# Never Trust a Doctor

Letting a physician cure your disease may kill you

August 1, 1996 By Kiki Mason

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It’s funny how memories can return to you. There I was, motoring around the house in a waddling, gimpy sort of way, when it came back to me that my grandmother had edema, too. She had swollen legs and hips all throughout my childhood. I was even making the same sound she used to make, a kind of low, motorized moan.

If Grandma was in pain or discomfort, however, you sure didn’t know it. She was too busy bossing everyone. Bad health never stopped her from shopping or lunching. Every saleswoman and maître d’ at the better places in town knew her and knew exactly what she desired. Even my grandfather, who wasn’t afraid of God or anybody, was wrapped around her pinkie. She was the ultimate Empress Dragon Lady, and I learned two important things from her: How to boss people, and how to treat doctors.

Grandma had an endless array of health problems, yet she never took shit from a doctor. She hated doctors and hospitals and the entire medical system with a passion. She discarded doctors as if they were Kleenex. If she didn’t like a doctor’s look, attitude or prognosis, he was gone. After several experiences being beaten up by procedures, tests and operations, she began to refuse a lot of recommended treatments. She would look me in the eye and say, “They’re all quacks. You don’t need most of those tests, and hospitals will kill you faster than any disease. They just want to make more money, and all they do is beat you up. Stay away from them as much as you can.”

Perhaps she knew, in some way, that someday I would need this advice. All I know is that Grandma lived to be 86, about 10 years longer than was expected. Oh -- and she died in the hospital with a strong suspicion of physician error. Yes, Grandma had it going on, and she’s watching over me now.

She must be. I have some of the best doctors in the world, and they all love me. But they’re still doctors, Western doctors, and they’ve been trained to operate in a certain system. Letting them cure the disease may kill you.

They broke the mold when they made Joe Sonnabend. He looks like the Nutty Professor and doesn’t have the pompous certitude of so many medical personnel. His office doesn’t look like a doctor’s office is supposed to, and he often seems disorganized. If you’re patient, however, he eventually finds whatever has been misplaced, and he is absolutely the best AIDS diagnostician

around. He catches the things that even the most experienced doctors miss. He calls me when I'm avoiding him and makes me come see him. "This is not a phone relationship," he yelled at me once.

He also makes house calls when I'm feeling shitty and bucks me up when my will to live falters. It was Joe who talked me into my last hospital experience, where I was beaten to a pulp in less than 48 hours, and it was Joe who talked me back into living when I came out.

Then there's Cathy Hart, my doctor at New York Hospital. She's calm and collected, doesn't panic easily, stays positive and exudes a quiet warmth. She respects my knowledge and independence, and is patient with the fact that I ignore almost everything she advises me to do. She treats me like an adult.

Unfortunately, when you're in the hospital, you're not really in the hands of your doctor. You're in the clutches of some wet-behind-the-ears Doogie Howser asswipe who has just spent 10 years having every possible emotion, except perhaps greed and envy, beaten out of them. Thank God I know how to spread terror, even after 100 milligrams of Demerol and a bronchoscopy. I had the little wimp pissing his pants in no time. As for the night nurse from hell I was saddled with, I kicked her ass out on the second night and got the head nurse. But even as strong as I am, they still fucked with me. If I ever go into a hospital again, I am arranging 24-hour guard duty by my strongest friends. At least then maybe I'll get some sleep.

The doctors, of course, have their little friends, the drug companies, and they walk hand-in-hand down the road to hell. Let's talk about my little protease nightmare. I started the Abbott protease inhibitor, ritonavir, the day after chemo, succumbing to pressure from my doctor and a variety of well-wishing friends. The morals of this story are: Never make decisions when your mind isn't clear, and isolate yourself from the fear and panic of those who love you. There's nothing wrong with taking a day to be alone, getting some information and making your own informed choice.

I did the dose escalation as I was supposed to, I took the drug with lots of food and ate lots of fatty things, which was supposed to aid in drug absorption. By the time I reached the full dose, I had become incredibly sick. "There's some GI discomfort," my doctor said. Really? My guts felt like they had been run over by a tractor. The drug managed to make me both nauseated and hungry at the same time. I had crippling diarrhea and cramps. I was woozy and stupid for most of the day. I never had a good day on this drug and was basically miserable and dysfunctional. I was told that the side effects would clear up in two or three weeks if I just "stuck with it." I heard about people who sailed right through the drug, and yet everyone that I spoke to had had side effects -- which did become tolerable. But this is certainly not the way to live.

"Let's face it," said my friend Spencer, who does PR for Treatment Action Group and has been on the drug for a while. "This is a terrible drug, no matter how you cut it." Spencer went to a meeting where some Abbott honcho pompously announced that everyone with HIV should be on this drug. "I'll tell you what," said Spencer. "You take this drug for four days at full dose and then we'll see what you say." This is a basic problem with Western medicine. The people who invent these drugs

are a bunch of “science as God” wonks who don’t think or care about the misery of side effects or toxicity. A doctor’s version of a well-tolerated drug is a lot different than yours. And remember, they all lie and sugar-coat the side effects.

Abbott was completely irresponsible in rushing this drug out without a physician-education program, proper patient information and a real list of the incredible number of drug interactions that occur with this product. Even the updated information they’re putting out now is half-baked.

Finally I took back control of my life and my medical decisions. I stopped taking ritonavir and felt better in three days. I have gone on some new drugs, at my own pace, slowly and carefully. I have made my happiness and taking care of myself a top priority. I have committed to as few medical treatments as possible.

My acupuncturist makes me feel better. So does my masseuse. But somehow I never leave a doctor’s office feeling good. Making your own medical choices means becoming educated about the disease and the treatment options available to you. That means lots of hard work and becoming your own doctor. It also means living with your choices even if you’ve made a mistake. I’ve made my own choices and I’ve lived with the consequences.

But at least I’m still alive. A lot of people who blindly put their fate in the hands of a doctor aren’t.

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