

Chris

Category: Stories

written by Lisa deMauro | August 28, 2009

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My big sister Chris, 55, had recently returned to her first career, nursing, when she wrenched her back one day while helping to lift a patient. After weeks of physical therapy proved unhelpful, her internist ordered some tests, which indicated that her back injury might signal something more sinister. She'd had a lumpectomy for a "stage 0" breast cancer five years earlier, and her doctor advised her to make an appointment with the newly appointed head of a brand-new cancer center nearby.

Chris and I were nine years apart—a difference that precluded any sisterly rivalry—and we'd always been very close. She'd occupied a central role in my life: first, as a playful second mother to me, then as my ideal of teenage glamour, and finally as a friend with whom I shared confidences about the joys and sorrows of grown-up life. When it became clear that she might be getting bad news, I needed to be with her, just as my parents did.

The three of us converged on the Pennsylvania town where Chris was living. We met her in the hospital lobby, hugged each other for long moments, then headed off together to meet with the oncologist.

Our collective mood was one of defiance born of family history: My mother had had a mastectomy in the distant 1950s, and my father had had surgery for thyroid cancer and was currently being treated for prostate and colon cancer. We were determined to be positive: Here we are! A family that faces down cancer! Survivors!

Of course, we were also terrified.

What we needed in that moment was a superhero—a confident, compassionate medical warrior who would stand between our family and the unthinkable possibilities, armed with brilliance, sensitivity and a detailed check-list of treatment options. What we got, inevitably, was a human being—one spectacularly ill-suited to our needs.

In a private sitting area we sat, huddled close for safety, and watched the white-coated oncologist approach. He greeted us with a smile that held no warmth, sat in a chair facing us and served up his news. In brief, factual sentences, as if summing up a case history in a textbook, he explained that Chris's back pain was almost certainly a symptom of breast cancer that had spread to her bones. There would be more tests, but he felt little doubt of their results.

It's a cliché to hate the person who delivers bad news, but this man left us no choice. Chris, divorced and with only her own income to rely on, asked just one question: "Will I be able to go back to work?"

The doctor smiled apologetically. "Did you want to go back to work?"

That's how we learned that she wasn't expected to recover.

A few days later, we met Chris's radiation oncologist. He was a gentle-seeming soul, perhaps even compassionate, but with no apparent concept of tact. He asked us to wait in a spare, corporate-looking conference room, and my parents and I exchanged numb looks as we hovered protectively around Chris.

The doctor came back in, placed a film on the lightbox, then beckoned us over. "Take a look," he said, pointing. "Here's your bone scan."

He might as well have said, "Here's your death sentence."

It's impossible to describe the hollowed-out, otherworldly feeling of that moment: We stared at images of a brightly lit miniature skeleton shot through with black dots. Tumors everywhere, too many to count—in the ribs, the thighs, the pelvis, the skull.

What did we say to each other then? Or in the car later on? I don't remember.

Chris was prescribed painkillers and scheduled for rounds of radiation. In the weeks that followed, she suffered terrible pain in her back and legs, along with violent nausea; she never went more than an hour without vomiting. My parents moved in with Chris to shop and cook, drive her to treatment and offer support. I obsessively searched the Internet trying to figure out *what to do*. I made weekly trips with offerings that I hoped would bring relief: ginger snaps, aloe juice, licorice, a microwavable pillow for the pain.

Weeks turned to months and Chris failed to improve—yet through all of this, the oncologist seemed weirdly disengaged. It was hard to get his attention; he seldom returned phone calls. It felt, in fact, as if he'd lost interest in her case. Clearly this wasn't going to be a success story. Perhaps, in his mind, he'd already moved on.

I feel deeply ashamed that through all those months we couldn't pull ourselves together and say, "Enough is enough." Finally, though, the oncologist pushed us over the edge. During a rare visit to his office, Chris began to vomit. For a second, he looked horrified. Then he laughed, patted her back and said, "She'll be all right."

That pat on the back did it.

We harnessed our outrage and started over: sifting through names, making calls, searching for someone who would accept Chris's insurance. When we did find a candidate, we had to gather Chris's massive medical dossier and lab reports and struggle to get her focused—most of the time, she felt too ill to leave the house—hoping all the while that the next doctor would actually know how to help.

Finally, we found one who did. My sister's "good" oncologist was a gentle, genuine, white-haired man who seemed able to read the situation and offer

exactly what was needed. Before he did anything else, he listened: to Chris, to learn what her daily experience was like; to my parents and me, to learn what our concerns were and what we needed in order to offer Chris support. His first priority was determining why she'd been so nauseous. When he changed her pain medication, eight months of vomiting came to an end in one afternoon.

In choosing a course of treatment, he took his lead from Chris. He never required her to look farther than the next appointment, nor did he go out of his way to remind her that her time was limited. He seemed to feel that the quality of her life, rather than his expertise, was the most important factor in her care. He brought peace and calm to our family and helped relieve the shame and hopelessness that my parents and I had felt.

Almost four years after meeting her first oncologist, Chris died. I believe that the outcome would have been the same no matter who treated her. But I know that fleeing her first, inadvertently cruel, care providers to seek the care of compassionate people made all the difference in her day-to-day experience.

I have infinite respect for the intelligent, courageous people who make oncology their life's work. But I've seen that it isn't enough to be knowledgeable or technically proficient. My sister's experiences convinced me of the vital importance of finding a caregiver who understands how to give care in every sense.

Chris's first physicians were doctors but not healers. Her last physician showed us that, although Chris's illness couldn't be cured, she could still experience healing. And, in fact, this healing offered the deepest comfort to my sister and to all of us who loved her.

About the author:

Lisa deMauro is a long-time freelance writer and editor and a recently minted school counselor. She has had the opportunity to contemplate death and dying through the long final illnesses of three close family members. "I have found that, for me, the greatest terror lurks in the shadows of silence and denial; the process grows less frightening as the light shining on it intensifies."

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