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The medical care that is not care

Melissa Musick Nussbaum | Feb. 20, 2010

My daughter-in-law practices medicine in Denver. She tells me of an uninsured man with an incarcerated hernia who came to the emergency room in need of immediate surgery. They could not find a surgeon willing to operate on an uninsured patient. The emergency room physicians reduced the hernia -- a temporary fix at best -- and the man went home.

While this man and others struggle to get health care, I stand with my 91-year-old mother struggling to stem the tide of tests, procedures and hospitalizations. If many young people seldom see doctors for even simple preventative treatment, many old people become professional patients whose last years are spent in waiting rooms and labs, in hospital beds and inside MRI tubes.

My mother is in heart failure. Her legs swell. She is short of breath. We sit together in the cardiologist?s office, waiting.

I am with my mother because she is almost completely deaf and increasingly blind. I am the translator between doctor and patient. Of course, even before her hearing and sight failed, my mother had no desire to learn about her medical care. Everything from aspirin to morphine falls under the general heading of pain medication and the mild antidepressant her doctor prescribed years ago gets grouped in its sister category of happy pills.

I was with my mother once when the nurse asked if she took any medication. A name from the news popped into Mother?s head and she said, ?Oh, and interferon. I take that several times a day.?

Every head in the room turned in my direction as the assembled stood wondering why I hadn?t thought to tell them my mother was suffering from hepatitis, cancer, multiple sclerosis or any of the other serious ailments for which interferon is prescribed.

I cleared my throat and called loudly: ?Or maybe it?s ibuprofen. Could that be it, Mother? Ibuprofen??

She nodded her head and said, ?Well, it?s one of those ?I? names.? As indeed it was.

My mother has outlasted one cardiologist and is now seeing a young woman who knows my son and his wife from medical school. Having a doctor who cannot recall where she was when President Kennedy was

assassinated seems out of order.

?Kennedy?? my mother scoffs. ?How about someone who remembers Pearl Harbor??

My mother was born during the last summer of the First World War.

The doctor wants to start my mother on a daily regimen of Lasix, a diuretic.

I shake my head no. I say, ?Mother still goes to the Y three days a week for a water exercise class. She won?t go if she?s taken Lasix that morning. She?s afraid of having an accident in the pool. And if that happened, she would never go back to class. I?d rather have her exercising with her friends than sitting at home taking medication.?

The doctor listens, and says, ?Okay, you may be right. How about this? Lasix four days a week, every day she doesn?t go the Y. And you call me if the swelling and shortness of breath gets worse.?

I wonder what happens to the elderly who don?t have advocates.

There are other complications on other days. My mother?s sodium is too low. Her potassium is too high. Sometimes the results of blood tests prompt calls from the doctor?s office to ?bring Mrs. Musick to the hospital immediately.? We get the proper treatment but never before having an IV inserted into my mother?s arm. Without fail, the IV fluids leak into the tissue near the injection site, causing pain and swelling. I call the nurse who has to remove the needle and position it to another spot. I caution the nurse that my mother?s skin is like wet tissue paper. Even a rough brush along the surface can tear it.

The nurse is careful as she removes the tape holding the needle in place. And still, my mother?s skin tears, the wound opening wide as the tape is peeled back. It will be a long time healing. If we cannot keep the wound dry, she will miss more days at the Y.

When my mother is catheterized in the hospital, she gets a urinary tract infection. When she takes a sleeping pill to help her sleep in the uncomfortable and unfamiliar bed, she hallucinates.

These might be understood and accepted as unhappy side effects of a cure if my mother were ill, but she is not. She is old. There?s a difference.

Here?s what my mother needs and wants: She needs company. She needs exercise. She wants to hear the news and the neighborhood gossip from someone willing to look her in the eyes and speak very loudly. She wants to go to Mass every Sunday and to every family celebration, even if she dozes off in the middle. She wants to have her picture taken with the newborn great-grandchildren so ?they?ll have something to remember me.? None of these require much in the way of money or expertise, though they do require expenditures of time and patience, the currency I hoard with more zeal than any Scrooge his cash.

Here?s what she neither wants nor needs: She doesn?t want to be called ?Grandma? by strangers in scrubs whose grandma she most assuredly isn?t. She doesn?t want to be stuck with needles or cut or prodded by people who poke an obviously sore spot and then ask, ?Does that hurt?? And as she told me after an endoscopy, ?I don?t care what?s wrong with me; don?t ever let them put that thing down my throat again.?

It isn?t that she wants to die. In fact, she swore she would not die with a Republican in the White House. Now I think she?s holding out for midterms. But the defensive form of geriatric medicine most doctors feel pressured to practice brings neither the vitality of life nor the peace of death.

I do not know where the line items for ?companionship? and ?listening? go in the health care bills. I do not

know when we discuss the differences between disease and the natural end of life. I do know that my mother?s heart is failing. No amount of money and no amount of skill will restore its health. There are a finite number of beats left.

We have decided to spend as many of the beats as we can with her friends or at my table or in the garden where the apple tree blossoms, so sweetly and so briefly.

[Melissa Musick Nussbaum is coauthor with Jana Bennett of *Free to Stay, Free to Leave: Fruits of the Spirit and Church Choice* (Wipf and Stock).]

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