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Getting It Right At The End Of Life:

With the help of a palliative care team, the author's terminally ill mother dies on her own terms.

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At my mother's recent memorial service, lots of people asked to speak. We got to hear from friends and family who had known her from each of the eight decades of her vibrant life. While the details varied, there were important consistencies across all of the wonderful memories that were shared: her great warmth, infinite curiosity, pioneering spirit, and utter inability to tell a joke. But most of all during the formal remarks and informal conversations that followed, everyone in the standing-room-only crowd recalled my mother's fierce independence and drive to do things "her way." And nowhere was this drive better demonstrated than in her determination to go out on her own terms. For this she had needed my help, and I very nearly blew it.

When—just a few days after her eighty-ninth birthday—my mother was diagnosed with a colorectal mass (we would later learn it was cancerous), she restated to me what I long knew to be her fervent wish: no treatment of any kind beyond symptom relief. NO invasive procedures, NO chemo or radiation, NO life-prolonging treatments. NONE! She wanted only one thing: to spend the rest of her days, however many or few there were to be, in her apartment in her lively and supportive community. My job was simply to help make sure her wishes were honored. As it turned out, this was not so simple at all. Just days after the initial diagnosis, despite my mother's long-standing, clearly stated, and just-repeated wish, I found myself reluctantly making an appointment for a preoperative examination with a surgeon for a procedure to reroute her intestine around the mass.

How had we ever come to even consider this?

The Limited Option

For as long as I could remember, my mother had made it clear that she did not value longevity for longevity's sake. Her greatest fear had always been living past the point when she felt good about being alive. "Can you believe it?" a friend or relative would sometimes exclaim in delight about a markedly diminished elderly relation. "She just celebrated her *ninety-sixth birthday!*" In response, my mother would shudder in dismay and reply that she hoped that she would not face a similar fate.

Thus, from the instant she learned about the colorectal mass, my mother told every one of the endless series of doctors who paraded by her bedside that she was really OK with the situation, as long as she could opt to do nothing about it and have a peaceful end when the time came. Though increasingly weak as the days wore on, she remained clearheaded and articulate. And when her voice faltered slightly, or when she got tired of repeating herself, I spoke up for her, and she would nod vigorously in agreement.

Nonetheless, on the fourth day in the hospital, a surgeon arrived at my mother's bedside with a different agenda: to discuss the risks and benefits of two surgical options for addressing the threat posed by the mass. One option was to surgically remove the mass entirely, while a second option involved rerouting the intestine around the mass, which would otherwise be left intact. Since the mass was growing slowly, the surgeon explained, and since there was no sign of cancer anywhere else, my mother was a good candidate for the second, more limited surgery, which was less invasive and promised a speedier recovery.

In fact, the surgeon confidently pronounced my very frail mother an "excellent" candidate for this surgery and predicted a relatively insignificant recovery time with only minimal pain and discomfort. But—oh yes, there was one more thing worth mentioning: The "limited option" involved a colostomy. A hole would be created surgically in my mother's belly, out of which stool would exit into a pouch. The pouch would need to be emptied regularly (once a day or so) to avoid leakage. My mother would need to find a well-fitting pouch to minimize the risks of skin irritation, the extent of odor, and the possibility of leakage. And she'd need to learn to change the bag (it takes practice), adjust her already limited diet, and perform the necessary skin care. Besides this, there would be anxiety about whether the bag would bulge visibly or, worse yet, soil her clothing. Yet the surgeon was certain that, with the new technologies and products for colostomies that were available, my mother would adjust in no time.

When I asked what would happen if my mother declined surgery altogether, the surgeon provided a chilling answer. Doing nothing, he told us, would cause her colon to rupture, followed by sepsis. This would be accompanied by acute and possibly prolonged abdominal discomfort and eventually excruciating pain. He painted a graphic picture of what would be happening inside her body to cause this pain. It would be a gruesome way to die. No way would he ever let his mother suffer through that, the surgeon pronounced. His face suggested he was horrified to think that we might even consider it.

In the face of the surgeon's specialized knowledge and the high degree of confidence he projected, our certainty about my mother's long-abiding wish waivered. I, in particular, struggled to reconcile what this expert was telling us with my admittedly vague understanding of the alternative: palliative care.

The surgeon left the room, and my mother began to weep silently. I could not remember when I had last seen her cry, but it had been decades at least. Her hope of a dignified death had been dashed, and she found herself facing a choice between excruciating pain or surgery with a colostomy, with all of the attendant ramifications. She clearly feared she might end up

one of the “lucky ones” who “get to live”—in an increasingly physically and cognitively feeble state—to ninety-six!

Probing Questions

I reluctantly scheduled a pre-op appointment for later that month, but I also reached out to a close friend who specializes in research on patient engagement. She encouraged me to probe more deeply the surgeon’s predictions and assertions about the likely impacts of undergoing

surgery, as well as the consequences of declining it. What exactly did a “relatively easy” recovery mean for an eighty-nine-year-old woman who weighed only 118 pounds? How would a colostomy actually affect the quality of her life? Could the pain of a ruptured colon be effectively controlled by a clinician who specialized in palliative care? I sought answers to those questions.

I started by investigating the surgeon’s assurances regarding the simple-to-use and odor-free technologies that were available for colostomy patients, since I knew that this would be of particular concern to my mother. We faced the added complication of her Parkinsonism (a condition related to Parkinson’s disease that, in my mother’s case, left her unable to stand or walk), for which she needed the services of a full-time home attendant.

I called M. R., one of my mother’s former aides, who knew her needs, abilities, limitations, and sensitivities at least as well as I did. I trusted M. R. to give me straight answers. I asked if she had had any experience with the colostomy paraphernalia and if she thought my mother would be able to change the bags as easily as the surgeon had suggested. If she couldn’t, were home attendants allowed to assist with this activity? God forbid that my mother would have to end up in a nursing home just because of a colostomy.

M. R. assured me that Mom would most likely be able to change the bags herself, though she offered to check on whether an aide would be permitted to help. But then she got to the more central issue: “*You know your mother*,” she told me. “You know how much she cares about personal hygiene. She will *not* like the smell. Even if it is not a strong smell, *she* will smell it. They will tell you there is no smell, but I will tell you *your mother* will smell it. It will bother her. *A lot*.”

M. R. went on to describe having cared for an outgoing and sociable retired lawyer who became so self-conscious following his colostomy that he had become “a recluse.”

For my mother, this would be a truly catastrophic blow. Formerly very active and outgoing, she had already lost a great deal, including her mobility and much of her independence, to Parkinsonism five years earlier. Nonetheless, she remained surrounded by a large cadre of devoted and lively friends—some of whom she had known for decades. When I visited her in the unique Upper West Side community in Manhattan that had been her home for fifty years, we would sit on the bench in front of her building, and, without exception, an average of three or four people per hour would stop to sit and chat. Her apartment door was never locked, so friends and neighbors were constantly popping in to play Scrabble, watch a film, discuss a book, or bemoan the deteriorating state of the world.

Over the previous five years, my mother had already begun to feel that her life had been irremediably diminished. Aside from the Parkinsonism, she was growing extremely frustrated with the continuous, if gradual, cognitive decline associated with “normal aging” and the impact it was having on her memory and her ability to use her computer, cell phone, television, and other mainstays of modern life. The prospect of social isolation or other additional losses was more than she should have been expected to bear.

This bleak outlook strengthened my resolve to learn more about whether palliative care could be effective against the specific risks of “doing nothing” as described by the surgeon. The following morning, as my mother was preparing to be discharged from the hospital, a doctor arrived to check her status. We mentioned that she was happy to be headed home, and that our next step would be to identify a palliative care specialist who might be able to tell us whether and to what degree the dire consequences of declining surgery could be mitigated.

As luck would have it, the doctor told us that he was trained in palliative care. He immediately validated my mother’s decision to reject treatment and offered his unequivocal assurance that she would not need to face an excruciating end. He explained that he could immediately sign her up for home-based hospice, which would include palliative care. This was the first that we had heard of this program.

The Magic Words

Looking back, I can’t say whether the surgeon who advised my mother was intentionally engaging in scare tactics. He probably wasn’t. Yet his highly subjective, rosy picture of life after surgery and his ghastly view of the alternative were based on his own values, fears, and preferences rather than those expressed by my mother, an elderly woman who above all else feared a longer and increasingly limited existence. Moreover, he was either ignoring, or ignorant of, the potential mitigation of pain and suffering that could be offered through effective palliative care.

Of course, at that moment we were equally ignorant about what palliative care entailed, and how effective it could be for those who decline other treatments.

I’ll never understand why the option of hospice with palliative care was not presented to us early in my mother’s hospital stay, given her very clear statements of her wishes when she was first told of the existence of the mass. It was only when we finally said the seemingly magic words—“we would like to confer with a palliative care doctor”—that we learned that my mother’s wishes could in fact be granted. I shudder to think about what might happen to people who are less persistent or do not know what to ask.

I later learned that this omission was not merely an unfortunate oversight, but a potential failure to comply with Chapter 331 of the Laws of 2010 in New York State, commonly known as the Palliative Care Information Act. This law requires that all patients facing an illness or condition that is reasonably expected to cause death within six months be given counseling concerning palliative care and end-of-life options. The New York State Department of Health webpage devoted to the act explains that the purpose of the law is to “ensure that patients are fully informed of the options available to them...so that they are empowered to make choices consistent with their goals for care, and wishes and beliefs, and to optimize their quality of life.”

The law states that it is the responsibility of the “attending health care practitioner” to provide the necessary information and counseling. In my mother’s case, I do not know which of the countless doctors who checked in throughout her hospital stay met that description. Clearly that aspect of the law has to be clarified to produce the desired effect.

Perhaps what's needed is the equivalent of a Miranda warning for patients facing terminal illness: You are not required to accept treatment, and if you opt to decline it, a palliative care doctor will be provided for you who will ensure that your pain is fully and effectively managed. But such a requirement would be just the start.

For a law like New York's to be truly effective, hospitals need well-staffed palliative care departments with team members who routinely visit seriously ill patients and who can systematically present palliative care options, both as part of and distinct from hospice. In addition, physicians who treat patients with potentially terminal, or even significantly life-limiting, diagnoses should understand palliative care treatment well enough to be able to discuss it comfortably and meaningfully. Training in medical school and through organizations such as the Center to Advance Palliative Care can help achieve this goal. Otherwise, there will always be situations like the one my mother and I faced, when a patient's choices are inadvertently circumscribed by the limitations of one particular specialist's knowledge, assumptions, or beliefs.

It might not be easy to get practitioners to accept a patient's request for palliative care as a rational and legitimate alternative to more aggressive treatment, however. A colleague who is researching informed consent recently told me that a survey (not yet published) at four hospitals showed that 45 percent of doctors believed that they are in a better position than patients to decide what their patients need.

My mother would have had some choice words for those doctors. She would have pointed to the last six months of her life as evidence of the soundness of her choice. Spared the aftermath of a surgery she did not want, my mother ate and felt better than she had in months. Everyone commented on how well she looked and how upbeat she seemed. She took in several museums and a show. We strolled through Riverside and Central Parks and spent a glorious day at the New York Botanical Garden. She enjoyed visits from friends and family members, including some whom she had not seen in many years. Capping it all was a show of her beautiful watercolors, attended by over a hundred neighbors, friends, and relatives. It was entirely fitting that she chose to donate the proceeds from the sale of her paintings that day to Morningside Retirement and Health Services, a nonprofit organization associated with her co-op whose services had proved invaluable to her as she "aged in place."

Throughout this period, my mother's outstanding hospice team delivered on the promise of compassionate, effective palliative care. The team was careful to include her, her aides, and me in all discussions of her care. They told us what to expect and educated us about what developments might signal the need for a change in regimens. This was certainly not "doing nothing." Palliative care in my mother's case involved active monitoring and managing of her diet, digestion, and medications to maximize her comfort and quality of life. My mother felt engaged, respected, and supported—and she experienced virtually no physical pain.

Slipping Away

About two weeks before her death, my mother began to feel very weak. She became increasingly frail and showed signs of anxiety. She stayed in bed for a couple of days, something entirely new for her. She called me a couple of times to tell me she was certain that “this was the end.” She stopped being interested in visitors and even in phone calls. Then one day she experienced an extremely sharp pain as her home attendant was transferring her from a chair to her bed. The hospice team provided medication that eliminated both her anxiety and the pain.

A few evenings later, I woke her from a nap to ask her if she wanted dinner. She said she thought she might, so I gave her a dose of morphine in anticipation of moving her to the dinner table in another half-hour. When I went to get her, she demurred: “Why would I want to move *anywhere* when I am *so* comfortable right here?” Those were her last words. She fell back asleep, and sometime that night she lost consciousness. Over the following two and a half days, in keeping with her wishes, she was heavily medicated as she slowly slipped away.

The evening before she drew her last breath, her nurse stopped in, gently stroked her brow, and spoke to her. Mom showed no signs of hearing her. Her nurse assured us that my mother was in no pain and encouraged me to keep speaking to her, which of course I did. I told her how much I loved her, and that I was truly grateful that she had been so clear about what she wanted. For it was because of the clarity of her wishes, and her steadfast and openly expressed desire to see them honored, that together we were ultimately able to get it right.

Policy Checklist

The issue:

Learning, understanding, and honoring patients' wishes about their end-of-life care can be challenging for family members and health care providers alike. All would benefit from knowing how to ask questions and how to listen to the answers to ensure that patients know and understand the full range of options that are available to them, including palliative care.

Resources:

Agency for Healthcare Research and Quality. AHRQ's Making Informed Consent an Informed Choice: training modules for health care leaders and professionals, <https://www.ahrq.gov/professionals/systems/hospital/informedchoice/index.html>

Center to Advance Palliative Care, <https://www.capc.org/>

Compassion & Choices, <https://www.compassionandchoices.org/>

Conversation Project, <http://theconversationproject.org>

Institute for Healthcare Improvement, Conversation Ready, <http://www.ihi.org/Engage/Initiatives/ConversationProject/Pages/ConversationReady.aspx>

Related reading:

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