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The Life You Save: Nine Steps to Finding the Best Medical Care -- and Avoiding the Worst

Dying in America: A Necessary Conversation

No one likes to discuss uncomfortable subjects like death and dying. But we're going to do it this month, because it's a necessary topic and there's a good reason for now being the time to stop putting off the conversation.

Last month, the Institute of Medicine (IOM), issued a 500-page report called "[Dying in America](#)." It encouraged everyone to talk about how we die. It promoted the universal need for everyone to understand the emotional and practical preparation that can help us, to the best of our ability, leave this world in the medical manner we hope.

The IOM is an independent, nonprofit organization affiliated with National Academy of Sciences. It works independently of government to provide unbiased, scientific advice to decision makers and the public.

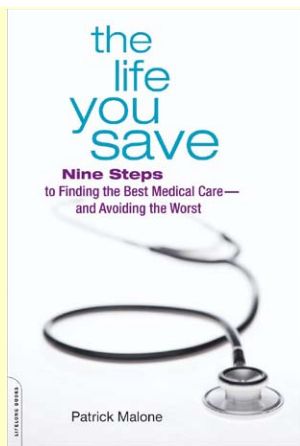
Here, we review its report, why end-of-life care is complicated and what to do in order to be treated the way you want at the end of your life.

Plan Early for the End

As summarized in a story by [KaiserHealthNews.org](#) (KHN), "It is time for conversations about death to become a part of life." You cannot plan for anything meaningful -- a career, a relationship, medical treatment -- if you can't communicate what you want.

Knowing what you want requires understanding what's available, and working well in advance of the need to make sure your loved ones and caretakers follow your plan. The IOM report emphasizes that such planning should start early. You plan for the most comfortable death as you would the most comfortable retirement.

The IOM recognized that most Americans have not documented their wishes for end-of-life care. A national survey in 2013, according to KHN, found that 9 in 10 Americans believed it was important to



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discuss end-of-life care with their families, but fewer than 3 in 10 had done it.

The IOM's response is a "life-cycle model of advance care planning." That means people should plan regular conversations as part of their primary medical care. They should revisit what's discussed in those patient-doctor conversations if they are diagnosed with a chronic illness or genetic condition, whenever a medical problem takes a turn and again in the final year of expected life.

The institute suggests people establish a schedule for when to discuss end-of-life care. You might start when you get a driver's license, because it's appropriate to consider being an organ donor (and, by extension, consider that one day you might be a recipient). You discuss it again when you get married, have children, etc.

The point, says the IOM, is to "help normalize the advance care planning process by starting it early, to identify a health care agent, and to obtain guidance in the event of a rare catastrophic event."

Later, I'll discuss what a health-care agent is.

Advance Planning Leads to Better Care

If you get sick and incapacitated, and are unable to express yourself, caretakers and loved ones must guess what you want. They might apply their standards to your situation, which might not be what you would have chosen. For example, you might not want a feeding tube if doctors have determined that you have severe brain damage from which you will not recover. If the person who must make that decision for you doesn't know that would be your choice, he or she might assume you want all possible measures taken even if the chances of success are slim.

Such care decisions are made more difficult because, as the IOM report concluded, the American health-care system is poorly equipped for end-of-life care. A story last month in the [New York Times](#), "Fighting to Honor a Father's Last Wish: To Die at Home," illustrated how horribly wrong things can go even when you *are* able to communicate what you want. An elderly man was constantly shuttled between the hospital and a nursing home, largely, it turned out, not because it was the best care, but because the facilities made more money than if he had gone home, as he, and his family, had wished. Bogus ways kept turning up to justify the unwanted and unneeded care.

The value of palliative and hospice care has become clear in recent decades, but there's a shortage of doctors practicing it. Like anybody else, other medical professionals are reluctant to hold the honest and

difficult conversations everyone should have about end-of-life issues. And there isn't enough money or organizational support for the needs of ailing and dying patients.

Palliative care treats symptoms -- pain, stress -- for both patients and their families. Hospice care is given to patients whose condition is terminal; they are not expected to live beyond six months. The goal of both is to relieve suffering and improve the quality of life. Usually, hospice care is provided in the patient's home.

As explained by the [National Institutes of Health](#), palliative care can begin at diagnosis, and be given at the same time as the patient receives treatment; hospice care begins when it is clear the patient is not going to survive the illness and after treatment of the disease is stopped.

Research has shown that people who receive palliative and hospice care may live longer than patients who don't.

As KHN pointed out, 85 in 100 hospitals with more than 300 beds offer palliative care, but many patients still might not have access to a specialist, including those who aren't hospitalized or who live in rural areas.

The IOM wants medical schools, accrediting boards and state regulatory agencies to expand end-of-life training and certification requirements.

Medicine Is Not Magic

Patients sometimes see doctors as gods, and doctors sometimes encourage and enjoy the flattery. But death levels the field, and everyone would do well to acknowledge it.

Writing in the [New York Times](#) just after the release of the IOM report, Dr. Barron H. Lerner, professor of medicine at New York University, recalled how his father, also a physician, was angry at how patients died in this country, "too often in hospitals and connected to machines and tubes he knew would not help them."

After his father witnessed too many older people dying badly in nursing homes or hospitals, or returning home even sicker, he became a supporter of the "medical futility movement." If medical interventions have little or no chance of improving health or quality of life, that thinking goes, they shouldn't be used.

His father had an elderly patient with a broken hip, complications and infections who was treated, his father said, by juggling antibiotics that risked severe drug side effects. Another severely demented patient was connected to a feeding tube and a respirator, even though, his father said, he was "never going to get better. ... his family will not accept that reality and continues to pray for a miracle, which will not be forthcoming."

The medical futility movement advocated that doctors, Lerner wrote, "should be able to withhold interventions that they believed would merely prolong the dying process," but that it "did not experience great success."

Of course not; it seems paternalistic and ethically dubious. But

contributing to its unpopularity were patients and their families who demanded these interventions out of desperation and an inability to let go, as much as compassion for the patient. So, Lerner wrote, "[P]hysicians, with ethicists and lawyers looking over their shoulders, and, at times, with substantial money to be made, provided them."

Lerner said his father would have appreciated the IOM's recommendations that Medicare and other insurers reimburse physicians who take the time to discuss end-of-life care with their patients; that funding grow for home health services that would keep extremely ill patients out of the hospital; that young physicians be trained in palliative care.

Medicine as Part of the Problem

I wrote a couple of years ago in my patient safety blog that "[Doctors Die More Gently Than the Rest of Us](#)" because they understand the futility of much end-of-life treatment. As individuals, they generally make different decisions from what their patients or their professional community might make. But even when patients choose minimal intervention if the chances of success are slim, they're often unable to enjoy that choice, because the medical industry is programmed to overtreat at the end of life.

A recent story reported by [NPR, WYNC and Kaiser Health News](#) detailed how end-of-life care in New York and New Jersey is more likely to harm than help patients because of institutional custom and the profit motive. In the story we mentioned earlier, the man who only wanted to go home but was forced into nursing homes lived in New York.

More people in those states die in hospital intensive care units on ventilators or feeding tubes, they have more doctor visits and more tests, treatments and drug prescriptions, and more money is spent on their care by the government, private insurers and the patients simply because the region has a lot of hospital beds.

"One of the truisms of healthcare is that whatever resources are available, or whatever beds are built, they tend to get filled," Dr. David Goodman told the journalists. He studies end-of-life care at Dartmouth College's Geisel School of Medicine.

Also, the medical "culture" of New York is built around highly trained specialists and sub-specialists who see it as their job to cure illness.

So "if there's a cancer it needs chemotherapy, ... if there's heart failure, it needs a procedure," said Dr. Diane Meier, a geriatric specialist at Mount Sinai Hospital in New York and the director of the Center to Advance Palliative Care.

That leads to a lot of specialists constantly referring patients to each other because it's how they were trained and because it's good for business.

"If I'm an endocrinologist, if I refer to the cardiologist, the cardiologist will refer back to me for endocrine problems," said Meier. "It's like a cottage industry."

But that reflexive overcare is coming under increased scrutiny, because hospitals get a single payment from insurers for each

patient, and they lose money when someone's overtreated and overtested.

"The sort of open faucet of money, where whatever you do, the more we'll pay you, and the more complicated thing you do, the more we will pay you, and the more risky thing you do, the more we will pay you -- there's a recognition now that, really, the party's over," Meier told the reporters.

Medical professionals must start questioning why people with end-stage dementia are repeatedly hospitalized in the final months of their lives, why they die in the ICU, why they and their families suffer when the providers know there's no hope and that everyone ends up paying the bill.

Design Your Plan of Action

A couple of years ago, my [newsletter](#), "Who Speaks for You When You Can't Talk to the Doctor?" discussed how you can make your medical wishes known when you are unconscious otherwise unable to be your own patient advocate. Many of those measures pertain to end-of-life care, and still apply, such as understanding your odds of ending up in the ICU, making a living will and signing a medical power of attorney or an advance care directive.

Check out [this link to a website that offers free, state-specific care directives and powers of attorney documents](#) that you can use for a legally valid document wherever you live.

A recent story in the [Los Angeles Times](#) demonstrated how dying can be as comfortable as possible for everyone when these and other steps are taken in advance.

When the mother of Gary Spivack and Betsy Goodkin was diagnosed with cancer, she was determined to beat it. Even so, her children recalled, she had made her end-of-life wishes known: If death was imminent, she did not want any heroic measures to try to save her life. And she wanted to die at home.

And when it was clear that the cancer could not be overcome, she went home to die, in the room she chose, with her children at her side. Hers was a dignified death because she knew what she wanted, and so did they. And, this time, the medical industrial complex cooperated, and enabled her.

In addition to the legal documents mentioned above, practice these habits as part of your end-of-life plan:

Communicate. Have frequent conversations about your end-of-life goals with your doctors and loved ones.

If you have a life-threatening disease, know your treatment options, and the rate of effectiveness for each one. If your doctor advises a treatment, ask what is its goal -- cure? Alleviation of symptoms and pain? Ask how many of the doctor's patients have undergone the treatment, and with what results. Ask if he or she consulted with other practitioners, and if so, why.

Insist on shared decision-making. End-of-life conversations

should be between equal partners, you and your doctor. Both must accept that these are emotional discussions that demand honesty on both sides.

Make sure to address not only your desires, but the feelings of your family, as well as any spiritual considerations.

Discuss comfort care. Talk about palliative and hospice care well before you might need them. Ask your doctor if he or she has experience in these specialties, and if not, to whom you should speak for that care. Ask if the hospitals for which he or she has admitting privileges offers palliative care.

Find out if your doctor can help you plan for hospice care in your home, and if not, to whom you should speak for that care.

Choose an advocate. Make sure someone who knows you well -- a family member or close friend -- can serve as your patient advocate/health-care agent. This person or people should be the ones you most trust to represent your interests and who will be strong in ensuring that your wishes are respected and carried out. This person cannot be your doctor or any health-care provider who is treating you.

Review your advance care directives. The documents spell out what you want for your last days and name the person who is empowered to make medical decisions on your behalf.

Be specific; state what you want to have happen and what you don't. Make sure the documents are signed by two witnesses who are not your doctor or the person you name as your health-care agent. You can also have these documents notarized.

Give copies to your health-care agent, family members, close friend and your doctor. Ask that they be included as part of your medical record.

Get your doctor's orders in writing. Patients and doctors often sign a document called Physician Orders for Life-Sustaining Treatment. Generally, you fill it out when your anticipated life span is six months or less. In addition to making sure your advocates have a copy, keep it in a prominent place where caregivers and paramedics can see it. It's pink, and hard to miss.

The Four Big Questions

Atul Gawande, the surgeon and New Yorker writer, has a new book out on the topics in this newsletter. An [excerpt ran in the New York Times](#) the other day. He spent three years researching it by talking with doctors, patients, nurses, families and others on the front lines of end-of-life stuff.

Medicine, he says, has failed in failing to realize that many people have priorities other than extension of the date of their death, and the way to find out about those priorities is to ask. The best questions, for both family and doctors to ask:

1. What's your understanding of your health or condition?
2. What are your goals if your health worsens?

3. What are your fears?

4. What tradeoffs are you willing to make -- or not make -- to achieve your goals?

When well-meaning medical people overlook these questions and the dialog that follows, it's wrong, Gawande says. His words:

"People want to share memories, pass on wisdoms and keepsakes, connect with loved ones, and to make some last contributions to the world. These moments are among life's most important, for both the dying and those left behind. And the way we in medicine deny people these moments, out of obtuseness and neglect, should be cause for our unending shame."

So now is the time to ask those questions -- and listen to the answers.

Recent Health Care Blog Posts

Here are some recent posts on our patient safety blog that might interest you.

- Antibiotic-resistant "super bugs" are the target of a new [federal campaign to do something serious](#) about this threat to the public health.
- The rights of patients to recover money damages when they've been badly harmed by medical error and malpractice is back in the news. Tort "reformers" are painting the current effort to amend California's damages cap as an effort by "greedy trial lawyers" to make money. The funny thing is, even the [advocates of restricting patient rights admit that their plan wouldn't make medical care any better or more affordable](#).
- The overuse of testosterone for treatment of a mostly fictitious condition called "Low T" might be in, finally, for an [FDA crackdown on the drug's manufacturers and promoters](#).

Past issues of this newsletter:

Here is a quick [index of past issues of our newsletter](#), most recent first.

Here's to a healthy rest of 2014!

Sincerely,



Patrick Malone
Patrick Malone & Associates

