

The Worst Patient

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In *"The Patient From Hell: How I Worked With My Doctors to Get the Best of Modern Medicine and How You Can, Too"* (DaCapo Press, \$25), Stephen H. Schneider, a renowned climatologist and a professor of biological science at Stanford, uses his own successful battle against a rare form of non-Hodgkin's lymphoma as a model for how patients can push back against the health care system's pressure to treat everyone as "the mythical average patient."

Schneider is a 1992 winner of a MacArthur Fellowship for his work in global climate research. But he is not a medical doctor and is not giving medical advice, a point he takes pains to make. The book is not anti-doctor, he says, but rather an effort to encourage patients to work with their doctors to determine whether they might benefit from care that deviates from standard methods of diagnosis and treatment.

As a scientist, Schneider came into care better equipped than most patients to understand that medicine "by the book" can yield treatment that fails to respect the medical -- and social -- needs of individual patients. In his case, for example, he and his wife -- who served as his advocate -- successfully fought what doctors ultimately acknowledged was an arbitrary ban on whole-body radiation for patients over 55. He was 56 when he received his diagnosis in 2001. Schneider also persuaded his doctors to continue low-dose chemotherapy treatments during remission in a bid to prevent recurrence.

Schneider acknowledges that his professional stature afforded him a greater level of access and consideration than a typical patient might expect, but even that didn't keep his doctors from resisting his efforts to be an active participant in his own care. Persistence is key for any patient, he says, insisting that every patient (or advocate) has the right to demand answers to three basic questions: What can happen? What are the odds of its happening? How do you know and how can you verify the answers to the first two questions?

--Gregory Mott

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