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# To End Our Days

## *The Social, Legal and Political Dimensions of the End-of-Life Debate*

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## To End Our Days: The Social, Legal and Political Dimensions of the End-of-Life Debate

In recent years, questions concerning the end of life have become the subject of intense public debate and disagreement. Legislatures and courts, religious leaders and scientists, citizens and patient advocates have all weighed in on issues ranging from whether the terminally ill should have the right to take their own lives to how much treatment and sustenance those in the last stages of life should receive.

Much of the controversy centers on physician-assisted suicide – called “aid in dying” by some supporters – in which a terminally ill patient is able to end his or her own life with the help of medical professionals. In the last 20 years, four states – Oregon, Washington, Montana and Vermont – have legalized physician-assisted suicide, and at least a half dozen others have considered the issue.

Controversies over assisted suicide also have played out in U.S. courtrooms – perhaps most famously in 1999, when Michigan doctor Jack Kevorkian, who publicly claimed to have helped more than 100 people end their lives, was convicted of second-degree murder after personally administering a lethal dose of drugs to a terminally ill patient. More recently, in August 2013, a Pennsylvania woman made [headlines](#) after being charged with illegally assisting her elderly and ill father in committing suicide by allegedly giving him a large dose of morphine. A trial date has not yet been set in her case.

The end-of-life debate also encompasses more general questions about euthanasia, including whether and when it is permissible to end life-sustaining treatment of someone who is unable to make the decision for him- or herself. This question has been the subject of a number of high-profile legal cases, most recently in 2005, when courts – and even the U.S. Congress – became involved in the fate of Terri Schiavo, a severely brain-damaged woman whose husband and parents fought over who had the right to determine whether she should continue receiving life-maintaining sustenance.

Almost a decade later, the nation also is divided on end-of-life issues. For instance, a [new public opinion survey](#) by the Pew Research Center finds that the American public is closely split on the question of physician-assisted suicide, with 46% supporting the practice and 45% opposed to it.

Most [religious traditions](#) oppose assisted suicide. However, two religious groups – the Unitarian Universalist Association and the United Church of Christ – support giving terminally ill patients the right to determine when they will die. In addition, there are groups within a number of other traditions, including the United Methodist Church, that are trying to change their churches’ current positions against assisted suicide.

## **From House to Hospital**

The debate over the legal, ethical and political implications of death and dying is not new. But the modernization of health care in the 20th century dramatically changed the nature of the end of life and has cast this old debate in a different light. Beginning a little more than a century ago, people began to routinely die in hospitals rather than at home.<sup>1</sup> More importantly, new technologies, such as the artificial respirator, allowed doctors to prolong life, often for substantial periods of time, and new drugs, such as morphine, allowed doctors to alleviate pain and to painlessly end patients’ lives.

By the 1950s, a small body of writers and thinkers in the United States and Europe had begun to argue in favor of allowing terminally ill patients to end their lives, or allowing the families or guardians of terminally ill patients to end life-sustaining treatments. These arguments gained wider acceptance in the 1960s as the civil rights movement, the sexual revolution and other social movements helped to expand notions of personal freedom and autonomy.

In the 1970s, the end-of-life debate vaulted onto the national stage in the U.S., thanks in large part to the highly publicized case of Karen Ann Quinlan, a 21-year-old New Jersey woman who had fallen into a coma and was judged to be in a “chronic and persistent vegetative state,” unable to survive without the help of an artificial respirator. Efforts by Quinlan’s family to remove her life support were thwarted by her doctor, leading to a lawsuit and a ruling by the New Jersey Supreme Court that patients (and by extension their families) have a right to terminate life support. After her life support was removed in 1976, Quinlan continued breathing on her own for

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<sup>1</sup> Today, according to figures provided by the Centers for Disease Control and others, fewer than a third of all Americans die at home, while most of the rest end their days in hospitals, nursing homes or elsewhere. For more information, see <http://www.cdc.gov/nchs/data/hus/hus10.pdf>.

nearly a decade, although she remained in a vegetative state until her death from pneumonia in 1985.

In 1990, the right-to-die debate reached the U.S. Supreme Court in a case involving Nancy Cruzan, who had been in a persistent vegetative state for nearly five years when her parents asked that her feeding tube be removed. In *Cruzan v. Director, Missouri Department of Health*, the court, in a 5-4 decision, implicitly recognized for the first time a constitutional right to refuse treatment in extraordinary circumstances. Cruzan died the day after Christmas in 1990, less than two weeks after being removed from life support.

In some ways, the *Cruzan* decision presaged another high-profile case, that of Terri Schiavo, a severely brain-damaged woman whose husband (who was also her legal guardian) fought against her parents to remove the feeding tube that was keeping her alive. Schiavo became a national media story from 2003 to 2005, as those favoring the “right to die” and those favoring the “right to life” battled over her fate in the courts, in the court of public opinion and even in the U.S. Congress. But throughout the struggle, courts consistently ruled that Schiavo’s husband had the ultimate right to decide what his wife would have wanted, and with all appeals exhausted, she died on March 31, 2005, after her feeding tube was removed.

The public battles over Cruzan, Schiavo and others have led hospitals and other health care organizations to encourage Americans to better prepare for end-of-life decisions by planning ahead. Indeed, adults today are routinely encouraged to fill out legal documents such as living wills or advanced health care directives, especially if they are ill or older.

With living wills and advanced directives, people often appoint someone to act as a proxy for them to make treatment decisions if they are incapacitated and unable to do so themselves. These documents also usually give specific instructions and preferences for medical treatment in particular cases. For instance, terminally ill patients often give directions not to be given nutrition or breathing assistance via a mechanical respirator if they lapse into a coma prior to death. Patients nearing the end of their lives also often sign do-not-resuscitate orders, which direct medical staff not to attempt to restart their hearts if they stop.

## **Assisted Suicide in Legislatures and the Courts**

Since 1990, a number of states have held referenda on legalizing physician-assisted suicide or aid in dying for certain terminally ill patients. Voters rejected such measures in Washington state in 1991 and California the following year, in both cases by a 54%-46% margin. In 1994, however, supporters of assisted suicide won their first victory when Oregon voters narrowly approved (51% to 49%) a law allowing terminally ill patients to take their own lives with the assistance of a doctor. Although the law did not immediately take effect, owing to court challenges and a second state referendum that unsuccessfully sought to nullify the act, the state's Death with Dignity Act came into force in 1997.

Between 1998 (the first full year the Oregon law was in force) and the end of 2012, 673 people took their own lives under the state's law, according to official records. The number of people availing themselves of their right to die under the statute has steadily grown over the years – from 16 in 1998 to 77 in 2012. However, more people have received prescriptions for life-ending drugs than have used them.

In 2008, the citizens of Washington state once again voted on an assisted-suicide law. This time, voters, by a 58%-42% margin, approved the ballot measure, and, in March 2009, Washington's Death with Dignity Act took effect. According to figures provided by the state, 353 people died under Washington's law from 2009 to 2012. And more people in Washington have availed themselves of their right to die in each succeeding year.

In December 2009, less than a year after Washington's law took effect, the Montana Supreme Court ruled that there was nothing in state law preventing a physician from assisting a terminally ill but mentally competent patient in ending his or her life. In April 2013, opponents of assisted suicide in the state tried to legislatively overturn the Montana Supreme Court's ruling, but the bill was narrowly defeated in the state Senate, leaving the court's ruling in place.

In May 2013, Vermont became the fourth state in the nation to allow physician-assisted suicide after both houses of the state's legislature narrowly passed the Patient Choice and Control at End of Life Act and Gov. Peter Shumlin signed it into law.

The laws in Oregon, Washington and Vermont apply only to patients who are terminally ill and likely to die within six months, a diagnosis that must be confirmed by

two physicians. In addition, eligible patients must possess the mental capacity to give informed consent; and must sign a written request for medication in front of two witnesses who can certify that the patients are mentally competent and acting voluntarily.

There are no formal procedures in Montana because the legalization of aid in dying came about as the result of a court decision rather than the approval of a law. And while the state's Board of Medical Examiners issued a statement in 2012 holding all doctors who choose to help terminally ill patients die to "professional standards" and saying that it would evaluate any complaints against doctors involved in assisted suicide on a case-by-case basis, no specific rules exist.

Those who oppose assisted suicide also have won significant victories in recent years. Voters in Maine and, most recently, Massachusetts, have rejected ballot initiatives that would have legalized the practice. In addition, legislative efforts to legalize assisted suicide failed in a number of states, including California and, just this year, New Jersey.

The battle over assisted suicide or aid in dying also has been fought in courtrooms around the country. In addition to the 2009 Montana Supreme Court decision allowing doctors to assist terminally ill patients in dying, state courts in Alaska and Florida have considered whether terminal patients have the right to take their own lives. In both the Alaska and Florida cases, the states' highest courts ruled that there is no right to assisted suicide.

There also have been a number of high-profile federal court cases involving assisted suicide. In 1997, in *Washington v. Glucksberg*, the U.S. Supreme Court ruled that while the Constitution guarantees the right to refuse medical treatment (*Cruzan*), it does not give patients the right to assisted suicide. At the same time, *Glucksberg* did not prevent states from legalizing assisted suicide. In 2006, the high court, in *Gonzales v. Oregon*, weighed in on the issue again, rejecting an effort by the U.S. attorney general to use a federal drug law to prohibit doctors in Oregon from prescribing lethal doses of drugs to terminally ill patients under the state's Death with Dignity Act.

Outside the United States, a number of countries, including Belgium, Colombia, Luxembourg, the Netherlands and Switzerland, either specifically allow or do not restrict assisted suicide. Other countries, such as Great Britain, France and South

Africa, have debated the issue but, so far, do not allow terminally ill patients to get help from medical professionals in ending their own lives.

### **Right to Die Debate**

Opponents of physician-assisted suicide include organizations that represent doctors, such as the American Medical Association, disability-rights advocates and most major American religious groups, from Catholics and Southern Baptists to Jews and Muslims. Opponents contend that the safeguards contained in the laws, even if well-intentioned, miss the larger point: that suicide is a personal tragedy, not a personal choice. Furthermore, they say, it is often an unnecessary one, in the sense that the problems that cause a person to consider suicide – such as excessive pain, depression or despair – are often manageable. “In most cases, physician-assisted suicide comes about as the result of the failure of our health care system or our families and communities,” says C. Ben Mitchell, a professor of moral philosophy at Union University, an institution based in Jackson, Tenn., that is affiliated with the Southern Baptist Convention.

Opponents also say that the practice will inevitably lead to abuses, such as patients who might be pressured to take their own lives by family members and others who wish to save money or end the burden of caring for someone with a debilitating illness. “There is this focus today on what you can produce and what you can do,” says John Di Camillo, an ethicist at the National Catholic Bioethics Center in Philadelphia, Pa. “So when people get to a place where they think they are only taking or draining resources, they and others start to think they are just a burden, and that’s sad.”

Finally, opponents contend that physician-assisted suicide is at the top of a slippery slope that could eventually lead to involuntary euthanasia of people who are severely handicapped or infirm. When society starts sending a message that some people’s lives are worth less than others, they say, it opens the door to terrible possibilities.

Supporters of the practice include some more socially liberal religious denominations, some civil rights groups and some organizations that advocate on behalf of the rights of patients, particularly the terminally ill. These groups and others argue that “physician aid in dying” – they contend that calling the practice “suicide” unfairly imbues it with negative connotations – is not about forcing or pressuring anyone but rather is about giving people with no hope of recovery the choice to end their lives before their physical pain becomes unbearable or before they fully lose control of their mental

faculties. “This is about compassion,” says Peg Sandeen, executive director of Death with Dignity National Center, a Portland, Ore., group that advocates for aid in dying. “A compassionate society does not allow people to suffer unnecessarily.” It’s also about personal autonomy, she adds. “This lets [people who are dying] make their own choices during the last stages of their lives,” she says.

In addition, supporters of aid in dying argue that giving people the option to end their suffering does not devalue human life. On the contrary, they say, physician aid in dying promotes human dignity by allowing those in the last stages of potentially painful and debilitating illnesses to end their lives on their own terms. “Death with dignity is really about living life, and not death,” Sandeen says. “For the terminally ill, life is often medicalized, centered around doctors and treatments,” she explains, adding, “This frees up people in the final stages of life to really focus on life and the meaning of life, rather than doctors and medicine.”

*This article was written by David Masci, Senior Researcher, Pew Research Center’s Religion & Public Life Project.*