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Deciding issues around end of life care and assisted dying

CORINE PELLUCHON

Translated by Cadenza Academic Translations

NEITHER MAXIMAL ETHICS NOR MINIMAL ETHICS IS THE ANSWER

Before legislating on an issue that divides society, it is important to outline a methodology for determining the conditions that will make it possible to establish the common good.¹ In the move from ethics and personal perspectives to politics and drafting legislation, the objective is to find agreement against a backdrop of disagreement, considering different actors with different interests and views of the good, but also looking back at the legislative mechanisms that regulate practices within a country.

Two pitfalls must be avoided. The first consists of basing collective decision-making on an essentialist view of the good that cannot be made general in a democracy and which, raised to a legal standard, would mean that one group of individuals has the right to define on behalf of all others the way in which they must live and die. This “maximal” form of ethics also

1. This article takes a more in-depth look at the ideas discussed and handled in the Terra Nova research note published on March 4, 2014 (“Peut-on parvenir à un consensus sur l’aide active à mourir?” http://tnova.fr/system/contents/files/000/000/232/original/03032014_-_Corine_Pelluchon.pdf?1432549176, last accessed September 12, 2018); particularly the question of the conditions that would allow for deliberation on this topic. It also incorporates new elements that have been added to the debate in France, in particular the revised version of the law incorporating the proposals from Jean Leonetti and Alain Claeys, which has created new rights in favor of patients and terminally ill individuals (Law 2016-87).

has the weakness of making religion the basis for the laws that orchestrate the peaceful coexistence of civil liberties in a pluralist society characterized by the separation of religion and politics.²

No bill on assisted dying can therefore be seen as the product of careful deliberation if it immediately alienates one of the camps or a group of the actors concerned, or if it is based on biblical commandments. Yet this is what happens when the prohibition on homicide is used to condemn euthanasia, which in the countries where it has been decriminalized is only carried out upon the express and voluntary request of the individual concerned and cannot therefore be identified as murder. Conversely, those such as the members of France's Association for the Right to Die with Dignity (ADMD) who affirm that an individual's right to choose his own death is an expression of the ultimate freedom and a human right forget that medically assisted suicide takes place within a healthcare organization and that the view of care providers must thus also be taken into consideration.³

Minimal ethics, which recognizes only the principle of autonomy and claims not to promote any particular world view, is the second pitfall.⁴ Following Mill, its primary enjoinder to prohibit all actions that harm others is relevant to all issues that concern morals or regulate the relationship between freedoms.⁵ It saves us from moralizing judgements in politics and from a confusion between law and morality that results in "criminalizing victimless crimes,"⁶ in the words of French philosopher Ruwen Ogien. However, the problem of assisted dying is unique in that it does not simply involve a conflict between individual freedoms, since the assistance of care givers is required. Assisted dying cannot therefore be considered in the same light as suicide which is, by definition, a private act carried out without support from the medical establishment. The impact

2. Ruwen Ogien, *L'éthique aujourd'hui. Maximalistes et minimalistes* (Paris: Gallimard, 2007).

3. The ADMD (Association pour le Droit à Mourir dans la Dignité [Association for the Right to Die with Dignity]) was founded in 1980 by Michel Landa. Its current chairman is Jean-Luc Romero. See <http://www.admd.net/>

4. The term "minimal ethics" refers to the work of Ogien, but in bioethics, it is Engelhardt who presents an "ethics devoid of content" as the only appropriate solution in a pluralist society where we live as moral strangers and where no body has the authority to judge between the different substantial views of good. See H. Tristram Engelhardt, *The Foundations of Bioethics* (New York: Oxford University Press, 1996), 68-69.

5. John Stuart Mill, *On Liberty* (London: John W. Parker and Son, 1859).

6. Ogien, *L'éthique aujourd'hui*.

of this practice on healthcare professionals and on the way in which care is provided must be taken into consideration, in order to encompass all aspects that might feed into decision-making.

GOING BEYOND OVERLAPPING CONSENSUS

With these two pitfalls identified, it should be added that the approach consisting of politicizing the issue of assisted dying is not designed to determine the possible object of an overlapping consensus produced from areas of common ground.⁷ Such a consensus, which would amount to adopting a smaller common denominator, would not be enough to escape the status quo. It would also suggest that the common good in a sense pre-exists deliberation, or that an appropriate collective decision can be reached by juxtaposing different opinions. However, if we are discussing how to establish the common good, it is because the solution does not exist *a priori*. A suitable law proposal can only emerge if we follow three stages, which I will cover in the following three sections. It is also important to consider how the various participants must approach the discussion in order to allow for deliberation on such a sensitive subject.

The first stage consists of setting out the arguments for and against legislation in favor of euthanasia and assisted suicide. This effort at clarification is crucial, since the agreement against a backdrop of disagreement that we hope to obtain cannot result from an overlapping consensus, but only from a consensus through confrontation of the different positions. Ultimately, such positions will therefore change from how they were before the deliberation.⁸

These positions reveal what we believe we have the right to expect from the state and from the medical establishment: does my freedom to take my own life mean that the state must give me the means to do so in a less violent manner than by poisoning or defenestration? We must also ask whether the act of killing someone at his request can be considered part of care provision. And finally, these value conflicts are related to questions

7. John Rawls, *Political Liberalism* (New York: Columbia University Press, 2005 [1993]), 164-168.

8. The expression “consensus through confrontation” is borrowed from Jean-Marc Ferry, *Valeurs et normes: La question de l'éthique* (Brussels: Éd. de l'université de Bruxelles, 2002), 63-64. However, the way in which we define it, particularly in the conclusion of this article, is ours alone.

that cannot be decided, such as knowing the limits that individuals place on the power they grant over their life and death. Although we may be faced with irreconcilable values in relation to these issues, it is important that the arguments underlying the beliefs of the opposing camps are clear, as they usually remain unspoken in debates or are referred to with varying degrees of clarity. Knowing what divides us is a prerequisite for finding a solution that makes it possible to establish the common good by debating an issue that concerns everyone and cannot be determined by a single camp or seized upon by a political party.

The second stage requires us to take stock of the existing legislation in France, and to acknowledge that laws have a history, which varies from one country to another. As such, the suggestion that one solution would be to model new legislation on the 2002 Belgian law that conditionally decriminalized euthanasia overlooks the fact that in France, since 2005, decisions to limit and withdraw treatment from patients in a coma have been guided by the Leonetti law.⁹ The French legal framework that enables all patients, even at the end of life, to refuse all treatment, does not provide a solution to all problems, but the law of April 22, 2005 was the first to tackle the issue of patients who cannot express their wishes by determining the conditions in which life support can be withdrawn when it is judged to be disproportionate to the patient's status and the course of his illness. Any bill in favor of assisted dying must therefore recognize the advances enabled by the Leonetti law and indicate its limitations by making a distinction between individuals in a coma, for whom solutions exist that avoid both euthanasia and futile treatment, and patients who are competent and expressly request medical assistance to commit suicide.¹⁰ As noted by Hume,¹¹ if the historical context of laws is not taken into account, legislative developments can be rough and inappropriate; this reminder also provides an opportunity to precisely define a topic that is often confusing.

Finally, we must ask whether continuous deep sedation for terminally ill patients—a proposal by Claeys and Leonetti included in the law of

9. "Loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie (1)," <http://www.legifrance.gouv.fr/eli/loi/2005/4/22/SANX0407815L/jo/texte>, last accessed September 12, 2018.

10. Competence, a term used in both law and medicine, refers to the capacity of patients to self-determine and make autonomous choices.

11. David Hume, "Of the Original Contract," in *Essays and Treatises on Several Subjects*, Volume 2 (London: T. Cadell, 1748).

February 2, 2016—is adequate, or whether individuals who have access to palliative care, but do not or no longer wish to receive it, should be allowed to have it withdrawn when they feel further treatment is futile. Can their claims be heard without care givers—who, for the most part, are repulsed by the idea of taking their patients’ lives—feeling violated in the exercise of their profession? Is there a solution that might satisfy those patients calling for assisted dying without making assisted suicide and euthanasia the standard responses to the problem of end of life suffering, given that palliative care, which everyone recognizes to be both appropriate and unequally available across the country, is designed to relieve patients and allow them to die with dignity?

SETTING OUT THE OPPOSING ARGUMENTS

The first argument pitting supporters of euthanasia and assisted suicide against their opponents concerns the interpretation of individual rights: does my freedom to take my life mean that care givers have an obligation to provide me with the lethal product I will ingest (assisted suicide), or administer it to me (euthanasia)?¹²

How we answer this question depends on what we believe we have a right to expect from the state and from the medical establishment. For some, rights to freedom are first and foremost rights to beliefs, and the purpose of the state that regulates medical practice is to satisfy individual demands as long as they do not oppose the freedom of another. In the event of a healthcare professional refusing to practice euthanasia or to provide the patient with a lethal drug, one may invoke the conscience clause as in the case of doctors who do not wish to practice abortion, but who are obliged to send patients seeking abortion to one of their colleagues.

12. Even where patients cannot take their own lives due to their physical condition, and receive assistance from a third party, this is termed assisted suicide, with euthanasia involving not only the intervention of a healthcare professional, but also meaning that patients expressly ask for someone else to inject them with the lethal drug so they do not have to do so themselves. See Comité Consultatif National d’Éthique (French National Consultative Ethics Committee, CCNE) opinion no. 121, July 2013, <http://www.ccne-ethique.fr/fr/publications/fin-de-vie-autonomie-de-la-personne-volonte-de-mourir#.VmlO5sHLTIU>, last accessed September 12, 2018.

This line of argument equates calls for access to euthanasia and assisted suicide with the struggle that culminated in the legislation allowing abortion. The Veil law of 1975 was not however passed in confirmation of the idea that women have the right to do what they wish with their bodies and therefore the child they carry, but primarily with a view to ending backroom abortions. A public health issue irrelevant in the case of euthanasia, unless we accept the argument that people die badly because there is no law allowing euthanasia! The line of reasoning that emphasizes the autonomy of the individual who is solely competent to decide whether his life has meaning is however a convincing one. What harm do those who wish to receive medical assistance to commit suicide do to others? A law allowing euthanasia and assisted suicide would not force anyone to use it! Finally, is it not unjust to leave those who wish to die to use violent means, particularly when we know that the wealthiest patients will go to Switzerland, where for 3,000 to 5,000 euros they can inject a lethal drug that will give them a gentle death—a euthanasia?

All of these points are passionately challenged by opponents of assisted suicide and euthanasia. Pointing out the distinction between suicide, which is a private act, and assisted suicide and euthanasia, which involve care givers, they argue that individual rights are not the only ones that must be considered when it comes to a practice carried out within a care organization. Furthermore, the role of the state is not only to satisfy the demands of individuals, but also to monitor the impact that laws may have on care givers and on all citizens as a whole, in particular those who may be vulnerable.

At the end of life or even in serious or disabling disease, it is not in fact unusual for patients to express a wish to die. All care givers supporting patients with advanced cancer, or those providing individuals with end of life care, have been confronted with these requests for euthanasia and assisted suicide. They are often cries for help, reflecting the individual's distress and fear of being abandoned, and in most cases do not persist: usually, when pain relief is provided, current quality of life is ensured, and patients and those close to them are given proper support, they no longer wish to take their own life.

Conversely, requests for euthanasia may easily be triggered in sick people and those who have lost the sense of their own dignity because they are isolated and feel as if they no longer have worth in the eyes of others.

Would a law legalizing or decriminalizing euthanasia not risk normalizing suicide by presenting it as the response to end of life suffering: as if, to remove a problem such as depression, fear of death, or the difficulties of living with a disabling disease, we could simply remove the patient? Would not palliative care, which demands significant financial resources and multiple skills, and requires an individualized and holistic approach to personal care that considers the individual as a patient—i.e. a still-living human being deserving of our full attention—be undermined if assisted suicide and euthanasia were permitted?

The final argument dividing the two camps concerns what is meant by care. Supporters of euthanasia and assisted suicide believe that helping a patient who asks to die is part of care provision and demonstrates the care giver's concern for the patient. Others, invoking the "primum non nocere" of the Hippocratic Oath, see this act as contrary to the *raison d'être* of care givers. The former group accuse health care professionals who refuse to take patients' lives of cowardice, and the French state of hypocrisy. They also condemn clandestine euthanasia and proclaim that we are living in a paternalist society, in which doctors refuse to listen to calls for euthanasia.

The opposing group describe their experience of supporting end of life care. They recognize that clandestine euthanasia exists or has existed—notably in the early years of the AIDS epidemic, when little was known about how to relieve pain and the side effects of treatment and disease progression led to unbearable patient suffering—but highlight that a great deal of progress has been made in terms of administering pain relief, sedation, and even in the procedures guiding decisions to withdraw and limit treatment, which prevent patients with advanced cancer from undergoing further chemotherapy. They also add that, despite a strained financial context, in which there are insufficient patient beds, we must fight to improve palliative care options and ensure they are offered from the beginning of a serious disease rather than only a few days before death, as is often the case.¹³ Before introducing legislation on euthanasia and assisted suicide, which arise from legitimate fear of a bad death, we must

13. Laurent Beydon, Corine Pelluchon, Sadek Beloucif, et al., "Fin de vie, euthanasie et suicide assisté: une mise au point du comité d'éthique de la SFAR," *Annales françaises d'anesthésie et de réanimation* 31, no. 9 (September 2012): 694-703.

ensure that individuals no longer die in the emergency room, in conditions stripped of dignity for patients and their loved ones.¹⁴

Opponents of assisted suicide argue that we cannot simply brandish a law that legalizes or decriminalizes euthanasia as if it were the solution to the problems of end of life care or present the Belgian legislation—whose inclusive nature is made clear by the fact that, since 2014, minors have the right to euthanasia—as a remedy, and close our eyes to the abuses that led to the euthanasia of schizophrenics in Switzerland in 2005.¹⁵ This would be burying our heads in the sand: taking an ironically backward step in the name of a progressivism that is merely the flipside of an elitist view of life making us believe that vulnerable individuals do not deserve to live. In the view of their fiercest opponents, arguments in favor of assisted suicide and euthanasia are the arguments of healthy people who forget that no one knows how they will react to the approach of death and do not want to accept that, in most cases, it is patients themselves who request further treatment.

These arguments resurface in all debates on assisted dying, without a solution that would satisfy both camps appearing to be possible. In order to discover whether such a solution might exist, we must first take a look at the existing legislation in France, with a focus on its strengths and limitations, and an analysis of the way it has developed through the proposals from Claeys and Leonetti.

THE LAW OF APRIL 22, 2005 AND THE REVISIONS
PROPOSED BY CLAEYS AND LEONETTI

The definition of “unreasonable obstinacy” outlined in article L1111-13 of the law of April 22, 2005 provides guidance for doctors caring for

14. Every year, approximately 13,000 people die in French emergency rooms. See the Observatoire de la fin de vie (French End of Life Observatory) 2013 report on end of life care in the elderly: <http://www.ladocumentationfrancaise.fr/rapports-publics/144000058/index.shtml>, last accessed September 12, 2018.

15. Adrien de Tricornot, “La justice allemande enquête sur un ‘suicide assisté’ en Suisse,” *Le Monde*, November 18, 2005; Tony Sheldon, “Dutch euthanasia law should apply to patients ‘suffering through living’, report says,” *British Medical Journal* 330 (January 8, 2005): 61. See Corine Pelluchon, *L'Autonomie brisée: Bioéthique et philosophie* (Paris: Puf, 2014), 84-85.

patients who are no longer in a position to express their wishes, and for whom a decision on limiting and withdrawing care must be taken:

When an individual, in the advanced or terminal phase of a serious and incurable condition of any kind, is unable to express his wishes, the doctor may decide to limit or withdraw treatment that is ineffective, disproportionate, or has no other purpose than to simply artificially prolong the life of this individual, after following the collegiate procedure outlined in the code of medical ethics and consulting the trusted individual mentioned in article L1111-6, the family, or failing that, someone close to the patient and, if applicable, the patient's advance directive. The doctor's decision, with supporting information, must be added to the patient's medical record.¹⁶

Although individuals in a coma are not terminally ill, this text provides a framework for decisions to limit and withdraw treatment, along with article L1111-4 of the French Public Health Code, which supplements the law of March 4, 2002 and concerns individuals who are unable to express their wishes by recalling the need for the collegiate procedure and the consultation with the trusted individual (article L1111-6), the family, or someone close to the patient. It also refers to advance directives.¹⁷ Article R 4127-37 of the Public Health Code, which defines the obligations of physicians, is also used in making decisions that result in withdrawal of life support and thus the patient's death.¹⁸

Lawyers for Vincent Lambert's parents used article L1111-4 to contest Dr Eric Kariger's decision to withdraw treatment from this patient, who had been in a minimally conscious state since 2008.¹⁹ The lawyers argued that the patient's wishes, which had not been set down in writing, were

16. See footnote 8.

17. They do not have binding status in this legal text. See also article 1111-11 of the Leonetti law.

18. Legislators wanted to avoid placing the burden of the decision to withdraw treatment on the family: the decision is made with family members, but not by them.

19. Vincent Lambert is a forty-year-old former nurse, now tetraplegic and in a minimally conscious state, who has been hospitalized at Reims University Hospital since 2008. In April 2012, an end of life protocol was put in place by Dr Eric Kariger with the agreement of the patient's wife, but his parents have mounted several legal challenges, including following the opinion from the French Council of State in 2014. He remains on artificial life support. In March 2016, the Reims guardianship judge gave Vincent Lambert's wife, Rachel Lambert, guardianship of her husband, which does not appear to have provided a solution to the dilemma. See Corine Pelluchon, Jean-François Mattéi, and Marie-Josée Mathieu et al., "Une médiation pour Vincent Lambert?," *Libération*, September 13, 2015, http://www.liberation.fr/debats/2015/09/13/une-mediation-pour-vincent-lambert_1381694, last accessed September 9, 2018.

not the same as those stated by his wife, who favored withdrawing life support. Dr Kariger was also accused of having an inadequate basis for his interpretation of continued treatment as ineffective and disproportionate.

There is no universally accepted interpretation of unreasonable obstinacy, and the Vincent Lambert case highlights the difficulties of applying the Leonetti law, which assumes, if the patient has no advance directive or trusted individual, that the family agrees on whether to continue or withdraw treatment and on what it believes to be the patient's wishes. In the case of Vincent Lambert, the family rift made it impossible to make a decision on whether to withdraw treatment. This does not mean that the Leonetti law cannot be applied to patients suffering from the same kind of brain damage as Vincent Lambert, but given the current context, as a result of family rifts and the erosion of medical authority, there appeared to be a need to shift this legal mechanism, often said to have been implemented to protect doctors from legal action, toward a greater affirmation of individual autonomy. One solution was to make advance directives binding, as recommended by Claeys and Leonetti and enshrined in the law of February 2, 2016. Ideally, they would even be made compulsory.

It is difficult to know in advance how we will react if we are affected by a degenerative disease. Equally, we cannot precisely foresee how we will experience the final moments of our life. Studies of the "disability paradox" and the experience of supporting patients with Alzheimer's disease who appear to be at peace despite the fact that some want to take their own life when first diagnosed, serve to question the suitability of advance directives.²⁰ Since individuals may change their mind, in relation to end of life care and degenerative diseases, we might take inspiration from the German model, which allows patients to draw up advance directives of wishes. Like standard advance directives, these allow individuals to state in advance what they would like doctors to do or not do when they are no

20. Cees M. P. M. Hertogh, "The Misleading Simplicity of Advance Directives," *International Psychogeriatric Association* 23, no. 4 (2011): 511-515; Susan E. Hickman, Bernard J. Hammes, Alvin H. Moss, and Susan W. Tolle, "Hope for the Future: Achieving the Original Intent of Advance Directives," *Hastings Center Report* Special Issue (2005): 526-530; Laraine Winter, Susan M. Parks, and James J. Diamond, "Ask a Different Question, Get a Different Answer: Why Living Wills are Poor Guides to Care Preferences at the End of Life," *Journal of Palliative Medicine* 13, no. 5 (2010): 567-572.

longer able to express these wishes, but they are distinguished by the fact that an authorized representative, designated by the patient, must ensure that the advance directive, written at the time the patient was competent, still expresses his wishes.²¹

Yet when it comes to brain damage, which affects an organ that constitutes an individual's social identity, shouldn't individuals decide now upon the limits at which they feel that care would become futile?²² Anyone can say whether they would want to be kept in a persistent vegetative state, or even in a minimally conscious state. Such a declaration, which could be made to an individual's primary care physician and recorded on his Carte Vitale (state health insurance card), would spare patients' loved ones from having to decide what happens to them in the unfortunate event that they have a stroke or suffer a traumatic brain injury causing serious and irreversible damage that can be measured medically with brain imaging.²³

The objection to this proposal, which was not included in the law of February 2, 2016, is that it requires lifting the taboo on death. To counter this, we might argue that autonomy is demanding and requires people to ask themselves difficult questions, including those relating to the possibility of a fatal accident occurring. Otherwise, if autonomy is judged to be too high an ideal, we must unflinchingly accept medical paternalism, while knowing there is a risk of our loved ones clashing over what we might have wanted in a particular situation.

French law thus provides a framework for decisions to limit or withdraw treatment. How should we view the inclusion, in the former version of the Leonetti law, of a proposal relating to continuous deep sedation for terminally ill patients, allowing them to pass away in their sleep?²⁴ For some individuals the end of life phase is long and difficult, particularly

21. CCNE opinion no. 121, p. 31. See also Dominique Thouvenin, "La loi n° 2005-370 du 22 avril 2005, dite loi Leonetti : la médicalisation de la fin de vie" in *Fin(s) de vie – Le débat*, ed. Jean-Marc Ferry (Paris: Puf, 2011), 303-368.

22. Pelluchon, "Peut-on parvenir à un consensus sur l'aide active à mourir?," 15-16.

23. On the contribution made by brain imaging to resuscitation and anesthesia, see my interview with Louis Puybasset, "Les décisions d'arrêt et de limitation de traitements en réanimation-anesthésie," *Cités* 66, no. 2 (2016): 31-40.

24. There are three situations: patients are conscious and request it at the very end of life; they request withdrawal of treatment and die, but are not at the very end of life; they are unconscious and the doctor considers continued treatment to be disproportionate. In this article we primarily consider the first two situations.

in cancer care. The titrated sedation provided in palliative care consists of lowering the patient's awareness and relieving pain with analgesia.²⁵ When this sedation is lifted and patients regain consciousness, they are able to receive their loved ones for a few moments. This practice is justified by a broader view of death as a process and the dying person as a person who is still alive, and not yet dead. It also reflects recognition of the importance in end of life care of maintaining the social relationships that allow individuals to say their goodbyes to their loved ones and their friends and family to prepare for separation. However, in some instances palliative sedation is no longer appropriate at the very end of life, when individuals are ready to die and too exhausted to receive anyone. This is why many patients do not request euthanasia, but continuous deep sedation until death. Such sedation may possibly hasten their death, which is in any case imminent.

Palliative care has reached a stage in its development where we also need to consider its limitations. Is it not sometimes futile, as demonstrated by patients who have undergone aggressive treatment, have access to palliative care and say they no longer want it? Do not patients who request withdrawal of a treatment such as dialysis and state that they do not want palliative care also have the right to die in their sleep, receiving continuous deep sedation?

Given what has been said about the guidance provided by the Leonetti law on decisions to limit and withdraw treatment in individuals who are unable to express their wishes, and the importance of not pursuing, even before that point, disproportionate treatments that amount to futile medical care, we could say that assisted dying only makes sense for competent individuals who are terminally ill and who, when offered access to palliative care, state that they no longer want or do not want such treatment.

The revised law of April 22, 2005 provides an answer to some problems, but what answer can be legitimately given to terminally ill individuals who do not want continuous deep sedation, but request assisted dying? This issue, shelved by the authors of the revised Leonetti law, concerns only a small number of people—insofar as the majority of requests for

25. Palliative sedation consists of adding pain relief to sedation which, when titrated, does not hasten the patient's death. Titration is the regular adjustment of doses of drugs, giving the patient improved comfort.

euthanasia recede when palliative care is provided—but does however merit consideration.²⁶ We therefore need to consider the options for carrying out assisted dying, given that the vast majority of health care professionals do not consider the act of killing to form part of care.

METHODS OF ASSISTED DYING

Assisted dying can take three, or even four, forms: euthanasia, medically assisted suicide (practiced in hospital or on the premises of an organization), and pharmacologically assisted suicide. The first two forms directly involve care givers and the medical establishment, as it is a healthcare professional who injects the lethal drug into the patient or provides it to him so he can perform the injection himself. These are the solutions that the Belgian, Dutch, and Luxembourg laws adopted in the 2000s, rigorously setting out the conditions in which euthanasia and assisted suicide were legal, in particular via “due care criteria” serving to verify after the event that medically assisted dying was practiced within the regulations without abuse. In Switzerland, assisted suicide is permitted as long as it is carried out “for unselfish reasons,” and there are also institutions such as Exit or Dignitas that provide individuals who wish to end their life with a lethal drug, meaning that the suicide does not take place in hospital, but on their premises.²⁷ In all of these cases, once the process has begun and the date is fixed, the patient takes his own life or, as in Belgium, is euthanized.

Another form of assisted dying has been possible in the US state of Oregon since 1997, in Washington state since 2008, and in Montana since 2010.²⁸ The primary care physician responsible for the individual confirms that he is truly terminally ill, i.e. the serious and irreversible disease from which he is suffering leaves him with a life expectancy of less than six months, and that he is competent. The patient’s request must be provided

26. The request for euthanasia is estimated to persist in around 3% of terminally ill patients.

27. This results from an interpretation of article 115 of the Swiss Penal Code. By “default,” Swiss law considers an assisted suicide carried out “altruistically” not to be homicide. Physicians write the prescription, but they do not inject the patient with the lethal drug, i.e. euthanasia is prohibited in Switzerland.

28. Oregon.gov, “Death with Dignity Act,” <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx>, last accessed September 12, 2018.

in writing and confirmed after a period of two weeks, and another physician must provide a second opinion. The primary care physician then gives the patient a prescription that allows him to procure the product, whether or not he chooses to take it. In other words, this approach does not mean that the patient inevitably commits suicide but, in the hypothetical situation in which he fears a difficult life, he knows he has this option. Recent studies have shown that, across all patients with a prescription, 62 percent commit suicide, while others do not take the lethal dose of barbiturates and die “naturally.”²⁹

This method of assisted dying has two advantages for patients. The first is that individuals who fear a bad death are reassured by having *the ability* to end their life if their condition deteriorates. The second advantage is that suicide is not inevitable and most importantly can be delayed—unlike the individuals who request euthanasia or contact Exit or Dignitas once they feel their condition deteriorating, who must make the request while still competent, but in doing so determine the day and time of their death. Under Oregon’s Death with Dignity Act, on the other hand, which is restricted to people who are terminally ill, patients must be competent when they make their request, but can ingest the product at the last minute. The legislation therefore allows patients to live longer while knowing that, if things get worse, they have a way out.

If we consider the impact of this system on care givers, it is also clear that they play a much smaller role than in Belgium or the Netherlands. Patients receive assistance, as the lethal drug is dispensed to them by a pharmacist, but the responsibility of physicians is limited to confirming that patients are terminally ill and competent. The prescription given to the patient does not equate to saying: I recognize that the only way you can die with dignity is to commit suicide. In Oregon, physicians do not have to make a decision on the right to suicide, but must simply ensure that patients meet the two criteria allowing them to exercise this right. The patient makes the decision alone, and suicide remains a possibility. Assisted dying is “demedicalized” to the greatest possible extent. This legal mechanism is both less paternalistic and less symbolically violent than the

29. Oregon.gov, “Death with Dignity Act Annual Reports,” 2011, <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ar-index.aspx>, last accessed September 12, 2018.

legalization or decriminalization of assisted suicide. It does not require physicians to judge the morality or immorality of suicide or medically assisted suicide, whether this judgment is general or specific, linked to one situation or another. Each individual decides what he wants to do at the end of life, in situations that cannot be entirely foreseen.³⁰ This is a form of assisted dying, but it is primarily pharmacological, since the role of the medical establishment relates only to the means used, not to the end.

If we take a step back and ask what would make sense for the community, given existing laws, diverging opinions, and the impact of any legislative change on medical practices and care givers, it is undeniably difficult to find an argument against pharmacologically assisted suicide. While reservations may remain regarding assisted suicide, due to the fear of abuse and the fact that decriminalizing assisted suicide and euthanasia risks inducing demand for death, can we truly say that this solution has no benefit in extreme situations?³¹ Could it not achieve a broad consensus that allows us to break free from the status quo and resolve difficult cases while in no way undermining the progress made since the law of April 22, 2005; namely the development of palliative care, the framework for decisions to limit and withdraw treatment from individuals who are unable to express their wishes, and the strengthening of patient autonomy, which was one of the objectives of the law of February 2, 2016?

DELIBERATION: A CONSTRUCTIVE APPROACH

When seeking to establish a common good, it is not only the tolerance linked to the recognition of moral equality between individuals that must be cultivated, as when seeking to reach an overlapping consensus. The content of the laws must go beyond identifying a smaller common denominator between individuals, as the objective is not solely to achieve civil peace, as if justice were limited to the external agreement of freedoms.

30. This solution is also distinguished from the exception of euthanasia advocated by the CCNE in 2000 in opinion no. 63 by being both clearer—since euthanasia is prohibited and only the patient decides—and less binding—as suicide remains only a possibility.

31. To prevent blurring of the line between the act of care and the act of killing, ideally the suicide would take place outside a hospital establishment. However, this solution is not often workable.

To find a suitable solution to a question that divides citizens, individuals do not only need to listen to one another, but must also reflect on what makes sense for all and thus make public use of their reasoning by taking a constructive approach. In the case of an overlapping consensus, people tolerate one another but very often make no effort at all to move toward the position held by others. In contrast, the reconstructive approach taken here means that the common good is defined after the event, the product of a consensus through confrontation that requires richer debate. This is only possible if the philosophical views underlying the various ideological positions are clearly set out, and if everyone looks beyond their personal beliefs to what might be right for society and advance the common good.

When it comes to the issue of assisted dying, this approach requires the opposing camps to soften their positions. For opponents of assisted suicide and euthanasia, this involves collapsing the opposition between palliative care and assisted dying and taking seriously the persistent requests for euthanasia expressed by patients who no longer want palliative care and feel that continuous deep sedation is not for them. As for those supporting the decriminalization of assisted suicide and euthanasia, it is important that, while making sure the voices of those patients whose requests to end their life are not considered are heard, they understand that laws cannot be changed without an appreciation of their history and all the actors concerned.

If such efforts are made, we will be able to reach a consensus on the issue of end of life care that goes beyond the objectives, on which everyone appears to agree.³² This consensus by confrontation, which does not aim to reconcile different points of view, could provide a model for successful deliberation on a problem that intimately affects all individuals, but is also political and must be decided by legislators. The law cannot substitute itself for the exercise of medicine—an art that requires careful judgment and involves a relationship. Neither is it designed to state the point at which

32. These include the fact that palliative care must be developed and made equally available across the country; that it must be offered immediately to patients with a serious disease, and not two or three days before their death; that care givers must receive adequate training throughout their career in order to apply the law properly; that improvements must be made in the way in which diagnosis is announced to patients and treatments are administered in accordance with the principle of proportionality; and that the collegiate procedure is not merely token, but involves in-depth consideration of the medical decision.

treatment becomes futile, as this limit is assessed subjectively based on what each individual judges to be important in his life. The role of the law is however to provide a framework for practice. This is why deliberation conceived as a method that not only invites us to weigh up the pros and cons, but also requires all individuals to ask themselves how the common good can be established, may allow us to transcend controversy and the status quo and move toward a more democratic approach to the complex issues we face today.

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