

# Massachusetts' Death with Dignity Act that would legalize physician-assisted suicide expected to be decided on November ballot - Magazine - The Boston Globe

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By Scott Helman | Globe Staff April 29, 2012

Ryan Huddle/Globe Staff

IN THE FALL OF 2010, Lee Fronk Johnson and his wife, Mary Lou, set off on a long-awaited trip abroad, with planned visits to Prague and Budapest and a weeklong cruise down the Danube. On October 12, the Johnsons, of Portland, Oregon, stopped over in Reading, where their oldest daughter, Heather Clish, lives with her family. They expected to stay one night. But when Lee Johnson arrived at his daughter's house, he was not himself.

Johnson, who was 65, would go to sit in a chair, miss it, and fall to the ground. He would say he was going downstairs to the basement but walk up to the second floor. "It was very clear that something was wrong," Clish says.

Clish, her husband, and Clish's mother came to an unavoidable conclusion: Johnson was in no condition for an overseas adventure. He initially resisted their assessment. "I can push through," he said. But he realized they were right. The Johnsons called off their trip. Instead of heading to Logan International Airport, Mary Lou drove her husband to Massachusetts General Hospital.

An emergency room evaluation, CAT scan, and subsequent biopsy revealed tragic news. He had terminal, inoperable brain cancer, the same kind that had killed Senator Ted Kennedy a year earlier. Before coming to Boston, the Johnsons had known something was amiss — indeed, Mary Lou had stopped riding in the car with her husband because he'd been running red lights. He had tried to downplay it, tried to will himself to Europe. Now he was facing the final chapter of his life.

Mark Ostow

Heather Clish, of Reading, is a proponent of the Death with Dignity Act. Her father used Oregon's law to take his own life peacefully.

Not long after the diagnosis, Johnson said he needed to return to Oregon. He knew his home state granted terminally ill patients the choice to end their lives with a lethal prescription. Johnson had grown up in a large, poor family in Utah, fleeing chaos at home from age 13 to work summers on Wyoming ranches. He retired at 55 after a career with the federal government, then took up woodworking.

He had looked death in the eye before — his helicopter was shot down twice in Vietnam — and was fiercely self-reliant. The idea of determining his own end appealed to him. "I have been an independent person since I was 13 years old — for more than 53 years," he wrote in an e-mail to a friend. "It is my quiddity; the core of how I have survived those 50 years." Johnson said he cherished the power to pick the time and place of his death. "It is," he wrote, "simply the last choice I can make for myself."

And so Johnson and his wife, after about two months of treatment in Boston, went home just before Christmas. He submitted to another round of chemotherapy. His family took him on a final trip to Cannon Beach, on the Oregon coast. They arranged for palliative care. Mary Lou got him out of the house as regularly as she could. Amid all this, Johnson, after completing a series of steps required under Oregon law, acquired a lethal dose of Seconal, a barbiturate.

By March of last year, Johnson's condition was rapidly worsening. He had fallen. His mobility was increasingly limited. He was in pain. On Thursday, March 17, he called Clish and said it was time. She flew out. He tried one final treatment. His wife took him for a last Heath Bar Blizzard at Dairy Queen. They arranged for hospice care. And then, on the evening of Monday, March 21, Johnson decided he was ready to go.

The family gathered. They shared memories and traded jokes. "He was like, 'Hey, isn't anybody going to at least bring some flowers in here?'" Clish says. "So we got some flowers." Clish pulled up US Geological Survey maps on her laptop to make sure she understood exactly in which Utah canyon he wanted his ashes spread. They played Emmylou Harris, one of his favorite artists. They served him toasted Haystack Bread, from a Cannon Beach bakery, topped with his wife's homemade raspberry jam. Around 8:30 that night, after everyone had said their goodbyes, he drank the Seconal solution from one of his favorite Scotch glasses.

Clish and her two sisters filled his ears with pleasant images. Mary Lou lay in his arms, as he'd wanted. He had earlier told her, "I hope I will be holding you when I take my last breath." Johnson slipped into what looked like a deep sleep. After about 15 minutes, his pulse stopped.

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Mark Ostow

Deborah O'Hara-Rusckowski, a critical-care nurse, opposes the ballot initiative. She sees too much risk that patients would end their lives prematurely.

A YEAR LATER, Heather Clish has become a leading advocate for affording terminally ill patients in Massachusetts the same choice her father had. Clish and other supporters are pushing a ballot initiative to legalize the practice they call Death with Dignity, more commonly known as physician-assisted suicide. Voters will almost certainly decide at the polls this November whether it should be allowed here, as in Oregon and Washington, the only two states where voters have explicitly authorized it.

Under the Massachusetts proposal, which is virtually identical to the laws in Oregon and Washington, terminally ill, mentally competent adults deemed to have six months or less to live would have the freedom to obtain a fatal prescription. They could qualify only after going through a process designed to ensure that they are not being coerced and that they fully understand what they're doing. They would administer the drugs themselves. Any doctor opposed to the practice could opt out of writing the prescription.

Massachusetts has had its share of contentious ballot questions, but few, if any, have played to the conscience the way this one promises to. It is sure to generate vigorous discussion even in an election cycle dominated by a presidential contest and a competitive US Senate race. As Clish's story illustrates, the debate is animated by personal experience, with people on all sides weighing the proposal's merits through their own prisms — their work as doctors, nurses, and caregivers, the suffering and death of loved ones, and anxieties about what their own final days will look like.

For proponents of assisted suicide, Massachusetts, as a socially progressive, prominent East Coast state, represents the next frontier. It poses a major test for a movement that has had difficulty gaining traction beyond the Pacific Northwest. Supporters face a challenge in part because Massachusetts is among the most Catholic states in the country, and the Church has long opposed the practice.

Indeed, the ballot initiative would also test the Catholic Church's influence. Church leaders in Massachusetts have already begun a campaign to defeat it.

Opposition extends well beyond the church pews, though, with some self-described liberals, doctors, and specialists in end-of-life care mobilizing against it. A number of them object on moral grounds, believing suicide is wrong and doctors should never abet it; others fear that the sick will be misdiagnosed and end their lives prematurely. "Assisted suicide sounds good in a world where we have perfect knowledge," says John Kelly, a longtime disability rights advocate in the state who's helping organize opposition. "It's impossible to forecast accurately how long someone has to live."

Ultimately, it will be up to voters to weigh competing opinions, reflect on their own beliefs, and resolve thorny ethical questions: Do the potential benefits for terminally ill patients and their families outweigh the risks of abuse and misdiagnoses? And, as is asked in the debate over abortion, should people be at liberty to make such a choice on their own, or can civil society claim a moral stake in their private medical decisions?



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Mark Ostow

Opponent John Kelly, a disability rights activist, points out the risk of misdiagnoses and the impossibility of knowing exactly when a patient will die.

PHYSICIAN-AIDED DYING has been debated in the United States and internationally for more than a century, resulting in numerous attempts to sanction various practices. Most have failed. Then, in 1994, Oregon voters narrowly approved a ballot initiative granting eligible patients the authority, under strict conditions, to obtain a lethal prescription.

Leaders of the successful campaign made a point of setting it apart from European experiments in euthanasia and from the work of Jack Kevorkian, the renegade doctor who developed his own methods of helping people die, often without regard for the law. Indeed, the Oregon statute (like the Massachusetts proposal) says explicitly that it does not authorize “lethal injection, mercy killing, or active euthanasia.”

When the Death with Dignity movement began 20 years ago, says lawyer Eli Stutsman, one of its founders, doctors were already quietly helping grant patients’ wishes to end their lives. Advocates for assisted suicide set out to codify and regulate the practice. “Physicians were doing this in the country,” Stutsman says, “and they still are.”

Legal challenges to the Oregon law held it in limbo until 1997, when the US Supreme Court affirmed that state’s right to enact it, and voters there resoundingly rejected a repeal effort. (The Supreme Court reaffirmed the law in 2006.) In 2008, Washington state voters followed suit, approving a virtually identical ballot initiative, which took effect in March 2009. A 2009 state court decision in Montana seemed to open the door to assisted suicide in that state, though that remains in dispute.

Ballot campaigns elsewhere have failed, however, including a close vote in Maine. In fact, New England has proved to be inhospitable territory for efforts to legalize assisted suicide. Legislative attempts have stalled in New Hampshire and Massachusetts. Lawmakers in Vermont, who appeared close to enacting an assisted-suicide law earlier this year, have since backed away.

National Gallup polls have indicated that Americans, over the past half century, have grown more accepting of doctors helping patients end their lives. Fifty-six percent of respondents in a May 2007 poll said that when a person has an incurable disease and is living in severe pain, a doctor “should be allowed by law to assist the patient to commit suicide if the patient requests it.” But the topic remains highly contentious. A Gallup Poll a year ago suggested that Americans were nearly evenly split over whether assisted suicide was “morally acceptable.”

Backers of the Massachusetts ballot initiative say they are heartened by their own polling here, and a plurality of respondents in a recent public survey indicated support. (The Massachusetts Legislature, under the ballot-initiative process, has until this week to act on the proposal; if the House and Senate don’t approve it — and no one expects them to — supporters need only collect 11,485 signatures by June 21 to put it to voters in November.)



So what do we know about the experiences of Oregon and Washington? Quite a bit, it turns out, because the states collect a good deal of information about the people who have sought the prescription. One of the surprises has been how many patients acquire the drugs but don't end up using them.

In Oregon, 935 people had received lethal prescriptions through 2011, and 596 of them died from ingesting it. The rest either chose not to take it or died of their illness before they could. The number of people taking advantage of the law has climbed steadily over the past 15 years; in 2011, 114 people received the prescription and 71 died from it, the highest tallies to date. Men and women have used it at roughly the same rate, and their biggest end-of-life concerns have been losing autonomy and dignity, according to doctors' reports. Most recipients have been suffering from cancer.

The patterns so far in Washington resemble Oregon's. In 2009 and 2010, 152 people received a prescription, and at least 87 died from it. Most suffered from cancer. As in Oregon, those with the highest education levels were most likely to obtain the prescription.

Death with Dignity advocates say the laws are working as intended. A relatively small number of people, they say, have voluntarily, humanely, and peacefully ended their suffering. "I would say the greatest teaching from Oregon is that so many fears — legitimate fears, fears about patient safety, end-of-life care — have been allayed," says Barbara Coombs Lee, the president of Compassion & Choices, a Denver-based organization that advocates for such laws and helps patients who use them.

Even some personally opposed to assisted suicide agree Oregon has proved many of the concerns to be overblown. "When all things are considered, the arguments in favor of continued prohibition of physician-assisted suicide are not particularly compelling," Daniel E. Lee, an ethicist and professor at Augustana College in Rock Island, Illinois, wrote in a 2003 essay for the *Hastings Center Report*, a prominent ethics journal. Lee (no relation to Barbara Coombs Lee) wrote that it's perfectly appropriate to maintain moral reservations, as he does. But he said that was not enough to "stand in the way" of those who want to make a different choice.

Opponents of the Massachusetts ballot initiative point to a handful of cases where they say the safeguards haven't worked. One is the story of Kate Cheney, an 85-year-old Portland, Oregon, woman suffering from stomach cancer whose request for a fatal prescription was initially denied after a psychiatrist questioned her mental capacity. Cheney then got a second opinion, ultimately won approval to obtain the prescription, and ingested it in August 1999. To opponents, her case raises troubling questions about whether her family and her health maintenance organization, both of which backed her decision, exerted undue influence.

Another oft-cited case is that of Barbara Wagner of Springfield, Oregon, who died at 65 from lung cancer. Much of Wagner's treatment had been covered by the Oregon Health Plan, the state's Medicaid program. But toward the end of her life, the program, making a judgment call about the low odds for success, sent her a letter saying it would not cover a drug called Tarceva, which her oncologist had prescribed in hopes of extending her life. The same letter listed assisted suicide as one of the options the program *would* cover, prompting Wagner to say at the time, "They won't pay for me to live, but they will pay for me to die."

In the end, the Oregon Health Plan's reluctance to pay for the drug proved to have merit. Wagner received Tarceva free from a pharmaceutical company but died a few months later. Still, the Oregon Health Plan, though it continued covering lethal prescriptions, stopped sending such letters.

And then there's Jeanette Hall of King City, Oregon, who voted for the Death with Dignity Act at

the polls. In 2000, Hall was diagnosed with cancer and inquired about assisted suicide. She thought about refusing treatment. Her doctor encouraged her not to give up. So she didn't. Twelve years later, she is still alive. Her experience informs her belief that Massachusetts ought not follow Oregon's lead. Indeed, if there's one overriding concern shared by opponents of the ballot initiative, Hall's story illuminates it: a fear that doctors will make errant prognoses, leading patients to end their lives when they may have many months, or years, left.

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Mark Ostow

Dr. Marcia Angell wishes her father had had access to a fatal prescription; now she is fighting for others to have that end-of-life choice.

DEBORAH O'HARA-RUSCKOWSKI thinks about all this as a veteran critical-care nurse, but also as the daughter of a woman diagnosed with lung cancer at age 70. Her mom, a smoker, was thought to have an 11 percent chance of making it more than a year. She made it three, dying at age 73 in 1995. From those three years, O'Hara-Rusckowski says, there are memories her family will cherish forever, even from the final days, when her mother was heavily sedated. "I was sleeping in the same room with her" one morning, O'Hara-Rusckowski says. "She woke up at 3 and looked at me and said, 'What are you doing here?' I said, 'Mom, you're awake!' And she just put her hands on my face and told me how much she loved me."

It's moments like these that O'Hara-Rusckowski fears other families will miss out on if physician-assisted suicide becomes legal. Maybe her mother would have never chosen that option, but what if she had?

The difficulty in predicting with certainty how long a terminally ill patient will live is one reason assisted suicide has divided doctors and caregivers in Oregon and Washington — and is a point of robust debate in the Massachusetts medical community. "Medicine's an art," says Dr. Lynda Young, a Worcester pediatrician and president of the Massachusetts Medical Society, which recently reaffirmed its longstanding opposition to physician-assisted suicide. "Sometimes you're wrong."

Some doctors who oppose assisted suicide also believe it's a perversion of their mission, which is to heal and not harm. "I really see it as being the corruption of medicine," says Dr. Mark Rollo, a longtime family physician in Fitchburg who is part of a coalition opposing the ballot question.

For Rollo, O'Hara-Rusckowski, and many others on the front lines of medicine, legalizing assisted suicide is the wrong solution to real problems in end-of-life care. For one, they say, terminally ill patients are often depressed, and their mental state impairs their thinking. Instead of sanctioning their desire for suicide, opponents say, we should help them. "In my heart, I feel like anyone who would want this is not getting the kind of services they should be getting," says Hope Hallett, a nurse in a skilled-nursing facility sponsored by the Catholic Church. (The Massachusetts measure would let physicians determine whether depression is affecting an applicant's judgment; if that determination is made, the doctor could not issue the prescription without the approval of a mental health specialist.)

Critics also say the push for assisted suicide ignores advances in palliative care, or treatment to make patients as comfortable and pain-free as possible as they battle their illness. The emphasis, says Dr. Elizabeth Lamont, a medical oncologist at the MGH Cancer Center, should instead be on making sure doctors, nurses, and hospitals employ the full arsenal of available palliative procedures. "When people say, 'There's nothing more to be done' or 'There's nothing more we can do' — that's just not something I believe in," says Lamont, who is also an associate professor at Harvard Medical School. "There's always something that can be done."

Dr. Marcia Angell, of Cambridge, isn't so sure. A pathologist by training, Angell was the first woman to serve as editor in chief of the prestigious *New England Journal of Medicine*. She's now a senior lecturer in social medicine at Harvard Medical School and a leading advocate for the Death with Dignity ballot initiative. Doctors can't always alleviate suffering for the dying, she says, and patients should have the option to end it themselves. That, she argues, is consistent with the greatest obligation of doctors — to care for people as best they can, in accordance with their wishes.

Besides, Angell argues, top-flight end-of-life care and the choice of taking a lethal drug can coexist. "Good comfort care and the availability of physician-assisted suicide are no more mutually exclusive than good cardiologic care and the availability of heart transplantation," Angell wrote in a 1997 *Journal* editorial. In fact, studies suggest that Oregon's Death with Dignity Act has only improved end-of-life care in the state.

Angell and other supporters also say it's wrong to cast one's decision to take a lethal prescription as a choice of death over life. Coombs Lee uses the analogy of people trapped in the World Trade Center in New York during the 2001 terrorist attacks. "People didn't jump when they first heard there was a fire," she says. "They jumped when the fire was in their face, and the death they were facing imminently was horrific."

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COOMBS LEE'S ANALOGY raises a fundamental question: If someone is near death and hastens it with a prescription, is it truly suicide? This is why some Death with Dignity advocates bristle at using the word "suicide" at all. The debate extends to the letter of the law. Under the Massachusetts proposal, as in Oregon and Washington, the death certificates of those who use the law would list their underlying illness, not suicide, as the cause of death. What's more, is ingesting a lethal prescription morally distinct from removing a ventilator or a feeding tube? Terminally ill patients and their proxies make those decisions every day.

The Catholic Church, for its part, makes a key distinction between refusing certain medical treatment and actively ending one's life. Church policy on end-of-life care has long differentiated ordinary from extraordinary means of prolonging life. That is, it's morally acceptable, in the church's view, not to go to extraordinary lengths. But there's "a big ethical leap" between rejecting procedures or treatment and ingesting a fatal prescription, says the Rev. J. Bryan Hehir, the

secretary for health care and social services in the Boston Archdiocese. “We distinguish between a low-key approach to dying and a purposeful action to take someone’s life or that they take their own life,” he says. “That is the dividing line.”

Cardinal Sean P. O’Malley of the Archdiocese of Boston said in 2000 that assisted suicide was “not an expression of compassion, it is a flight from compassion.” Then the bishop of the Fall River Diocese, he wrote in a pastoral letter: “Like many facile solutions, it is immoral. What passes for mercy is really an act of isolation and abandonment.” O’Malley echoed those sentiments in September 2011 in a homily at an annual Mass for Massachusetts lawyers and jurists.

In addition to making a spiritual case against the ballot question to parishioners, church leaders intend to work with a broad coalition of organizations to turn the Massachusetts electorate against the measure, relying on the more secular argument that it would be bad for our shared humanity. One major task of that group, as for the advocates on the other side, will be raising money. Sustaining a media blitz in the fall, a critical component of swaying public opinion, will not be cheap.

As November nears, expect to hear testimonials on both sides from people like Heather Clish, who remains grateful that her dad was able to die the way he wished. “This is not a choice that is right for everybody,” Clish says. “But for each of the people who have chosen it, no matter how small the number, it is of immeasurable value.”

Marcia Angell is sure her father, had the option been available to him, would have made the same decision. In the 1980s, Lester Angell, who lived outside Orlando, developed prostate cancer, which metastasized and caused him great pain. He underwent treatment and made it through a few years. Then on March 14, 1988, at age 81, he fell as he tried to enter his bedroom. His wife couldn’t lift him, so she called the EMTs, who helped him into bed. The EMTs planned to return in the morning and bring him to the hospital for evaluation.

Like Clish’s father, Marcia Angell’s was an independent spirit, a civil engineer and conservative Republican who believed in self-reliance. Lester Angell kept a pistol in the drawer of his night stand, covered by a towel. Fearing this was his last night in control of his own fate, he used it to take his life, making sure the bullet didn’t pierce the wall between his room and his wife’s. He gave his family no warning. But they knew him. His final act was hardly a surprise. Marcia Angell called her brother to break the news. “I said, ‘Daddy died,’ ” Angell recalls. “And he said, ‘Did he kill himself?’ And I said, ‘Yes.’ ”