

I Am Your 'Difficult' Patient

by Brenda Denzler

In 1978, the New England Journal of Medicine ran an article that has since become a classic in its field. "Taking Care of the Hateful Patient" offered advice to physicians dealing with patients that they hated to see on their schedule. Today the term of choice is "difficult," but it's the same patient that is described. In this short essay, a "difficult patient" herself speaks to the issue.

When I first heard the term "difficult (or hateful) patient," I winced. Difficult? Yet the word had the ring of truth, because I knew it described me—or the "me" I was. Maybe the "me" I still am, though I try hard not to be? I am your "difficult" patient.

When I was diagnosed with inflammatory breast cancer, a comorbid condition soon made itself apparent—a rather severe case of PTSD caused by two traumatic hospitalizations in 1958-59, when I was just 5 years old. The first was for a tonsillectomy during which the ether didn't work well enough. Then, 12 weeks later, the second was for a (probably iatrogenic) near-fatal case of hepatitis B. By the time of my cancer diagnosis 50 years later, I had a quietly smoldering, morbid mistrust and fear of medicine and those who worked there.

A discerning look at my life history would have revealed the deeply buried PTSD. For instance, the recurring nightmares wherein someone is going to do something to me "for my own good," but they haven't bothered to ask me what I want, what I think about it, or even explain exactly what they are planning. Yet somehow, I know...and it terrifies me. I try to get their attention, but they ignore me. I am totally powerless. I wake up from these dreams in a blind panic, often sobbing uncontrollably.

Now, with a cancer diagnosis, I was going to have to let a group of strangers do (almost literally) incomprehensible things to me "for my own good." Fifty years of relative health had not prepared me for this.

My PTSD erupted quickly and forcefully. I was far more terrified than most cancer patients, and terrified of very different things—things my treatment team couldn't

fathom. The person who had the best handle on the situation was the oncology psychiatrist. He (and I) soon named the PTSD and in rough terms figured out its origin. But like my oncologists, he was handicapped by my medical past when it came to treating me. Somehow we all stumbled our way through, though my desperate attempts to cope with my terror and mistrust were often more than my team could handle.

For instance, wanting to initiate an open and honest dialogue, I shared with them my insight about having PTSD, explaining that to me they were only a tiny, tiny bit less scary than the cancer itself. They found this revelation more offensive than enlightening.

Also, I needed different kinds and quantities of information and different approaches to conveying it than your average patient. I had at least a dozen well-considered questions to ask at every clinic visit—which made for lengthy visits that were tolerated but not exactly appreciated by my team. More questions would present themselves late at night and on those long, empty weekends. After looking for answers on my own, I would send my team emails to ask the questions that remained. They felt bombarded and harassed—especially if those questions challenged their earlier statements or treatment decisions.

I was highly distressed at the thought that some of my treatments could give me secondary health problems. Weren't they supposed to cure me—not harm me? I'd work very, very hard to come to some kind of peace with these risks, and then one of the team would make a dismissive and patronizing comment about my concerns, as if they weren't legitimate. This would extinguish the tiny glimmer of trust in the treatment (and those delivering it) that I was trying hard to nurture. Once, I called up a doctor who had just (unwittingly) done this to me and went off on him, which did nothing to bridge the gulf in understanding that lay between us.

Communications had to be spot-on. If there was any kind of discrepancy between what they said would happen and what actually

happened, it felt huge to me. It made me feel that the trust I had placed in what they told me had been betrayed—as if I had been manipulated via half-truths and untruths into doing what they wanted ("for my own good!"). And I called them on it, respectfully but pointedly. They felt attacked for being human and making what to them seemed like a small, inconsequential and honest error.

Then there was the mastectomy. My deepest terrors lay in the loss of control that surgery represented. I would lose my personhood and become a "slab of meat" on the operating room table, rendered unconscious, unable to breathe for myself and totally at the mercy of a new set of strangers. I negotiated with the surgeon for a couple of accommodations that addressed some of my concerns, and I wrote our agreements into every set of surgical consent forms I signed.

From the moment I woke up in the OR, however, I realized that she had ignored our agreements. Politely but very pointedly, again, I called her out on it. These were not small, inconsequential errors. They were major violations of my trust. Patient Relations and the Risk Management folks were alarmed, of course—but not for my sake; mostly just because of the litigation risk I certainly now presented.

By the time I was ready for radiation, my coping skills were worn thin. As we finished setting me up for my first treatment, I lost it big-time, sobbing uncontrollably. "Why do you have to hurt me? Why can't you cure me without hurting me? Why do you have to hurt me? Why do you have to hurt me?" Eventually, I wasn't sure who was asking—the 5-year-old child, or the 50-something woman. Whoever it was, I couldn't stop crying.

During the next six weeks I never broke down like that again, but there were many days when I lay there getting treatment and cried silently. And of course, I had a constant stream of questions about the medical use of radiation based upon my reading on the subject—questions that I pursued doggedly with everyone from the dosimetrist to the head of radiation oncology.

I am your difficult patient.

I don't mean to be. I don't want to be. But I am. The things that I have to do to try to manage my terror of you and what you propose to do to me are often the things that make you come to hate me.

I'm sorry. No...not for my efforts to cope. I refuse to apologize for who I am, especially since I didn't do this to myself. Rather, I'm sorry that your well-intentioned but clueless colleagues almost 60 years ago created this unmitigated terror within me. I'm sorry because you, like me, have to live with the consequences today.

I've spent the last eight years of my life trying to understand your world better, so that I can live more at peace with it and be less afraid of you. But the effort to understand must be mutual. You need to understand me better, also. Not just as someone who is demanding and difficult, but as someone who has been deeply scarred by those who came before you.

Brenda Denzler was diagnosed with inflammatory breast cancer in 2009. She became a cancer survivor on the very day she was diagnosed.



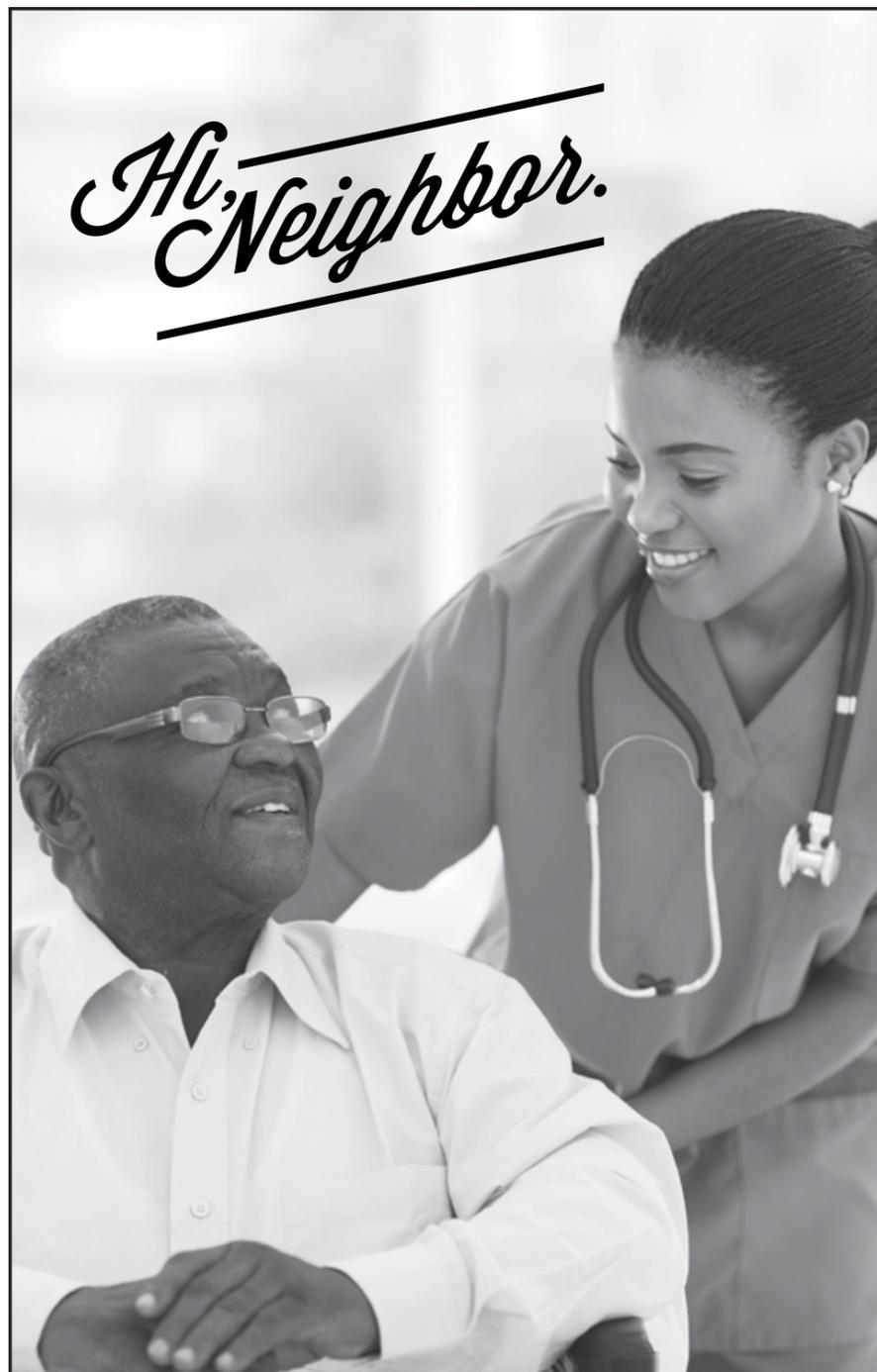
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