

# **A Better Ending: A new beginning for the end of life**



**Tuesday, March 22, 2016  
6:00 – 7:30 p.m.**

The Joseph B. Martin Conference Center  
The New Research Building  
Harvard Medical School  
77 Avenue Louis Pasteur  
Boston, MA 02115



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## **A Better Ending: A new beginning for the end of life**

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### **Moderator**



#### **Lachlan Forrow, MD**

- Associate Professor of Medicine, Harvard Medical School
- Director, Ethics Program, Beth Israel Deaconess Medical Center
- Director, Palliative Care Program, Beth Israel Deaconess Medical Center
- President Emeritus, Albert Schweitzer Fellowship

### **Speakers**



#### **Muriel Gillick, MD**

- Professor of Population Medicine, Harvard Medical School
- Director, Program in Aging, Harvard Pilgrim Health Care Institute
- Physician, Division of Aging, Brigham and Women's Hospital



#### **Angelo Volandes, MD, MPH**

- Assistant Professor of Medicine, Harvard Medical School
- Faculty Member, Department of Medicine, Massachusetts General Hospital

## About the Speakers:

### **Lachlan Forrow, MD**

Lachlan Forrow is an associate professor of medicine at Harvard Medical School and director of the Ethics Program and Palliative Care Program at Beth Israel Deaconess Medical Center in Boston. He also serves as president emeritus of the Albert Schweitzer Fellowship, and immediate past president of the Albert Schweitzer Hospital in Lambaréné, Gabon. Forrow earned his AB (summa cum laude in philosophy) from Princeton University in 1978 and his MD from Harvard Medical School in 1983. Forrow served as chair of the Massachusetts Expert Panel on End-of-Life Care from 2008-11, and lead author of its landmark report *Patient Centered Care and Human Mortality: The Urgency of Health System Reforms to Ensure Respect for Patients' Wishes and Accountability for Excellence In Care*. In 2007, Forrow was awarded a Lifetime Achievement Award for Community Service from Harvard Medical School. Forrow has lectured and published numerous articles and book chapters on issues in medical ethics education, palliative care, medical decision-making and the social responsibilities of physicians.

### **Muriel Gillick, MD**

Muriel Gillick is a Harvard Medical School professor of population medicine in the Department of Population Medicine, which resides within the Harvard Pilgrim Health Care Institute. She also serves on the medical staff at Brigham and Women's Hospital. Gillick received her BA from Swarthmore College and her MD from Harvard Medical School. She completed a residency in internal medicine at Boston City Hospital and a geriatrics fellowship at Boston Medical Center. Her area of interest is ethical issues near the end of life, a field in which she has published widely, including four books for a general audience, the most recent of which is *The Denial of Aging: Perpetual Life, Eternal Youth, and Other Dangerous Fantasies*. Her work has appeared in medical journals such as the *New England Journal of Medicine*, the *Annals of Internal Medicine* and *Health Affairs*.

### **Angelo Volandes, MD, MPH**

Angelo Volandes is an assistant professor of medicine at Harvard Medical School and a faculty member in the Department of Medicine at Massachusetts General Hospital. Volandes' research is focused on improving decision-making at the end of life and is supported by the NIH, the Agency for Healthcare Research and Quality, the Alzheimer's Association and the Informed Medical Decisions Foundation. He received his BA in philosophy from Harvard College, his medical degree from the Yale School of Medicine and a master's of public health from the Harvard T.H. Chan School of Public Health. Following medical school, Volandes completed a residency in internal medicine at the University of Pennsylvania. He then completed fellowships in medical ethics at Harvard Medical School and Brigham and Women's Hospital. He was named the Edmond J. Safra Faculty Fellow in 2004-2005 at the Harvard University Center for Ethics. His first book, *The Conversation: A Revolutionary Plan for End-of-Life Care* was published in January 2015.

## The empowering potential of end-of-life care

Posted January 25, 2016

Beverly Merz  
Executive Editor, *Harvard Women's Health Watch*

When we scan the medical journals for research to report, we often ask ourselves whether an article suggests something many of us can do to improve our health or well-being. It might come as a surprise, but the articles on end-of-life care in recent issues of the *Journal of the American Medical Association* and *The New England Journal of Medicine* actually fit that bill. And they delivered good news.

These articles' collective message is that there is much that medical teams can do to ensure that people have the best days possible in their final months and weeks, and that they die without undue suffering. The takeaway: palliative care and good communication can make all the difference between a difficult death and a peaceful passing. Even if you're young and healthy, it's good information to have if a loved one is facing a terminal illness.



### What palliative care can do

Palliative care isn't designed to treat disease, but to improve the quality of life for people with life-threatening illnesses and their families. A palliative care team concentrates on relieving symptoms and stressors and helps the ill person articulate his or her preferences and set goals. The team may also help explain what to expect as the disease progresses. In one study, people with metastatic cancer who began palliative care early — while they were still undergoing

chemotherapy — reported less pain, had lower rates of depression, and even lived longer than people who didn't receive palliative care until their last few weeks.

Comfort care is a form of palliative care that focuses on easing a person's suffering in his or her final days by relieving symptoms often associated with dying, including pain, anxiety, breathlessness, coughing, and dry mouth. While the care team does everything possible to reduce the person's pain and stress, they also refrain from administering medications, monitoring vital signs, using feeding tubes, and doing other uncomfortable procedures that are unlikely to benefit the person. In effect, people can spend their last days without being tethered to IV lines and monitors.

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### **Why communication with the health care team is so important**

Dr. Jennifer Temel is an oncologist at Harvard-affiliated Massachusetts General Hospital who treats people with advanced lung cancer. She emphasizes that the medical team will support each person's decisions — whether to undergo aggressive treatment in the hope of a recovery along with palliative care, or to receive only palliative care — but that the person should make those decisions based on a realistic sense of the severity of their illness. “When people are diagnosed with a life-threatening illness, it's important that they understand what their condition is, what the treatments are, the purpose of each treatment, and what they might expect to gain,” she says. It's important to let the care team know what's important to you or your loved one so they can help you make decisions that are in line with the person's preferences, she adds.

Whether you or a loved one is the person facing a serious illness, you may want to let the care team know the following:

- Your own understanding of the illness and prognosis, so they can clear up any misconceptions you may have. In particular, ask the team to explain any medical terms that aren't clear and have them describe the risks and potential benefits of any therapies they propose.
- The kinds of information you want to have, and what (if anything) you would rather not know.
- Who should be involved in discussions about care, and whether decisions will be made alone or collaboratively.
- Your, and your family's, main worries or fears about the situation.
- Your values, goals, and preferences.
- What you consider “unacceptable states” — for example, being fed through a tube or being on a ventilator indefinitely.

### **Have the conversation with your family early**

It's always a good idea to explore these questions before you or a loved one develops a serious illness. According to the Centers for Disease Control and Prevention, more than half of us haven't let our family members know how we'd like to be cared for at the end of our lives. If you want help broaching the subject, The Conversation Project, a collaboration of columnist Ellen Goodman and the Institute for Healthcare Improvement, offers a starter kit of suggestions.

#### **To learn more...**

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## As cancer death approaches, palliative care may improve quality of life

Posted July 11, 2012

Howard LeWine, M.D.  
Chief Medical Editor, Internet Publishing, Harvard Health Publications

Although dying is a fact of life, few people want to think about it. But one group that must think about dying is people with advanced cancer who are told they have just a few months to live. What helps them end their days as peacefully as possible?

- being at home instead of in the hospital
- not undergoing chemotherapy or other active cancer treatment
- not having a feeding tube
- talking with a chaplain or other minister, and spending time in private religious activity
- having a good relationship with the health care team
- not being anxious

Those are the findings from an important survey of almost 400 men and women with advanced cancer who were surveyed an average of four months before dying. Their caregivers were also asked about the person's end-of-life experience. The study, conducted by researchers at Harvard-affiliated Dana-Farber Cancer Center and Brigham and Women's Hospital, was published yesterday in the *Archives of Internal Medicine*.



"What the results suggest is that attention to patients' psychosocial needs, their spiritual needs, their comfort, their worries, their need to not be abandoned by their health care team and to feel valuable and significant are the things that matter most to the patients and their families," researcher Holly G. Prigerson, M.D., told HealthDay. "It's not . . . how much chemo or what procedures are performed or heroics. In fact, it's the opposite. It's the human connection that seemed to be the most important [for] good quality of end-of-life care."

### Quality of life — important at all stages

It can be a challenge to ensure good quality of life at the end of life and a peaceful death. The knowledge that you are dying often provokes intense anxiety and fear, for yourself and your loved ones. Talking through this anxiety and fear with your loved ones, friends, and a minister or other spiritual guide can help.

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Doctors can sometimes make things worse, not better. With cancer and virtually every other disease, we want the treatments we've recommended to work, and sometimes take it personally when they don't. Some doctors have a hard time accepting a person's decision to stop treatment, and may strongly lobby for one more try.

In a commentary on the *Archives* article, Drs. Alan B. Zonderman and Michelle K. Evans remind doctors what our real mission should be:

*"The challenge of providing care for patients with advanced cancer lies not in knowing which modalities may offer the best chance for disease response and prolonged survival. The challenge is in physicians' and other care providers' abilities to develop and maintain effective integrated relationships with their patients that are strong enough to provide the communication channel to convey the emotionally difficult messages relevant to prognosis, the true efficacy of therapy, the futility of care, and when active palliation is the best treatment modality available."*

In other words, we need to make sure we listen very hard to what our patients want, give them the straight truth, and help them make the decisions that are right for them.

## Palliative care

When it's clear that there's no stopping cancer, heart failure, or other conditions, palliative care can help create a situation that maintains quality of life and leads to a "good death." Palliative care

- focuses on both emotional and physical needs
- makes relief of pain and suffering a top priority
- provides active support to loved ones and caregivers, and provides information about how to take care of someone at home.

Since a single doctor or nurse usually can't handle all of these issues, palliative care generally involves a team approach.

If you have advanced cancer, heart failure, or another disease that is likely to end your life, or you are caring for someone with such a condition, talk with a trusted doctor or nurse about palliative care so you are prepared when the time comes. More information about palliative care, and how to get it, is available from the Center to Advance Palliative Care (<http://hvrld.me/YFLpM>).

### To learn more...

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## Understanding key medical procedures and programs

Here are explanations about common medical procedures that may be performed when a person is incapacitated or at the end of life. As you read, think about whether you can foresee conditions under which you would, or would not, want certain procedures or care.

Of course, you needn't make these important decisions by yourself. We encourage you to talk to your doctor about your goals and get his or her recommendations about what care to seek given your state of health.

### *Artificial nutrition*

When you are unable to swallow anything by mouth, this procedure supplies nutrients and fluids through a nasogastric tube inserted through your nose into your stomach (short-term), a tube inserted directly through your abdominal wall into your stomach (longer-term), or intravenously (through a vein).

Artificial nutrition may be used as a bridge when the underlying problem is temporary and the person is likely to recover. It may also be used long-term to help keep a person with an irreversible condition alive, although it will not necessarily improve quality of life. In older, frail people, artificial nutrition is not thought to extend life or prevent complications.

### *Cardiopulmonary resuscitation (CPR) and advanced cardiac life support*

If your heart or breathing stops and you become unconscious, CPR can be used to try to resuscitate you. When emergency medical personnel perform CPR, they use three combined techniques. The first is artificial respiration using a mask placed over the mouth and nose, which is attached to a tube and bag. The bag is squeezed and released, moving air in and out of the lungs of a person who has stopped breathing. The second is artificial circulation, which entails repeatedly pressing on the chest to squeeze blood out of a heart that no longer is pumping. The third is defibrillation, which involves using a medical device called a defibrillator that delivers an electric shock to the body to reset an abnormal heart rhythm. If these measures fail, the next step is advanced cardiac life support, including intubation and mechanical ventilation, plus drugs to stimulate a stopped or failing heart.

In movies and TV dramas, CPR seems to be astoundingly successful. The reality is less rosy: an overall revival rate no higher than 22% in the hospital, and as low as zero in the community for older, frail individuals.

Successful CPR depends on a variety of medical circumstances, including what kind of illness the person has, how severe it is, and how long after cardiac arrest CPR is started. When someone has a terminal illness, the odds of revival are extremely low. Moreover, CPR can injure the body. For example, bruising on the chest is common, and ribs sometimes get broken in the process. A



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sore throat in the aftermath of intubation and ventilation, and soreness and achiness due to defibrillation, are common, too. Death from cardiac arrest is sudden and mostly pain-free.

### ***Defibrillation***

As part of CPR (see above), an electric shock delivered to the body may restart the heart if it has stopped beating or return it to a normal rhythm if it is beating abnormally. A person's body jerks when the shock is delivered, but recipients of a shock are usually unconscious, so they don't feel it. Some people who are sick or dying decide to forgo defibrillation because they simply feel it's "too much." Most people who experience defibrillation won't remember it, though they may feel sore and achy afterward.

### ***Hemodialysis***

When you're well, your kidneys maintain the right balance of fluids and essential minerals (sodium, potassium, calcium, and others) in your body, and clear wastes from your blood. If your kidneys fail temporarily or permanently, a dialysis machine can mimic these tasks by filtering your blood. Typically, needles are placed in two sites in an arm. Blood flows through one tube into the machine to be filtered, then is pumped back into your arm through the second tube. Dialysis usually requires three weekly sessions, each taking three to five hours, at home or at a clinic. Depending on your overall life situation, you may feel this is well worthwhile, or you may decide to forgo it, which would ultimately lead to death. People who choose not to have hemodialysis may do so because of physical exhaustion, discomfort, and the time involved, particularly if other health issues compromise their ability to lead a meaningful life.

### ***Hospice***

When curative treatments can no longer help or when further treatment seems futile, many people seek comfort care for troubling symptoms like pain or difficulty breathing. Hospice, a medical benefit covered by Medicare and most other health insurance providers, is a program of care designed to deliver this. In 2011, 1.65 million Americans received hospice services, and 45% of people who died in the United States were under the care of a hospice program.

Hospice takes a team approach to care, drawing together the skills of a doctor, nurse, home health aide, social worker, spiritual counselor, and volunteers. You need a doctor's referral to hospice, stipulating that you have been diagnosed with an incurable condition and are expected to die within six months. That doesn't always happen, of course, and some people stay with hospice for much longer. It's worth noting that your doctor may suggest hospice long before you are actively dying. Rather than a signal of "giving up," the extra support and compassionate care provided by hospice may be welcomed by you and your loved ones.

As a hospice patient, you may remain at home, move to a hospice facility if one is available, or receive hospice services at a hospital, assisted living facility, or nursing home. The hospice team responds to the wide-ranging needs of the dying person, family, and caregivers. Hospice may

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deliver such helpful supplies or equipment as a hospital bed, oxygen, or medications to help quell pain, anxiety, or infections that interfere with breathing. Usually, grief counseling is offered for family and caregivers during the year following a death.

### ***Intensive comfort care (palliative care)***

Whether people die at home or in a hospital or nursing home, significant pain and breathlessness is common in 20% to 40% of cases. Intensive comfort care, also known as palliative care, aims to keep a patient comfortable and pain-free by using a combination of evidence-based measures to treat distressing symptoms. Often, people choose comfort care through hospice or their current doctors when further curative treatment is no longer helpful or desired.

### ***Intravenous hydration***

When a person is unable to swallow anything by mouth, this procedure supplies a solution of water, sugar, and minerals through a tube placed into a vein. If the problem is likely to be short-lived — five days or so — hydration alone may be sufficient to provide necessary liquids and calories; otherwise, artificial nutrition must be considered as well.

Like artificial nutrition, hydration may be used temporarily when the person is likely to recover sufficiently to take fluids by mouth. Or it may be used long-term in the case of an irreversible condition to help keep a person alive, although it will not improve quality of life. People who choose not to have artificial hydration may wish to avoid the discomfort involved or may wish not to prolong the dying process.

### ***Mechanical ventilation***

A machine called a ventilator or respirator (sometimes called a breathing machine) pushes air into the lungs, replacing or supporting the lungs' normal function when a person cannot breathe unassisted. Patients on a breathing machine may be conscious or unconscious. A tube attached to the machine is inserted into the nose, mouth, or throat and passed down into the trachea (windpipe). This is called intubation. The discomfort of the tube in the windpipe requires most people to take sedatives, which render them not fully conscious. When the breathing tube is inserted through the nose or mouth, a person cannot talk.

Mechanical ventilation can be used short-term as a bridge to recovery, or long-term. People on mechanical ventilation for longer than a week also need other organ-sustaining treatments, including artificial nutrition and a catheter to remove waste from the bladder. They move their bowels into a bedpan. Bedsores may occur. If a person becomes well enough to come off the ventilator, rehabilitation will be needed. If the breathing tube needs to be used for more than two to three weeks, it will be moved from the nose or mouth and inserted into the windpipe through a surgical incision in the front of the neck (a tracheostomy).

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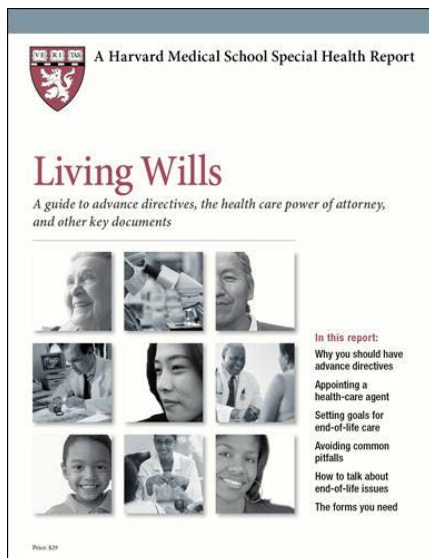
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When a person is terminally ill, mechanical ventilation may prolong the dying process, but it cannot treat the underlying condition or improve quality of life. People who choose not to be placed on mechanical ventilators may make that decision for several reasons, including not wanting to be sedated or unable to talk. Some people don't want their families to see them tied to machines in an incoherent state or do not want to spend what may be their last days in a hospital bed.

### *Organ-sustaining treatment*

A set of drugs, medical procedures, and machines that can keep a person alive for an indefinite period of time, but which cannot cure a terminal condition, is collectively known as organ-sustaining treatment. A few examples are hemodialysis, mechanical ventilation, and artificial nutrition.

Often this is called "life-sustaining" treatment, though some experts argue that "organ-sustaining" treatment is a more appropriate description. While such treatments can serve as an important bridge to recovery, sometimes they merely prolong death without supporting meaningful life.



### **To learn more...**

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## Creating your advance directives

Once you've chosen a health care agent and decided how much guidance you want to give, you may be completely ready to create your advance directives. Or you may want to do some additional thinking. If so, the information that follows on considering your goals for care and working with scenarios can help you get started.

### What are your goals for care?

All of us have goals for care, stated or not. After an illness or injury, we may hope to return to our lives feeling and acting the same as always. But that may not be possible.

Of course, medicine also advances rapidly. New tests, medications, and technologies arrive at a speed that outstrips our ability to see how these changes will affect our lives. Spelling out a goal — rather than simply focusing on a handful of scenarios — may give your doctors much-needed latitude to consider options that will help you reach that goal, if possible, or to explain why it isn't feasible.

One common goal is recovering from an illness or injury sufficiently to return to activities that make life meaningful to you. If this is your goal, you need to offer guidance on what is — and isn't — meaningful life.

"Some people say, 'As long as I can open my eyes, sit up, and recognize my family, that's all I want. I don't care if I have to be fed and bathed and have my bottom wiped by someone else,'" says Dr. Anne Fabiny, assistant professor of medicine at Harvard Medical School, chief of geriatrics at Cambridge Health Alliance, and medical editor of the *Living Wills* Special Health Report. "Then I say, 'Great. I know what you want and we'll make the decisions we need to make sure your goals are achieved.' Somebody else might say, 'You know what? If I can't read a book and talk about it with my family, if I can't feed myself and toilet myself, and my condition is only going to get worse, I don't want to be alive.'"

When recovery isn't possible — if you have an incurable cancer, for example, or your body is winding down from a combination of illnesses accumulated over time — your goal may shift to comfort care, which focuses on easing pain and other distressing symptoms so that you are better able to enjoy the time you have left.

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### **Working with scenarios**

Many states' living wills present several scenarios, then ask what types of care you would want if you were unable to make and voice your own decisions. Here are four scenarios often used:

- You are likely to die within a short time, and organ-sustaining treatments would only delay, but not prevent, death.
- You have permanent and severe brain damage with no known hope of recovery, and organ-sustaining treatments would only delay death.
- You have brain damage and are in a coma from which you are not expected to awaken or recover, and organ-sustaining treatments would only delay death.
- You have reached an "end-stage condition" and your health is so poor you cannot mentally or physically care for yourself, and organ-sustaining treatments would only delay death.

Yet many experts in the field are leery of such scenarios. Why? They are too simplistic. Life rarely falls so neatly into place, and real medical situations may be much more complex. It's impossible to predict what will happen and what new options for care will be available. And it's hard to know how you will feel about certain treatments and quality-of-life issues when actually facing them.

Stay flexible, urges Charles P. Sabatino, director of the American Bar Association Commission on Law and Aging and legal editor of the *Living Wills* report. "Never say never. I see people re-draw the lines all the time as quality-of-life issues that seemed unacceptable in a state of health — being unable to feed or toilet themselves, for example — are reconsidered from a state of illness."

If you have a health care agent, make it clear that your wishes are to be treated as guidance, not binding instructions. Think about conditions that you feel would make life unacceptable, such as an inability to recognize family members or sustaining severe, irreversible brain damage.

### **Who needs to have your advance directives?**

Sometimes, people put living wills and health care power of attorney forms in a safe deposit box. That's safe if the house burns down, but won't be much help if you're unexpectedly hospitalized without them. Instead, take the following steps:

- Give your health care agent and any alternate agents a copy of your health care power of attorney (and your living will, if you have one). In an emergency, your agent may need to fax or email the documents to doctors or a hospital.

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- Ask your doctor(s) to scan copies of directives into your electronic medical record or put paper copies of your directives into your file.
- If you are in the hospital, ask to have a copy of your directives put in your chart. (Your health care agent or a family member should do this if you are unable to do it.)
- File the original documents in a safe spot in your home (and tell your agent, family, and friends the location). Hospitals may ask to see an original, so it's important that people can find it when necessary. The National Hospice and Palliative Care Organization suggests writing the location of the original on the copies.
- Put a card in your wallet that has your health care agent's name and contact information. Also note where you keep the original and additional copies of your directives.
- If you are living at home and have a non-hospital DNR or POLST form, remember that you or your health care agent may be required to display a signed form, or you may have to wear a special bracelet identifying a DNR decision.
- If a lawyer drew up your advance directives, he or she may keep a copy, too. Ask if this is the case and, if so, how long the copy will be kept in the files.
- Also consider using an advance directive registry to enable health care providers to gain access to your written wishes via the Internet. Your state may operate a registry, or you can use a national registry. The registries may be free or may charge fees. Before choosing one, consider how access is granted to the documents and how much effort it will take to update them when necessary. Typically, a user name and password is required for security. This information can be kept on a wallet card and in the glove compartment of your car, as well as given to appropriate people.

### **To learn more...**

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## **Troubleshooting: Pitfalls, fixes, and tips for tough conversations**

It's important to write advance directives, but you may hit some roadblocks once you embark on the process. This section takes a look at a few common pitfalls and offers suggestions for how to avoid them. Hopefully, the scenes that follow will not only encourage you to write advance directives, but also suggest words that may make tough conversations easier to start and continue.

### *Failing to choose a health care agent*

**The pitfall:** Peter and Chris had been loving partners for four years. They talked about practically everything under the sun. One day, Peter had a car accident that sent him to the hospital with serious injuries. Because they weren't married, Chris could see Peter only during visiting hours. Much worse, Chris didn't have the authority to make important decisions for Peter's care, which fell instead to Peter's only living relative, a sister. She lived on the other side of the country and wasn't at all close to Peter or Chris. This could have been avoided if Peter had designated Chris as his health care agent.

**The fix:** Choose a health care agent and fill out the form. If you change your mind at a later date, you can name a different agent.

### *Choosing a health care agent, but never getting around to having "the conversation"*

**The pitfall:** Dante asked Maria to be his health care agent, but somehow never got around to sharing his health goals and fears. When Dante developed complications after getting pneumonia and became unable to communicate, Maria was distraught. She had a hard time making decisions because she felt so unsure of what Dante would want.

Maria's experience is all too common. When an illness or accident strikes, people often feel stunned, surprised, and saddened. Meanwhile, real decisions must be made, sometimes urgently. When an agent has little or no guidance, it's terribly hard to deal with an emotional response to the situation, yet clearly think through options.

**The fix:** Tell people what you want. If you haven't had this conversation because you aren't completely certain about what you want, that's okay. Try, at least, to talk about what your priorities or goals in living would be if you had a serious, potentially fatal condition.



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If you're the health care agent, start asking right away, preferably before papers are signed. You can say, "I need to know what kind of care you'd want if you get really sick, or if there's some kind of catastrophe." Or, "We all really care about you. We love you and want to make sure you get the kind of care you want when you need it and can't tell us what you'd prefer. So that we won't have to guess — and maybe guess wrong, which would be awful — can we talk about what you'd want?"

Count on having more than one conversation. Try to be patient enough to consider "what if" questions even if the subject makes you anxious and upset. Check back every now and then — especially when an illness occurs or a decline in abilities is apparent — to decide if there has been any shift in goals. Sometimes people adapt to new limitations set by illness or accidents, which may prompt a change of heart about what makes life worth living.

### *Not properly describing your wishes, or making your wishes too specific*

**The pitfall:** Rashid told Ellen he would never want to be on a ventilator — not in a million years, even if he was seriously ill. In fact, he was horrified by this prospect because his father had spent the last days of his life "hooked up to machines." Then he had a bad accident at work and ended up hospitalized, in a coma. His prognosis was reasonably good — the doctors felt it was likely he would come out of it. There was a catch, though. When Rashid was taken to the hospital, he was unconscious, and no one knew his wishes. His heart and breathing stopped, so CPR was performed. To stabilize him, the emergency team put him on a ventilator before Ellen arrived with a copy of Rashid's health care power of attorney. Ellen knew Rashid never wanted to be on a ventilator. However, she also realized that if Rashid had understood that a ventilator could be a bridge to a full recovery, he might have been more flexible in his wishes. Now she had to determine whether to have the doctors take him off the ventilator.

**The fix:** Avoid absolute instructions about specific treatments unless you are currently approaching a decision about the specific treatment. You might not fully understand the medical terms and implications of your choices. Have a conversation with your doctor as well as your health care agent about what you really want. A dialogue is more likely to turn up "what if" questions: What if a ventilator were needed as a bridge to recovery? Would it be all right to use it for a trial period if doctors thought it might help you regain consciousness?

If you're a health care agent, probe gently for more information. You needn't take "You know my wishes — don't keep me tied to machines and that's it!" as the final answer. Ask questions and listen carefully. "What is it you fear?" "What if there was a good chance that you could be returned to health?"

## **A Better Ending: A new beginning for the end of life**

Longwood Seminars, March 22, 2016

### *Having family members who disagree*

**The pitfall:** Suzanne was dying. Now in the later stages of dementia, she could no longer eat or drink on her own. Suzanne had never appointed a health care agent, and her son, Henry, and her daughter, Cynthia, battled bitterly about appropriate treatment. Usually their opinions were 180 degrees apart. Each insisted he or she knew their mother best and thus knew what she would have wanted.

“Should a feeding tube be placed?” the doctor asked.

“No,” said Cynthia, believing that a feeding tube would only prolong death. “I know my mother wouldn’t have wanted to live like this.” Henry disagreed, saying their mother loved life and would want to live as long as she could. The disagreement had to be resolved through a consultation with the hospital ethics committee and intervention by a mediation lawyer. Ultimately, Suzanne did not have a feeding tube placed.

**The fix:** Name a health care agent now, while you are able to do so. Relatives may still argue, but your agent will have the legal authority to decide. When there’s total gridlock and no one is willing to budge, people often go to court demanding to be named a legal guardian, a process that can take weeks and be very costly. A judge has to choose between the parties, or can decide to appoint a different guardian. Meanwhile, attention and energy better directed toward caring for the patient is pulled into the conflict. The patient gets lost in the shuffle, and everyone on the hospital team must tread water while the family hashes it out in court. If you’ve chosen a health care agent, you may be able to head off serious disagreements by sharing your wishes with everyone in the family. If you know ahead of time that someone is likely to vehemently object, you can choose to disqualify that person from weighing in on medical decisions by writing that instruction in your directives.

#### **To learn more...**

This information was prepared by the editors of the Harvard Health Publications division of Harvard Medical School. It is excerpted from our Special Health Report *Living Wills*, available at <http://hvrld.me/YleFO>.

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## Web advice and directive downloads

A veritable Babel of websites has sprung up to offer advice on advance care planning or access to electronic forms. Two solid entries are **The Conversation Project** and **Five Wishes**.

Founded in 2010 by newspaper columnist Ellen Goodman and like-minded colleagues, **The Conversation Project** focuses on helping people talk to loved ones and doctors about desires for end-of-life care. The multimedia website offers a mix of how-to advice and thought-provoking personal stories and quotes from a wide range of people who've embarked on these conversations.

A free starter kit is available in English and Spanish. It uses prompts to help you collect your thoughts on the role you prefer to play in health decisions, where you'd like to be cared for and what sort of care you want, ways to kick-start and guide an end-of-life conversation, and many other important issues. A similar questionnaire is designed to help you talk to your doctor. For more information, see [www.theconversationproject.org](http://www.theconversationproject.org).

Written very simply, **Five Wishes** is an advance directive that conveys your personal, spiritual, and emotional wishes as well as medical ones. It was developed in Florida in 1997 through the nonprofit organization Aging with Dignity and currently meets the legal requirements for advance directives in most states. Available for \$5 at this writing, Five Wishes can be filled out online in English or by hand on a paper form, available in 26 languages. The form encourages you to answer five direct end-of-life questions:

- Whom do you choose to make decisions on your behalf?
- Which medical treatments do you want or not want?
- How comfortable do you want to be made?
- How do you want people to treat you?
- What do you want loved ones to know?

For more information, see [www.fivewishes.org](http://www.fivewishes.org).

### To learn more...

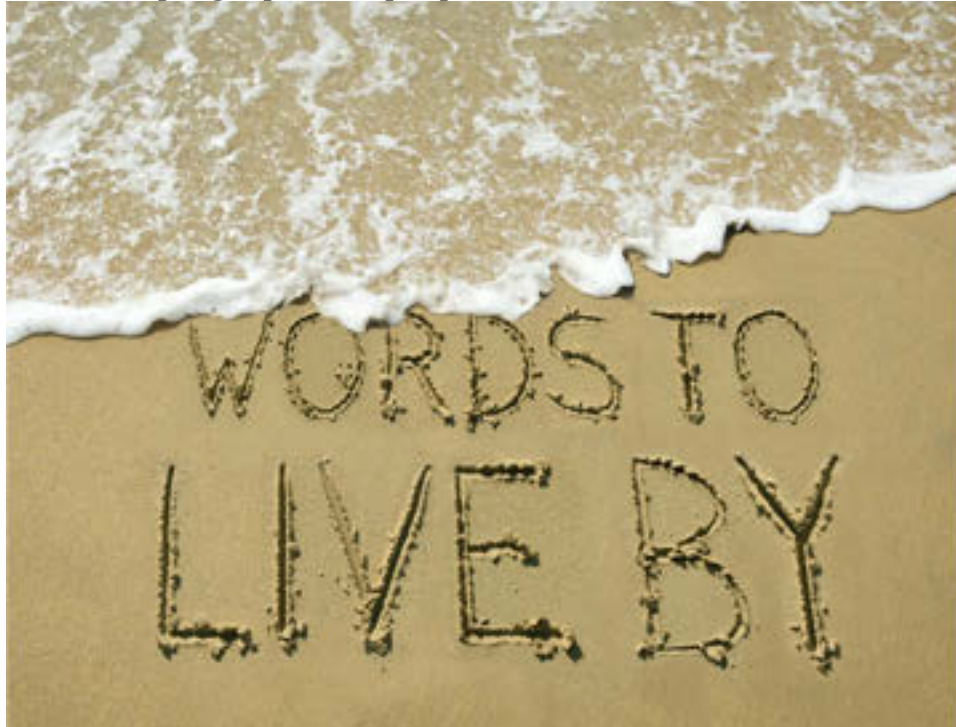
This information was prepared by the editors of the Harvard Health Publications division of Harvard Medical School. It is excerpted from our Special Health Report *Living Wills*, available at <http://hvrld.me/YleF0>.

# Words to live by

January 21, 2011

David Cameron, Harvard Medical School  
(From *Harvard Medicine Magazine*)

When helping a patient prepare for death, talk about life instead



Joanne Wolfe is no stranger to situations charged with the sort of emotional intensity that would shake most of us to the core.

Take, for example, the time a group of clinicians under her supervision was caring for a teenage girl who was going to die from a metastatic brain tumor. The team was desperate to discuss with the girl and her mother a potential nonresuscitation order.

Without such an order, resuscitation is the default treatment, and the doctors worried that the girl could end up on a ventilator, with her mother forced to decide whether such life support should continue.

So, at different times the doctors had presented the girl and her mother with the various options and had asked, “What do you want us to do?”

Each time they brought the issue up, however, the girl and her mother evaded the conversation. The doctors came to Wolfe for advice.

“That’s often the way it’s done,” says Wolfe ’89, an HMS associate professor of pediatrics and director of pediatric palliative care at Boston Children’s Hospital and Dana-Farber Cancer Institute. “Doctors spell out a menu of options without any real context, and the patients are expected to simply choose what they want.”

Wolfe recommended a more oblique approach. Rather than asking the patient to make a choice, they asked her to make a list. The girl was encouraged to write down all the things that she wanted, in no particular order, from the sublime to the silly. Nothing was out of bounds.

She put together a document that Wolfe still uses to mentor physicians.

I want a hot tub, the girl wrote. I don’t want to be intubated. I want to believe in God. I don’t want chest compressions. I want to be able to walk again.

Wolfe continues to be struck by the blended goals the patient put on paper once she was given the opportunity to express herself without conditions. This allowed the girl to find her voice, and from there the decisions flowed naturally.

Eventually she died comfortably, without resuscitation, intubation, or chest compressions.

“The point,” says Wolfe, “is to allow the patient’s desires to establish a framework, and then you, as a physician, can own the responsibility for making a recommendation.”

Doctors are trained to save lives, not to inform patients that they are at the end of theirs. There is, however, a growing consensus in the medical profession that for too long end-of-life conversations have been marginalized to a few brief options that a doctor presents to a patient only after all other

interventions have been exhausted. And even then, it occurs rarely. This approach is both a tragedy and source of crisis.

Physicians need to know that there are ways to have these conversations, ways that can produce effective and profound outcomes. Just as doctors are trained in the latest interventions, they need to learn how to compassionately, effectively, and honestly guide patients through their final days.

### **Deafening Silence**

In the world of medical specialties, palliative care is a newbie. Only in 2006 was it recognized by the American Board of Medical Specialties as an official subspecialty. Although this may seem inexplicably tardy, consider that as recently as 50 years ago, doctors often withheld a terminal diagnosis from a patient. Susan Block, an HMS professor of psychiatry and medicine and co-director of the HMS Center for Palliative Care, recalls the early days of her own residency, roughly four decades ago, when physicians routinely excluded patients from end-of-life decisions. The doctor called the shots, and there was little transparency.

“This was very typical of the field,” she says. “And I was morally troubled by that.”

While this sort of paternalism is increasingly the exception, there is still no standardized approach to addressing end-of-life issues. As a result, these conversations happen too infrequently.

“Patients, of course, are ambivalent,” says Block, “and doctors are often too attached to the patients or too insecure about their own competencies. It becomes a collusion of silence.”

Even when the subject is broached, the conversations tend to happen late. In one study involving patients with metastatic cancer, the first conversation about end-of-life care occurred, on average, 33 days before the patient died, and three-quarters of the conversations were initiated by someone the patient had never before met.

The content of these talks tends to take the form of a data presentation: Here is the reality of your condition. Here are the options. Here are all the pros and cons of each option. Choose.

“As a palliative physician once said about me, the problem is that we’re explain-aholics,” says Atul Gawande ’94, Samuel O. Thier Professor of Surgery at Brigham and Women’s Hospital and author of the 2014 book *Being Mortal*. “We think that what people lack is information. But what they lack is more complicated. People have goals and priorities in their lives besides just living longer—and they want doctors who can understand that and help tune their care to those priorities.”

In other words, for physicians to effectively engage patients in end-of-life discussions, they need to fight their tendency to focus on data and instead engage patients on a fundamentally human level.

“This requires transitioning from sounding like medical retailers to being like counselors,” adds Gawande, “ones whose approach is, ‘Tell me what matters to you, and I’ll tell you which options seem best based on that.’ ”

### **Voice Activation**

There’s an irony about end-of-life conversations. When done correctly, they’re really not about the end at all. In fact, they are probably more about life than any other conversation you’ll ever have. The incongruity is not lost on many palliative-care experts.

“I don’t find that phrase helpful with most patients,” says Lachlan Forrow ’83, an HMS associate professor of medicine and director of palliative-care programs at Beth Israel Deaconess Medical Center. “Kierkegaard said, ‘Life can only be understood backwards; but it must be lived forwards.’ We don’t actually know when it is truly the end of life until someone’s died. It’s the living that’s the most important thing.”

Wolfe dispenses with “end-of-life” altogether and instead uses “goals of care.” And according to Block, the conversations aren’t about dying at all. “These conversations are about goals and quality of life—issues that are meaningful to patients.”

The approach taken by Wolfe and her colleagues when talking with a child’s family illustrates Block’s point:

*Tell us about your child as a person. What is she like, and how has that changed since she’s become ill?*



*Tell us your understanding of your child's illness.*

*What is most important to you and your child?*

*What are your hopes?*

*What are your worries?*

*During difficult times, what gives you strength?*

“These kinds of questions help you adapt your approach to the language and values of the family,” says Wolfe.

Angelo Volandes, an HMS assistant professor of medicine at Massachusetts General Hospital and author of the 2015 book *The Conversation*, begins these conversations gently.

“I ask, ‘What’s a good day in your life like? Tell me about a happy day.’ I get rid of all the medical language. I get rid of any disease language or prognosis. I try to get rid of any framework of Western medical technology and simply have them tell me what a good day looks like to them.”

### **Speak for Yourself**

If the medical field has suffered from a lack of training, incentives, and guidelines concerning such conversations, Block and Gawande are working to change that. For five years they have been working with others to develop and test what Block calls a “serious-illness care program.” It is both a program for improving physicians’ skills in communicating and planning with patients who have serious illnesses and a support system to ensure that patients who would benefit from these conversations have them.

The program begins with a simple step. A doctor looks over her patient list and for each individual asks herself one question: If this person were to die within a year, would I be surprised? If the answer is no, then it’s time to have a conversation.

The physician, together with others in the program, then receives a two-and-a-half hour training program based on a seven-question guide to what Block calls “patient-centered conversations about serious-illness care goals.” Patients are also told in advance that the physician caring for them is going to initiate this conversation and are instructed in how to prepare for it.

Once the conversation is complete, the doctor documents it in the patient's electronic medical record, so that any physician in the patient's care continuum can access it.

A clinical trial evaluating the program's effectiveness is ongoing, and preliminary analysis is encouraging, says Block, suggesting that doctors involved in this program have these conversations earlier and more often than other doctors, and that patients are indeed experiencing better quality of life.

### **Training Tapes**

Volandes is also developing an educational curriculum, but he is tackling the problem from a different angle. Rather than training doctors, he's training patients.

Volandes and his colleagues have created nearly 100 videos in ten languages that offer patients advice on how to "explore goals of care" with their physicians. Other videos describe many of the aggressive medical interventions about which patients with life-threatening diseases are often asked to make decisions. The videos provide concrete demonstrations of how these interventions might affect the patients' daily lives.

"This is really a re-envisioning of the patient-doctor relationship," says Volandes.

So far, more than 200 health care systems, hospitals, hospices, and clinics have made these videos available, including Mass General. A study at the hospital, authored by Volandes and colleagues and published this year in the *Journal of General Internal Medicine*, showed that only 43 percent of seriously ill patients have a goals-of-care conversation with their physicians. When patients viewed the videos that number rose to 81 percent.

The study also found that, in general, about 22 percent of seriously ill patients receive some sort of unwanted intervention. But for patients who have been given access to the videos, that percentage was four.

"If we give patients more knowledge," Volandes says, "we can radically change what happens in health care. Now we have data to show that you can actually budge the needle if you empower patients."

## **The Human Condition**

If, ultimately, end-of-life conversations are less about death and more a focus on life itself, then working in this field is not so much about perfecting medical interventions as it is about perfecting being human—an insight so simple it's radical.

This awareness was driven home to Block a few years back when she went to a parent-teacher night at her son's high school. That day had been particularly brutal for her, heartbreaking and poignant, and she was barely keeping it together. At some point, a father of another student approached her and asked, "How was your day?" She burst into tears. The man, no doubt, was a bit shocked, but Block didn't hold back and told him everything that had happened. When she finished, the man, who worked in finance, looked at her and said, "I would give anything to have a day as close to what it means to be a human being as you've just had."

**Reprinted from...**

<https://hms.harvard.edu/harvard-medicine/voices/words-live>

# Right time for ‘end-of-life’ talk

February 8, 2012

By Rob Levy, Dana-Farber Cancer Institute Communications  
(From *Harvard Gazette*)

The vast majority of patients with incurable lung or colorectal cancer talk with a physician about their options for care at the end of life, but often not until late in the course of their illness, according to a new study by Harvard-affiliated Dana-Farber Cancer Institute investigators published in the Feb. 7 issue of the *Annals of Internal Medicine*.

The researchers found that such belated conversations tend to occur under particularly stressful conditions — when patients have been admitted to a hospital for acute care. And the doctor who shares in the end-of-life care talk is often a hospital physician rather than an oncologist who has treated the patient for much of his or her illness.

Together, these circumstances may deprive patients of the opportunity for extended reflection and deliberation that would have been possible months earlier, when the conversation also could have occurred under less trying and hectic conditions, the authors suggest.

“Previous studies have shown that patients who discuss their end-of-life care preferences with a physician are more likely to choose palliative, comfort-focused care over aggressive measures, and [to] receive hospice or other care consistent with their wishes. But studies haven’t looked at the timing of these discussions, or where and with whom they occur,” says the study’s lead author, Jennifer Mack of Dana-Farber/Children’s Hospital Cancer Center. Mack is also an assistant professor of pediatrics at Harvard Medical School (HMS).

The new study, which involved 2,155 patients with stage IV (highly advanced) lung or colorectal cancer, found that 73 percent of the patients had a conversation about end-of-life care with a physician, according to medical records or an interview with the patient or a companion. Among the nearly 1,000 patients who passed away and whose records document an end-of-life

care discussion with a physician, the median time of those discussions was 33 days before death.

Other findings pertain to the location of those discussions and the type of physician involved. Of the more than 1,000 end-of-life care discussions in medical records, 55 percent occurred in the hospital. Oncologists documented end-of-life care talks with only 27 percent of their terminally ill patients in the study.

Data for the study was provided by the Cancer Outcomes Research and Surveillance Consortium (CanCORS), a multi-region, population- and health system-based study of more than 10,000 patients with lung or colorectal cancer. Researchers interviewed patients at two time points and analyzed their medical records 15 months after diagnosis.

“It’s encouraging to see such a high percentage of patients had end-of-life care conversations with a physician,” Mack says. “There’s a concern, though, that so many of these talks are taking place late in the trajectory of the disease.”

Previous studies had estimated that fewer than 40 percent of patients with advanced cancer had end-of-life care discussions. Mack theorizes that this lower figure may reflect that earlier studies didn’t record end-of-life talks that took place shortly before patients’ death.

Other research has suggested that physicians may delay end-of-life care discussions because of a natural reluctance to broach the subject, or because it conflicts with physicians’ problem-solving, hope-giving image. While such motivations are understandable, Mack says, they may work to patients’ detriment if they postpone the conversations too long.

Mack and her colleagues are planning future studies to examine the quality and content of end-of-life care conversations, and then explore whether having such talks earlier in the course of illness can benefit patients.

The study’s senior author is HMS Professor of Medicine Jane Weeks of Dana-Farber. Co-authors include Angel Cronin and Nathan Taback of Dana-Farber; Haiden Huskamp and Nancy Keating of Harvard Medical School; Jennifer Malin of the University of California, Los Angeles; and Craig Earle of the Ontario Institute for Cancer Research.

The study was funded by grants from the National Cancer Institute, the U.S. Department of Veterans Affairs, the American Cancer Society, and the National Palliative Care Research Center.

**Reprinted from...**

<http://news.harvard.edu/gazette/story/2012/02/right-time-for-%E2%80%98end-of-life%E2%80%99-talk/>

# Video can help patients make end-of-life decisions

June 1, 2009

By Sue McGreevey, Massachusetts General Hospital  
(From *Harvard Gazette*)

Realistic picture of dementia can be critical to informed decision-making  
Viewing a video showing a patient with advanced dementia interacting with family and caregivers may help elderly patients plan for end-of-life care, according to a study led by Massachusetts General Hospital (MGH) researchers.

In their report in the journal *BMJ*, the investigators found that participants who watched such a video in addition to listening to a verbal description of the condition were more likely to indicate they would choose only comfort care if they developed advanced dementia and also said they felt the video was helpful to their decision-making process.

“Decisions at the end of life can be complex and abstract; the video makes it real,” says Angelo Volandes of the MGH Department of Medicine, the study’s lead author and an instructor in medicine at Harvard Medical School. “Patients may not have experience with conditions like advanced dementia or the medical interventions involved, other than what they have seen on television or at the movies. Videos of real patients can offer more realistic images.”

Asking patients about their preferences for treatment in situations they may face in the future is an essential part of quality care, the authors note; but giving patients a clear understanding of the options they are considering and making sure that messages delivered by different health care providers are consistent can be challenging. Terms that have a specific meaning to medical professionals may be interpreted very differently by the general public.

To give patients a clearer idea of what advanced dementia involves, the research team developed a decision-support tool combining a standard verbal description of advanced dementia – including the fact that patients with the condition cannot move about independently, eat by themselves, or communicate with others – and a two-minute video of an 80-year-old



dementia patient that clearly shows her inability to walk, to eat, or to communicate with family members.

While the system had been evaluated in a previous study involving middle-age participants, it had not formerly been tested in older individuals or in a way that allows comparison to verbal explanation only.

The current study enrolled 200 patients from four primary care or geriatric practices in the Boston area. Participants were 65 or older and had no significant cognitive impairment, based on a standard test of mental functioning. After an initial introductory interview – which included gathering basic demographic and personal health information, along with assessment of their knowledge about dementia – about half the participants listened to a narrative describing advanced dementia and then watched the video.

The other participants, the control group, only heard the narrative description. Then all participants had a second interview that included asking their preferences for the type of care they would prefer to receive if they developed advanced dementia – the options being care designed to prolong life at all costs, limited care designed to maintain physical functioning, and comfort care focused on relieving pain and maximizing comfort.

Among the control group that only heard the narrative description of advanced dementia, 64 percent of participants indicated they would choose comfort care, 19 percent limited care, and 14 percent life-prolonging care. Among participants who also viewed the video, 86 percent said they would choose comfort care, while 9 percent would choose limited care and only 4 percent indicated life-prolonging care. Most participants were contacted six weeks later and again asked about their care preferences, and while 29 percent of the control group indicated a change, only 6 percent of those viewing the video had changed their preferences.

“We also asked those who watched the video about their response to it, and the vast majority said they found it to be helpful, were comfortable watching it, and would recommend it to others. We want patients to be as informed as possible when making decisions at the end of life but not coerce them or unduly influence them in any manner,” Volandes explains.

“Since projections indicate that more than 13 million patients will develop dementia by 2050, it is critical that patients understand their options for end-of-life treatment and be able to communicate their preferences to their physicians,” he adds. “Using videos in patient-doctor discussions is new, so we need further work and studies before the use of videos like this can become a standard part of clinical care.”

Co-authors of the BMJ study are Michael Barry, Kenneth Minaker, Yu Chiao Chang, and Areej El-Jawahri, MGH; Michael Paasche-Orlow, Boston University School of Medicine; Muriel Gillick, Harvard Medical School/Harvard Pilgrim Health Care; Francis Cook, Brigham and Women’s Hospital; Elmer Abbo, University of Chicago; and Susan Mitchell, Hebrew SeniorLife, Boston. The study was supported by grants from the [Foundation for Informed Medical Decision Making](#), the [Alzheimer’s Association](#), and the [Hartford Foundation](#).

**Reprinted from...**

<http://news.harvard.edu/gazette/story/2009/06/video-can-help-patients-make-end-of-life-decisions/>

# How doctors die

January 21, 2016

By Emily Wilson, Brigham and Women's Hospital  
(From Harvard Medical School News)

On three of five measures of the intensity of end-of-life care, physicians received significantly fewer intensive interventions than the general population.

Overall, physicians were less likely to die in a hospital compared with the general population (27.9 percent vs. 32 percent, respectively), and during the last six months of life they were less likely to have surgery (25.1 percent vs. 27.4 percent) and less likely to be admitted to the ICU (25.8 percent vs. 27.6 percent).

The study was led by Harvard Medical School researchers from the Center for Surgery and Public Health (CSPH) at Brigham and Women's Hospital. The findings appear in the January 19 issue of [JAMA](#), in a special themed issue focusing on end-of-life care.

"Our analysis confirms what we've long speculated, which is that physicians, who are more likely to have first-hand experience with the burdens and futility of end-of-life care, are less likely to have surgery or be admitted to the ICU during the last six months of life, or to die in the hospital," said Joel Weissman, deputy director and chief scientific officer at CSPH and associate professor of health care policy at Harvard Medical School.

Weissman wrote the research letter along with colleagues at the Mayo Clinic and the Center for Research on End-of Life Care at Weill Cornell Medical College.

"This information is extremely relevant to what is happening in the health field, especially now that Medicare has agreed to compensate doctors for the time they spend counseling patients about end-of-life care decisions," he added.

“Patients often ask their doctors what they would do or what they would choose for their own family members,” said Zara Cooper, HMS assistant professor of surgery at Brigham and Women’s Hospital, CSPH faculty member and co-author of the letter.

“This research could have a significant impact on clinical practice, especially in the way that health care professionals communicate with patients and family members about end-of-life care options,” she said.

The analysis included non-health maintenance organization Medicare beneficiaries aged 65 years or older who died between 2004 and 2011 in Massachusetts, Michigan, Utah or Vermont, and was based on the availability of electronic death records and the ability to link to Medicare data.

Researchers used data from these records to look at five validated measures of end-of-life care intensity during the last six months of life: surgery, hospice care, intensive care unit admission, death in the hospital and expenditures.

They then compared the use of these measures between physicians and the general population (excluding other health care workers and lawyers) and between physicians and lawyers, who are presumed to be socioeconomically and educationally similar, and between lawyers and the general population. There were 2,396 deceased physicians, 2,081 lawyers, and 666,579 from the general population included in the analysis.

Physicians were less likely to die in a hospital compared to lawyers (27.9 percent vs. 32.7 percent, respectively), but did not differ significantly in other measures.

“These results suggest two key points: When doctors themselves are facing death, they avoid intensive medical care, which we can assume is due to their knowledge of just how violent and futile those efforts typically are; also, doctors and lawyers have the resources to enable them to die at home, which suggests that financial concerns and lack of caregiver availability may be barriers to dying at home for less educated and affluent patients,” said Holly Prigerson, senior author and co-director of the Center for Research on End-of-Life Care at Weill Cornell.

“The findings provide a form of doctor testimonial recommending less aggressive end-of-life care and highlight the need for economic and human resources to support home deaths,” she said.

Investigators note that additional research is needed to explore how complex decision-making processes and satisfaction with end-of-life care are related to these findings, and to see if the results found in this analysis will hold true in other states once data becomes available.

**Reprinted from...**

<https://hms.harvard.edu/news/how-doctors-die>

# **Link found between religious belief, intensive medical care at end of life**

March 17, 2009

Dana-Farber Cancer Institute  
(From *Harvard Gazette*)

In a new study of terminally ill cancer patients, researchers at Dana-Farber Cancer Institute found that those who draw on religion to cope with their illness are more likely to receive intensive, life-prolonging medical care as death approaches — treatment that often entails a lower quality of life in patients' final days.

Previous research showed that more-religious patients often prefer aggressive end-of-life (EOL) treatment. The new study — to be published in the March 18 issue of the *Journal of the American Medical Association* — examined whether these patients actually receive such care. The study's findings suggest that physicians tend to comply with religious patients' wishes for more-aggressive care.

“Recent research has shown that religion and spirituality are major sources of comfort and support for patients confronting advanced disease,” says the study's senior author, Holly Prigerson, of Harvard affiliated Dana-Farber and Brigham and Women's Hospital (BWH). “We focused specifically on positive religious coping, on people who rely on their faith to handle the stresses of serious illness and approaching death. Our findings indicate that patients who turn to religion to cope in times of crisis, such as when facing death, are more likely to receive aggressive care” at life's end.

The study involved 345 advanced cancer patients at seven hospital and cancer centers around the country. Participants were interviewed about their means of coping with the illness, their use of advance care planning tools such as living wills and durable powers of attorney, and their preferences regarding end-of-life treatment. Investigators then tracked each patient's course of care during the remainder of his or her life.

An analysis of the data showed that patients identified as positive religious copers had nearly three times the odds of receiving life-prolonging care, in the form of being on a ventilator or receiving cardiopulmonary resuscitation, in the final week of life. Even after researchers accounted for the influence of important factors such as age, ethnicity, or other coping techniques, the connection between religious coping and aggressive EOL care held up.

The researchers also found that religious copers in the study were less likely to have completed advance medical directives, such as a living will or do-not-resuscitate order, which can limit the extent of such interventions in advance. The effects of religious coping on the use of intensive medical care in the last week of life remained significant even after adjusting for differences in advance care planning.

In interpreting the results, study lead author Andrea Phelps of Dana-Farber and Beth Israel Deaconess Medical Center (BIDMC), and a clinical fellow in medicine at Harvard Medical School, says that “beyond the significance of religious faith in coping with the emotional challenge of incurable cancer, it is important to recognize how religious coping factors into extremely difficult decisions confronting patients as their cancer progresses and death appears imminent. Beyond turning to doctors for advice, patients often look to God for guidance in these times of crisis.”

The study did not explore why religious copers often tend to prefer and receive extensive end-of-life care, the authors note. The researchers hope to examine such questions in future studies.

“Our results highlight how patients’ ways of coping, particularly their use of religious coping, factor prominently into the ultimate medical care patients receive. This suggests that clinicians should be attentive to terminally ill patients’ religious views as they discuss prognosis and treatment options with them,” said Prigerson, who is also an associate professor of psychiatry at Harvard Medical School. “A greater understanding of the basis of patients’ medical choices can go a long way toward achieving shared goals of care. Financial support for the study was provided by grants from the National Cancer Institute, the National Institute of Mental Health, and the Fetzer Institute.



The study's co-authors include Deborah Schrag, Tracy Balboni, Alexi Wright, Elizabeth Trice, and Matthew Nilsson of Dana-Farber; Paul Maciejewski, John Peteet, and Susan Block of Dana-Farber and BWH; and M. Elizabeth Paulk of the University of Texas Southwestern Medical Center, Dallas.

**Reprinted from...**

<http://news.harvard.edu/gazette/story/2009/03/link-found-between-religious-belief-intensive-medical-care-at-end-of-life/>

## For More Information

\*If clicking on a link below does not take you to the website, please copy and paste the URL into your browser\*

### **More help navigating end-of-life options can improve care for dying patients — and reduce costs**

Angelo Volandes

June 14, 2012

*The Boston Globe*

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July 16, 2014

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