

## [msnbc.com](http://www.msnbc.com): Living wills often ignored

### 'Good deaths are fewer than bad deaths," says psychologist

By Susan Brink



Fri., Feb. 26, 2010

Living wills and advance directives were the hope for end-of-life decision-making decades ago.

"In the 1970s, we had a great confidence that there were some simple reforms that would help," says Dr. Daniel Callahan, cofounder and president emeritus of the Hastings Center, a bioethics research center. But the reforms haven't materialized, he says. A 2004 survey by FindLaw, which provides online legal information, found that 36 percent of Americans have a living will.

**Even when people have filled out living wills, doctors often ignore them. "Good deaths are fewer than bad deaths," says Rev. Dr. Walter Smith, clinical psychologist and CEO of HealthCare Chaplaincy, a New York research and clinical practice organization that combines palliative care with multifaith spiritual care. "When people's wishes in the end are not honored, that's a bad death."**

Living wills may be asking the wrong questions, says Dr. Terri Fried, researcher at the Veterans Affairs Connecticut Healthcare System. Her study in the April 4, 2002, *New England Journal of Medicine*, found that when older people with serious illness and limited life expectancy were told details of the outcomes and consequences of treatment, 88 percent of those who would accept lesser disabilities said they would opt out of aggressive treatment if it rendered them bed bound, unable to get to the bathroom alone, unable to recognize loved ones or in need of round-the-clock help.

"If you look at the language of living wills, they say 'I would, or would not, want to receive X intervention,'" says Fried. Better questions, she said, would probe how people want to live, or under what conditions they would not want to live.

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# msnbc.com: Hospice, palliative care aim to ease suffering

## Palliative care is designed to help patients understand options

By Susan Brink



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Americans often confuse hospice care, which precludes aggressive medical treatment and usually requires a prognosis of six months or less, and palliative care. The nub of the difference is that a palliative care team can be providing pain relief, psychological and spiritual support — even as another medical specialist is aggressively trying to cure or treat disease.

Palliative services are designed to help patients and their families sort through their options — some of which may help restore the patient, while others may increase suffering for a minimal health benefit.

Recognized in 2007 as a specialty by the American Board of Medical Specialties, palliative care focuses on improving quality of life, regardless of treatment choices.

It is provided by a team headed by a doctor or nurse trained in the specialty, says Dr. Porter Storey, executive vice president of the American Academy of Hospice and Palliative Medicine. Most teams have a social worker who can help families find community resources such as home health or nursing home care, and many have a professional chaplain to provide spiritual counseling. Other team members can include a patient's other doctors, physical therapists, dieticians, pharmacists and volunteer caregivers.

Patients or their families can ask their physician for a consultation with a palliative care team. "We are often called in when things are complicated and no one knows what to do next," says Storey.

Sometimes, the consultation will result in a patient deciding to forego further aggressive treatment. But that's not always the case. "In my practice I've seen people who thought they couldn't tolerate more chemo because of nausea," says Storey. "When that problem is taken care of, they can get more treatment. We often enable people to get the treatment they need."

But palliative care isn't always available. A 2005 report by the American Hospital Association found palliative care teams available in 70 percent of U.S. hospitals of 250 beds or more — but only in 30 percent of all hospitals.

To arrange for a palliative care consultation, Storey says, call your hospital to see if they have a team. Or call a local hospice provider. While hospice organizations provide a different kind of care, most can help people find palliative care specialists. "Lots of hospices are trying hard to fill the gap, working in collaboration with palliative care," says Storey.

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## msnbc.com: Bunny's last days: When living will isn't enough

Octogenarian had planned for everything — until a stroke put her in limbo



Bunny Olenick had a living will, an advance directive and had named her sons as health care proxies by the time she suffered a massive stroke, but her family still found themselves grappling with hard questions.

By Susan Brink



Fri., Feb. 26, 2010

When 87-year-old Bunny Olenick suffered a massive stroke in December 2008, doctors told her family there was no chance she could recover fully, although her limitations probably wouldn't be known for months. A neurologist told her sons that if she did survive, her ability to communicate would be diminished, and she would likely need around-the-clock care for the rest of her life.

What would Bunny want them to do? Phil Olenick, 59, and his brother Steve, 57, knew that modern American medicine can offer few compassionate exits from this life. Artificial measures in the intensive care unit at Brigham and Women's Hospital in Boston — things like ventilator-assisted breathing or feeding tubes — stood a chance of prolonging life for Bunny Olenick but in a condition they knew she would abhor.

In the era of modern medicine, there is often no easy way to navigate between an acceptable quality of life and a death with dignity. That was underscored by two recent studies in the *New England Journal of Medicine* showing that some aggressive measures might actually increase pain and speed declines among frail elderly.

But palliative care specialists, relatively new players on the health care scene, offer comfort, support, pain control and, if requested, spiritual counsel to people such as Olenick's family, helping them sort through often confusing and ambiguous medical options. Unlike hospice care, which requires patients to forgo aggressive medical care, palliative care allows patients to continue any level of medical care they desire. They help people make tough decisions that are less about dying than about how they want to live at the end of their lives.

Palliative care specialists also have strong opinions about how the American health care system should be changed to help people confront the realities of their illnesses, grapple with their fears and ultimately be at peace with their decisions. In their vision, medical decision-making for critically ill patients would include information about options at the end of life.

Over the summer, the end-of-life issue touched off a political firestorm over the health care reform proposal being debated in Washington. The Democratic provisions included allowing Medicare to pay for periodic end-of-life counseling, but former Republican Gov. Sarah Palin of Alaska said the legislation would lead to [“death panels.”](#)

Some critics remain concerned that legislation that requirement reimbursement for palliative care could nudge people toward discontinuing aggressive medical care. “I would want to make sure that legislation would not tilt the decision-making,” says Dennis Smith, senior fellow in health care reform at the Heritage Foundation. Any end-of-life decision, he says, must rest with patients, their families, their doctors and their spiritual advisers with no outside pressure.

Supporters argue that palliative care strives to get patients and their families talking about their own values and wishes, and then carry them out. Studies show the frank discussions that palliative care engenders can ease pain, forestall guilt and increase the chances of a peaceful death. And, significantly, they can save money.

### **What would Bunny want?**

Like most families with a terminally ill loved one, Olenick’s sons were not thinking about money. They were thinking about what she would want.

Their mother, whose passions were the arts and progressive politics, had lived an active and intellectually engaged life. Bunny lived about half of her life in New York, where she was assistant director of an art center on Long Island. When she and her family moved to Boston, settling in Brookline, she worked as an executive producer at the public television station, WGBH, where she created cultural programming including ice ballets, musicals with political themes and Soundings, a series designed to make the music of contemporary composers understandable.

She became tech-savvy enough to exchange daily text messages with her son Steve, a lawyer in Hubbardston, Mass. Her son Phil, president of the recording company Audiolink, and his fiancée Gwen Frankfeldt, live in nearby Cambridge and were frequent visitors to her Brookline apartment.

Steve and Phil Olenick paid close attention to her every move and gesture following her stroke. Unsure if she was asleep or unconscious, Bunny’s sons saw that she wouldn’t wiggle her toes on command — but she would return a hand squeeze. She repeatedly pulled out a temporary feeding tube.

Olenick had done all she could to give her family instructions about her death. She had spoken to her sons about her wishes, filled out an advance directive, a living will, and had named her sons as health care proxies — all legally accepted documents and procedures designed to insure that a person’s end-of-life wishes are spelled out and honored. Yet even they weren’t prepared for the many difficult questions they faced.

### **'Why am I still here?'**

Bunny Olenick’s sons knew of her longstanding wish not to live in a highly dependent state. A few months before her stroke, when she fell and suffered a broken pelvis, thumb and upper arm and a detached lens in one eye. She spent five days in an intensive care unit, followed by seven weeks in a rehabilitation center. When her ophthalmologist told her that her vision would not get better, she was distraught. “I remember her saying, ‘Why am I still here?’ ” says Phil Olenick.

She never recovered fully, couldn’t drive any longer, was annoyed by her walker, and sometimes didn’t have the energy to join her friends in lunch or discussion groups.

Her sons saw her gestures and her rebellion against the tubes in her body as indications that she was ready to die. It was time to be direct. “Do you want to live?” her son Steve quietly asked her. She shook her head “no.” To convince himself that she understood, he persisted. “Do you want to die?” he asked. She nodded her head, “yes.”

He was as sure as he'd ever be. “I could see that she was afraid she'd live,” says Steve. “I kept saying, ‘Don't worry, Mom. We'll do what you want.’” Phil told her that her granddaughter, Jean, away at college, was on her way.

Her sons said that before her stroke, they had believed that they understood her wishes. Yet when they examined the decision-making grids and flow charts of her written instructions, they were confused about the details of the many complex options. She had decided that she didn't want to be intubated or put on life support. Did that preclude temporary nasogastric tubes for nutrition? A respirator was against her wishes, but what about a short-term oxygen mask?

One neurologist told them it could be months before they knew the extent of her potential recovery. Another neurologist said it was unlikely she would regain the abilities to get out of bed, communicate or feed herself. A nurse was even more pessimistic, “saying, ‘I've seen a lot of this and, believe me, she's not going to get better,’” recalls Steve Olenick.

With uncertain medical opinions, they called on Dr. Muriel Gillick, a palliative care specialist. “She was very neutral, very supportive,” says Steve Olenick. “By no means did she ever suggest that our mother shouldn't be treated.”

She encouraged them to explore tough questions. How much function would Bunny Olenick need to regain in order to live a life she would deem satisfactory? How would she feel about living bedbound, either in a nursing home or with around-the-clock home care? She explained that when a neurologist talks about partial recovery, the doctor may mean wiggling a toe, not walking, talking, eating and interacting.

“She was dying, and would die no matter what they did,” says Gillick. “The issue wasn't whether she would live or die. It was what the path was going to look like.”

### **'This is a new experience for mankind'**

Predicting who will find an acceptable quality of life from modern medicine, and who will receive treatment that proves futile, frustrating and cruel can be next to impossible. Sometimes doing something is more harmful than doing nothing.

“I've had older, dying patients who would try to turn to Bible stories to get them through. But no one in the Bible died like this,” says Joanne Lynn, director of the Washington Home Center for Palliative Care Studies and author of books including “Sick to Death” and “Not Going to Take it Any More.” “This is a new experience for mankind.”

**The players in each unique end-of-life drama often speak in what amounts to almost different languages, says Rev. George Handzo, vice president of HealthCare Chaplaincy in New York City, which provides palliative care. Physicians, speaking medicalese, can rattle off percentages, procedures, probabilities and a laundry list of interventions: respirators, resuscitation, feeding tubes. Patients are listening through a filter of their own values: Will I recognize my children? Will I walk, get out of bed, or taste food again?**

“The medical system is talking science,” he says. “Families are thinking religion and values.”

A range of studies since 2000 have shown that palliative care programs increase patient comfort and relieve symptoms while improving the lives of caregivers and families.

The programs also save money. A study of 25,000 patients reported in the Sept. 8, 2008, Archives of Internal Medicine found that those who received palliative care and were discharged cost almost \$1,700 less than those who didn't receive palliative care. Among patients who died in the hospitals, those who received palliative care cost an average of nearly \$5,000 less than those who did not receive such care.

The savings come, in part, when patients and their families choose less aggressive treatment. In his book, "Hard Choices for Loving People," chaplain Hank Dunn describes both the benefits and potential hazards of typical end-of-life aggressive medical treatment. For example, less than 2 percent of frail, elderly patients survive a CPR attempt, and those who do could suffer broken ribs, punctured lungs or irreversible brain damage.

Yet in hospital intensive care units, short of a specific "do not resuscitate" order, CPR is the default response when a heart stops. "I think it's insane that we offer patients and families interventions that have a 1 percent chance of doing any good, are extremely expensive and just don't work," says Gillick.

It is that type of intervention that Bunny Olenick's sons sought to avoid.

Steve and Phil knew that there was a window of time following her stroke when their mother might die gently, and it was during that period that they decided to forego treatment for her in the hospital's intensive care unit.

She was moved to a medical ward and put on comfort care. Four days after her stroke, Jean arrived. She brushed her grandmother's hair and spoke softly. And as though waiting for that last good-bye, on Dec. 22, 2008, Bunny Olenick died peacefully.

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