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# NARRATIVE MATTERS



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## Living Life In My Own Way—And Dying That Way As Well

*A health foundation executive receives a diagnosis of terminal breast cancer and, with the help of a doctor who respects her goals, forgoes aggressive treatment in favor of palliative care.*

BY AMY BERMAN

**T**he day I found out that I was terminally ill, it was misty, just barely raining, appropriately gray and damp. It was November 2010; I was fifty-one years old. My life was normal—wonderful, in fact.

My mother and I, both in our raincoats, both carrying umbrellas, were walking down a city sidewalk miles from home when my cell phone rang. It was my oncologist calling to give me test results; she knew I'd want them before

a medical appointment the next day. She told me gently. I hung up.

"It's stage IV," I told my mother. "The bone biopsy showed that the cancer has spread. It's in my lower spine." I paused. "This is the worst case—it's bad." The diagnosis seemed to drop from the sky, rain clouds turned to lead, crashing down on us. We hugged, crying, rain and salty tears mixing. My tiny mother. Her tall daughter. One wet, raincoated shape as we held one another, our umbrellas forgotten.

"Take three deep breaths," I finally managed to say to her. We tried. But as we inhaled, suddenly both of us began laughing, uncontrolled belly laughs, despite—and in defiance of—the damp death sentence that had just fallen from the sky.

That was eighteen months ago. Now, in April 2012, the medical countdown toward the end of my life continues. And I've done a lot thinking about how best to live the limited time I have left.

### From Feeling Fine To Cancer

Earlier, even as I was being diagnosed, I felt fine. I looked the same, too—with one exception: A small, red, rough-textured spot (not a lump) about the size of a pea had appeared on my right breast. I was educated as a registered nurse and led quality improvement efforts as a health care administrator, and now I am at a foundation focused on improving the health of our nation's older adults. But even without that background, I'd have known something was wrong. Anyone would.

My primary care physician quickly arranged for me to have scans and a biopsy at a local hospital. Both of us were aware that the red spot might be cancerous.

The night before my hospital appointment, I was wide awake, reading. Today, breast cancer, in general, has a five-year survival rate nearing 90 percent. But inflammatory breast cancer, which I suspected the spot might be, is different. It's an especially aggressive form of breast cancer where the breast itself eventually can become red and swollen ("inflamed"), and even develop a diseased open wound. But most frightening is that it tends to spread to other parts of the body. Of those who are diagnosed with inflammatory breast cancer, at which point it's usually stage III or IV cancer, only 40 percent live five more years.

By midnight, my research had revealed that despite all the funding going toward curing breast cancer, what seemed to me an insignificant amount

goes toward finding a cure for inflammatory breast cancer. By 2 a.m., I knew who was involved in inflammatory breast cancer research, what kinds of clinical trials were happening, and where. The next morning, before most people had sipped their first cup of coffee, I was in the hospital, watching as a radiologist extracted “core samples” of my breast tissue. In a clear, informational way, she explained what she was doing and what she was seeing. She noted eventually that the samples appeared to be malignant. I appreciated her honesty.

When the biopsy results were back, I met with an oncologist in New York City, where I work. She had been recommended by a leading geriatric oncologist I knew through my foundation activities. After she gave me a physical exam, we sat quietly in her office lined with its reassuring books and diplomas. She looked me in the eye and in a soft voice told me the diagnosis: inflammatory breast cancer.

I didn't flinch. Hearing it said out loud was almost anticlimactic. I'd thought so. And the radiologist who'd taken the biopsy had gently helped prepare me for the news.

I told the oncologist that I knew inflammatory breast cancer was incurable, and that there was no cure in the offing. She confirmed what I'd read about the survival odds. My oncologist told me she didn't like the word “terminal,” but I knew that's what she meant. I might have far less than five years to live. “Not...five...years.” How simple it sounded. How final.

She asked me how I wanted to move forward and what my goals were. My thoughts drifted to my grandmother, who'd had Alzheimer's disease. I remembered how she disappeared into the illness, frail, sad, and frightened. “I want to feel good for as long as possible,” I told the oncologist. “Don't push to extend my time if I'm not able to have that.” She nodded and put her hand on mine.

“Here are my suggestions, then,” she said. “I'll arrange a body scan to see if the cancer has spread.” If the disease was still confined to the breast, she said, “I think we should be aggressive. That could give you a better chance at a longer, better life. But, if the cancer



has spread far beyond the breast, we can talk about less aggressive approaches that could slow the cancer but have fewer side effects for you.”

The body scan showed a “hot” spot in my lower back, an area that the injected irradiated glucose had been drawn to. It could mean cancer, or something as benign as a minor back injury that was healing. The only way to know was to remove a small piece of bone from the spine—so I underwent the surgical procedure. When I awoke, my back felt bruised. I had to sit down quite carefully for the next week.

### A Newer Treatment?

It can take years before scientific breakthroughs and innovations become common medical practice. Although no cures were on the horizon for my disease, I figured some newer ways to treat this kind of cancer might exist.

I'd come across information about an oncologist, a specialist in inflammatory breast cancer, at a respected cancer center in a nearby state. Might he be able to help me? My New York oncologist assured me that if the specialist could suggest a treatment, she'd work with him on my care. She sent me off to an appointment with him, and she gave me her blessings and slides of my cancer cells packed in a Styrofoam box.

It was that rainy afternoon when I was walking with my mother when my cell phone rang, with my oncologist explaining that the breast cancer had spread to

my spine. It meant that I'd be telling the specialist the next day that I had the worst possible diagnosis.

That day came, and as we walked into the lobby of the top-notch cancer center, we saw that contemporary art graced the airy space. The aroma of freshly brewed coffee from a café mingled with the scent of flowering bouquets. An attentive nurse directed me into the office of the preeminent inflammatory breast cancer expert.

He wore a tepid smile and a dark moustache, and he greeted me with little fanfare. His eyes eagerly focused on the slides prepared by my oncologist in New York City. After a perfunctory hello, review of papers, and a brief physical exam, he outlined his recommendations. He advised intensive chemotherapy, radiation, and a mastectomy, followed by more chemotherapy.

Why? I knew there was no cure for stage IV inflammatory breast cancer.

“This is not a cure,” he told me. “But if you respond to the treatment, you might live a little longer—although there are no guarantees. All of my patients use this protocol.”

I asked why he wanted to remove my breast when the cancer had already spread to my spine. “You don't want to see the cancer. Do you?” he answered, looking annoyed.

I was stunned—then angry.

The specialist never asked me what I wanted. He didn't mention *my* needs or treatment goals. He didn't know—or seem to care—that my hope was to extend my quality time on this planet rather than merely linger. He didn't care about the toll of the treatments on my body and my remaining days.

Were I to choose his one-size-fits-all approach, I'd strip myself of the very type of life I'm pleased to have now, probably without gaining any benefit. If I'd detected even a whiff of caring about me as a person or as a patient, I'd have explained, “No, that's totally wrong for me. I want to work, enjoy family and friends, do things that are important to me—while feeling good—for as long as possible. Once I can't, I'm not interested in aggressively extending the length of my life.” But it didn't seem worth it with a doctor who used the same protocol with every patient.

My mother and I left quickly.

## Patient-Centered And Palliative Care

Thank goodness my oncologist wasn't like that specialist. Instead of ignoring my wishes and goals, my doctor was embracing them and keeping me as informed as possible. She'd discussed the diagnosis, prognosis, and possible treatments, and she'd asked me about how I wanted to proceed. Together, the two of us chose a treatment regimen that would slow tumor growth, while protecting what was precious to me: my quality of life.

Too many other patients have doctors like that specialist. A cancer-survivor friend told me that her oncologist once said, "I wish I could just treat the cancer; patients get in the way." Another friend, with stage IV cancer, was advised by her oncologist to skip a three-hour car ride to visit her new granddaughter because she'd miss a chemo appointment—one that would do nothing to change the fatal nature of her advanced disease.

Why do these and so many other doctors miss that patients have their own needs and desires? William Osler, who's been called the founder of modern medicine, understood. As he put it, "The good physician treats the disease. The great physician treats the patient who has the disease."

I realize that doctors want to cure, to save lives, to instill hope. Perhaps that also makes it difficult for them to tell patients they're dying. Maybe, hoping that each terminally ill patient will be that one-in-a-million miracle outlier who lives, doctors temper their words. "Terminal" becomes "advanced illness." The words "we're going to treat this aggressively" are uttered even though *treatment* isn't *cure*. Patients like the sound of "treat aggressively." It seems as if doctors are fighting for us, but few truly understand what the phrase means. Because of my nursing background, I know all too well.

Is there a downside to aggressive treatment? You bet. In the case of incurable cancer, it can mean rounds of radiation or chemotherapy, or both, with side effects of crushing fatigue, overwhelming nausea, burned and peeling skin, permanent pain or numbness of fingers and toes, and the cognitive impairment known commonly as "chemo brain." The "treat aggressively" approach can leave

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patients bruised and battered, wishing they were dead.

Yes, perhaps, a few months of added life come with it—but at what cost? Furthermore, recent evidence suggests that people with certain cancers might actually live longer—and better—using a palliative approach, such as the one I'm taking.

For many patients, especially in the United States, "palliative" is, alas, a vague term, a word and medical approach they've heard of but don't understand. If patients knew what it entailed, I bet many more would opt for it—precisely as I did.

To be clear: It's *not* hospice care, although palliative care and hospice care often occur in tandem. Rather, the focus of a palliative approach is to prevent patients from suffering. If, in the course of an illness, suffering and pain become inevitable, then a palliative approach provides relief. It can be used at the same time as cures are being put in place—going hand-in-hand, for instance, to relieve side effects, such as nausea. It can be used with chronic conditions, such as back pain.

A palliative approach often is medically multidisciplinary, focusing on pain, symptoms, the needs of the family, and the ability to function at all ages and all stages of life. Palliative care can also provide comfort and symptom management at the end of life, which is why it's frequently used even during hospice. It's about providing the best possible quality of life, whether that means offering a cure; minimizing the burden of a chronic disease; or, as in my situation, focusing on maximizing comfort.

In my case, because my progressing illness is incurable, I've chosen a solely palliative approach. Instead of waging war with a disease that can't be cured, my doctors and I are focusing on treatment that optimizes how I function and addresses my symptoms, including com-

fort care for pain symptoms, for when I'll need it.

I've been fortunate so far, in that my pain isn't bad. I get twinges in my right breast. If at some point it is overtaken by disease, I'll probably have it surgically removed as a comfort measure. I also have a dull ache in my lower spine that I notice primarily if I stand too long or carry a heavy bag. As more serious problems arise, my doctors and I—eventually with the help of a palliative care physician—will address them.

But our nation's health care delivery system still defaults to aggressive treatment for all illnesses. If patients knew the true benefits—and true drawbacks—would that be their choice? Or would they go the palliative route instead?

Recent studies suggest that fully informed patients nearing the end of their lives are less likely to choose aggressive care when they understand what they can realistically expect. They also are less anxious, and they rarely end up in intensive care units or on ventilators.

The "triple aim" of American health care, according to Don Berwick and colleagues, should be better health, better care, and lower costs. Palliative care for inflammatory breast cancer? Check. Check. Check.

It's outrageous that we're more likely to receive full disclosure when buying a house than when seeking medical care. An overhaul of consumer protection in health care is long overdue.

## Creating A Better Way

There are things we can do today that would be game changing for patients, providers, and payers in this country. And for people like me, who are struggling with a serious illness, these would just plain be the right things to do.

Providing information about the benefits of a palliative approach to medical care is high on this to-do list. It's a kinder, gentler approach to care that many people don't know exists but would surely embrace if they knew about it and it were made available to them.

I'm still on the young side, but for older Americans, who are the focus of my professional life, gaining this kind of knowledge goes hand-in-glove with requiring conversations about goals of care during the annual Medicare

checkup. In fact, palliative care should be available across the life span; should be part of discussions with patients who need help with symptoms and pain; and, if patients aren't yet enrolled in Medicare, should be covered by private insurance.

Some people have voiced concern that creating a Medicare benefit that paid physicians or other primary care providers to have end-of-life discussions with their patients might somehow lead down a slippery path to government control over health care decisions and "care rationing." That makes absolutely no sense. Such conversations are essential. Without them, patients have no control over crucial decisions that deeply affect their lives.

What patients really need to be wary of are rationed information and rationed decisions, meaning any attempt for their quality of life to be decided—rationed—by someone else. Whenever doctors fail to ask what patients and families think, what it is they want, that's actually what's happening.

I want every patient facing end-of-life decisions—which, when you think about it, eventually will be all of us—to have access to the kind of open communication I'm receiving. Each patient deserves to understand the diagnosis, the probable course of his or her disease, and the likely timetable. Each deserves to be asked about personal goals. Each deserves to be an informed participant and help decide about treatment options. Otherwise, it means that somebody else decides how we live and how we die. Doctor-patient conversations of this sort are a fundamental right and a basic element of good care.

Furthermore, it's not enough to simply say these conversations should happen. Money talks—and talk costs money. Doctor-patient conversations during annual Medicare checkups must be reimbursed, and preferences should

## **It's the ultimate win-win to allow patients some control about how their lives will end, just as patients are able to choose how they live them.**

be carefully documented in a way that can be shared with other members of the health care team.

As the federal government enhances so-called meaningful-use guidelines for electronic health records, these systems should be required to include patients' goals, because it doesn't get more "meaningful" than these. One-quarter of all Medicare spending occurs during the final year of people's lives. If even a small percentage of patients at the end of life rightfully and knowingly opted for a less-is-more approach—as I am—it would more than offset the modest Medicare reimbursement costs for conversation time.

Additionally, we as a nation need to understand and use the Medicare hospice benefit more fully—not just in the last week, or month, of a patient's life. The benefit was designed to help patients and their loved ones get the support they need in the final months of life, eventually shifting the priority from the person's treatment to the person's comfort.

Families often say they wish they'd known about the services earlier. Much more information should be made available to patients and their families about the high-quality, low-cost care provided by hospice so that people know about it well before the final weeks. We can improve quality and lower costs by initiating hospice care earlier. And I sincerely hope that a demonstration project mandated by the Affordable Care Act—one

that allows patients in certain hospices to receive disease treatment while in hospice—becomes the norm for the land.

Some patients don't want to take part in their own end-of-life decisions, or any medical decisions, for that matter. Some want to be sure aggressive means are used until the end. That is their right—their decision.

Others, like me, want to be fully involved, to have detailed conversations. That's my right, and I think many patients would want it too, if given the option. No matter the decisions that are made, we need to have a health care process that supports patients' rights in the way in which they want to be supported. We also need a process that helps doctors, in the midst of their dedication to extending our lives, to learn that the length of patients' lives isn't the sole consideration. It's the ultimate win-win to allow patients some control about how their lives will end, just as patients are able to choose how they live them.

As you read this piece, I'm getting close to two years into a terminal diagnosis. I have the most deadly form of breast cancer, and it will eventually kill me. So far the disease seems to be held at bay by one small yellow pill each night, some extra vitamins and minerals, and a monthly infusion to stave off problems like spontaneous fractures because of the cancer eating at my spine. No treatment will work forever, though. I know that. But however my story evolves—then ends—I'm at peace. And I'm living just the way I want to. ■

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