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When deer knock on the door in the night

Melissa Musick Nussbaum | Feb. 28, 2011 My Table Is Spread

On Dec. 27, my mother was diagnosed with pneumonia. We kept her home, Foley catheter and all. A visiting nurse came each day to give her a shot of the antibiotic Rocephin.

On Jan. 4, she was diagnosed with C. difficile, a nasty gastrointestinal infection commonly seen in elderly patients whose guts have been wiped clean of bad, and good, bacteria following a course of antibiotic treatment.

She was treated with Flagyl, yet another antibiotic.

We were able to ease most of the discomfort of the pneumonia with a higher concentration of oxygen and lots of rest. But there was no respite for my mother from the ravages of C. difficile. It stinks, it hurts and it destroys skin. Mother was exhausted but she struggled to get up repeatedly to reach the bathroom. Sometimes she made it; mostly she didn?t. Add humiliation to the mix. We had to keep her clean, but she cried out when we washed and wiped her sore bottom.

My daughter, a nurse, taught me to swab my nostrils with Mentholatum when the smell makes me gag. Now the smell of Mentholatum makes me gag.

She survived the pneumonia and the C. difficile, but she is sadly altered. She sleeps more, and she has lost interest in the world, in politics, in food, even in family affairs. Family matters she does recall are often hopelessly jumbled, as the fixed cast of related characters changes partners, adds new members unknown to any of the rest of us, switches names and locales and histories.

She tells me that deer knock on her door in the middle of the night and my husband walks in to her bedroom in the wee hours of the morning asking questions she cannot answer. On a day when the temperature never made it to zero, my mother says her door flew open to reveal a man dressed only in swim trunks, his feet, chest and head bare. She says he looked at her and seemed ?surprised to find somebody in here,? then ?he jumped over the wall.?

With all the other losses, Mother has lost that hallmark of Southern womanhood, her sense of context. It?s not that Southern women don?t do the unmentionable; it?s simply that they know the time and place for the unmentionable to be done. Last Sunday, she joined us for Mass and dinner. Our oldest son and oldest daughter

and their families were with us. We were in the pew with 14-month-old Leo and 2-year-old Mary Clare climbing about and clamoring for Goldfish crackers. My son turned to me as I wiped Leo?s distressing nose yet again and whispered, ?You?re sitting in steerage.?

Just then my mother began hacking up phlegm. The coughing and the consecration unfolded together, one loudly and wetly, one quietly and drily.

I turned to my son and whispered, ?I live in steerage.?

At dinner, my grandson Eamon sat between Mother and me. Eamon is in first grade and therefore acutely aware of loose teeth. But he was distressed when his great-grandmother took out her dental bridge and begins picking out bits of stuck food during the meal.

He poked me and whispered, ?Ma-Maw, Atoo?s taking out her teeth.? Then, more quietly, for Eamon is a kind soul, ?It?s kind of gross.?

?She doesn?t understand, Eamon,? I whispered back. ?Just don?t watch. Look somewhere else.?

And Eamon, who is as literal as he is kind, turned his head and slowly chewed his Brussels sprouts, his eyes fixed on me.

Yesterday, an occupational therapist came to the house. She is going to work with Mother to see if some of the strength and skills lost to illness and age can be regained.

First, she had to ask Mother some questions. I was there with Vicki, the dear woman who helps me with Mother?s care. Mother calls her ?my friend, Vicki,? and indeed she is.

Vicki and I were cautioned not to prompt or coach Mother but to allow her to answer the questions on her own. The three of us have perfected a kind of memory dance designed to obscure just how much has been lost. I call it a dance because it is, in its own way, graceful and fluid. ?Oh, Mother, you remember Elaine. In Hondo? She fell and broke her hip?? And it appears, as dancers sometimes appear to be flying, that she does remember Elaine in Hondo with the broken hip.

Yesterday, Mother, unaided, could not say her address or the names of her city or state. She did not remember the month or the year. She did remember her birth date. She could not give the name of the current president, though, shaped as she was by racial attitudes in early 20th-century Texas, she could recall that he is ?black.?

So, here we are, hanging on to the ethical and religious directives for the end of life as the shipwrecked hang onto a lifeboat, and still we are wondering. When we first began this journey seven years ago, my husband was careful to sit and talk with my mother. They discussed what procedures she did and did not want done in her last weeks and months. No to ventilators. No to radiation or chemotherapy cancer treatment. No to resuscitation. She did not, she told him, want to end up on a respirator in the ICU like my uncle, unable to speak, unable to say goodbye.

As it turns out, that?s the easy part. Here?s the hard part:

A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the patient?s judgment offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community.

How about antibiotics for the treatment of pneumonia? Is that an extraordinary measure or proportionate means? What if past history suggests that with antibiotics she will survive the pneumonia? What if past history also

suggests that, with antibiotics, she will suffer debilitating side effects and life-threatening imbalances in certain chemicals and in the levels of blood thinner in her system? What if the antibiotics kill the pneumonia-causing bacteria, but stress her kidneys to the point of failure? What if, after two rounds of antibiotics, her blood is so thin that the new concern is uncontrollable bleeding, in her brain, in her stomach, from a bump or a knick or a garden-variety nosebleed?

Now add in this: The elderly patient wants to live. Indeed, as the dementia robs her of sense and memory and -- a key word in the ethical and religious directives -- judgment, she clutches ever more at unadorned, and, perhaps unknowing, life. Just breathing, she will settle for that.

Does the strain on the caregiver matter? Especially if the caregiver, as is most often the case, a woman? I think of the paucity of married women saints, and then I think how many of them are valued precisely because of the excessive burdens they carried, almost always in the service of family.

Are you disappointed that I think of myself? That I am so offended by bad smells and unpleasant sights when a human life is at stake? Me, too. I thought better of myself, and, frankly, I thought better of death and dying.

I thought it would be more like Beth?s death in *Little Women*. I memorized that chapter, ?The Valley of the Shadow,? when I was 9 years old. And what delight to weep, again and again, at Beth?s gentle and -- there is no other word for it -- pretty death.

Here, cherished like a household saint in its shrine, sat Beth, tranquil and busy as ever; for nothing could change the sweet, unselfish nature, and even while preparing to leave life, she tried to make it happier for those who should remain behind.

There was no mention of bloody diarrhea or lacerated bedsores or lacerating anger.

So add this as well: a caregiver whose motives are neither clear nor trustworthy. She is weary and she is sad, but on whose behalf? Does she truly want to see her mother?s suffering end, or her own? How does she judge ordinary or proportionate means when every single treatment proves the high school physics theorem that for every action there is an opposite and equal reaction?

I swore after this last bout of illness that I would not subject Mother to Rocephin injections or Flagyl again. Subject Mother, or me?

As it turns out, I am grateful to be part of a church that won?t keep its nose out of my business, because my business is not as clean as I would have you believe. Long experience has taught the church how quickly resolution and good intentions wane. So, curiously, I find myself wanting more, rather than less, from the bishops.

?The task of medicine is to care even when it cannot cure.? Yes. But where is the line, the land of ?even when?? If we can cure the pneumonia, should we? Must we? Given the cascading effects of the treatment itself, does curing constitute a sin against caring?

I try to keep my moral obligation. But I no longer understand what ?ordinary? or ?proportional? mean in these disproportional, extraordinary days.

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