Live as if You'll Die Today

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My mother knew when she was going to die. She knew the exact date and even the estimated time.

Thin and sprightly, she was relatively healthy, except for controlled hypertension. And she was completely and undeniably sane. She simply valued, as she said, “quality over quantity.” And therefore, 20 years in advance, she chose to end her life at the age of 70.

A critical component of her plan was to maintain, until her final day, the high quality of life she wanted. Yet after age 60, she began having problems getting any doctor to see her more than a few times.

That didn't have anything to do with her plans for ending her life, because, rightly or wrongly, in doctors' offices she kept those ideas to herself. It was because she didn't actually want “full-service primary care” any longer. She wanted “patient-centered” care, care that took into account her particular healthcare needs, as she defined and articulated them.

The path she chose was not untrodden—publicized widely were the relatively recent case of the 92-year-old widow of a former French Prime Minister, Mireille Jospin, and that of 77-year-old retired Columbia University scholar, Carolyn Heilbrun. My mother died as these women did—by her own hand only because she wanted to avoid a possibly uncomfortable, but by no means imminent or foreseen, death. But although her decision was not unique, it was clear to me that my mother's thoughts and actions were extreme. Still, over her lifetime she had observed relatives and friends after strokes, confined to wheelchairs and nursing homes, incontinent, dependent, and demented. And she didn't want to take too much of a chance at ending up, herself, unable to move or make her own decisions. Seventy, she simply decided, was old enough to have been able to enjoy life, but not too old to run a high risk of a slow death.

I loved my mother very much, and I suffered greatly in anticipation of her carrying out her plan. I tried to discourage her from her it, but anyone who really knew my mother also knew that she was not likely to listen to others once she had made up her mind about something so important. I felt terrorized by her plan, because years in advance I didn't just guess that my mother would not be around after 70, I *knew* it. And I was angered by it, because the reason I would be losing her was not fate but rather her own selfishness.

And yet...emotions aside...I could see the logic in her ideas. The thought of an uncertain future that might contain more suffering than she was willing to tolerate terrified her. The possibility of not being listened to terrified her. Losing control terrified her. So she took control.

When my mother visited a doctor in order to get medication for her hypertension, I sometimes went with her, even though I didn't completely agree with her ideas. The doctors were always enthusiastic to see her initially. “You're over 60 and seem to be in excellent health,” the stranger in the white coat would say, shaking her hand.

“I'm fine except for my high blood pressure,” my mother would reply, smiling. Trying to steer the subject away from her general health and onto her medication needs, she would proceed, “I have this prescription here, you see. It says what medications I'm on. Your assistant took my pressure already, and you can see that it's normal. So everything's working. I just need a refill.”

“Well,” the doctor would respond, flipping through the meager pages of her chart, “you're right that you seem to be doing fine with those medications. And you say that you're not having any side-effects?”

“No, I feel fine. So could you just renew my prescription? I don't want to take up any more of your valuable time.”

“Well, yes, I am satisfied with how your pressure is controlled. But...when is the last time you had a mammogram?” the doctor would query her with a puzzled look. “Or a colonoscopy? I don't see any mention of that in what you've written down. And you say you don't have any records from past tests? None? You've never had *anything* checked?”

So my petite mother would shake her head, making her ear-length dyed blond hair bounce back and forth against her cheeks. “I'm really not a big believer in tests,” she would sigh and then persist, “What I want to avoid, you know, is a stroke. And you could really help me out by...”

“Well, if you've never had a mammogram or a colonoscopy, then we might want to schedule something for you right away. And how about a Pap smear? I could do that right here, you know. It won't take long. If you'll just put on this gown, I'll be back in...”

And that signaled the beginning of the end of another patient-provider relationship. My mother would demur regarding the Pap smear, claiming that at her age she did not feel comfortable taking her clothes off in front of someone she had only met once. Pretending to study the orders for the tests intently, she would promise to make appointments for the scans, knowing full well that she would throw the orders in the kitchen garbage can when she got home. Always stubborn, this character trait had only intensified with age, and she was completely unwilling to go along with procedures that, while perhaps reassuring to the doctor and to other patients, she thought might suck up too much of the extremely valuable time that she had left.

Of course, because each physician was different, each relationship was different. Some doctors saw her for a longer period of time than others. Some questioned her more about why she did not want the tests. But in the end, her refusal to acquiesce presented a stumbling block to providing care-as-usual, and because the physician did not address this obstruction directly or try to find a way to work around it, it loomed larger and larger, until it became an impasse.

It could all have been different. A physician colleague of mine has pointed out that he might have solved the problem by asking my mother's permission to reiterate at each visit the risks and benefits of preventive examinations and testing, thereby acknowledging his own discomfort while simultaneously respecting her choices. I think she would have gone along with that. What was too frightening for my mother was the possibility of being forced into a cycle of testing and treating, of having her living will ignored, of being hospitalized without her consent, of having "heroic" measures taken to assuage the values of strangers, of having her maxim turned on its head—*quantity* over quality.

The final conversations varied, but they tended to go something like this: "You didn't take any of those tests?" the doctor would ask. "And you're not going to let me examine you at all, except for taking your blood pressure? Well, then, I am afraid that under these circumstances we really have a problem on our hands."

"I only came here for medications for my high blood pressure," my mother would retort.

"But you could have so many other things wrong with you. If you want me as your primary care physician, I wouldn't be practicing ethical medicine if I didn't try to examine you fully. Won't you even let me give you a complete physical?" the doctor would implore.

"I don't need to be examined for things that might kill me," my mother would explain, getting up from the chair and heading toward the door. "We're all terminal in our own ways—I just want help staying terminally *healthy*."

For my mother, health meant walking four miles every day, sleeping without nightmares, and never having headaches. It also meant keeping her blood pressure under control. She had never been afraid of not knowing everything going on within her own body, but she *was* afraid of a doctor who would not listen to how she wanted to deal—or not deal—with the unknowns.

Most patients want to be heard, although not for my mother's reasons. She walked far off the beaten path, yet lessons can often be learned from outliers. And while my mother did not want to know about potential nodes or blockages or tumors, she *did* want to establish a relationship with a physician. As she told me over the phone one afternoon, after the final visit to yet another doctor, "Darling, I know they think I'm nuts. But I have my own definition of my own health. It's taken me a long time to develop, and it makes sense to me. Why can't they just accept that?"

"I don't know, Mom," I exhaled quietly. "You want something that can't be molded into a shape that fits neatly into predefined boxes. And maybe that's just too much to ask."

Although, for her sake, I wish it hadn't been.

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