

HEALTH

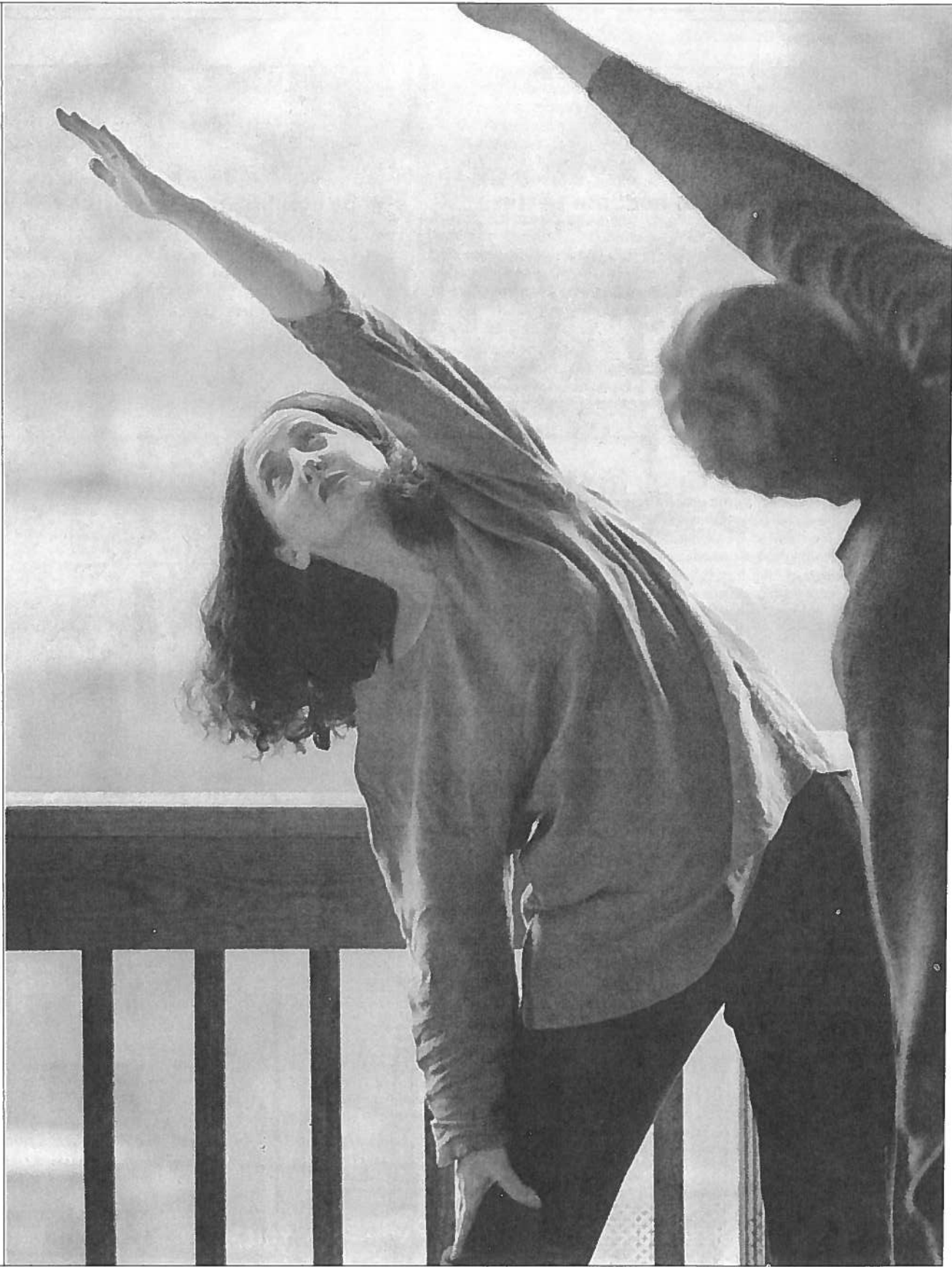
TUESDAY, NOVEMBER 14, 2000



Growing Through Cancer

All cancer patients want to get better. At Smith Farm, they seek to become better people.

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All cancer patients want to get better. At Smith Farm, they seek to become better people. • By John-Manuel Andriote

GROWING THROUGH CANCER

Jim Wilner was caught off guard when he was asked what kind of funeral he would like.

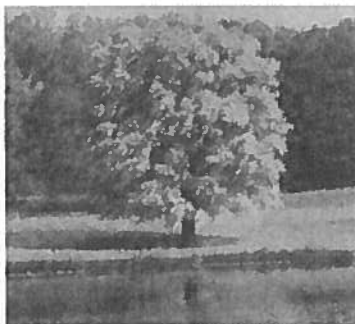
Though he was battling an often-deadly form of lymphoma, and though he had expected to share some very personal feelings during a weeklong retreat with other cancer patients, he hadn't really considered the details of his own death. Talking about such a matter would have been inconceivable a week before, when the people now sitting with him were strangers.

The others went first, and mostly described their funerals as quiet gatherings of loved ones.

"Sounds boring to me," Wilner eventually told the others.

No, Wilner declared, warming to the subject, he would "go out in style"—the style of a Viking warrior. His body would be placed on a longboat, he declared, and the ship would be set afire and pushed out to sea. A Valkyrie would swoop down to spirit his soul off to Valhalla.

"That's the kind of funeral I want," says Wilner. "It shows



Shanti Norris, left, demonstrates yoga at Smith Farm in Maryland's Frederick County, whose grounds, above, help clients relax during retreats.

you lived well—and died well."

Wilner was a member of the first "cancer help program" retreat sponsored by Smith Farm Center for the Healing Arts, a Washington area group affiliated with Commonweal, based in Bolinas, Calif. Founded in 1976, Commonweal is a small but influential group that, with retreats, workshops, education and other activities, focuses on the effects cancer has not on the body, but on the mind and spirit. In November 1996 six people from the Washington area and a married couple from Chicago met at Rockwood Manor, a woodsy 30-acre estate in Potomac.

Wilner told his fellow cancer patients that he also admired the Vikings—"the original bad boys"—for their ability to live in the present moment. To someone facing a life-threatening illness, this sounded right—a Nordic version of "one day at a time." Then there was the Vikings' single-minded focus on the battle at hand, joining comrades in a grand crusade and finding glory in

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Smith Farm requires participants to be under medical care elsewhere so they can focus purely on the psychological, personal and spiritual ramifications of the disease.

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the outcome, whether it be life or death.

By the end of their week at Smith Farm, the members had decided they all aspired to be Vikings, and they gave themselves that name before they disbanded.

Four years later, the six surviving Washington area Vikings—the Chicago man has died—continue to meet each month. Some have had successful treatments and no recurrence of cancer. Others are fighting for their lives.

Jim Wilner is among those currently cancer-free. Just back from a three-week visit to the south of France, he is, at 58, a man changed by his cancer and by his week at Smith Farm. "My life has been a lot richer since I got this disease," he says. "I am aware of time."

California Roots

Like Commonweal, Smith Farm does not provide cancer therapy or medical treatment; it is independent of any medical institution. It requires participants to be under medical care elsewhere so they can focus purely on the psychological, personal and spiritual ramifications of the disease.

The program, which serves people with all kinds of cancer, has raised its profile in its four years of operation in the Washington area. To assist in its work for women with breast cancer, the Smith Farm program has been awarded \$140,000 in the last two years by the Susan G. Komen Breast Cancer Foundation's Race for the Cure. Last year Smith Farm was co-recipient of the Komen Foundation's Virginia Kelly Award, named for President Clinton's mother, who died from breast cancer.

Barbara Smith Coleman, founder of Smith Farm—an accomplished artist and sculptor, a cancer survivor and Commonweal alum—originally planned to create a retreat and education center at her farm on Kent Island, on Maryland's Eastern Shore. That plan was nixed by neighbors' protests. Undeterred, Coleman recalls, she sought another site in the Washington area. The program had to be located in the Washington area, she says, because it was "here that hearts seemed tight."

While Smith Farm's offices are in Washington, the quarterly retreats are now held at Hallwood, a center located near Sugarloaf Mountain, a few turns and a couple dirt roads from I-270 in Frederick County, Md. A calm lake, acres of woods and clear country air provide a comfortable backdrop.

Although many independent programs have adopted some of Commonweal's approaches, Smith Farm is the only program modeled directly after Commonweal and in which the California organization's founders play active roles.

Locating a satellite center close to the nation's cancer research establishment was an important move for Commonweal, says founder Michael Lerner, who received a MacArthur Foundation "genius" grant in 1984 for his pioneering work.

"It is clearly valuable that this model of intensive support



Barbara Smith Coleman, artist, funder, founder, cancer survivor—and the "Smith" of Smith Farm—helps clients symbolize their emotions by creating mini-landscapes in trays of sand.

for people with cancer is being offered in the nation's capital," he says, "not only with respect to its proximity to the National Institutes of Health and the National Cancer Institute, but also with respect to its proximity to and availability for the Washington community."

Smith Farm Executive Director Shanti Norris says its simple: "Our humble goal is to help transform the medical community."

The Smith and Commonweal programs introduce participants to the full range of unconventional treatments that research has found to be useful in strengthening the body's natural defenses. They can also strengthen individuals' will to live by improving their quality of life. These include spiritual therapies such as prayer and healing touch, psychological approaches such as support groups and imagery and physical activities such as yoga and massage.

While these techniques have been used throughout the world for centuries, considering them integral aspects of modern cancer care represents a radical departure from traditional Western medicine's focus on treating the disease rather than the person with the disease.

"Healing can take place at a physical, emotional or spiritual level," says Lerner. "It can take place both in conjunction with curative treatment—and where curative treatment is impossible, where one is even in the process of dying."

The Retreat

Each Smith Farm retreat includes only eight or nine people. Most participants live in the Washington area, though about a third come from other areas, some of them because the better-known Commonweal has a lengthy waiting list for its programs.

Participants tend to be what Norris calls "exceptional pa-

tients." They are informed and motivated, and they tend to be skeptics who are sifting through all the information pitched their way by doctors, hospitals, family members and friends. They also are typically open to what she calls a "balanced approach" that blends scientific approaches with the spiritual resources of the world's "wisdom" traditions.

Another way they tend to be exceptional is in being able to afford the \$1,480 for the weeklong retreat—though Smith Farm, like Commonweal, reduces the fee for those who need assistance.

These patients are joined by a staff of about a dozen, including massage therapists, chefs, discussion leaders and medical staff. Barbara Black, a massage therapist with a private practice on Capitol Hill, offers Swedish acupressure massages at the farm's retreats. Louisiana native Laura Pole, an oncology nurse specialist before becoming a natural foods chef, has served as either chef or chef's assistant for the retreats since 1997, preparing low-fat vegetarian meals—often several different foods at a single meal because many patients have special dietary needs.

Besides the professional skills they bring, Norris says, Smith Farm staff members tend to be "wounded healers." They are "people who have worked on their own issues and suffered enough themselves that they come in with no judgments, and with the ability to bear witness to the deepest pain—and help transform that pain into meaning."

Smith Farm's work also involves art, used as an indirect route to participants' feelings and thoughts. Whether painting or creating "sand trays"—in which participants arrange small figures and blocks to create a symbolic mini-landscape of their thoughts and feelings—Coleman says participants "get in touch with the real stuff . . . deeper and older than the secrets."

"We make war on secrets," she says. "Very gently, subtly."

The Vikings

When Don Zauderer arrived at the Smith Farm's location in Potomac in 1996 and was shown the sand tray exercise, he recalls his reaction: "I thought this was San Francisco bullshit."

And yet, in this calm and bucolic setting near Great Falls, the college professor had begun to feel some closeness with these people, something he hadn't felt even with his best friends during the previous 17 years when he and his wife Judy had kept his lymphoma diagnosis to themselves. Everyone had talked about their deepest fears and hopes about the disease. This seemed a safe place. So why not try the sand trays?

Zauderer selected items from among the shelves of dollhouse-sized figures, marbles, animals, blocks and other things and placed them in the sand in an effort to symbolize the things he valued most. "I had little schools in my sand," he recalls. "They represented my hope that I would live to see my children graduate from school and graduate

school—and that I could continue putting together graduate programs” at the university.

Before he realized it, Zauderer found himself crying—long and hard. He’d somehow articulated in the sand what mattered most to him in his life, and why his life was worth all the pain and effort his body was now demanding.

“That process of weeping was a powerfully therapeutic experience,” says Zauderer. “It got rid of all the anxiety that had been pent up inside of me.”

Zauderer was among the small group of strangers destined that week to become the Vikings.

So was Katherine Anthony, who in April 1996 had found out that she had metastatic breast cancer. In October, Anthony had just finished chemotherapy and stopped wearing a wig to hide the downy fuzz covering her head.

Usually a private person, Anthony was somewhat anxious about what lay ahead during the week. “I had concerns about this ‘group sharing’ business,” she says, recalling that she thought, “What is this ‘60s kind of stuff?!”

Smith Farm staff had turned the retreat center into a haven, the rooms filled with comfortable furniture; one room was cleared of everything but yoga chairs. Coleman made sure every bedroom had bouquets of flowers, creating an environment distinct from and more tranquil than the participants’ daily lives. Participants were expected to refrain from constant contact with home or other activities that would distract them from the task at hand.

Each day was structured in what Anthony calls a “mindful” or “prayerful” way, though she hastens to add that there was nothing “religious” about it.

Yoga eased everyone into the morning, followed by breakfast and group discussion. After lunch were afternoons of sand tray creations, massage, quiet conversations and outdoor walks. Another session of yoga, and the day wound down with dinner and evening discussion about traditional and complementary treatment options.

“The intent,” says Anthony, “was that you learn to incorporate some of [the calm and reflection] into your own lifestyle, and put that kind of space into your life.”

Between his June 1996 diagnosis with non-Hodgkins lymphoma and becoming a Viking, emergency room physician Rick S., who asked that his last name not be used, says he had been “delving into all kinds of herbal and traditional medicine, researching and studying, trying to figure out what to do—but not really addressing the emotional stuff I needed to do.”

He found the Vikings ideal fellow travelers for this part of his journey. He said the retreat was “a rare opportunity to go away for a week and just delve into what cancer meant to me with another seven people who were doing the same thing.”

By the end of the week, all the Vikings knew something important had happened. One immediate change in Katherine Anthony, who now took seriously the talk about creating “sacred space” in one’s life, was a crash campaign to redecorate her office. Impersonal bric-a-brac was replaced by objects with personal meaning. Now her office would be “a place that would

help me keep this focus,” she says.

Rick S.’s take-away was a clear understanding of his own fears.

“I went with a fear of the disease,” he says. Afterward he realized “it really wasn’t so much the fear of dying that was of concern to me—but not living with integrity, not living the way I want to live.”

Story Time

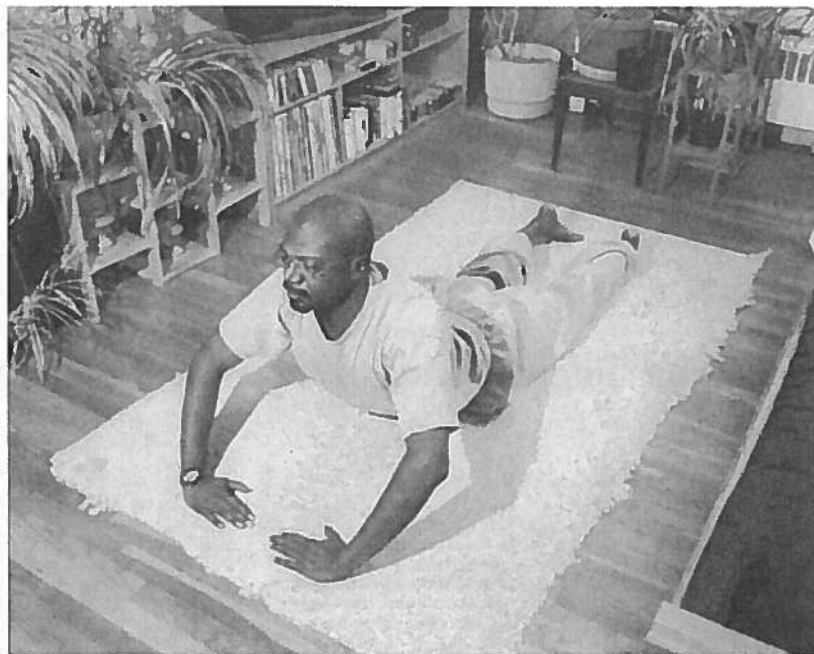
At the heart of the retreats are the participants’ personal stories about having cancer.

Says Rachel Naomi Remen, Commonweal’s co-founder and Smith Farm’s first medical director and herself a long-time sufferer of Crohn’s disease: “We all have within us access to a greater wisdom, and we may not even know that until we speak out loud.” At the same time, she adds, “a deep trust of life often emerges when you listen to other people’s stories. You realize you’re not alone; you’re traveling in wonderful company.”

Group discussions during the retreats encourage therapeutic storytelling. Michael Lerner facilitates these discussions for two of Smith Farm’s quarterly retreats; the other two are led by Richard Grossman.

Author of four books—including “The Other Medicine” (Doubleday, 1985), a key work on complementary medicine—Grossman at age 79 also has a private practice in Connecticut doing what he calls “health counseling,” largely for people recovering from such “heavy traumatic issues” as cancer and brain surgery. Grossman says of his and his colleagues’ time at Smith Farm, “We always come away from these weeks feeling it’s the best work we do.”

Garry Lipscomb, shown here exercising at his home in Northeast Washington, spent time at Smith Farm after he was diagnosed last year with cancer. He now pursues a holistic approach to his disease.



Grossman says the group discussions “place value on attending people, not trying to fix people.” This he contrasts with today’s hurried interactions between doctors and patients. He suggests that many people are unhappy with the medical system today because of the disappearance of the feeling that the doctor is actually present with them. “They poke, jab and prod,” he says, “but they don’t always caress and touch.”

Michael Hawkins, Smith Farm’s medical director, brings mainstream credibility to the operation. Before becoming associate director of the Washington Cancer Institute in 1999—a position he continues to hold in addition to his duties at Smith Farm—Hawkins was director of clinical research at Georgetown University’s Lombardi Cancer Center. Before that he was chief of the investigational drug branch of the National Cancer Institute (NCI), where he oversaw the development of new chemotherapies and evaluated complementary and alternative therapies.

Norris describes Hawkins as “a new hybrid,” an oncologist who straddles traditional and mind/body medicine.

It was a 1997 talk by Remen that got Hawkins thinking there might be a better way of caring for cancer patients than what the patients themselves often call the “slash and burn” approach—surgery and radiation and only marginal attention paid to the effects of these experiences on emotions, relationships or remaining days of their lives.

In his office just off the Washington Cancer Institute’s patient wards, Hawkins leans back in his chair, stockinged feet comfortably crossed, to quietly explain what this has meant to him.

“I want to change the institutional mind-set,” he says. “It is my belief that physicians are only as tuned in to their patients’ suffering as they are to their own.” Hawkins has proposed a “healing center” at the cancer institute, a place for physicians and others who work with cancer patients to bring their grief and feelings of powerlessness to find support and renewal.

“As an oncologist you feel on the same wavelength as your patient, you have the same goal,” says Hawkins. “There is a certain honesty and intensity. But that intensity and need to do something for your patients can also burn you badly.”

The movement toward patient “empowerment”—becoming well-informed about one’s illness, taking an active role in treatment decisions and viewing the doctor as a partner rather than an authority figure—represents a radical shift in American medicine.

Says James Gordon, a physician who directs the Washington-based Center for Mind-Body Health, “a new kind of medicine” is developing in this country that sees patients as fellow human beings and looks to other healing traditions, “not simply seeing them as anthropological curiosities.”

At the NCI there is a shift toward considering quality of life is

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Smith Farm medical director Michael Hawkins—who is also associate director of the Washington Cancer Institute—brings mainstream credibility to the operation.

“There is a tenacity toward life,” writes Rachel Naomi Remen, “without which even the most sophisticated of medical interventions would not succeed.”

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sues and a new openness to a more holistic approach to treatment and care, according to Jeffrey D. White, director of the NCI's two-year-old Office of Cancer Complementary and Alternative Medicine.

“There are systems of medicine in the world that de-emphasize the disease process and emphasize the mind-body connection,” White says. “They deal more with health, whereas we deal more with pathology. That's what we're looking at.”

In fact this whole-person approach to cancer care—often called integrative or biopsychosocial medicine—is becoming the norm rather than the exception in major cancer centers and hospitals.

Barrie Cassileth is chief of the Integrative Medicine Service at Memorial Sloan-Kettering Cancer Center in New York, the world's oldest and largest private cancer treatment and prevention institution. She notes that Sloan-Kettering now offers a cancer help program very similar to Smith Farm's.

But it's important to remember, Cassileth says, that the recent focus on the psychological and social impact of cancer has been made possible largely by the success of mainstream cancer treatments like chemotherapy, radiation and surgery.

“Quality of life has only become an issue,” she says, “since enough patients have been around long enough to worry about quality of life.”

A Sentence to Life

In her large yet cozy living room, her sacred space, Viking Katherine Anthony speaks frankly, and with regular outbursts of happy laughter, about the perspective her Smith Farm experience has given her.

“I say I'm a person living with cancer,” she says. “It explains the situation but it's not that I'm the disease. Once in a while you hear ‘cancer victim,’ but *not* being a victim is what Smith Farm is about.”

Long an active gardener, Anthony says she “was ready to pave over the front yard” after her diagnosis because she had no energy for it. But on this August morning—more than four years later, in between trips to Chicago for ongo-



Despite initial skepticism, Don Zauderer became a Smith Farm “Viking” during a retreat for cancer patients in 1996.

ing medical care, two days before her 51st birthday—the yard is a sea of colorful perennials. It has helped her understand life's fragility and continuity.

“It has taught me there would be a spring,” says Anthony. “That has sustained me.”

Remen calls it “the drive to remain incarnate,” this will to live even in the face of devastating illness. “There is a tenacity toward life,” she writes, “which is present even at the intracellular level, without which even the most sophisticated of medical interventions would not succeed.”

When you meet Garry Lipscomb, you don't think cancer. His casual mention of training for the Marine Corps Marathon only reinforces your impression that this is a healthy, energetic 43-year-old man.

Lipscomb's stressful job working with Whitman-Walker Clinic's AIDS clients seemed to account for the digestion problems that had been diagnosed as irritable bowel. But in February 1999 he learned that his family's history of colon cancer was playing itself out in his own body. This delay in getting an accurate diagnosis meant that by the time he found out what was really wrong he was already dealing with Stage Three tumors with infected lymph nodes.

Chemotherapy was a nightmare, he recalls. He was lethargic, sensitive to sunlight, and had changes to his skin pigment and nails. Conversations with a homeopathic physician and with Hawkins convinced Lipscomb that a holistic approach to his illness was the way he wanted to go—and that Smith Farm would be a valuable adjunct to his medical care, vegetarian diet and supplements.

After Linda Greensfelder's late husband, Ted, went through the Smith Farm program, she says, “he literally came back a changed person.”

A typical Type-A Washington lawyer, she says Ted had never made time for the kinds of things Smith Farm focuses on, the things that can enhance life for anyone. After his retreat, though, Greensfelder says Ted was filled with a new sense of purpose and meaning—even as he battled his own final enemy. “Cancer was not the terminal event,” says Greensfelder. “It gave him the opportunity to be alive.”

In fact, she says, Ted came to refer to the pancreatic cancer that would eventually kill him not as a death sentence, but as his “new sentence to life.”

He went out like a Viking. ■

John-Manuel Andriote, author of “Victory Deferred: How AIDS Changed Gay Life in America” (University of Chicago Press, 1999), last wrote for the Health section on a local nutrition program for AIDS clients.

Resources for Holistic or Complementary Cancer Care

■ Smith Farm Center for the Healing Arts
Smith Farm Cancer Help Program
1632 U Street NW
Washington, DC 20009
202-483-8600
Contact: Shanti Norris
email heal@smithfarm.com
www.smithfarm.com

■ Commonweal
P.O. Box 316
Bolinas, CA 94924
415-868-0970
www.commonweal.org

■ American Cancer Society
1599 Clifton NE
Atlanta, GA 30329-4251
800-227-2345

800-227-2345
www.cancer.org
ACS offers information for patients on various types of cancer, cancer risk, prevention, detection, diagnosis and treatment.

■ National Coalition for Cancer Survivorship
1010 Wayne Ave., Fifth Floor
Silver Spring, MD 20910
301-659-8868
www.cansurvivorship.org
NCCS is the only patient-led advocacy organization working on behalf of people with all types of cancer and those who care for them.

• Cancer Care Inc.
1180 Avenue of the Americas
New York, NY 10036
800-813-HOPE
www.cancercare.org
This nonprofit organization provides online and telephone referral services including medical referrals, counseling, financial assistance information for nonmedical expenses and local support referrals for such services as housekeeping and health aids.

■ Cancer Information Service
National Cancer Institute
800-422-6237, TTY
800-332-8615

http://cis.nci.nih.gov
This free information service is perhaps the most comprehensive source of information about cancer and its treatments, offering numerous Web links and information about clinical trials.

■ Integrative Medicine Outpatient Center
Memorial Sloan-Kettering Cancer Center
303 East 65th St.
New York, NY 10021
212-639-4700
www.mskcc.org
The world's oldest and largest private cancer treatment,

prevention and research institution offers public information, medical referrals, clinical trials and helpful links.

■ OneBody.com
www.onebody.com
This independent, three-year-old information site was founded by a group of health care professionals, including alternative and conventional medical practitioners, to offer credible, unbiased information, matchmaking with qualified health professionals and other services.

—J.-M.A.