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

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

Nauset Light, a beacon for sailors, and Daubenspeck’s beloved Keeper’s House.
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 crocheted 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 Rochester 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 furrowing 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 ordinaries and anesthetists 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 on Tuesday that these factors practically assured me (not his word—he’s too circumspect) 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 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,
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 of- marron this 16-week schedule twice and see where we are. This protocol has been success- ful in 20% to 40% of the cases of this rather unusual kind of colorectal cancer re- currence. 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 treat- ment, not just been knocked down.

The main side-effect is mouth ulcers, be- cause 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 di- arrhea. 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 Philadel- phia 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 sen- tence. Perhaps I am only expressing my de- sire to enable me to shower, shampoo, change my ileostomy, tend to the g-tube, and fix a blight becomes a blessing?

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Tuesday, March 28, 2000: (First Chemo- therapy 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 Narnois 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 woods above. I imagined that cold, clear water swirling around and bathing the cancer in poison.

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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!”

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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 feel 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.”


**Tuesday, June 27, 2000:** Und so, 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.
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 purply 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 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 Zoloft, 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 9, 2000:** My latest CEA test, which will tell us if all this perversity has been worth it. I have to believe that it has.

**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 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 microphasia 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
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 Zoloft. 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 excretionary 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 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.
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 Zoloft 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. I noticed it was right after my same-day ureteral stent replacement, a week 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 to-day. 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,
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 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 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 so very enviable. I am blessed.

**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.

*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.*
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.”