Yesterday, I had a conference with Marc Pipas. We decided on another week of healing and strengthening before I start again with 5-Fu and leucovorin. They’ll fortify me against n+v with IV Zofran and Decadron to hold me for the



Daubenspeck was proud of having completed the Hurricane Island Outward Bound course; she's pictured above in a shirt from that experience. Below, she celebrates her birthday in 2000.



first 12 to 24 hours. And they agreed to give me a Zofran prescription so I'll have the pills by my bedside, instead of having to call in for them as needed. I look forward to returning to a pattern like I experienced with the first treatment in March—two or three days of tiredness (not wretchedness), followed by four days in which I can live normally and eat reasonably.

But the huge news is that I am now at my own abode! I will miss Andy's company and many kindnesses, but I know he deserves his own space back, as do I. Actually the dogs will miss him immensely, as he threw the ball for them day and night and lavished them with biskies.

On this perfect spring day—with every-

thing looking like a calendar photo, especially my white-blossomed crabapple—I could not have been anywhere else and felt so happy. I really do have my roots transplanted into this hillside soil. As if just being here were not joy enough, at noontime up the driveway comes Michael Whitman to set up my Trophy 250. What luck that I was here, so I could witness the installation of the new battery and the firing up of the slug-a-bed engine. A few weeks ago, I'd peered into the garage at the bike and said to myself, "What on earth were you thinking, Mary?" But today I say, "Why shouldn't I have a few more motorcycle memories before I quit?"

Tuesday, May 23, 2000: This morning we began chemotherapy all over again—with just 5-Fu and leucovorin. Maybe we'll make progress more slowly, but I am certain we'll make progress. In six weeks, we'll decide how to proceed from wherever we find ourselves. Meantime, I'll just be right here, right now, enjoying what I have.

Wednesday, May 24, 2000: Lord, forgive me my amazement, but on this first day after a chemotherapy treatment, I have just had a shower, done laundry, and eaten breakfast and lunch without so much as a hint of nausea. Why am I astonished when a prayer is answered?

Tuesday, June 6, 2000: I'm sitting in the hematology-oncology reception area waiting for my routine interview with Marc Pipas and Louise Meyer. Sometimes it seems that I am going through this cancer experience as a fact-gathering assignment for an article I'm to write. As such, I seem to be both outside and inside the experience at the same time. I imagine—no, I act—as if I can escape and return to my former comfortable normalcy: to the me who considered herself a cancer survivor, not a victim, just a few short months ago.

Tuesday, June 13, 2000: On Friday, I drove down to the Cape for the first time since The Bomb landed in my life. But where is the summer we're supposed to be easing our way into? It's been cold and rainy since April. I feel the grayness in my soul.

Wednesday, June 21, 2000: My birthday. Instead of my thoughts running to presents,

they run to wondering if I'll see another birthday. This new proximity to a likely early exit hangs like a vapor over every aspect of my life.

Yesterday I went in for treatment number five of my six-treatment cycle, and I learned how thin is the veneer of courage and equanimity that I present to the world—and myself. At the blood-drawing (done before each treatment to see if the corpus can stand another whack), a dull needle ripped a hole in the wrinkly, dry skin on the back of my hand—and in my fragile psychological skin. I nearly burst into tears; there's so much pressure of fear just below the surface.

I discussed my symptoms with Marc Pipas, and he prescribed an appetite-enhancing drug (\$200 for a two-week supply) and an antidepressant (Zoloft—\$80 for 30 tablets). I'm seriously considering returning the drug that's supposed to restore my appetite. Okay, so I have lost 10 pounds in a month and a half, but is that any reason to advance me toward my lifetime health-insurance limit? I have a hard time voting with my dollars for a system run amok.

"Nonsense," says Andy. "If you need the drugs' effects, you have to swallow your frugality with them."

"But it's the principle of the thing!" I cry.

"Principle, schminciple," says he.

Tuesday, June 27, 2000: Und zo, to add drama to this boring book, I am back in the hospital again. It was an awful Sunday that landed me here. Brother Steve was visiting, and we set out to fetch the VW and the Datsun from their winter resting places in Michael Woodard's barn. Just past Palmers', I gave another truck too wide a berth, slammed into a boulder in the gutter, and ended up with a blown tire and a ruined rocker panel. Poor Steve had to figure out the Explorer system of tire replacement, and I was of little or no help. Luckily, Michael stopped by en route home from the dump and helped us get back on track.

Later, Steve made me some of his famous scrambled eggs, but three-quarters through their deliciousness I lost everything. At 4:30 (or was it 7:30?), Stephanie came by and I was as flat as a roadkill pancake. I don't make good decisions in a weakened state (I now know), so I deferred to Steph's far better judgment and phoned the on-call oncologist, who said that I should come to the ER. Steph

took me in and stayed till 11:00 p.m., when they decided to admit me.

So I'm now getting lots of rest and regular mooshy/liquid nutrition. Everyone in a position to know says it was a good thing I came in when I did. I understand it's not unusual, and that makes me feel better—it is so easy to feel that I'm the only one failing this course, while the rest of my class is at home doing just fine, thank you, in the fifth week of a six-week cycle. (Well, this got me out of the sixth whack, didn't it? The lengths to which I will go . . .)

Steve and Mom have helped me see that someone other than me needs to be in the driver's seat now. (Doesn't my crash on Sunday tell me that?) I thought I had given up control already, but I guess I haven't. Steve gave me another good insight: the need to separate what is due to the disease and what is due to the treatment, because the latter is just the cost I've agreed to pay to defeat the former. That is enormously reorienting.

Wednesday, June 28, 2000: Marc says I can go home today as long as I promise not to give in to my tendency to minimize my symptoms. We now await the result of the latest CEA test, which will tell us if all this perversity has been worth it. I have to believe that it has.

Friday, June 30, 2000: Marc phoned to give me bad news: my CEA level is now rising rather than falling. We started at 313, went to 289, then to 110, but now it's at 189. The conclusion is that if 5-Fu and leucovorin plus CPT-11 worked (even though it almost killed me), and if 5-Fu and leucovorin don't work, then CPT-11 must be the agent my cancer is susceptible to. So we will resume chemo on July 18 using CPT-11 at some reduced dose that I can tolerate. It's depressing news. But choir practice this evening brought me back to the present.

Monday, July 3, 2000: Last night Andy and I went to the Quechee Polo Field to hear the Vermont Symphony Orchestra—finishing with Tchaikovsky's 1812 Overture and a fabulous fireworks display! The sky was a purplish gray by then—a great backdrop for the pyrotechnics. We drove there and back in my Z3, with the top down!

I'm a little concerned about a tiny hint of double vision I seem to have developed—to



If God wants me joyful, all He has to do is give me endless days like these last few. Not only have they been picture-perfect Cape Cod summer days, but yesterday several friends got my 16-foot pulling boat in the water. By evening she was at her new mooring.

go along with my very, very slight aphasia, which causes me to halt a sentence abruptly to evoke the right next word. Sometimes the word is there, it just won't come out. Other times the word in the chute is the wrong one. Only a few friends (one?) have noticed and only (they say) because they are used to my fluent, non-stop articulateness. (We are so modest.) Andy tells me not to worry—it's not brain cancer; it might be due to the Zolof, which Andy says is working. I guess I'll just report it and forget it.

Yesterday I sang with the choir for the first time since March 2. It was like coming home, though it took all the breath I had.

Friday, July 7, 2000: (Keeper's House) If God wants me joyful, all He has to do is give me endless days like these last few. Not only have they been picture-perfect Cape Cod summer days, but yesterday several friends got my 16-foot pulling boat in the water. By evening she was at her new mooring among other, lesser craft—even the lobster-boat owner said she was the prettiest boat in Horseshoe Cove.

I've been meaning to do this for a while now—though it seems less humorous than it used to—and that's to write down the ironies of my situation. Here goes (in no special order): I wrote a huge, well-received article for DARTMOUTH MEDICINE about the Cancer Center's new palliative-care program—and within a very few weeks of its publication I was a participant in the program. I still take my daily anti-osteoporosis medication—even though it's a pain to take and I've been given “months” to live; but I like the life-affirming aspect of this action (at the worst, I'll die stronger in the bone). I bought a motorcycle that I'm too weak to hold upright; fortunately, I bought a lighter one that I can handle. I go get my regular mammogram and have continued to be judged “cancer free” since my 1991 bout with breast cancer—then I go get chemo for my colon cancer.

Sunday, July 16, 2000: Yesterday was the annual family reunion in Pennsylvania. It is truly life-affirming that all these people convene willingly, never out of obligation, to spend a day associating in a most loving way with each other. I am surprised at how close to normal I feel. I even had enough energy to try the batting cages. The aluminum bat made my hands and wrists hum, and a fouled ball off my left foot made me realize why major leaguers wear ankle protectors (OUCH!). But I did well for an old lady with double vision: I hit all but one softball and all but three hardballs.

Tuesday, July 18, 2000: During my three-week vacation from chemo, I feel like I used to: I haven't taken a nap in a week and had some very full days during the past week away. I feel I can walk into the Poison Parlor tomorrow standing taller than I have since this all began in March, though I must get back in harness again with an unknown teamster cracking the whip: CPT-11, the wicked wonder drug.

Thursday, July 20, 2000: The good news is that the CPT-11 will be administered once every three weeks, which I hope means I can return to normal between each 300 mg dose (as opposed to a normal dose of 350). After each infusion, I'll go into the Clinic for the next seven days to receive injections of a white-blood-cell-promoting drug and a powerful diarrhea-preventative. The latter must be given twice a day, so I guess I'll have to learn to give myself one daily injection.

Marc's scheduling me for an MRI of my gray matter to be sure the cancer isn't there, too. He says that's very unlikely; I think it was my reporting the now-and-again micro-aphasia that made him concerned.

Wednesday, July 26, 2000: Is it an omen or a warning that I laid my little Honda down in the driveway this morning? I plan to take



Family gatherings meant a lot to Daubenspeck. She is pictured above (in the red hat) at Christmas dinner in 2000 at her brother Andy's and below (left) with her brother Steve's family.



my motorcycle driver's test later today. I hope my bruised shoulder (and lacerated-through-clothing right forearm) will be up to shifting.

But tomorrow, after my 4:30 brain MRI, Alisa will drive me and the pups to the Cape, tra-la. Relaxing at the Keeper's House. Messing about in boats. Eating lobster and bluefish. I can hardly wait.

Thursday, August 10, 2000: Here I sit, awaiting my infusion and the week of shots to follow, but my mind is still at the Keeper's Cottage.

I feel so well on this new regimen. Yes, I did have three full days of exhaustion, but it went away as abruptly as it had arrived, leaving me relatively hale and hearty and with a

fine appetite. I feel so well I am tempted to believe I'm in remission. (Dare I say that?) If not, then I am blessed to be able to enjoy whatever time I have before me.

Two weeks ago I had an MRI of my cranium. (Andy called it a brain search, done to see if I even have one. Ha-ha.) This was to settle the unlikely possibility that my now-long-gone micro-aphasia was caused by the disease rather than the Zolofit. And the envelope, please? I do have a brain. "A rather large one," said Marc Pipas. (Ha-ha yourself, Andy.) And there was no sign of abnormality. A relief, to be sure.

As I wrote this in the exam room, Marc walked in with Karen Skalla, head of the palliative-care program, and assuaged my unspoken fears: He says no one who feels and looks as well as I do should doubt that he/she is getting a beneficial effect from chemotherapy. Evidently disease progression in the absence of chemo efficacy involves noticeable and debilitating effects (the result of chemicals given off by the proliferating cancer cells). Thank God, I have none of that. So we'll continue to believe in miracles, and the wonders of modern medicine artfully applied, and do today's treatment and another in three weeks and then check the evidence via CEA and CT. In the meantime, I'm really buoyed by Marc's assessment of my status.

Wednesday, August 23, 2000: A dozen days of hope-thwarting diarrhea caused by the second CPT-11 treatment, untempered by even Sandostatin and Imodium, landed me in Room 117 at DHMC yesterday. Some days I'd pour out five times more water than I'd consumed. I lost 15 pounds in the 12 days and my blood pressure sank to 86/53. But coming back into this welcoming fold is not daunting anymore: I'm known by name, and I remember more of theirs each time. It's very easy to fall into their bed and their healing routines. I just need to be patient as they try to minimize the ill effects of the barbarous treatment I've chosen as my lifeline from this leaky boat of a body they're towing to port.

Sunday, August 27, 2000: I am still here in Room 117, my sixth day in captivity—held by some osmotic unbalance that has turned my intestine into a rushing torrent, like a storm sewer in a hurricane. This morning I think I notice a change in the right direction—a diminution, however slight, in output.

It's a battle for balance between the effects of this brutal chemotherapy and my determination to squeeze all the sweet pleasure I can out of life. In some ways, these months are among the most appreciated in my life, even as they are circumscribed by limits not of my own making. Odd, that combination.

Tuesday, August 29, 2000: Finally! This morning, something turned my intestinal tide: quality of ileal product improved, quantity diminished. If this progress continues, I can get the heck out of here tomorrow.

Wednesday, August 30, 2000: I am packing my bags so I'm ready the minute all the papers are signed to bolt outta here yet another time. Out there, I will be responsible for minimizing my fluid deficit by drinking water, juice, Gatorade, etc., until I fairly float away. As the CPT-11 toxins that caused this excretory extravaganza melt away, I believe I'll be able to resume my normal life. I'm scheduled for another whacking tomorrow, but I doubt that will happen on schedule. When it does happen, it will probably be at a reduced dosage—reviving the perennial question: if I take less to avoid side effects, will I obtain a lesser therapeutic effect? Each time I risk my life with chemotherapy, I seem to get a nice dip in my CEA level. But is it worth almost dying for? Fortunately, I have entrusted such decisions to Marc Pipas. I don't want to be in charge here. Odd, isn't it—after all, it's the rest of my life we're affecting. I guess I have just found that the best part of "the rest of my life"—however long or short it turns out to be—will be best lived outside the medical realm. If I have trusted, experienced people willing to manage that crucial department, I will be free to live the rest of my life more deeply, more spiritually, more productively.

Tuesday, September 12, 2000: Sometimes when I go through the ileostomy draining drill, a kind of sober resignation overcomes me. I realize I am tired of doing this but perhaps won't have to for much longer. Is this fatalism sent for a preparatory purpose? Or is it due to hearing CEA results that are no longer in single or double digits? Last week's was 380-something. Brother Tim says that's because the cancer took the upper hand while I was laid low by diarrhea. When we restart the chemo, he says, it will respond favorably

again. “We know that the CPT-11 works,” he reminds/reprograms me. And I guess we do—or some of us do.

Tuesday, September 19, 2000: I spent yesterday in the heme-onc clinic getting rid of the assumption that I also have bladder cancer. A late Saturday sign of hematuria worsened till I was excreting beet-juice-colored urine, prompting a pessimism that even Zolofit couldn’t touch. I also had dry heaves, so was avoiding fluid intake for fear of throwing up. I felt trapped by abysmal choices in a wicked downward spiral.

As I lay in a clinic bed getting hydrated, we traced the hematuria to a bladder infection—treatable and perhaps related to the expired life span of my ureteral stent. Marc says I can quit any time it becomes too much for me, mentally or physically. But now that I’ve seen what happens (rising CEA levels) when we don’t stay this course, how can I choose that option? I have to stay with this program in order to ensure myself some good days. If I quit, I slowly sink to a point where I get no more good days. I sense a fatalism has taken up residence on my front porch, oddly paired with my strong attitude of denial that all this is really happening to me—and will continue to happen to me until the end of my life. But underneath all this intellectualization lies God’s honest truth: I just want to lay down my head and cry, cry, cry for the loss of my beautiful, enviable life.

Wednesday, October 4, 2000: Over the past two weeks, I’ve developed a longer-term outlook. Maybe I just got tired of seeing myself as halfway out the egress; that wears hard upon the soul after six months. The first time I noticed it was right after my same-day ureteral stent replacement, a week ago Monday. The doctor (Elizabeth Gormley) told me the manufacturer recommended replacing the Gore-Tex stent every six months. “So,” she said matter-of-factly, “I’ll schedule you for follow-up in five months and replacement in six.” “Fine,” I heard myself say, never questioning whether I would be alive in five or six months. A few moments later, I allowed myself a delightedly surprised reaction to my own lack of morbidity.

Since then, I have found myself cheered by the simple calculation that since last March, when Rick Barth awarded me “maybe many months” to live, I have enjoyed



I believe, despite the last CEA reading and my bantam weight, that I am on an evener keel than I’ve been since March. But perhaps this is a variation of denial—self-preservational inurement to a state one can’t long contemplate without jeopardizing one’s sanity.

(well, mostly enjoyed) seven of them. I believe, despite the last CEA reading and my bantam weight, that I am on an evener keel than I’ve been since March 3. But perhaps this is another variation on the theme of denial—self-preservational inurement to a state one can’t long contemplate without jeopardizing one’s sanity. Nevertheless, it is a far better state to be in.

In the past 24 hours, the colors on the hillside across Dorchester Road have become brilliant, especially against their stolid evergreen neighbors.

Friday, October 6, 2000: Somehow, going into yesterday’s chemo feeling so well, I hoped it would go easier. But I walked out on collywobbled feet. I took a Zofran before dinner, hoping to head off any n+v from the get-go, and promised myself I’d pop another first thing in the morning. But that proved too late. At 11:30 last night, I lost my dinner to a rather violent emesis episode, and this morning I’m not even capable of keeping *nothing* down. I took another Zofran an hour ago and still went through a bout of dry-heaving that left me weak and teary. “This, too, shall pass.” It always does, but on top of learning that my CEA is not going down on solo CPT-11, it seems mighty discouraging—especially on a rainy, windy morning that has drained color from more than the trees.

Thursday, October 12, 2000: Karen Skalla finally solved the mystery of my insurance coverage. Aetna has readily cashed my premium checks but was equally persistent in disavowing my existence to all claimants. I’m in Dutch with the collection agency, which understandably wishes to get some, even partial, resolution of my Clinic and Hospital balances of \$11,000 and \$78,000, respectively. It turns out that Aetna changed the type of my policy (but not the coverage) back in early ’94, and also my ID number, although this fact was not conveyed to me and

nowhere was the new number represented on my claims or premium invoices. So I have been making claims against a nonexistent account for six years or so. Weird. Thank the good Lord for Karen’s persistence in pressing the issue. This has been so wearying, on top of everything else.

Wednesday, October 18, 2000: I am living a strange “life” of no real work but that of medical survival—each day lived close to the bone, close to the loo. But if it enables me to have seen this glorious autumn, then it is worth most any cost. I wonder if I wrung enough appreciation out of it to last me an eternity. I surely tried.

Friday, October 27, 2000: Yesterday morning I was shuffling reluctantly into line at the hematology-oncology reception desk, head bowed, stomach already feeling a tad queasy, anticipating another whack of chemotherapy and a week of borderline-successful side-effect management. “Maybe,” thought I, “I can stay out of the hospital this time.” The heavy fog I’d driven through to get there was nothing compared to the blanket of isolation I felt wrapped in. I was on the verge of tears and wished I could convince someone that I just couldn’t go through this meat-grinder today. Maybe next week, when my gut has had another seven days to recover.

All I had before the poisoning was a meeting with Marc Pipas, in which I planned to confess my unusual level of reluctance and then shut up. Take my medicine, so to speak. But Marc granted my wish for one more week of recovery—the cellular biologists be damned, he said in essence: what matters is how you feel and the good time you’re able to capture and savor. The rapid granting of the wish made me giddy with delight. Marc also said there are two new treatments he can offer me in January if the CPT-11 isn’t doing as well as we’d like. One doesn’t even have a name yet (“We’ll call it Fred,” I suggested,



Constants in Daubenspeck's life were a love of wheeled vehicles and a close relationship with her brother Andy. They're pictured together in 1946 above and in February of 2001 below.



evoking a smile). The other is oxaliplatin. I don't even want to know about their side effects—I'm just glad they are there.

Thursday, November 16, 2000: In the two weeks since writing in this volume last, I have experienced another poisoning session; the singing of another wholly transporting piece of choral music; and some curious and confounding bodily sensations that are probably meant to test me (aversion to the taste of my own saliva! narrowing of a bruised esophagus so even liquid causes pain!).

Wednesday, December 6, 2000: Little did I know that I had more to dread than throwing up after yesterday's infusion. The blood

work showed a 1.8 creatinine level (quite high) and a low creatinine-clearance level, indicating subpar kidney function—probably in the one in which the stent was replaced in September. This discovery precluded a chemo treatment (fine with me), for fear that the resultant diarrhea and dehydration could cause irreversible kidney damage. As a parting gift, I was told that (1) I'd need a CT scan on Friday, (2) we'd probably be scheduling me for another stent replacement ASAP, and (3) my CEA level is now at an all-time high of 600.

'Twas enough to set my head spinning. I feel like a steel marble in an arcade game, bouncing off barriers and careening through chutes: Ka-ching! Ka-CHING-CHING!

Saturday, December 9, 2000: Wednesday I felt mildly nauseated all day. A pain in my left side commenced around 4:00 p.m. and worsened after dinner. When the pain got bad enough, I took a couple of Tylenol and went to bed at 9:00 p.m., but . . .

Tuesday, December 19, 2000: I never did finish that entry. I'm not sure why, just 10 days later. When I try to keep this case organized in my head, time just becomes a blur. It's as if my memory of events fades to protect me from having to relive them. I drove myself to the hospital that pain-filled evening around 11:30. By 3:00 a.m., after a CT scan and a lot of evaluation, the pain was attributed to enlarged kidneys—both sides now. I was whipped into surgery to have the two-month-old ureteral stent replaced, and one installed in the other side as well. I was discharged late the next day.

Wednesday, December 27, 2000: Was that my last Christmas? Who knows, but in case it was, may I have a week of it, please?

I hope to be eligible for another marvy treatment tomorrow: white-blood-cell regeneration shots (neupogen), after the first go-round with a new chemo protocol—5-Fu, leucovorin, oxaliplatin, and Herceptin once a week for eight weeks (no more CPT-11). Maybe this will leave more of me to step up and take the next whack.

Sunday, December 31, 2000: I weigh 115 pounds—it seems that I've dropped into an even lower wrestling class. Now I can wrestle second-grade girls. On my good days.

Tuesday, January 2, 2001: Happy New Year from Hotel Hitchcock, where I've landed for another two-day (I hope) "tune-up." From Saturday's general flatness, I descended into a negative energy state of debilitating proportions. No amount of sleep or water intake seemed to arrest my decline. But the trip here was my first view of the new-fallen snow, beneath the bluest of skies, and I was happy to be out in it no matter how bad I felt or where I was headed.

Thursday, January 4, 2001: I had a sobering conversation with Marc. I have advanced cancer. It is compromising my ability to thrive. But for one of God's miracles, the end is in sight. What a difference accepting these truths makes. I have been ducking and dancing, bobbing and weaving, like some clever and agile boxer for lo these many months since last March. We've nearly exhausted the chemo options to even slow this disease process, and in doing so we've nearly exhausted me.

Suddenly the choice is crystal clear: (1) subject my hypersensitive body and its unresponsive cancer to this brutality until I die of unchecked disease—or of therapy, or (2) recover from chemotherapy and let God and my own healing powers direct the final act. I see now how impossible it has been to maintain a healing attitude while anticipating, experiencing, and recovering from this chemical onslaught. How much freer might I be to focus positively on whatever is to come without this debilitating distraction called chemotherapy?

I have not made the decision to forgo any more chemo, but I have formulated the criteria for making it: if Herceptin-oxaliplatin therapy shows any life-extending effect after eight treatments, then I'll continue it. But if not, I'll quit and try to get back to the good state I was in four weeks after the last CPT-11 treatment.

Wednesday, January 10, 2001: It appears that my essential blood values are through with their cellar-dwelling phase and are ready to head back to normal levels. The change came with a new sense of well-being, as if some switch had been flipped, allowing positive thoughts to reconfigure my tired old mental monitor. Andy says the pups miss me and stare down the driveway a lot, but I think they've lots to be happy about where they

are. I miss them something awful, though. It's bad enough imagining leaving the party soon, but leaving behind my best companions moves me to tears.

Thursday, January 11, 2001: Well, now. Here is an interesting exercise, assigned to me this morning by Karen Skalla. She says my type of cancer is not a slow-moving one—that once it gains the upper hand, it keeps it, blind to the fact that in doing so it destroys itself along with its reluctant host. So, were I to decide not to continue chemotherapy, due to its being either insufficiently beneficial or too lethal, I should have a plan for (quick!) doing whatever I want to do, while I'm still able to do it before I die.

Andy was here for this conversation, and I'm glad he was. After Karen left, we puzzled over what this "wish list" might contain, and it is remarkable for what it doesn't. Perhaps because I've already done so much in my life—traveled so many places, met so many interesting people—I don't have a "wanted to do" list at the ready. How would I spend my last month of feeling well? I concluded I would spend it just being with family and a few special friends.

Friday, January 12, 2001: I'm off IV fluids now, except for the electrolytes. My ostomy output has dropped to almost nothing. I still can't chew food because of two or three really angry mouth sores. But I believe they're going to let me out of here this afternoon. Then all I must do is hold my own outside these walls, knowing I can come back if necessary. But I feel that my stack of wellness chips is taller now than it's been in several weeks—the only threat to its stability being the decision to resume chemotherapy at some therapeutically beneficial but nonlethal level. I dread that decision, though I know what it must be: we simply have to find out if oxaliplatin-Herceptin works. And if it does, we have to employ it while the disease is still affectable. I gather that once it has gained enough momentum, the chemotherapeutic effect is piss in the wind, so to speak.

Tuesday, January 16, 2001: This is heaven on earth—waking up in my own warm nest, a big black Lab having shared my bed all night. The bird feeders are busy with breakfast action, which Toby ogles from time to time. Snow begins to sift out of the sky, set-



I've been given a reprieve from Thursday's chemo treatment. My assignment is to continue my journey to feeling good again. And what a blessed state that is. I can think of nothing short of remission that I'd rather have than a period of time simply feeling good.

tlung into the storm-twisted white pine, glazing it with wintry icing, a confectioner's vision in dark green and white.

I've been given a reprieve from Thursday's chemotherapy treatment. My assignment is to continue my journey to feeling good again. And what a blessed state that is. I can think of nothing short of remission that I'd rather have than some significant period of time simply feeling good.

And Karen Skalla just called to check up on me—she is my most candid caregiver, coming as she does from the palliative-care side of this management challenge. She encourages me to look past the next infusion, into a future that I should make my own and not just allow to happen to me. She and Marc and Louise are concerned that we can't act as if I will always be able to pull back from The Edge that chemotherapy almost inevitably brings me to. It's Karen's wish that we not kill me with treatment, and who but the troll in my head would quibble with that goal? (The troll cries, "Oh, fine then: let her die an agonizing death of her disease—that's much preferable!")

Friday, January 19, 2001: Yesterday's conference with Marc stunned me. Evidently my trips to The Edge are more dangerous than I realized: one in five patients entering a hospital with stage four (of four) blood debilitation like I've had does not survive his or her stay. And I thought of those visits as tune-ups! Perhaps my light treatment of them kept me out of the unlucky 20%. The other bit of news that made my jaw literally drop was that two CEA tests were done while I was in the hospital, and they were sky high: 1,400 and 1,600. Did I need to know this? I guess on this day of evaluating all evidence I did, but I am immediately filing them here so I need pay them no more mind; these numbers are debilitating.

Marc asked how I felt. I said that of the three options—more on-protocol chemo at a

reduced dosage; off-protocol chemo; or stopping all chemo—I have no committed preference. And that means I welcome educated advisors. Marc readily filled that request. In so many words, he said he believed the new regimen would not prove efficacious, given my CEA status. If I were a member of his family, he said, he'd refuse to give me any more chemotherapy. Pretty strong guidance. He did allow that given my past willingness to battle this nemesis aggressively, it was my decision to make. He also emphasized that I would not be "cut loose," that he would continue to see me every month and that the palliative-care team would be at my service. So do I want to squander good time risking great loss for small or no gain? No, I do not.

As I slowly but surely turned to face in this new direction, something in my core felt hugely relieved. I see abandoning chemotherapy as releasing my body from a gulag of torture. That release might even free spirit, mind, and body to work toward the miraculous remission I still beg of God each day.

Monday, January 22, 2001: My new life is heaven on earth: I have no more regular dates with debilitation. I begin each morning with a visit to my library, where I have provisioned what time I have left with books of all sorts, like nuts stored away by some hyperacquisitive squirrel. I spirit one or two volumes off to my bed, pile pillows around me, and read to my heart's content. Then, warmed by the sunlight and the thought, I tip myself to starboard and sink into the pillow-bank for a nap. My life, but for whatever coup is being prepared in my abdomen, is so very enviable. I am blessed.

Friday, January 26, 2001: Choir practice last night was wonderful aerobic exercise for body and soul. Of all my life's activities in community, I hope that I don't have to give up choir for a very long time.

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One more byline

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Today I ordered more ostomy supplies and the question was how many. Two boxes or my usual three? I chose two—20 changes at one per week is five months' worth. That sounded more realistic than seven months' worth. Is this pessimism or economy?

Tonight I'm going with Andy, inveterate Dartmouth hockey fan, to see the Green play Union. It's so nice to be able to share time with him, doing fun things that don't involve much thinking.

Tuesday, January 30, 2001: Marie Kirn, head of Hospice of Vermont and New Hampshire, gently reminded me that I need to sign up with Hospice if I want their assistance. I do, I just had been putting it off—the past week's nightly gut-aches (sometimes verging on agony) have been too much of a reminder that today's lack of peristalsis becomes tomorrow's intestinal obstruction, and I don't know if they'd do surgery on an old dog in my condition. Does it become impossible for me to eat eventually? And then what? I'd like not to begin dying anytime soon, please.

Wednesday, January 31, 2001: The resident bellyache is still in residence. I am lying low but not calling Marc. And why is that? Because I'm afraid this symptom is too central to *not* be an acceleration of the disease, that's why. Sitting here in pain is less discomfoting than hearing bad news from my oncologist.

Sometimes the gut pain hijacks my head into no-no land: the dark fen wherein I allow myself to anticipate how my demise will play out. I know not to do this, but sometimes the only way out is through the fen.

Tuesday, February 6, 2001: Last Thursday's meeting with Karen Skalla and ICU M.D. Tom Prendergast was an eye-opener. For all my interest and aptitude for managing my case, I am remarkably uncurious about the frightening aspects of my condition. Did I want to know that cancer causes so many ancillary adverse effects in its advanced stages? No, not until I had to, and I guess Thursday was the day to pull back the curtain a bit. But to find that, for instance, it can cause emboli that could land me in the ICU was a shock.

In the ICU, Prendergast said, I would be allowed solo visitors, 15 minutes per person per hour—and how many brothers do I have? Clearly, I do not want to spend my final time in the ICU. I want to spend it here in my beautiful aerie.

I asked how they'd handle another intestinal obstruction. "Do I starve to death in my bed?" I asked, ever the *minceur des mots*. No, I was gently corrected: a gastric tube could be installed to relieve pressure and enable me to eat liquid-y things for as long as they could be processed. (I recall that at The End, we're not that interested in food anyway—as I am beginning to notice.)

Thursday, February 22, 2001: Home again, after a wonderful two weeks in Pennsylvania. I'm sitting in the waiting area at the Cancer Center for a routine blood check and notice, with some satisfaction, that I feel like a visitor, not a regular. I'm to see Marc in an hour and Karen an hour after that, so I'll get two readings on my course position. This visit's burning question is whether the rock that appears below my sternum after ingesting anything is part of me or of the disease. (I still value the distinction, even if it is illusory.)

I acquired a nice big scratch in one lens of my \$700 glasses, and my reaction was "Well, we're not gonna have to worry about the expense of new glasses."

Epilogue: *Mary Daubenspeck died a month after her last journal entry—on March 24, 2001. Her brother Andy says that "Mary's last days were difficult. She never gave in, really, to the idea that she was dying. Her mind accepted palliative care, but her heart never did. She struggled to the end, which was very hard for those of us who loved her—we wanted her to suffer less than her struggle permitted.*

"Since Mary's death, her beloved Keeper's Cottage has become a focal point for our sense of loss (even, sometimes, anger); we spend time there doing things we used to do with her. Mary felt a special sense of stewardship for the Keeper's Cottage. Situated next to the Nauset Lighthouse, it symbolized for Mary part of the connection of humans to something bigger, something beyond the concept of 'owning.'

"In the same way, Mary was and still is her family's lighthouse. Her family and extended circle of friends are aware that Mary continues to inhabit our thoughts and feelings, affect our course, light our way." ■