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## Progress needed on end-of-life care

By Janice Lynch Schuster, Monday, April 18, 6:49 PM

In 1994, when my grandmother received a diagnosis of kidney cancer, her doctors also gave our family a prognosis, but no guidance: She had two to eight weeks to live, they said, and we should consult hospice.

Not knowing what to expect from hospice, we took what we could get, which proved to be very little in terms of pain relief and symptom management. There was the constant expectation that my family could step in as caregivers, that we could somehow manipulate and manage the machinery and technology intended to keep my grandmother comfortable through her final days. In the end, the hospice team's failure to treat her pain led to terrible suffering for us all.

Over the next decade I worked with Joanne Lynn, a physician whose pioneering work in end-of-life care led organizations around the country to push for change. We wrote books and articles; we worked with organizations nationwide, helping them to configure systems in which care at the end of life would include reliable symptom management, support for families, no surprises, customized care plans and continuity of care.

So I was even more disheartened than usual to hear the circumstances surrounding the death of a dear friend's mother a few months ago, when she was enrolled in hospice care. She had cancer, and after conventional treatments failed to lead to remission, had decided to forgo further treatment.

On the Friday before what would prove to be her final weekend, she managed a swim at her community pool and enjoyed time together with her husband of nearly 60 years. By Saturday, she was struggling with shortness of breath and air hunger — a terrible and frightening sensation. She died gasping for air and begging her husband for help; she died with a hospice nurse asserting that it was not hospice's philosophy to hasten death or prolong life.

I described this to Lachlan Forrow, director of ethics and palliative-care programs at Harvard's Beth Israel Deaconess Medical Center, and he said bluntly, "In 2010, giving inadequate doses of morphine to a dying patient who then suffers unnecessarily should be considered malpractice." And this was in hospice; I shudder to think how much preventable suffering takes place in other health-care settings.

## **Unnecessary suffering**

My friend's mother died needing what every dying patient needs and deserves: palliative care — the thorough assessment and treatment of symptoms, attention to the whole person and support for the entire journey we each will face at the end of life. My grandmother and my friend's mother both needed more access, if only by phone, to round-the-clock health professionals who could respond to what was happening, and both women needed higher doses of opioids.

Ironically, a few weeks before my friend's mother's death, the *New England Journal of Medicine* published a study that found that patients with lung cancer who received palliative care lived almost three months longer than those who did not. In an accompanying editorial, geriatrician and palliative-care expert Diane E. Meier also noted that the palliative-care patients had a better quality of life and lower rates of depression.

Much like hospice, palliative care is interdisciplinary, involving doctors, nurses, social workers and clergy, as well as a range of other health-care professionals, from nutritionists to pharmacists. Together, this team works with the patient and family to deliver care that is in keeping with what patients and families say they want, and to make changes as the disease progresses.

Much of the work depends on clear communication between families and health-care providers — but communication alone won't do the trick. Both the women I describe here had talked to their families and doctors about what they did — and did not — want done. But it turned out that these conversations were not enough to protect either woman from unnecessary suffering. Because so few of us have experience with dying loved ones, usually learning the ropes only when we suddenly find ourselves caring for a parent or spouse, we don't know what to expect, much less what to demand.

While efforts to encourage provider-patient communication are laudable (including recent legislation in New York state that requires doctors to talk to patients who have terminal diagnoses about their options for palliative care), communication alone will not improve the lot of most patients and families.

The information and counseling promised by the New York law would not on their own have alleviated the suffering endured by grandmother or my friend's mother, but they might have helped us understand what to expect and what to demand of our care teams.

## **Making some progress**

Over the years, I've picked up examples of what works to make care more effective and what private and public agencies are doing to make necessary changes.

Too often, advance directives or living wills cannot be found just when the information in them is needed most. We need to develop systems that track and store those documents, so that they are readily accessible in any situation.

One example comes from Oregon, where a team based at Oregon Health and Science University pioneered a one-page document called [POLST — Physician Orders for Life-Sustaining Treatment](#). The POLST specifies not only the treatments a patient does not want, but also those he or she *does* want, and in what circumstances.

Each POLST is written after discussions with the patient, family and physician, and carries the weight of a doctor's orders. Printed on neon-pink paper, it is attached to the front of the medical records of any adult facing serious, advanced illness; the form is also stored electronically, so it can be accessed at any time by emergency responders. The POLST program has proven so effective at getting patients the care they need that the approach is now in use or being developed in 30 other states and the District.

We also need round-the-clock, reliable access to health-care professionals who are expert in palliative medicine and hospice care. Aetna, the Connecticut-based insurance company, offers a care management program to all beneficiaries who have an advanced illness. Trained care managers try to educate patients about their options; they can direct patients to guidance about pain medication and psychosocial support, and help to ensure that advance directives are in place and honored.

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Aetna has developed an expanded hospice benefit as well. Unlike Medicare's hospice program, which is limited to patients who are expected to live for no more than six months and who forgo "curative" treatments, Aetna's allows patients to receive both palliative and curative treatments, and they can enter the program with a life expectancy of up to 12 months. An early study of that program found that enrolled patients were more likely than others to opt for hospice care and ultimately made less use of acute care, intensive care and emergency services. The program matched patient preferences better and also saved money.

The Department of Veterans Affairs has made sweeping changes to ensure that all veterans with a life-limiting illness have access to palliative care and hospice. A [2007 study](#) published in the Journal of the American Geriatrics Society describes how VA leaders changed policy, developed staff and programs, implemented partnerships with community-based hospices and measured outcomes.

Within three years, the number of veterans receiving VA-paid home hospice had tripled, and 42 percent of all veterans who died as VA inpatients had received a palliative-care consultation. A nationwide network, Hospice-Veteran Partnership, has proved instrumental in promoting home-based hospice care. Using the VA's electronic medical records system, managers were able to look at issues such as the effectiveness of pain management endeavors and how satisfied the patients' families were with the care. Studies of veterans who had palliative-care consultations have shown that they have better outcomes in terms of pain management and treatment preference, and their families were [more satisfied](#) with end-of-life care.

When the time comes, we need, at the very least, to have upfront, honest and continuing conversations with our doctors. Beyond that, we need information and action. We need an educated and compassionate workforce, and a system that has the incentives and the direction not only to treat symptoms but also to care for patients and families in the context of their pain and suffering.

Knowledge is power, even at a juncture in life when we feel most powerless and vulnerable. As Forrow at Beth Israel puts it, we need to “take back the night.” Each of us, he wrote to me, has reason to be concerned about our deaths: We must “demand that the system make the bad ones almost impossible and the good ones more common.”

**health-science@washpost.com**

Schuster is co-author of the second edition of “[Handbook for Mortals](#),” to be published by Oxford in May.