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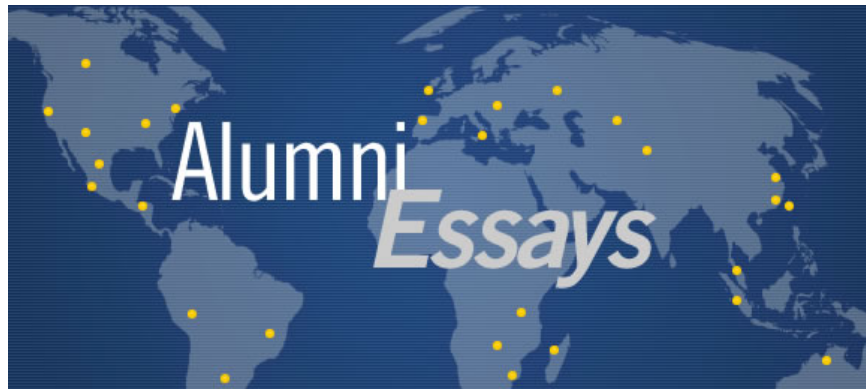
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Home Death

Josephine Ensign

"Natural death, almost by definition, means something slow, smelly and painful. Even at that, it makes a difference if you can achieve it in your own home and not in a public institution." ~ George Orwell



In his essay "How the Poor Die," Eric Arthur Blair (pen name George Orwell) describes his month-long stay in a French public hospital in the winter of 1929. He was treated for pneumonia in a crowded open-ward public hospital, where he observed many indigent patients dying under the indifferent care of "slatternly nurses" and doctors and medical students "... with a seeming lack of any perception that the patients were human beings." He fled the hospital before being discharged, but the hospital was a probable source of the tuberculosis that would later cause his death, at age 46, in a London public hospital.

Like the majority of people in the U.S., my father would rather not die in a hospital—public or private. Studies consistently indicate that more than 80% of patients wish to avoid hospitalization and intensive care treatment during the terminal phase of an illness. In most cases, hospital deaths are considered to be less than 'good deaths' because they are not where patients want to die, combined with the high-cost of hospital end-of-life care.

My father would rather die at home with his boots and gardening gloves on, surrounded by family and trusted caregivers. At eighty-nine years old and suffering from the ravages of advanced congestive heart failure, my father is one of the burgeoning number of the 'very old' frail elderly facing end-of-life decisions. And I am one of the even larger number of baby boomers approaching retirement while simultaneously helping care for an elderly family member. My father lives in Virginia; I live across the country in Seattle. Nevertheless, my father appointed me his health care proxy. I naively thought that being a nurse practitioner with an advanced degree in public health would help stack the odds in favor of my father having the home death he desires.

I know what it is like when end-of-life care works well. Four years ago I helped my mother have a relatively peaceful home death in hospice. She was eighty-five years old and died of breast and lung cancer. End-of-life predictions are, of course, much more accurate for patients with cancer than they are for patients with congestive heart failure. I had to intervene with her oncologist to stop the chemotherapy that was clearly doing more harm than good. But I expected that. Oncologists are programmed for aggressive treatment and have a difficult time, as the writer Atul Gawande says, letting go. My mother died six weeks after stopping chemotherapy, and two days after learning that her vote helped turn Virginia for Obama. Hers was a good death.

Although I was able to take time off from my job to help my mother in her final illness, my father was her primary home caregiver. Now, with my father living alone, he is hiring caregivers so he can qualify for home hospice. In the past six weeks he has moved through four different health care settings: acute care teaching hospital, nursing home for physical rehabilitation, back to his private home with visiting nursing, and now with home hospice. Besides Medicare, my father has good supplemental private health insurance, and he has sufficient savings to cover out-of-pocket expenses.

Despite my father's resources, helping him navigate his final days has been a Kafkaesque nightmare tinged with perverse humor. Having worked within the U.S. health care system as a primary care provider for thirty years, I was prepared for the lack of care coordination across health care settings. I was even prepared for his myriad health care providers misplacing his Advance Medical Directives. I keep a scanned copy with me

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at all times to e-mail or fax it to whichever health care site he's currently in. But I wasn't prepared for April Fools' Day this year.

For transparency and context I should add that I teach health policy to nursing students at a major academic medical center in Seattle. On April Fools' Day, a Sunday this year, I was in Seattle preparing notes for my upcoming class presentation on patient-centered care. One of my father's neighbors in Virginia called to tell me my father had skipped church to go to the emergency department of the nearby teaching hospital. He had been complaining of shortness of breath and not feeling well. It takes something serious for my father to miss church.

When I called the hospital to find out his status, the emergency department clerk told me I needed to tell her my father's "secret HIPAA patient password" before she could even tell me whether he was in the hospital. She added that they strictly enforce this password because the hospital has so many patients involved in gang shootings and domestic violence. She didn't change her mind when I pointed out that my father was an eighty-eight year old widower and retired Presbyterian minister who had signed his Advance Medical Directive forms appointing me his health care proxy in their hospital administrative offices less than a year ago. She said they had no record of it and they had to treat all patients the same, so my only option was to come to the hospital in person. I did make a notation for my health policy class that this interaction was a good example of the need for improved patient-centered care, as well as for more appropriate use of patient privacy rules.

By the time I got through the hospital gatekeepers to be able to talk to my father, a cardiac surgeon had been called down to the emergency department and had convinced him to sign consent forms for a high-risk, high cost, low-to-no-benefit, quasi-experimental transapical aortic valve replacement. Less than six months post-surgery, my father was back in the same teaching hospital for rapidly accelerating heart failure, and I was flying in from Seattle to advocate transferring him to home hospice.

In its current form, our healthcare system conspires against the possibility of older people having a natural, good death at home. While there are pockets of improvement in terms of fewer hospital deaths for the very old, there are accompanying shifts towards more patients seeing ten or more medical specialists in their last six months of life, greater use of intensive care units, and more patients dying in nursing homes. As with my father's experience, much of the blame falls on teaching hospitals: tenacious places known for medically aggressive treatment. I get the argument that this aggressiveness is what drives medical innovation and makes U.S. high-tech medical care among the best in the world. But when it comes to the care of the very old, that argument does not hold up—unless the elderly are donating their bodies to medical science before they are dead.

According to many studies (reflected in the Dartmouth Atlas of Health Care data) the number of teaching hospital beds in a region is associated with a higher percentage of hospital deaths without a concomitant improvement in overall population health. If the primary mission of teaching hospitals is to educate our future health care professionals, what is it we are teaching them about death and end-of-life care? Perhaps it would benefit everyone if we who work in academic medical centers remember that our students will soon be taking care of us in our own final days.

Josephine Ensign, MPH '92, DrPH '96, is a nurse and writer who teaches health policy at the University of Washington in Seattle. She writes the blog "Medical Margins" on health policy and nursing (josephineensign.com).

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