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## **A Cancer Patient Faces the Chaos of the American Health-Care System**

**by Rosalind Lacy MacLennan**

In mid December 2004, I stood up in the middle of my primary-care physician's waiting room, and said, "I am carrying a weapon of mass destruction in my breast. I have breast cancer. I came here for treatment, not for cemetery care."

At last. The receptionist looked up. After two phone calls in advance and a polite request at the front desk for my medical records and a referral to an oncologist, I had broken the wall of indifference. The office manager, for whom I had written out my requests on a form more than an hour before, came scurrying out with what I needed.

I had come to this office from my surgeon's office, several miles away, where I had heard my diagnosis. But he didn't have my complete medical file or the power to write the referral. I felt terrified and confused, but I was following orders from my Health Maintenance Organization (HMO).

The odds of surviving the duel with cancer now are far greater than they were 20 years ago or even 10 years ago, but going through the paces of the medical system is worse than playing a game of Russian roulette. After 17 cancer-free years, my fight with a recurrence is harder because medical insurance for doctors and patients is chaotic with regulations.

As I left my doctor's office, several other patients followed me outside. We agreed: frustration with the system is typical. No, they insisted, I was not out of line or selfish to demand attention. The professionals are so busy with forms, many don't pay attention. Doctors and patients today are caught in a web of bureaucracy that could cost lives. "You have to take care of yourself. You have to fight the bureaucrats to the end," one woman told me.

To begin with, the Framers' intention to "promote the general welfare" in the preamble to the Constitution did not include universal health care. Health is an individual, free-choice matter. The government, whether through Medicare, HMO regulations, or otherwise, should *never* be in the business of protecting me from myself or of telling a doctor how to practice his healing art.

Too often in the past two years, I've heard, "Don't do this. Don't do that." After a "normal-benign" mammogram report in December 2003, a technician told me, "Don't come back until you've let at least 11 months go by or your medical insurance won't cover your next breast exam." That rule comes directly from the official U.S. government CMS Site (Centers for Medicare & Medicaid Services): "For a woman over the age of 39, Medicare will only pay for a screening mammography after 11 full months have passed following the month in which the last screening mammography was performed."

Do the politicians think my cancer is going to wait for a photograph? Do they think I enjoy going to a radiologist to have my breast pinched and pressed into an X-ray machine? Am I going to overuse a test that exposes me to radiation? On the basis of a British medical journal report in 2001, controversy continues to spin around how useful and accurate the test is. Nonetheless, if I detect an abnormality why can't I go at any time or even bypass a test and go for a biopsy?

One medical-office manager told me the government's intention is to guarantee routine screenings for all women. The American Cancer Society reports that mammograms catch 90 percent of all breast cancers. Therefore, politicians want to equalize the availability to make sure everyone over 39 goes for the test (even though some women under that age develop breast cancer). To hold the medical professionals accountable, Medicare pays for mammograms annually.

Instead of providing encouragement, the rule acts as a deterrent. Many HMOs indirectly compete with Medicare. Both private and public companies, therefore, are heavily regulated. The regulation allows the insurance companies to *refuse* payment to hold down costs. So, although a radiologist's disclaimer states that any change in breast tissue within the 11-month period should send me back for another test, I believed the narrower interpretation of the rule.

So did my primary-care physician, who exchanged his role as a healing assistant for that of an insurance advisor. During my annual check-up in April 2004, he opined that a new lump, which I had found, lay in almost the exact spot as a benign tumor from two years ago. Therefore, reasonably, it was "scar tissue" from the biopsy.

Seventeen years before, in 1987, I had undergone a lumpectomy to remove a breast tumor. Radiation and five years of taking tomosifen pills followed. Since then, I had become athletic and vigorous, believing I fell into a 1 percent recidivism category. Rarely did I think of cancer. I didn't have time to be sick, I rationalized.

But what finalized my decision in my doctor's office last April was his reminder that my medical insurance would not pay for another mammogram so soon after the "normal" one in 2003. *In my opinion, his focus was on the system, not the patient — me.*

At that moment, I felt too intimidated to ask for another test or even a second opinion. My husband had made a job change. I was worried that our health insurance would refuse to pay for what seemed an unnecessary test. Basically, I didn't want to be labeled a hypochondriac.

Medicare and HMO rules distort our thinking. We are conditioned not only to believe that our health-care providers are gods because they rely on statistics, but also to believe that our health-care insurance will pay for routine needs, not just catastrophic illness. We are conditioned to be passive because we assume medical insurance will cover everything.

At the same time, doctors, even in computerized offices, resent filling out a glut of insurance forms to meet the demands of government scrutiny and liability insurance. Doctors in large practices must hire business managers to sort out the mess of paper work. Overhead costs go up. Consequently, doctor/patient rapport suffers, as it did for me.

Eight months later, the “benign scar tissue” had grown more prominent. When I called the primary-care office for the required referral to the radiologist, the receptionist, who didn’t know me, suggested I wait for my regular, scheduled mammogram at the end of December. Panicked by the resistance, I broke through my own conditioning and asked for a next-day appointment.

There it was, not only in my X-rays but also in the black hole of an ultrasound screen — a suspicious hard mass stared down at me. The following biopsy and lab reports confirmed my worst fears. This marble-sized lump, now grown to 2 centimeters, was a return of the Big C, breast cancer.

Enraged at myself for going along with the rules for eight months, for denying my instincts and not challenging the statistics, I jump-started treatment. Assurances that breast cancer is “slow-growing,” that a mastectomy could wait a month until mid January did not impress me. Uncertainty reigns until surgery. In full command, I demanded, “Get the cancer off my chest.”

Three months later and postmastectomy, I am grateful that aromatase inhibitors have arrived. Research advances have saved me. I am taking a hormone treatment or aromatase inhibitor drug, which reduces the amount of estrogen produced after menopause. (Aromatase inhibitors (AIs) cut the estrogen supply made and distributed in the body.) This new drug promises me survival with possible long-range side effects. I’ll take the trade-off — I’m alive.

But, at the same time, I am taking a stand against all assumptions that cancer *in any form* is slow-growing. We are not wrong to ask for immediate service. *Different grades of cancer grow at different rates.* Often, in postmenopausal women, invasive breast cancer is slow-growing. But there are exceptions. Some, like inflammatory breast cancer, spread like wildfire, faster than the estrogen receptor-positive cancers. Waiting can be deadly if the cancer is estrogen receptor-negative, a more rapid growing cancer that does not respond to aromatase inhibitors and requires more aggressive chemotherapy with harsher side effects. Some rare cancers have already spread from other sites. Ultimately, cancers have no respect for waiting.

Within the past 20 years, cancer research has made tremendous progress. Also screening and treatment programs are more available for poor women because of private breast-cancer foundations. Breast cancer should not be a death sentence, but women die of a treatable disease. Compared to ovarian or lung cancer, for example, breast cancer is easier to detect. So it is

upsetting to hear how a friend's mother died while waiting for insurance payments for treatment. "The insurance companies love to have you pay into the system, but they don't want to pay out," my friend says, describing a system that has grown dysfunctional.

Postmastectomy, I have met other women with breast cancers that have metastasized through the lymph nodes to other parts of their bodies. For eight months I played a game of roulette that could have produced the same result. In 2002, a tumor that was benign landed next to a lymph node. If malignant, that tumor could have spread to my lymph system. I could have been a lot sicker than I was in 2004. I was lucky.

Today beating cancer is still a game of chance. All too often, survival depends on long waits, a swamp of procedures, and unnecessary written referrals for insurance requirements. The perverted public and private systems exhaust the professionals and the patient.

We need to break through our conditioning and accept the facts that: (1) The U.S. Constitution does *not* guarantee the right to health care. Freedom means we take care of ourselves. The government should not be in the business of putting our lives at risk, under the puffed-up pretension of protecting us from ourselves. (2) Government bureaucrats have saddled Medicare and thereby HMOs with top-down health-care insurance regulations that make doctors servants of the system. The rules aren't sacred.

No government body, state or federal legislature, politician or bureaucrat is wise enough or has the omniscient knowledge to strong-arm a decision about an individual person's health care. An insidious trickster like cancer requires the invisible hand of the marketplace that serves the patient first.

Medicare/Medicaid should be abolished so that laissez-faire care can optimize individualized monitoring. We must transform the patient's role from passive to active: Let the patient and the doctor take charge. Get the cancer off our chests and the government off our backs.

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