Despite her own personal battle, Rebecca Dresser doesn’t view herself as a cancer “survivor.”

“Many people who have faced the disease are very courageous, but in terms of defeating cancer, really we were just lucky,” says Dresser, the Daniel Noyes Kirby Professor of Law and professor of ethics in medicine.

Dresser, the editor of and contributor to a new book on medical ethics and cancer, was diagnosed with head and neck cancer six years ago. While she has written and taught extensively about the legal and ethical dimensions of a variety of medical topics, personally enduring intense radiation and chemotherapy treatments spurred her interest in the ethics of cancer and cancer medicine.

For perspective, she reached out to other medical ethicists who had either had cancer themselves, or had a spouse diagnosed with the disease. One of them had experienced both. The group met twice at the university. Those meetings were tape-recorded and then transcribed. The transcript became the basis for their book, Malignant: Medical Ethicists Confront Cancer, published by Oxford University Press.

IN AN ESSAY PUBLISHED in the Hastings Center Report, Dresser also reviewed six themes that surfaced as she and the other members of the group talked and wrote about their experiences. First, she realized that “cancer patients and caregivers operate in crisis mode.”

“Cancer knocked us off our feet,” she writes. “We were disoriented and unsure how to proceed.” In that vulnerable state, cancer patients and their families sometimes make decisions that caregivers and others don’t understand, she notes. “Before facing cancer, we didn’t fully appreciate the psychology of patient decision-making,” writes Dresser.

Complicating things further, the many treatment options available—with their side effects and uncertain outcomes—often confuse cancer patients and their families. Combined with the pressure to act quickly, patients may take a “leap of faith” when selecting treatment options. As Dresser puts it, “We now have a better sense of the real obstacles patients encounter in trying to make informed medical decisions.”

Patients in the group become painfully aware that they have given up a good deal of autonomy to the disease and those working to defeat it. “Despite being privileged patients with good health insurance and insider status, we were at the mercy of an overburdened and highly imperfect health care system,” she writes.

ANOTHER THEME that emerged was how seemingly mundane decisions on the part of health care providers took on ethical dimensions. Does the doctor make eye contact when describing a treatment’s risks and side effects? Does he or she listen and respond when patients complain about those side effects? These seemingly minor behaviors take on an added dimension when the stakes are life and death.

Of course, not every patient responds to the disease in the same way; each patient brings to the table his or her own medical
history, tolerance for pain or discomfort, and past experiences with the medical establishment. Medical professionals need to be willing to adapt to meet the needs of each patient.

Finally, there is also considerable variation in how ordinary people and family members react to patients. While some are incredibly helpful and understanding, “a fair number of them have no idea how to behave toward seriously ill patients and their families.” Reactions by these people range from denial to simply ignoring the patient.

“Death and dying may have a bigger public presence than they once did, but too many people remain ill equipped to respond when serious illness strikes someone they know,” Dresser writes. “Malignant intends to begin a conversation about the ethics of illness in everyday life. We hope it will encourage colleagues to turn their attention to this neglected topic.”

Another broader response Dresser hopes her book will have is to raise the possibility of practicing “first-person bioethics.” While bioethics typically strives to be objective and dispassionate, facing the grim reality of a disease like cancer can make even the most analytical academic confront the fact that he or she is ultimately at the mercy of the medical establishment and a good portion of “luck.”

“Bioethics operates in the shadow of death,” Dresser writes. “A bioethics that fails to recognize and respond to the experience of illness will have limited value for patients and their families.”