MY MOTHER DIED AT AGE 90 YEARS FROM complications of a fall at home. The “at home” part was the triumph of her last decade. Having spent 3 years in a German slave camp during World War II, she was terrified of institutional settings. Assisted-living facilities and nursing homes were tantamount to prisons, in my mother’s view, and woe to anyone who suggested otherwise.

As a HIPAA (Health Insurance Portability and Accountability Act) designee, power of attorney holder, and lifelong confidant, I had been drilled from an early age to go to the mat with anyone who threatened her freedom to live as she wanted. This is your job, she commanded—over and over again until I wanted to cover my ears. Yet I understood the fear that underlay these 2-listed pronouncements and promised to do my best.

And so I did.

When hearing and cognitive losses set in during her 80s, I began accompanying my mother to physicians’ appointments. At first I sat quietly—my mother wanted me there, but she also wanted to run the show. Over time though, she became more tentative and anxious about medical procedures that she had once handled stoically. This led me to question the need for routinely prescribed screening procedures like Papanicolaou tests and mammograms. My mother did not sleep for days beforehand—were they really necessary?

See Invited Commentary

Some of my mother’s physicians engaged with these concerns, others coldly recited medical quality standards. Privately, I worried about challenging medical norms—what if something had happened as a result? I wanted to do right by my mother but how to achieve that was not always clear in the moment of decision.

Ironically, the person with whom I memorably “went to the mat” was one of my mother’s most conscientious physicians. He was a scholarly and gentle young physician in our small-town hospital. Like me, he also wanted to do right by my mother. But when it came time to discharge her after a 4-day hospitalization for atrial fibrillation and heart failure, he got so engrossed in triangulating data points from her voluminous electronic health record that he lost sight of the person he was treating.

The problem was the warfarin prescription he wanted to send her home with, along with stomach injections of enoxaparin until the warfarin therapy became effective. In the hallway outside her room, he excitedly told me that he had figured out a dosing and injection regimen that when added to my mother’s other heart drugs would reduce her stroke risk almost to that of “you or me.”

I listened in horror, picturing my mother’s life at home. She was an avid outdoors woman and gardener—and not of the flower bed variety. She had planted every bush and tree on the hilly property where she and my father built their American dream home and took pride in maintaining it after his death. She was outside every clement day, armed with hedge clippers or worse. Famous for her dogwoods that exploded in glorious flower every spring, my mother proudly shared the secret of her success: rigorous pruning, which she did herself with an 8-foot pole cutter.

Over time, my drop-in visits took on a first-aid aspect as I patched up scratches—and sometimes bloody gouges—from these horticultural adventures. Though my mother sweetly accepted administrations of hydrogen peroxide and admonitions to “Wear your gloves!” it was clear that nothing was going to keep her indoors or sedentary on a nice day. Working her land was my mother’s definition of living.

The physician knew this about my mother, and also that she lived alone. I had taken pains to brief him on her lifestyle because it ran so counter to the stereotype of women of her age and infirmity.

But his singular focus was on thinning blood sufficiently to counteract her sluggish heart’s penchant for throwing clots that could cause a stroke.

But is not warfarin-thinned blood dangerous in someone with my mother’s activities? I asked. He replied with percentages and relative risk equations. I countered with hedge clippers, pole cutters, and unsteady legs due to arthritic knees. He suggested I sit down with my mother to discuss lifestyle changes that would accommodate her prescriptions.

And so we went, back and forth until I asked him if there was an alternative to warfarin that might be safer for her—and also more likely to win her compliance. Baby aspirin, he replied, looking crestfallen. He pointed out that the research literature showed some benefit but less reduction in stroke risk compared with warfarin.

With a bit of coaching and a pill chart that we made together, my mother successfully added aspirin to her daily medication regimen and enjoyed 2 more years of relative independence in her home and garden. Her death, from complications of a fall while she was doing her laundry, came mercifully swift.
In retrospect, I am glad I was able to help my mother wrest the kind of treatment she wanted from the health care system, even if it fell short of science’s gold standard. But I wish I had had more help with these decisions. They are hard calls for clinicians, I realize, but they are even harder when you are on your own, trying to do right by a loved one.

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