

FEATURE STORY

Never Fear

BY PAUL ENGSTROM

Treatment anxiety can be conquered [and besides, it usually turns out to be unfounded].

Before the first of five surgeries for lung cancer, Lori Monroe grappled with multiple fears: her life would end in the operating room, the incision would be exceedingly large, surgery would fail, she would wake up in severe pain.

She also envisioned a nightmare scenario in which, following surgery, she would regain consciousness and be unable to breathe adequately.

All these fears proved groundless. “When I woke up after the first surgery, I was never that terrified again,” says Monroe, 49, who was diagnosed with stage 4 cancer in 2001.

Monroe, a registered nurse from Bowling Green, Kentucky, is like many cancer patients who, in addition to the many uncertainties associated with their disease, dread the thought of treatment, including its side effects and likelihood of success. Over the course of therapy, however, many come to realize, as Monroe did, that the outcome often is less horrific than they anticipated and there are effective ways to keep fear of treatment in check.

A survey conducted by Harris Interactive on behalf of the National Coalition for Cancer Survivorship and drug company Sanofi-Aventis was released in early 2008 and offers a glimpse of just how widespread and oftentimes illusory such fears may be.

Eighty-three percent of 326 adult cancer survivors (solid tumors only) said they were at least somewhat fearful before they underwent chemotherapy, but only 38 percent said their fears had been justified. Sixty-two percent acknowledged they had many misconceptions before treatment.

Fear of the unknown—including worries that therapy will be difficult—is normal; it may even be more overpowering than the diagnosis. Symptoms of anxiety include heart palpitations, high blood pressure, shortness of breath, chest pain, lightheadedness, trembling, sweating, nausea, heartburn, diarrhea, muscle tension,

irritability, and trouble focusing or solving problems.

However, unwarranted fear could be harmful because it may interfere with a patient's understanding about the purpose and rationale of treatments or cause patients to postpone much-needed therapy.



Challenging Misconceptions

The many different types of cancer and therapies, the extent of necessary treatment, and individual circumstances and attitudes vary widely, so it's difficult to draw general conclusions about the impact that age, gender, culture, and other demographic factors have on treatment fears.

Clearly, though, some cancers are more life-threatening and do require more aggressive and potentially frightening treatment. Depending on individual circumstances, some patients may take comfort in the fact that the arsenal of treatments for certain cancers, such as breast and prostate, has a relatively high success rate.

Paul Brenner, MD, PhD, a surgical oncologist and psychologist in San Diego who counsels cancer patients and has had prostate cancer for 10 years, says that, in his experience, the majority of fears about treatment stem from preconceived notions that may simply be wrong. He says that staying focused on the present and being "a witness of your thoughts" has enabled him and others to be more objective about their disease and the therapy necessary to fight it.

Another challenge for many patients is sorting through the reams of sometimes complex medical data available on the Internet and elsewhere, and putting it in context. For example, a patient who becomes alarmed about research suggesting that one or more treatments for his type of cancer were minimally effective in a large population may overlook that the findings don't apply in his particular case but instead reflect group, rather than individual, outcomes.

Rumors and other patients' gloomy personal tales can make matters worse. Tom Hiatt mulled over "every horror story, real or imagined" before undergoing low-dose hormonal therapy for metastatic prostate cancer, diagnosed in 2001.

“I was utterly petrified,” says the 68-year-old retired attorney from Hilton, New York. “I had heard all the stories—loss of hair, loss of muscle strength, total fatigue and nausea, and an inability to care for oneself.”

As it turned out, aside from a couple days when he felt a bit queasy, those fears never came to pass, Hiatt says. Two tactics that calmed his initial fears were speaking with three patients (drawn from a long list of names his oncologist provided) who had undergone similar therapy, and getting a second opinion from an oncologist who specialized in prostate cancer.

What's the Reality Behind the Fear?

Powerful Words

When the source of treatment information is a doctor, even the boldest of hearts may sink when words such as aggressive, powerful, invasive, or not generally effective come up. A lack of encouraging or empathetic words from physicians can be disconcerting, too.

Monroe, the registered nurse from Bowling Green, says she “went through a nightmare on the front end” after her lung cancer diagnosis seven years ago, especially when doctors cited the high mortality rate. Physician acquaintances advised her to just accept fate and not pursue therapy.

When Monroe asked an oncologist about diet and other possible counter-measures, “his attitude was, ‘Well, it doesn’t matter what you do,’ ” she recalls. Monroe says she “fired” this oncologist and found one who was more empathetic.



Lori Monroe's fear of lung cancer treatment dissipated once her treatment was under way. Photo by Alan Davis

Patients and experts agree that good communication with physicians and other members of the health care team, including nurses, social workers, therapists, and patient navigators, is critical. Indeed, the NCCS and Sanofi-Aventis survey

found that patients whose doctors made sure they understood the treatment plan had significantly less fear than those whose doctors did not clarify the plan.

“I tell people that in the best-case scenario, you’re going to have a relationship with a physician for a very long time, so you need to be comfortable with that person,” says Mary Lou Smith, a breast cancer survivor and co-founder of the Research Advocacy Network, an organization in Plano, Texas, that seeks to improve patient care by connecting patient advocates with researchers. But Smith also says it’s important to take into account a physician’s expertise, not just his or her bedside manner, even if the chemistry doesn’t seem quite right.

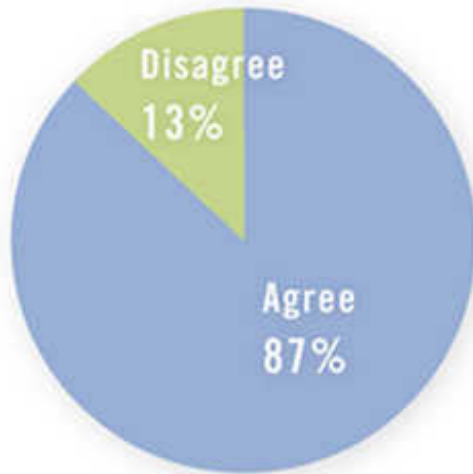
Equally important, according to Smith, is having a family member, friend, or someone else play the role of advocate and supporter—not only to absorb essential information and ensure the best care possible, but also to serve as a sounding board for fears, as patients may not feel comfortable telling their doctor about treatment anxiety. However, she cautions, for relatives who are themselves afraid and can’t shoulder the listener responsibility, a psychotherapist may be better suited.

Leaping the First Hurdle

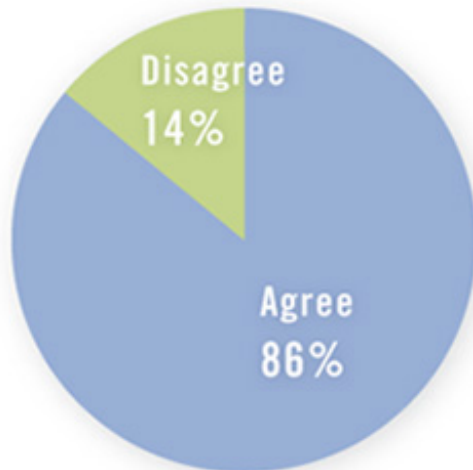
Anne McNerney knows a thing or two about fear. As a former breast cancer patient who underwent 16 rounds of chemotherapy plus surgery and six weeks of radiation, she is now a patient navigator at the University of Maryland Marlene and Stewart Greenebaum Cancer Center in Baltimore. She tells patients that getting past the first therapy session often allays fear significantly because “by and large, their imagination is so much more intense than the actual treatment.”

Part of McNerney’s job, aside from helping patients find their way through the health care maze, is to demystify treatment for them and listen to their concerns. Patients risk greater fear, she believes, if they collect too much information on their own about treatments, even though lots of facts may initially seem like a balm. The best course, she says, is “middle of the road”—enough information to be knowledgeable, but not so much that it is overwhelming.

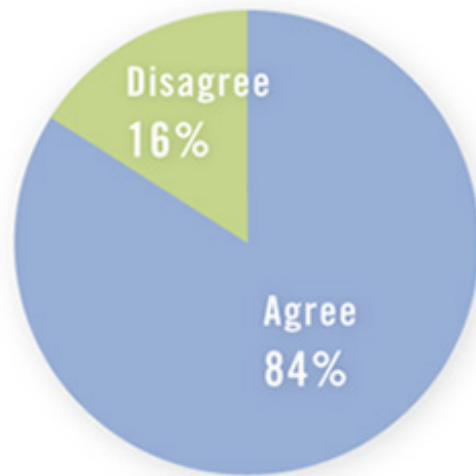
Fear of treatment may be an inevitable part of coping with cancer, but as McNerney, other health professionals, and patients can attest, it need not hinder sound decision-making or block progress toward treating the disease.



SIDE EFFECTS from treatment were more manageable because of the supportive care products available.



MY SIDE EFFECTS were well-managed by my health care team.



DISCUSSING the treatment plan with my health care team eased fears about chemotherapy.