“I Have Come Home”
Linda Flowers Writes of Coping with Cancer

May 19, Caring House, Durham, North Carolina:

And what is it, exactly, that I do all day?

First, though bored by the fact that I have to be here, I’m not bored as the time itself passes; I don’t feel bored. But, nonetheless, I’m hard-pressed to say just what it is that I do. In a word, nothing. I do nothing. I think.

I look out the window at the play of sun and shadow on the trees and shrubs, the sparrow walking across the driveway; running, really, almost bouncing. I hear the cars slow and then stop for the light at Pickett Road and Academy, and start up again when it turns green. I read as an anodyne to thought.

Who am I now? What?

My surgery for colon cancer was January 21, 1998, and since late April I have been here at Caring House, Duke’s hospice for patients getting radiation therapy. I drive over in the late afternoon for my treatment at 5:30. The table is narrow and hard and I must lie on my stomach, my arms cradling my head, the attendants positioning my body, and then I must not move as the machine does its work. I feel nothing. I can tell now by the sounds that I am radiated from four different angles, but there is no sensation as the rays penetrate my skin.
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For all I really know, the revolving machine above me might be emitting nothing . . . nothing at all; and this daily ministration might be as much an illusion, a hoax, as some suppose the moon walk. They play tapes during all this, Billy Ray Cyrus and Reba McIntyre as likely as Mozart. Some sessions they forget, and I wonder what else they are possibly overlooking. Their conversation is the same as that of other young women taken up with the rearing of children and getting supper on the table, and I think I am not much more a person to them than the machine itself. How deadeningly boring, utterly mechanical is their work. All day righting bodies on a table, inking lines on buttocks or breasts, heads or stomachs, the purple drawing telling them where to focus the machine’s magic.

I lie on the table and think this darkened room must be Plato’s cave, and that what I now see and feel is, can be, if not the only reality, the only one that matters. All I see are torso-like shapes, arm- and leg-shapes, the gray polyurethane body-molds in which some patients must lie or rest their limbs for radiation, and they look like the remains of some anatomy lesson or art class, maybe, some trial-and-largely error with shaping the human figure—or, on the good days, the torsos may look like the sleds onto which northern children fling themselves before plunging down some snowy hill. “Is man no more than this? Consider him well.” “Poor, naked wretches,” wherever they are.

I have begun to burn. In the Sitz bath when I arise may now be an emission of filmy tissue; rectal moisture is hot and maddeningly viscous. My buttocks have turned dark (like char-grilled, my sister says), and I can not sit easily; diarrhea, even with the medicine for it, is severe. They have begun to take Polaroids to keep in my chart, the snapshots of my nakedness harsh with color. Treatment is stopped for several days so that I may somewhat heal.

For months now nothing has been predictable, neither plans nor feelings, my body or my thoughts. At first, in Rocky Mount, I was told that I had a low chance of winding up with a colostomy, that my two tumors were both low in the sigmoid colon, and removal and re-stitching would likely be sufficient. Not so. Subsequent tests at Duke revealed that I had not two tumors but one, and that it was advanced and aggressive, having ballooned outward into the pelvic cavity and encroached upon my bladder. The colostomy that I had just a few weeks before found hardly thinkable was thus a foregone conclusion; a urostomy, of which I had had no inkling (and knew not even that such a thing could be done) was now very likely. Surgery scheduled to last from six to eight hours, in fact, required 14.

But even so, and after all said and done, I am nonetheless — blessed, I suppose. Current reports are good, and I am not (or not yet) ill from the chemo. Waiting for treatment at the hospital or living here in Caring House, I usually am the healthiest patient I see; or seem to be, anyway.

Yet I am forever changed, permanently altered physically, and in such ways that there can never be any sense of an ending; nor any forgetting. For the rest of my life there will be these ugly pouches attached to my abdomen: clammy containers for my waste. Already I despise having to think about them, the sheer
time I must spend each day monitoring and attending to my bodily functions. Stoma is a Greek word for "opening"; a clean, innocuous word for a surgical hole cut forever into the abdomen, the red intestine bulging upward from within. I am becoming, I suppose, "the thing itself, unaccommodated . . . no more [than] a poor, bare, fork'd animal." And on many days now, "How weary, stale, flat, and unprofitable/Seem to me all the uses of this world."

I have spent my life reading and going to school, and does that matter now? Does the poetry running in my mind, the literature I have studied and taught and still love, is any of it any more helpful, any better really than the clichés of my eastern North Carolina childhood? The ready phrases with which we faced hardship infuriate me now, even when I speak them myself. "Just take one day at a time," my sister tells me, "God don't send us any more than we can stand." To the first, there can be no response, and I no longer — if I ever did — believe the latter.

Do I believe the poetry? Yes. Usually. "Never, never, never, never, never," Lear cries out, raging against the fact of an individual human death when everywhere dogs and horses, rats even, may still live. "The worst is not the worst so long as we may say, 'This is the worst,'" somebody else says; and I believe that, too. "The art of losing's not too hard to master," wrote Elizabeth Bishop. "Then practice losing farther, losing faster."

But whether great literature or mere phrases, words never solved anything, of course, though my family's clichés may be as much their (if momentary) salvation, as my books are mine. I am grateful that I have both to lean on now: the language of my childhood and that of my formal education. Insofar as they tell the truth (or a truth), the poets have defined experience better and more lastingly than anyone else, and in the homilies on which I was raised, there is an inescapable rock-bottom-ness, a necessary and inarguable hardness. The only way to live, in fact, the only way you can live, is to take just one day at a time, whether or not I (or you) may hate hearing it.

Words will not make me whole again. Nonetheless, I am as much defined by language as ever I was before I knew I had cancer — maybe more. I could not think exactly the thoughts I do think had I not read what I have read; nor could I feel exactly as I do. And, insofar as I am able to deal with cancer at all, it is largely because I can talk — and perhaps write — about it. Education, and I think especially education in the humanities, is equipment for living, and of such props, we mere, fragile, and ineluctably vulnerable human beings, well — we need all the help we can get.

May 19, toward midnight:

Days when the urostomy leaks (most days that is), or when the colostomy breaks from my body, or I have a fever, I am consumed with the time needed to deal with this. But it's when these matters are essentially O.K. that I realize how much time they, in fact, really do require. And I think again of what, in The Sound and the Fury, Quentin's father tells him: I give you this watch, he says, not so that you may remember time, but so you may forget it now and again. Yes. That's what we all want to do: forget time; and when things go well, we do just that. But illness (and its consequences) is time's reminder. The winged chariot at our back now gaining on us.
I am wracked by fears both reasonable and not. What will I do if — when, I should probably say — the cancer comes back? Having now taken all the paid leave-time from teaching available to me, it’s not just the usual bills about which I worry, but the insurance: without a job (if it should come to that), I am, also, without insurance, and at age 53 I am too young for Medicare. “When it comes back,” they say at Caring House, the patients who are here for the second or even third time, “it comes back with a vengeance.” “It’s in your system,” they say, “and it’s gonna’ come out. Some how. Some way. Sooner or later.”

What will I do, I worry, when — if — I am old? No girl looking after me in a nursing home is going to take the time and care necessary for emptying or changing these pouches. Sans eyesight, how will I manage to help myself? When I can no longer be certain of hands and fingers performing as I would have them? Or even, possibly, of self-possession, of awareness, of knowing that this is urine, this excrement, and that I need to be cleaned up? I imagine a room occupied by the shuffling old, a television (or whatever will have taken its place by then) endlessly playing, and my caregivers chattering away, polishing their nails and chewing gum. I lie on a single bed in my own waste, in a room not my own and without my books, shared with who knows how many others and — What will be in my mind then?

Or if the very worst should happen and, for who knows what reason, I should be homeless or, God forbid, even imprisoned, then what? But . . . there must be prisoners even now with colostomies or urostomies, just as among the old or disabled in nursing homes, and what happens to them? How do they cope? The mere knowledge of an inmate’s helplessness or need must be, for some, grounds enough for cruelty.

Not to mention the expense (“Oh, reason not the cost!”). A box of five urostomy flanges, of the kind I use, costs anywhere from $25 to $30; a box of ten pouches is about $35. Currently, I need a new flange each day, a new pouch about every two or three days, for a total weekly cost (conservatively) of about $45, not including the adhesive bond, Transpore tape, and surgical gauze that I find, also, necessary. Colostomy pouches cost about $30 for a box of ten, and I use two or three each week; total expense, about $6. For both urostomy and colostomy supplies per week, say — $50-$60; all of which, at present, my HMO pays for.

But for how long? Already it has required a letter from my urologist for my insurance to provide enough flanges: one a day is far and away more than what Medicare allows, and my HMO (as do most insurance companies) follows Medicare guidelines in determining its compensation for these supplies. And what if my college should decide to change companies? Go to an insurance provider that pays but a percentage of such costs, or — nothing at all? Two hundred-fifty dollars a month (at least) would be a financial strain but, if I had to pay it — and, without insurance, I’d have no choice — I could. Now, that is; now while I am still working.

But if I should be unable to work? Jobless? No insurance company’s going to sell me an individual policy, given my history and present condition, and, even if so, certainly not at a premium I could pay on my own. My parents never had any insurance of any kind. Neither Robert and Geneva Flowers lived in this tenant house in Faison, NC, in 1941.

Robert and Geneva Flowers lived in this tenant house in Faison, NC, in 1941.
I could pay on my own; my parents never had any insurance of any kind. Neither did anybody else we knew, except, perhaps, with a burial association. What did they do in such situations, these farmers of forty and fifty years ago? Some, when it became available, must have gone “on the welfare”; a comparatively few may have been able to sell some land. But the others? If medical costs were so much less then than now, so, too, was the availability of money; doctors and hospitals may have charged just in the hundreds of dollars, but when I was a child in the 1950s, even a few dollars (five or ten) were hard to come by.

They did what they had to do, whatever it was. Went without sometimes, made do with what was at hand; improvised, tended to each other, grew old in their 40s and 50s, held on as long as they could, suffered, and died. Most illnesses, then as now, cured themselves; others, they knew more or less how to doctor. My grandfather made a poultice for his arthritic knees out of the leaves we stripped for him from the peach tree in our yard. For my croup, Mama gave me a drop or two of kerosene in a teaspoon of sugar; for a bad cold, I had to drink a tea made from sassafras roots that Daddy dug from our lower field.

About the only store-bought medicines farm people had were such things as Vicks Vapor-Rub, lineaments of one name or another, Castor Oil, Smith Bros. cough syrup (or drops), Lydia Pinkham, B.C. Powders, aspirin maybe. “Ain’t gonna’ die nohow, till your time comes,” they said, and “When your time comes, you gone.” La conditionne humane. Balzac knew nothing that eastern North Carolina farmers didn’t know, even if they weren’t able to write it down.

The night before the surgery, after my sister and niece and friend had gone back to their room at the Brookwood, and the doctors had finished telling me what they expected to encounter in the morning, I lay in my darkened room, the corridor at last quiet, the elevator stilled, and I thought that, if I had to, I could die. Mamma and Daddy had died; Rachel and Annie Lou and Dorothy had died, sisters that I had not imagined ever losing; uncles, aunts, all four grandparents, cousins. My friend Jim had killed himself; Fay and Shelby Jean had had cancer, suffered, and died. No one was ever more afraid of dying than my father, and he had died alone in his hospital room on Virginia’s Eastern Shore. Mama had died in Goldsboro alone, in an institution.

I’ve had the life I chose, I thought; everybody dies, and if I die tomorrow, that’ll be all right. It didn’t occur to me then that surgery might be the least of it; that I might come through the operation splendidly, as, relatively speaking, the chemotherapy and radiation, and, nonetheless, be not finished with the experience: that, no matter what the morning might bring, I would never again be the same. For most of us, we become ill and then we get well, and, wonderfully, we forget the very worst we have endured, the body as much as the mind.

But not now; not this time. Nobody talks much about colorectal cancer (though, after lung cancer, it kills more people than any other), and certainly not about the unpleasantness of dealing with colostomies and urostomies. My own ignorance had been profound, and even when I learned the facts, I was not ready for the truth: that as a survivor I would feel both grateful and butchered, ashamed when at first my sister and the nurses had to bathe me and change my bags, and shame and loss when I looked at my body.
In time, I will, I suppose, forget much of my stay in the hospital, at first the immobility, and then my own leaden weight as I struggled to sit up, to turn in bed, to reach for the telephone or a book; that is, I will lose the feeling of the experience. Bodies remember, however; flesh retains its indentations, intestine knows it’s been re-routed, muscles and nerves, severed. Stomas don’t go away.

And if I’ve had the life I chose, there are those who’d say it was pretty empty: no husband, no children, no lover. Should I be thankful now that I have never defined myself in either domestic or sexual terms (insofar as I have thought to define myself at all)? Never seen or thought of myself especially in terms of how men might respond to me? Or should I the more regretful for now being beyond such considerations? Would my body now be appreciably harder to accept if I were a beautiful, alluring woman, and would such a woman, in coming to terms with her new life, be thankful that at least she had had men at one time, even if now nobody wanted her? Or would she look bitterly at herself and curse? Both, maybe? Because my life hasn’t been like hers, have I now lost less than she? Or is it the other way around? Has the woman with little sexual past, finding herself in my condition, lost more? And . . . does the question matter, after all? I don’t know. I know only that I have lost a dimension of myself whose depth I never before felt; never truly knew I had; and I am glad that there is no one now whose sexual acceptance — or rejection — I must consider.

It started in November with blood in the toilet water. Not much, but enough. Enough. Blood like the Georgia O’Keeffe poppy, petals dispersing, fading atop the water as I looked at it. Enough to scare me into seeing my doctor on Monday morning — an engagement from which all else followed: the colonoscopy, at which even I could discern the vast difference on the screen between the healthy-pink coil of my colon and the two bloody, angry-looking, torn-looking lesions that disfigured it; the naming of the thing — “a well-differentiated adenocarcinoma of the lower sigmoid”; the referral to Duke for further testing; the surgery; the radiation, chemotherapy, monitoring and follow-up.

But, of course, it was neither this simple, nor this fast. The fact is that I had not felt up to par all that fall semester: sluggish, vague abdominal rumblings escalating into episodes of severe pain, a lack of energy and concentration. Nothing much to speak of, really; the kind of things you attribute to pressures at school, to being over 50, to — I suppose, life in general. On a daily basis, my psoriasis was more of a problem than anything else, and I blamed the way I felt on it, too, and on the Methotrexate I was taking for it.

To the country women of my childhood, such ailments would scarcely have been worth mention. My mother must have worked much of her life in the fields enduring far worse. She’d have torn an old sheet into strips, folding it into pads for the blood, and gone on to the tobacco barn — and who would have known she had anything wrong with her, really? Blood was what women expected, and if there was more than usual or they saw it on their clothes at the wrong time of the month, if their cramps seemed likely to cut them in two, why there wasn’t much to be done about it.

My mother and aunts had nobody but themselves with whom to talk about such things, and if — as my mother was — they were especially private, they’d likely have suffered largely in silence. Few country people in the 1950s and ’60s had indoor plumbing. They’d have had no toilet water in which they might have seen blood.

Nothing so alien was discernible if you looked down into the dark holes in the outhouse, and the bucket we used at night and my mother dumped each morning never bore close examination. Bodily functions may have been the stuff of jokes, but otherwise they were
When I was a child the doctor did come out to our house one time. My mother had been ill for what seemed like forever, until finally she no longer got out of bed. The day was very cold: bright and glittery cold, and the doctor came into our sitting-room where Mama was, blowing on his hands cupped at his mouth. (I think they had forgotten me.) We had a coal-burning heater, an upright, and it was hotter than hot, the tin flue cherry-red in spots. When he had finished examining Mama the doctor had said, “That stove's too hot,” which I had repeated the rest of the day — “That stove's too hot. That stove's too hot” — making a little singsong of it until I was threatened with a spanking if I didn't hush. I never forgot that when the doctor drew back the covers, I had seen dark purplish clumps of blood on the sheets and between my mother's legs. It had looked like the hog's liver quivering in the pan at hog-killing time.

But I didn't know then, and don't know now, what Mama had wrong with her. Country people didn't always think to get the name of what ailed them. They'd have had to ask. Doctors knew that these were people who had to get up the next morning and go back to work. Women still had the cooking to do, the house to keep, the clothes to wash, no matter what. Children and husbands needed them. A father still had to get the crop made and housed, and if he was laid-up and couldn't work, who was there to see that it all got done? Such people carried on with their lives, nobody the wiser usually.

Far more inexplicable to my parents (if they were still alive) than my having cancer, would be my telling — my writing — about it; that, and the fact that even though I didn't work at all for months, nonetheless I still got paid; or that I have insurance that's real, that's not a swindle (which they'd have expected). Disease they understood; the kind of safety net even working people have now, they'd likely find little short of miraculous.

My worry that I might now lose what I have was one they must have lived with, day in and day out; yet, they never voiced it. (Not to me, at least.) Talk about becoming disabled, of not being well enough to work, of having to quit, I never heard. They'd complain if they hurt or felt bad, but not often, and not with any sense that the ailment (whatever it was) wasn’t going to go away; or if an ache or uneasiness lingered on, why . . . it just did, and that was all. But if you got sent to Duke, you were as bad off as you could possibly be; you might not live, and we knew people of whom it was said that they'd likely never come back home.

I am blessed. After the surgery, the initial recuperation in Faison at my sister's home, the many weeks at Caring House, I have, at last, come home.
More Memoirs and Sources of Information and Support for People Living with Cancer:

Cornucopia House, a comprehensive cancer support service for cancer patients, survivors, families and friends. Offers free support groups, education, classes, workshops, and a library. 1777 Fordham Blvd, Suite 104, Chapel Hill, NC 27514, (919) 967-8842.


Linda Flowers is Professor of English at North Carolina Wesleyan College in Rocky Mount. Dr. Flowers received a B. A. from UNC-Greensboro; an M.A. from Ohio State University; and an M. A. and Ph.D. from The University of Rochester. Her particular focus was Medieval and Renaissance Literature. In 1990, Flowers published her highly acclaimed book about her experiences growing up in Eastern North Carolina, Thowed Away: Failures of Progress in Eastern North Carolina (University of Tennessee Press). This text is based on the diary Linda kept during her surgery and recovery in 1998. (Photos used by permission.)

“That my book about Eastern North Carolina might touch a chord with some people, and with several ready-made audiences—teachers, social workers, health personnel, civic organizations, book clubs, readers in general...I had not anticipated. What these groups are responding to in Thowed Away, I think, is its human dimension: the focus on real men and women having to make their way in the face of a changing, onrushing and typically uncaring world...This humanistic apprehension, I tell my students, is as necessary for living fully as anything else they may ever hope to have...they must recognize and nurture it in themselves...to realize more fully the potential of the human spirit.”

— Linda Flowers, July 1992

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North Carolina Humanities Council
425 Spring Garden Street
Greensboro, NC 27401
phone: 336-334-5325
e-mail: NCHC@gborocollege.edu
web site: www.nchumanities.org

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