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The End of Life?

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FOLLOWING THE GUIDE?

WHY DUTCH AND BELGIAN EXPERIENCES ON ASSISTED DYING SHOULD CONCERN OTHER COUNTRIES [1]

Theo A. Boer

In 1994, the Dutch were the first in the world to legalise assisted dying. With no country going before us and no one to teach us, assisted dying was formalised in the form of a special clause in the Burial and Cremation Act. Doctors would not be prosecuted as long as a number of safeguards were observed, including the patient's informed request, unbearable suffering, no prospects of improvement, a second doctor's advice and the use of medically advised methods. The Assisted Dying Act followed in 2001, not differing much from the 1994 clause, and with Belgium following its northern neighbor in 2002. Five regional review committees, consisting of a lawyer, a physician and an ethicist, keep an eye on the practice and assess (after the fact) whether a case of assisted dying complied with the law. Two forms of assisted dying are practiced: euthanasia, where a physician puts a patient into a coma, followed by the injection of a muscle-relaxant; and 'physician assisted suicide' (PAS), where a physician provides a drink containing a lethal dose of a sedative. The vast majority of patients (95%) prefer euthanasia. Assisted suicide without the help of a physician is illegal.

In more than one respect, the Netherlands has

or regulating prostitution and soft drugs. Age-long experiences in working shoulder-to-shoulder to keep the water out, irrespective of religious differences,

form the basis of this practical wisdom. In the Dutch acceptance of assisted dying, it was argued that doctors in other countries – especially some Roman-Catholic countries – practice the killing of patients in unbearable suffering just as frequently, but do it in the dark, whilst the authorities are looking the other way. In contrast, the Dutch consider it a 'Protestant' virtue to be transparent about what one cannot avoid. If a compromise is necessary, let's face it. '*Pecca fortiter* - sin courageously.'

Although I was a euthanasia-skeptic from the beginning, I could, and can, imagine the odd exception of killing a patient when nothing else can ease their unbearable suffering. Many are familiar with the classroom example of the truck driver, stuck in his cabin after crashing into a concrete wall, begging a bystander to kill him before he is devoured by the blaze. And it was, and is, my conviction that in view of the widespread support for assisted dying, pursuing some form of legalisation would be the wisest and most respectful course. When I was invited to join one of the aforementioned regional euthanasia review committees eleven years ago, I was happy to contribute. In the period 2005-2014, on behalf of the Ministries of Health and of

Almost all of them met the legal criteria; only a handful were sent to the Public Prosecutor. I was impressed by the heartbreaking situations in which many patients find themselves at the end of a deadly disease. Not for a moment do I have any doubt about the professional and personal integrity of the physicians involved. Assisted dying is hardly ever administered lightly. Most physicians need time to prepare themselves for this intense decision, and afterwards many of them take an afternoon or day off to recover.

For a decade and a half, this system seemed to provide the necessary means to stabilise the number of cases and to prevent the expansion of grounds for seeking assisted dying. We received delegations from abroad and told them how robust and humane the Dutch solution was. Roughly from 1994 through 2006, the numbers remained stable and even went down a bit. As recently as 2011, I assured a European ecumenical audience that 'the Dutch system may be worth considering.'[2]

However, that conclusion becomes harder and harder to support. Unexpectedly and for no obvious reasons, the numbers started going up from 2007 by an average of 14% per year. Perhaps the country had needed a decade or two to get used to the whole idea of an organised death; once settled, the 'supply' of assisted dying may have started to generate its own 'demand'. In 2015 the number of cases stood at about 5,500, three times the 2002 figure.[3] With overall mortality numbers rising by a mere 7% during this same period, 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 non-voluntary deaths (where the patient is not competent) annually. Luckily the trend here is down; however, the number of palliative sedation cases - patients being deeply sedated without receiving nutrition or hydration - is also rising, estimated at between 17,000 and 23,000 cases yearly, or 12-16% of all deaths. Although not active killing, palliative sedation may in a number of cases shorten a patient's life. Furthermore, contrary to the claim made by many, the Dutch law did not bring down the numbers of suicides. In the past six years, these went up by 35%. Estimates of people killing themselves by no longer eating or drinking (sometimes referred to as auto-euthanasia) range from 1,500 to 4,000 a year. No doubt, human involvement in the Netherlands in the moment of death and in the way people die is higher now than it has ever been before in peacetime.

Another important development is a shift in the type of patients who receive assisted dying. Whereas in the first years the vast majority of patients - about 95% - were those with a terminal disease in the days or weeks before a natural death was expected, an increasing number of patients are receiving assisted dying because of dementia, psychiatric illnesses or accumulated age-related complaints. Terminal cancer now accounts for less than 73% of the cases. Many of the remaining 27% could have lived for months or years, some even for decades. Cases have been reported in which the suffering largely consisted in being old, lonely or bereaved. Just as happened in Oregon, 'dying with dignity' has become virtually synonymous with 'assisted dying'. For a considerable number of Dutch citizens, euthanasia is assisted dying as an exception, public opinion is shifting towards interpreting it as a right, with corresponding duties on the part of doctors to act.

A current draft law 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 material to High Schools, where my teenage kids go, intended to broaden their support for euthanasia as a normal means of death.[4] And despite the fact that euthanasia for children under 18 (the Dutch law makes it possible from age 12) is rarely practiced, there is a strong movement towards making it available for children of any age. This is a groundbreaking development, given the fact that for decades the Dutch restricted 'euthanasia' to competent patients. Furthermore, NVVE initiated a network of travelling euthanasia doctors, called the 'End of Life Clinic', which provides assisted dying for patients whose own doctors will not provide it. On average, these 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. It's death, or nothing. Since 2012, about 750 cases have been reported by its doctors.

> EUTHANASIA IS FAST BECOMING THE PREFERRED, IF NOT THE ONLY ACCEPTABLE, MODE OF DYING FOR CANCER PATIENTS. WHEREAS THE LAW TREATS ASSISTED DYING AS AN EXCEPTION, PUBLIC OPINION IS SHIFTING TOWARDS INTERPRETING IT AS A RIGHT, WITH CORRESPONDING DUTIES ON THE PART OF DOCTORS TO ACT.

Like so many other Right to Die societies, NVVE sees a law allowing assisted dying not as a final outcome, but rather as only one step in the right direction. Why grant an assisted death only to some? This same logic can be found in other Right to Die societies all over the world. 'Is the six-month requirement in Oregon, Washington, Vermont, and now California arbitrary?', the US based Final Exit Network asks. 'What if you suffer from ALS, Parkinson's, or many other neurological diseases; cancer or another debilitating disease that may last many years?'[5] A recent promotional of NVVE to its connections, a pill box containing fifty tiny peppermints entitled 'Last Will Pill', illustrates its resolve to make a suicide pill freely available to anyone aged seventy and older. A proposed law making such a pill possible will be presented to the Dutch parliament before the end of 2016. All this would be unthinkable, were it not for the existence of the Assisted Dying Act. Even the review committees have been unable to halt these developments. Indeed, their leadership welcomes the further liberalisation of the practice of assisted-dying, arguing that doctors are finally discovering the full potential of the Act.

Australian documentary film, 'Allow me to Die'. It features an 84-year-old Belgian lady, Simona, who, only minutes after receiving the report about the sudden death of her daughter, decides that she will have euthanasia.[6] After failing to help her with an antidepressant, Simona's doctor - 'I have performed euthanasia a hundred times, maybe' - decides to grant her request. Three months after the death of her daughter, Simona eats her last breakfast and rides her last miles on a home trainer. 'I am ready to meet my daughter', are her last words. Although her physician assures himself that 'all is well', the audience is left in confusion: is this dying with dignity? Is this what the Dutch and Belgian laws had in mind, back in the 1980s and 1990s?

In fact, it is not. The context in which the Dutch law originated was clearly and undisputedly one of extreme terminal suffering in which doctors, with no effective means to ease the suffering, decided to break the rules in the name of humanity. So the question then, and now, is: will we ever be able to allow the exception without questioning the rule? In an editorial in May 2001, the Christian Century refers to ethicist William F. May, whose words continue to be of importance:

> *I can, to be sure, 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. [But] 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.*[7]

In many countries, there is debate regarding the moral grounds for assisted dying. I have become increasingly aware that answering the moral questions is not the same as settling the legal ones. No doubt a law may be a relief to patients who otherwise might have suffered too long. For some, the option of assisted dying during a cancer treatment increases their wellbeing and helps them to cope with their illness, without ever 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 given the level of palliative care in the 1980s and 1990s. In a study published five years ago, Else Borst, under whose ministership the euthanasia law was accepted by the parliament, is quoted as saying that assisted dying came too early in the Netherlands: 'We did it in the wrong order. We gave in to the political and societal pressure for euthanasia [before we had properly arranged palliative care]'.[8] The good news is that, in both the Netherlands and Belgium, the level of palliative care has increased significantly over the past fifteen years, even in comparison to their neighboring countries.[9] Not any less significant is the observation that, once assisted dying becomes legal, good palliative care does not keep patients from requesting it. Although some patients still request assisted dying out of fear that palliative care will be ineffective, an increasing number see euthanasia as a good death even after a trajectory of good palliative care.

suffering. The 'burning truck' example no longer applies to most cases of assisted dying. With palliative care becoming better and an Assisted Dying Act in place, the focus has shifted from benevolence - assisted dying as 'mercy-killing on a patient's request' - to autonomy, a swift death as a patient's right.

In a way, this shift towards autonomy comes in quite naturally. With societies becoming more secularised, why not organise a right to decide about one's own death? However, I have an altogether different view: a liberal view on assisted dying reveals an incompetence to think through secularism to its logical conclusion.[10] The elephant in the room is the belief of many that death is not the end. Back in the 1980s, important protestant Dutch theologians argued in favour of euthanasia on the basis of the conviction that death is the transition to a better existence. Thirty years of secularisation later, the logic goes along similar lines: why go on suffering when a swift and dignified death is available? And why not be united with relatives and other loved ones and enter an existence of peace, light and love - a hope expressed by even many of those with primarily secular convictions? In a documentary film, the euthanising doctor, right before performing the act, tries to provide comfort by saying: 'What will happen now, nobody knows, but I am sure that a lot of good will be laying ahead of you'.[11]

As a Christian, I share this hope for an afterlife in which suffering will be turned into joy. But how are we to know for sure? How can one be so certain that one's loved ones, not one's enemies, will be waiting at the other side? We do not know, let alone have reason to end a human life because of this religious hope. Although I have a deep hope that God, in the end, will establish an afterlife without injustice or suffering, I think this should not be used as an argument in favour of a decision to end an earthly life. All too often, just as in Simona's case, assisted dying is portrayed as if one changes planes in a hub airport, leaving an airplane of misery and embarking on a flight to a tropical destination. But if there is any resemblance to flying, it would be that euthanasia is a controlled crash, not a changing of flights. If there is any good reason to opt for an assisted death, it is not the beckoning perspective of a life after death, but the excruciating and unbearable circumstances of life before death. Let us, secular and religious people alike, face death for what it is first of all: a transition between existence and nonexistence, between life and its absence.

> PERHAPS THE LESSON TO BE LEARNT IS THAT THE MAIN CONTRIBUTION OF CHRISTIAN THEOLOGY IN THIS FIELD WILL CONSIST OF ITS RESOURCES OF HOPE AND COMPASSION AND IN ORGANISING CARE. LET US CONCENTRATE ON THE REASONS FOR WHY PEOPLE WANT TO HAVE THEIR LIVES TAKEN...

he expressed his deep commitment to respecting life on earth. It is the Lutheran and, for that matter, the Christian paradox 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.[12]

> “...WHEN PEOPLE INVOKE THEIR AUTONOMY FOR HAVING THEIR LIVES ENDED, LET THEM BE RESPONSIBLE, NOT DOCTORS, LET ALONE THE AUTHORITIES.”

Other attempts to justify a decision to end one's life have taken place on the basis of the human right to self-determination. One of the most radical defenses is that of French theologian Jacques Pohier: 'God not only gave humans partial liberty. ... 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'.[13] Pohier seems to make the same error as those who assume that a belief in afterlife can be a factor in justifying assisted dying: it turns religion into an excuse for not taking the unique value of a human life here and now with the utter seriousness that life deserves.

As a theologian, I am rather inspired by a more secular approach. Immanuel Kant, that champion of human autonomy, rejected suicide as irrational. A deliberate ending of one's own autonomy is not autonomous any more than a nation's decision to choose a dictator can be called democratic. Perhaps the lesson to be learnt is that the main contribution of Christian theology in this field will consist of its resources of hope and compassion and in organis- ing care. Let us concentrate on the reasons for why people want to have their lives taken, and on the meaninglessness, loneliness and inability to cope with ill-health and loss of independence that undergird many of their requests. In that process, we need to speak openly about a patient's right to refuse life-prolonging treatment when he or she can no longer bear the suffering. All too often, the *ars moriendi* becomes narrowed down to active killing.

So, even if a deliberate choice to die - with or without assistance - may be justified in exceptional cases, I now conclude that there is reason for caution when it comes to putting such exceptions into a legal framework. As a mountain climber, I have learned to trust only those guides who are able to face both actual and potential dangers, rather than denying their existence. With the step to legalise assisted dying comes the responsibility to reflect critically, to be transparent about unforeseen effects and to adjust policy in the light of those insights. Neither the Netherlands nor Belgium have made a serious attempt to problematise the voluminous rise in the numbers, the ongoing broadening of the reasons and the paradigm shift from assisted dying as a last resort to it becoming a normal death. Once legalisation has been put in place, such critical reflection becomes even harder. To be sure, many cases of euthanasia and PAS in the Low Countries are in harmony with the original intentions of the law. But when it comes to life and death, just as in traffic, health care or anywhere else, there is no point in less drastic alternative is one case too much.

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 organise a patient's death. And it has led to an ever-increasing pressure on doctors to organise a patient's death, and no one knows as yet where this road will end. As Lord Falconer, architect of a recent British law proposal on assisted dying, recently remarked, it should be the patient, and the patient only, who both asks for his death and takes full responsibility for bringing it about.[14] I agree. Let doctors and other health care professionals concentrate on treating illnesses and providing palliative care. As our thinking on autonomy progresses well into the 21st century, let us take the rough with the smooth: when people invoke their autonomy for having their lives ended, let them be responsible, not doctors, let alone the authorities. Societal involvement should be directed at providing high quality care to all and protecting the lives of vulnerable people. Any law that makes assisted dying possible should stay clear of the impression that a society is ready to organise the killing of its citizens, even at their request.

Endnotes

1. This is an updated and elaborated version of Theo Boer, 'Rushing towards Death? Assisted Dying in the Netherlands', *The Christian Century*, April 13, 133 (4), 2016. Used by kind permission.
2. Theo A. Boer, 'Euthanasia and Dying Well: Some Remarks from a Dutch Perspective', *Focus of the Community of Protestant Churches in Europe* 1, 2011, 16-17.
3. Regional Euthanasia Review Committees, *Annual Report 2015*, The Hague, Ministry of Health, 2016.
4. https://www.nvve.nl/actueel/nieuws/lespakket-euthanasie-doodnormaal-van-start/ (accessed October 10, 2015).
5. http://www.finalexitnetwork.org/ (accessed October 10, 2015).
6. http://www.sbs.com.au/news/dateline/story/allow-me-die (accessed October 10, 2015).
7. William F. May, *The Physician's Covenant: Images of the Healer in Medical Ethics*, Philadelphia, Westminster, 1983, 87.
8. Anne-Mei The, *Verlossers naast God: dokters en euthanasie in Nederland*, Amsterdam, 2009, 206.
9. Kenneth Chambaere and Jan L. Bernheim, 'Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience', *Journal of Medical Ethics*, 2015, 0 (1–4), doi:10.1136/medethics-2014-102116.
10. Kevin Yuill, *Assisted Suicide: the Liberal, Humanist Case against Legalization*. New York NY, Palgrave Macmillan, 2013.
11. Rob Hof, *Regie over eigen leven en sterven*, Part 1: *Een gewenste dood*, Hilversum, NCRV, 2003 (Documentary Film).
12. For an elaboration of these thoughts in Dutch, see Theo Boer, *Vrij om te sterven. Nederland, religie en het zelfgekozen levenseinde*, Groen van Prinstererlezing 2016, Amersfoort, Wetenschappelijk Instituut voor de ChristenUnie, 2016.
13. M. Horwitz, 'L'euthanasie en débat', *Actualité Religieuse dans le monde*, 119 (15), February 1994, 26.
14. The Economist podcast 'The Great Debate: Assisted Dying', with Theo Boer, Lord Falconer, Baroness Finlay and Economist chief editor Zanny Minton Beddoes, 22 June 2015, https://soundcloud.com/theeconomist/the-great-debate-assisted-dying (accessed October 10, 2015).

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