

THE Christian CENTURY

Thinking Critically, Living Faithfully

PHYSICIAN- ASSISTED DYING

A Dutch ethicist
has second thoughts



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Choosing to die

Right-to-die legislation will go into effect this year in California, which will join Oregon, Montana, Vermont, and Washington in providing for physician-assisted suicide. According to a Gallup poll last year, 70 percent of Americans believe that doctors should be allowed to help terminally ill patients end their lives—and that figure has been on the rise for several years.

In this issue, two writers take a hard look at the practice of physician-assisted dying. Both tell cautionary tales.

Dutch ethicist Theo Boer examines the effect of laws in the Netherlands in place since 1994 which have allowed physicians to assist in deaths. He argues that once laws permitting physician-assisted dying are established, they change people's expectations in facing death. Once the door to assisted death is opened, it seems, it's difficult to keep it from opening further.

Boer, who reviewed many cases of physician-assisted death in the Netherlands as part of a government panel, noticed that the number of physician-assisted deaths began rising sharply in 2007. Requests were coming not only from terminally ill patients in extreme pain—the expected profile—but from people who might otherwise live for years.

Joseph Kotva probes the results of the 1994 right-to-die law in Oregon, which pioneered physician-assisted dying in the United States. Like Boer, Kotva notes that a strong concern for autonomy and self-sufficiency undergirds support for physician-assisted death. He finds that those seeking to end their lives were less likely to have intimate and trusting relationships, and they often perceived themselves as having few social supports.

The Netherlands presents an irony when it comes to the notion of individual autonomy: given a choice between having a physician administer a lethal dose (euthanasia) or having the physician merely provide a lethal dose (physician-assisted suicide), 95 percent choose euthanasia. They prefer that death come literally at the hands of another.

These articles should lead Christian communities to reflect on their own practices of care for the dying. The church has long been a central place for practices that address the isolation and the fear of isolation

that often come at the end of life. It can be both a space for difficult conversations about choices at the end of life and a place for communal care.

No matter how compassionate a community of care is, two critical questions remain: Where assisted dying becomes legal, can it be limited in such a way as not to undermine human solidarity and the holiness of every life? Where assisted dying is prohibited, can communal practices of medical and pastoral care be robust enough to prevent people from dying in loneliness, pain, and despair?

Churches can help address the isolation that often comes at the end of life.

Rushing toward death?

by Theo A. Boer

IN 1994 THE NETHERLANDS became the first country to legalize assisted dying. The Dutch added a clause to the Burial and Cremation Act allowing doctors to help a person die as long as the patient made an informed request and faced unbearable suffering with no prospect of improvement; a second doctor concurred in the decision; and medically advised methods were used. The clause was further codified by the Assisted Dying Act in 2001. Belgium followed suit with similar legislation in 2002.

In the Netherlands, five regional review committees, each consisting of a lawyer, a physician, and an ethicist, were charged with keeping an eye on the practice and assessing (after the fact) whether a case of assisted dying complied with the law.

Two forms of assisted dying are legally practiced: euthanasia, in which the action of the physician causes death, and physician-assisted suicide, in which a physician provides the patient with a lethal drink administered by the patient. The overwhelming majority of patients who make use of the law (95 percent) choose euthanasia.

The Netherlands has long been a pioneer in areas of social policy, whether in establishing health insurance for all, legalizing same-sex marriage, or regulating legal forms of prostitution and soft drugs. The Dutch have centuries of experience in working shoulder to shoulder—irrespective of religious differences—to keep the sea from flooding the land, and that tradition has shaped a practical approach to many issues. In accepting assisted dying, some Dutch have argued that whereas doctors in other countries—especially some Roman Catholic countries—practice assisted suicide outside the law, with authorities looking the other way, the Dutch are transparent about it. They face up to what cannot be avoided. It could be called a Protestant virtue: *pecca fortiter*—sin courageously!

Although I was skeptical about this legislation at the beginning, I could and can imagine the exceptional case of killing a patient when nothing else can ease unbearable suffering. Many are familiar with the classroom example of the truck driver who is stuck in his cabin after crashing into a concrete wall and begs a bystander to kill him before he is devoured by fire. It was and is my conviction that some form of legalization of assisted dying may be needed when public support reaches a certain level. This is a matter of democratic respect. This is why I agreed to join one of the review committees 11 years ago.

From 2005 to 2014, I reviewed close to 4,000 cases of assisted dying on behalf of the Netherlands' Ministries of Health and of Justice. Almost all of them met the legal criteria; only a handful of them were sent on to the public prosecutor. I was impressed by the heartbreaking situations in which many patients found themselves at the end of a deadly disease. I had no doubt as to the professional and personal integrity of the physicians involved. Assisted dying was hardly ever administered lightly; in fact, most physicians needed time to prepare themselves for this intense decision, and afterward many of them needed time off to recover.

A new type of patient is asking for help in dying.

For a decade and a half this system seemed to provide a means to stabilize the number of cases and prevent the expansion of grounds for seeking assisted dying. We told delegations from abroad that the Dutch solution was robust and humane. As recently as in 2011 I assured a European ecumenical audience that the Dutch system was a model worth considering.

But that conclusion has become harder and harder for me to support. For no apparent reason, beginning in 2007, the numbers of assisted dying cases started going up by 15 percent each year. In 2014 the number of cases stood at 5,306, nearly three times the 2002 figure.

With overall mortality numbers remaining level, this means that today one in 25 deaths in the Netherlands is the consequence of assisted dying. On top of these voluntary deaths there are about 300 nonvoluntary deaths (where the patient is not judged competent) annually. These are cases of illegal killing, extracted from anonymous surveys among physicians, and therefore almost impossible to prosecute. There are also a number of palliative sedation cases—the estimate is 17,000 cases yearly, or 12 percent of all deaths—some of which may involve shortening the life of a patient considerably. Furthermore, contrary to claims made by many, the Dutch law did not bring

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down the number of suicides; instead suicides went up by 35 percent over the past six years.

A shift has also taken place in the type of patients who seek assisted dying. Whereas in the first years the vast majority of patients—about 95 percent—were patients with a terminal disease who had their lives ended days or weeks before a natural death was expected, an increasing number of patients now seek assisted dying because of dementia, psychiatric illnesses, and accumulated age-related complaints. Terminal cancer now accounts for fewer than 75 percent of the cases. Many of the remaining 25 percent could have lived for months, years, or even decades.

In some reported cases, the suffering largely consists of being old, lonely, or bereaved. For a considerable number of Dutch citizens, euthanasia is fast becoming the preferred, if not the only acceptable, mode of dying for cancer patients. Although the law treats assisted dying as an exception, public opinion is beginning to interpret it as a right, with a corresponding duty for doctors to become involved in these deaths. A law now in draft form would oblige doctors who refuse to administer euthanasia to refer their patients to a willing colleague.

The Dutch Right to Die Society (NVVE), the largest of its kind in the world, offers course materials to high schools intended to broaden support for euthanasia as a normal death. NVVE seeks to make assisted dying available to children of any age. This is a groundbreaking development, given the fact that for decades the Dutch restricted euthanasia to competent patients. NVVE also initiated the End of Life Clinic, a network of traveling euthanasia doctors who provide assisted dying for patients whose own doctors will not agree to help them. On average, the traveling doctors see a patient three times before providing an assisted death. The clinic has neither the funding nor the license to provide any form of palliative care, so it

offers death or nothing. Doctors at the End of Life Clinic report that they've handled about 500 cases since 2012.

NVVE regards the law on assisted dying as only a step in the right direction, not as the final outcome. Why grant an assisted death only to some? they ask. Why limit it to those with a life expectancy of only six months? This same logic can be found in the arguments of the United States-based Final Exit Network, which suggests that such laws also cover those suffering from debilitating diseases that may last many years.

As part of its campaign, NVVE distributed pillboxes containing 50 tiny peppermints. Called the Last Will Pill, the box illustrates the organization's resolve to make a suicide pill available to anyone aged 70 and older. All of this would be unthinkable were it not for the existence of the Assisted Dying Act. Rather than halting these developments, the review committees have welcomed some of them.

The dramatic shift in the Dutch and Belgian approach to death was documented in the Australian film *Allow Me to Die*, which features the case of Simona, an 84-year-old Belgian woman (see the film at sbs.com.au/news/dateline/story/allow-me-die). Only minutes after receiving news of the sudden death of her daughter, Simona decides that she too wants to die and asks her doctor to help her. After treating her unsuccessfully with an anti-depressant, Simona's doctor decides to grant her request.

Three months after the death of her daughter, Simona eats her last breakfast and rides her last miles on her stationary bicycle. Her last words are "I am ready to meet my daughter." Although her physician assures himself that "all is well," the audience is left wondering: Is this dying with dignity? Is this what the Dutch and Belgian lawmakers had in mind back in the 1980s and 1990s?

I think not. When the Dutch law was enacted, the cases in view were those of dying patients enduring extreme suffering that doctors could not relieve. The law allowed doctors to

break the rules in the name of humanity. Now the question has become: Can a nation allow such an exception without people coming to question the basic rules?

In a May 2001 editorial on assisted suicide, the *CHRISTIAN CENTURY* cited the words of ethicist William F. May, which continue to be important: "I can . . . imagine circumstances in which I would hope to have the courage to kill for mercy—when the patient is irreversibly beyond human care, terminal, and in extreme and unabatable pain," wrote May. But, he went on, "Hard cases do not always make good laws or wise social policies . . . We should not always expect the law to provide us with full protection and coverage for what, in extreme cases, we may need morally to do. Sometimes the moral life calls us into a no-man's-land."

Answering the moral questions is not the same as settling the legal ones. No doubt laws like the Dutch have may provide relief to patients who otherwise might have suffered too long.

Brancacci Chapel

Young Masaccio died before
his paint had dried, but
his time-battered fresco tells all:
how man in the midst of figs and wine
reaches for the whole banquet
and loses all but the crumbs,
which taste like poison.

Their sin is fresh; the doors of Paradise
slam while heel still crosses the threshold,
driven out by the upraised sword
of a crimson-winged messenger of God
who points their way to a world of dust.
His flowing garment billows
around their nakedness.

They walk toward us, look like us.
His woe is inward, head bowed.
His hands cover darkened eyes;
from his mouth, muffled sobs.
Yet he strides forward
to face the wilderness
which yet he does not comprehend.

She does. Her foreshortened face, skull-like,
gazes up into the looming abyss.
Eyes strokes of gloom,
from her mouth a scream of agony
for what she sees ahead:
needles passing in dirty rooms,
children shrunk to skeletons,
men strapped with bombs.

Janie McCrary

For some, the option of assisted dying during a cancer treatment increases their well-being and helps them to cope with their illness without having to resort to active killing. To others, however, the offer of an assisted death by a doctor may weaken their confidence in palliative care and undermine their resolve to cope with their suffering.

The Dutch law may have been rational in the 1980s and 1990s given the level of palliative care at that time. A Dutch study published five years ago quoted Else Borst, who was deputy prime minister when the Dutch parliament passed the euthanasia law, as saying that assisted dying came too early in the Netherlands. "We did it in the wrong order," she said. "We gave in to the political and societal pressure for euthanasia" before the nation had properly arranged for palliative care.

The good news is that in both the Netherlands and Belgium, the level of palliative care has increased significantly over the past 15 years, even in comparison with neighboring countries. But it appears that good palliative care does not keep patients from requesting assisted dying. Although some patients still request assisted dying out of fear of ineffective palliative care, an increasing number see euthanasia as the form of a good death *after* a trajectory of good palliative care. The unbearable suffering that they refer

In Holland, assisted dying is being normalized.

to increasingly consists of meaningless waiting rather than physical suffering. The "burning truck" example no longer applies to most cases. The issue now is autonomy—the patient's right to a swift death, brought about by a doctor.

In a way, this shift toward autonomy is natural. With societies becoming more secularized, why not claim a right to decide about one's own death?

A curious element in this debate is the role played by the belief that death is not the end. In the 1980s, Dutch Protestant theologians like Harry Kuitert argued in favor of euthanasia, declaring that death is the transition to a better existence. Even after 30 years of secularization, arguments still follow a similar line. Many of those with primarily secular convictions say they hope to be united with relatives and other loved ones after death in an existence of peace, light, and love. In one documentary film, the euthanizing doctor tries to provide comfort by telling his soon-to-die patient, "What will happen now, nobody knows, but I am sure that a lot of good will be laying ahead of you."

As a Christian I share in the hope for an afterlife in which suffering will be turned into joy. But religious hope is not a reason to end a human life. I have a deep hope that in the end God will establish an afterlife without injustice or suffering. But all too often, as in Simona's case, assisted dying is portrayed as if one is changing planes at a hub airport, leaving a harsh climate and embarking on a flight to a tropical destination. Euthanasia is not like changing flights; it's more like a controlled crash. For

Christians, if there is any good reason to opt for an assisted death, it's not the beckoning perspective of a life after death but the excruciating and unbearable circumstances of life before death.

It is better for secular and religious people alike to face death for what it is first of all: a transition between existence and nonexistence, between life and its absence. This remark is often attributed to Martin Luther: "If Christ were coming again tomorrow, I would plant a tree today." It expresses a deep commitment to respecting life on earth. This is the Christian paradox expressed through the ages: we must treat life on earth as if there is no afterlife. Only then may we hope to inherit the coming life.

One of the most radical defenses of assisted dying is made by French theologian Jacques Pohier: "It is almost a blasphemy to assume that God gave us life without us being able to freely dispose over it, for better or for worse, according to our own judgment." Pohier seems to make the same error as those who assume that a belief in an afterlife can be a factor in justifying assisted dying: he turns religion into an excuse for not taking the unique value of a human life here and now with the utter seriousness that it deserves.

Perhaps the main contribution of Christian theology in this field lies in its resources of hope and compassion, and in organizing care. Let us concentrate on why people want to have their lives taken away, and on the meaninglessness, loneliness, and inability to cope with ill health and loss of independence that undergird many of their requests. We need to speak openly about a patient's right to refuse life-prolonging treatment when that person can no longer stand the suffering. But too

often the *ars moriendi*, the arts of dying, becomes narrowed down to active killing.

Neither the Netherlands nor Belgium has made a serious attempt to address the rising incidents of assisted dying and the shift from seeing assisted dying as a last resort to seeing it as a normal death. It appears that once legalization of assisted dying has occurred, critical reflection is difficult. To be sure, many cases of euthanasia and assisted suicide in these countries align with the original intentions of the law. But there is no point in stressing what goes well while ignoring the risks. If there's even one case of assisted dying for which there was a less drastic alternative, then that is one case too many.

The experience of the Netherlands and Belgium with euthanasia has put doctors in a precarious position. Many people now place doctors on an even higher pedestal than before—they are being asked to organize a patient's death. Lord Falconer, architect of a proposed British law on assisted dying, remarked that it should be the patient and the patient only who asks for his or her death and takes full responsibility for bringing it about. Let doctors and other health-care professionals concentrate on treating illnesses and providing palliative care.

I agree. When people invoke their autonomy to end their lives, let them and not doctors or any state authorities be responsible for their deaths. Societal involvement should be directed at providing high-quality care to all and protecting the lives of vulnerable people. Any law making assisted dying possible should stay clear of the impression that a society is ready to organize the killing of its citizens, even at their request. **CC**

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