# The Struggle unto Death

Essays

# The Struggle unto Death

***Jasper Doomen****

ABSTRACT: This article focuses on the legality of euthanasia and assisted suicide in the Netherlands. Euthanasia and assisted suicide are allowed in certain cases, but there is no consensus with respect to the extent of the situations in which physicians should not be prosecuted. I argue that the individual, and, more specifically, his suffering, should be the focal point, and that the present legislation falls short in this respect; no solution can as yet be offered to individuals whose suffering cannot be resolved through medical means and which cannot be subsumed under the terms the law specifies.

KEYWORDS: Euthanasia; assisted suicide; depression; existential suffering

SUMMARY: 1. Introduction. – 2. An outline of the legislation. – 3. An evaluation of the legislation. – 4. Towards a solution. – 5. Conclusion.

## 1. Introduction

That the interests of the individual should in principle be guiding in medical practice is not seriously questioned by anyone.[1] The way in which psychiatrists and other physicians are to treat the individual and which options should be open to the individual, by contrast, continues to be an important topic of debate. The Netherlands was one of the first countries to specify conditions the observance of which removes the illegality of euthanasia or assisted suicide. The present legislation covers many situations and may be said to respond to the suffering of individuals in these situations. Still, several situations remain for which it does not provide a solution. Some of these are discussed in this article.

## 2. An outline of the legislation

Termination of life on request and assisted suicide are illegal on the basis of articles 293 and 294 of the Dutch Criminal Code, but physicians are not punished as long as they adhere to the following criteria, specified in the Termination of Life on Request and Assisted Suicide Act.

a. The physician must hold the conviction that the request by the patient was voluntary and well-considered;

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[1] I say 'in principle', for in some cases difficult choices must be made. For example, it has recently been debated whether the medication to treat Pompe disease, Fabry disease and Cystic fibrosis, which is relatively costly and used by very few patients, should continue to be paid collectively. Such issues will presumably increasingly be raised as medical progress is made.

b. The physician must hold the conviction that the patient's suffering was lasting and unbearable;
c. The Physician has informed the patient about the situation he was in and about his prospects;
d. The physician and the patient hold the conviction that there was no other reasonable solution for the situation he was in;
e. The physician has consulted at least one other, independent physician who has seen the patient and has given his written opinion on the requirements of due care, referred to in parts a – d; and
f. The physician has terminated a life or assisted in a suicide with due care.

Similar laws as those which apply in the Netherlands have been adopted in Belgium and Luxembourg. In both countries, just as in the Netherlands, doctors are exclusively allowed to euthanize; in addition, they have to adhere to strict criteria, which do not differ significantly from those that apply in the Netherlands. An important respect in which these three countries differ from others that allow euthanasia is that euthanasia on non-terminally ill patients is legal. With respect to assisted suicide, by contrast, there are important differences between Belgium and the Netherlands. The Belgian law does not provide criteria under which circumstances it would be allowed, from which it may be inferred that it is not allowed, but the issue has raised doubts and debate.[2]

A known proponent of a perspective in which the right of self-determination is not decisive is the Belgian philosopher Herman de Dijn, who states: "The euthanasia act displays a profound opposition in our society, a struggle between conceptions of man and ideas about ethics that cannot be resolved by having everyone act in accordance with his or her own ideas. According to its opponents, the euthanasia act conveys a dangerous message: that certain lives are no longer worthwhile."[3] This is not the proper place to extensively evaluate the arguments for the various positions. I will instead focus on the individual's confrontation with his suffering, in order to ascertain to what extent the current Dutch legislation meets the demand that this suffering should be terminated. What is said here may also be of interest for readers who do not live in the Netherlands, for the theme that is discussed here is not particular to a specific country.

### 3. An evaluation of the legislation

The Termination of Life on Request and Assisted Suicide Act, which is based on articles 293 and 294 of the Dutch Criminal Code and specifies under which conditions terminating the life of another person at that other person's express and earnest request or intentionally assisting in the suicide of another person or providing that person with the means thereto is not punishable, has recently been re-evaluated; the problems that individuals whose suffering cannot be medically treated or even di-

[2] H. NYS, *A Discussion of the Legal Rules on Euthanasia in Belgium Briefly Compared with the Rules in Luxembourg and the Netherlands*, in D. JONES, C. GASTMANS, C. MACKELLAR (eds.), *Euthanasia and Assisted Suicide*, Cambridge, 2017, pp. 7-25, 10.

[3] This is a translation of the original Dutch text. The original text reads: «De euthanasiewet verraadt een diepe tegenstelling in onze maatschappij, een strijd tussen mensbeelden en opvattingen over ethiek die niet op te lossen is door ieder volgens zijn/haar idee te laten handelen. De euthanasiewet zendt volgens haar tegenstanders een gevaarlijke boodschap uit: dat bepaalde soorten levens niet langer de moeite waard zijn." H. DE DIJN, "Euthanasie: een cultuurfilosofische analyse». In: A. BURMS, H. DE DIJN (eds.), *De sacraliteit van leven en dood voor een brede bio-ethiek*, Kalmthout, 2011, pp. 71-87, 86.


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agnosed face was discussed at length. It is this suffering I wish to address here. The crucial criterion in the law is that there must be 'lasting and unbearable' suffering, to be determined by a physician;[4] the exemption itself only applies to physicians.[5] It should be noted that unbearableness is "[…] a highly subjective and difficultly objectifiable factor."[6] This given does not derogate from the fact that the assessment is still *medical*, which serves as a justification for the monopoly of doctors to act when the termination of life is concerned. This monopoly is, however, as I will argue, problematic in a number of cases.

'Unbearable suffering' may be interpreted broadly, covering both pain and (inter alia) "increasing dependence, an ever greater loss of dignity or the prospect of a gruesome death."[7] Yet the government does not go so far as to deem the *prospect* of suffering lasting and unbearable, inter alia as 'lasting' and 'unbearable' are indivisibly linked:[8] "The mere prospect of suffering, irrespective of whether this will result from pain, loss of dignity or fear of an undignified death, cannot, in light of the above, be characterized as lasting and unbearable suffering."[9] It becomes apparent from the evaluation that the fact that precisely that prospect is oftentimes the motive behind requests for euthanasia constitutes an important problem: "If one examines the reasons why people make a request to be euthanized, pain appears to be a factor in only a small number of requests. In actuality, what drives the request is almost always the loss of dignity that is to be expected."[10]

If this is correct, it is justified to say that the present legislation is not adequate to realize the desired goal. The problems will possibly increase with the impending population ageing. Research shows that a growing number of elderly people imagine themselves requesting euthanasia or having a suicide pill available.[11] The introduction of such a pill is, however, at least for the foreseeable future, a politically sensitive issue. In any event, world-weariness is not a recognized criterion to allow euthanasia or medical assistance in ending one's own life,[12] and neither is a 'finished life'.[13]

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[4] Termination of Life on Request and Assisted Suicide Act, art. 2; Parliamentary Documents: House of Representatives, 1993/1994: 23877, no. 1: pp. 4, 5. 'Lasting' is to be understood here in the sense that no prospect of improvement exists.

[5] Articles 293 and 294 of the Dutch Criminal Code.

[6] The original text reads: "[…] een in hoge mate subjectieve, en moeilijk te objectiveren factor." Parliamentary Documents: House of Representatives, 1993/1994: 23877, no. 1, p. 5.

[7] The original text reads: "'[…] toenemende afhankelijkheid, steeds verdere ontluistering of het vooruitzicht van een afschrikwekkende dood […]." Parliamentary Documents: House of Representatives, 1999/2000: 26691, no. 6, p. 70.

[8] Parliamentary Documents: House of Representatives, 1999/2000: 26691, no. 6, p. 60.

[9] The original text reads: "Het enkele vooruitzicht op lijden, ongeacht of dit zal voortvloeien uit pijn, ontluistering of angst voor een onwaardige dood, kan in het licht van het bovenstaande niet als uitzichtloos en ondraaglijk lijden worden aangemerkt […]." Parliamentary Documents: House of Representatives, 1999/2000: 26691, no. 6, p. 60.

[10] The original text reads: "Als je kijkt naar de redenen waarom mensen een euthanasieverzoek doen, is pijn maar een heel klein onderdeel van alle verzoeken. Eigenlijk gaat het bij het verzoek bijna altijd om de te verwachten ontluistering, het verlies van waardigheid." Parliamentary Documents: House of Representatives, 2013/2014: 31036, no. 8, p. 13.

[11] H. Buiting, D. Deeg, D. Knol, J. Ziegelmann, R. Pasman, G. Widdershoven, B. Onwuteaka-Philipsen, *Opvattingen van ouderen over levensbeëindiging*, in *Huisarts & wetenschap*, 56(3), 2013, pp. 102-105, 104.

[12] Parliamentary Documents: House of Representatives, 2007/2008: 31036, no. 3: pp. 4, 6.

[13] Parliamentary Documents: House of Representatives, 1999/2000: 26691, no. 6: pp. 30, 60.

A reform in this respect is pleaded by, amongst others, those who support the Citizens' Initiative Finished Life ('Burgerinitiatief Voltooid Leven').[14] In the wake of this initiative, political party Democrats 66 has submitted the bill Dignified End of Life ('Waardig Levenseinde'), but this only pertains to people of 75 years or older. If the pill is only made available to the elderly – leaving the issue of what the precise age limit should be[15] –, no solution has been offered to young people who face the same problem. Their position remains outside the purview of the law. This subject matter particularly lends itself to a medical *ethical* reflection, since the questions to which the subject matter gives rise cannot be answered by the medical profession itself.

This became clear in a case in which a general practitioner was found guilty of having assisted the suicide of a patient because the main criteria for medically assisted suicide had not been met, namely, that there has to be (in accordance with was indicated above) 'lasting and unbearable' suffering; he was discharged, however, the act, while principally punishable, not meriting a punishment in this case. As the Dutch Supreme Court expresses it: "The integral care which is to be provided by a general practitioner to patients […] may result in him being assigned with the task to alleviate the suffering of a patient which is not or not predominantly caused by a somatic or mental condition, but which is the consequence of the lack of a life perspective. Given, however, that that physician then enters into a domain that lies beyond his professional competence, he may not, in his capacity of medical professional, form a judgment regarding the unbearableness, lastingness and untreatableness of that suffering."[16]

The question is, then, what, if any, recourse may be available to an individual who is confronted with suffering that cannot be qualified in medical terms, i.e., a case where neither depression nor a physical illness is diagnosed. In cases of 'existential suffering' the Supreme Court commands that a physician "consult others who may be helpful in finding a meaningful fulfillment of one's daily existence."[17] Who these 'others' might be is not elucidated and this may differ from one case to the next, so that a problem of referral will ensue (should a priest, rabbi or humanistic counselor – to mention just a few possibilities – be approached?). More importantly, no solution is provided for someone for whom, in spite of the availability of such possible alternative support, no meaningful fulfillment can be found.[18] This is not to be taken as criticism of the Supreme Court; the possibility to provide ade-

[14] Parliamentary Documents: House of Representatives, 2013/2014: 31036, no. 8: p. 3.

[15] It is difficult to generalize, and for some people the prospect of having to live until the age of 75 may be dreadful while others may welcome the possibility to live (well) beyond that age.

[16] The original text reads: "De door een huisarts te verlenen integrale zorg aan patiënten […] kan meebrengen dat hij zich voor de taak gesteld ziet om het lijden van een patiënt te verlichten dat niet of niet in overwegende mate zijn oorzaak vindt in een somatische of psychische aandoening, maar het gevolg is van het ontbreken van levensperspectief. Omdat die arts zich dan evenwel begeeft op een terrein dat buiten zijn professionele competentie ligt, zal hij zich niet als medicus een oordeel mogen vormen over de ondraaglijkheid, de uitzichtloosheid en onbehandelbaarheid van dat lijden." Dutch Supreme Court, December 24, 2002, *NJ* 2003, 167, par. 8.2.

[17] The original text reads: "[…] het inschakelen van anderen die behulpzaam kunnen zijn bij het zoeken naar een zingevende invulling van het dagelijks bestaan." Dutch Supreme Court, December 24, 2002, *NJ* 2003, 167, par. 5.

[18] Cf. M. PARKER, *Words and reasons: psychiatry and assisted suicide*,in *Australian & New Zealand Journal of Psychiatry*, 46(2), 2012, pp. 80-83, 80: "[…] the person who competently asks for [assisted suicide], in

quate support in such cases simply does not exist at the moment. Steven Pleiter, director of the End-of-life Clinic ('Levenseindekliniek'), expresses the problem as follows: "We, too, face patients who 'suffer from life' – that is what we call it – and who have become detached […]. We cannot aid these patients under the present standard, since it is based on the presence of medical suffering. At times, dire situations occur, in which elderly people gravely suffer from life. In my view a proper solution should be available in such cases. The present Euthanasia legislation does not offer such a solution."[19]

## 4. Towards a solution

What is the best way to approach this problem? It must, first of all, be acknowledged that removing lasting suffering in some cases is tantamount to ending the life of the individual, namely, in those cases where suffering from life itself is concerned: the suffering permeates life to such a degree that it is no longer acceptable. The only one who is able to determine this highly subjective given is the individual: it is no longer acceptable to him or her. As Bozzaro puts it: "Only the patient may determine with which symptoms and in which situations he suffers and when these become unbearable for him."[20]

In order to accommodate people whose suffering is not covered by the Termination of Life on Request and Assisted Suicide Act it is necessary to change article 294, section 2, of the Dutch Penal Code. This article penalizes, as was pointed out above, assisted suicide; only physicians who observe the demands specified in the Termination of Life on Request and Assisted Suicide Act are exempted. In order to confront the problems while acknowledging that some cases do not concern medical issues, non-physicians should also be exempted from punishment.

The cooperative Coöperatie Laatste Wil ('Last Will Cooperation'), an association whose goal it is to make it possible for individuals to end life on their own terms, without the intervention of a physician (or anyone else), announced that it would communicate the details of an easily obtainable means to end one's life without pain to its members. It would organize meetings in 2018 during which people who had been member for at least six months would have the option to buy a means (a powder) to end their life. They would first be informed about the nature of the product (the side-effects, e.g., would be explained) and they would also be presented with alternatives to terminating their lives. In addition, special vaults had to be procured so as to make sure that no one else would have access to

circumstances that we can sympathise with, is not always motivated by psychological pain *for which there is an acceptable alternative*."

[19] The original text reads: "Ook in onze praktijk hebben we te maken met patiënten die "lijden aan het leven" – zo noemen wij dat – en die onthecht zijn […]. Wij kunnen deze patiënten binnen de norm zoals die op dit moment geldt, niet helpen, omdat de norm uitgaat van medisch lijden. Er komen soms heel schrijnende situaties voor waarin ouderen zeer lijden aan het leven. In mijn ogen zou daar een goede oplossing voor moeten zijn. De huidige Euthanasiewet biedt die oplossing niet." Parliamentary Documents: House of Representatives, 2013/2014: 31036, no. 8, p. 9.

[20] The original text reads: "[…] allein der Patient [kann] bestimmen […], unter welchen Symptomen und Situationen er leidet und ab wann diese für ihn unerträglich werden." C. BOZZARO, *Der Leidensbegriff im medizinischen Kontext: Ein Problemaufriss am Beispiel der tiefen palliativen Sedierung am Lebensende*, in *Ethik in der Medizin*, 27(2), 2015, pp. 93-106, 97.

the product. Despite these measures, it deemed it necessary, having consulted with the public prosecution service, to communicate to its members on March 26, 2018 that it would not make the product available, for fear of prosecution.

This demonstrates the difficulty of making the means to commit suicide available, its distribution to others arguably conflicting with the present legislation. Whatever one may think of such legislation, certain precautions should obviously be in place – crucially, it must be clear that there is a genuine death wish. With this in mind, one may argue that a physician still has a role to play: "If physicians' professional expertise enables them to deal with the existential questions arising in connection with VE [voluntary euthanasia] and PAS [physician-assisted suicide] based on suffering caused by illness or injury – as the conventional view presupposes that it does – it would be inconsistent to deny VE and PAS for persons in purely existential distress by claiming that physicians' professional expertise does not extend to existential questions."[21]

Young's solution, to have both a physician and a non-medical, professional counsellor assess individual cases, may, since he argues that if consulting the latter does not change the outlook of the person requesting assisted suicide this should be allowed,[22] be advisable. In any event, it must be borne in mind that assisted suicide is still *sui*cide (killing one*self*). It would be both peculiar and undesirable to penalize assisted suicide if suicide (or attempted suicide) is not.[23]

## 5. Conclusion

The evaluation of the Termination of Life on Request and Assisted Suicide Act makes it clear that no adequate solution may be offered to elderly people who are 'through with life'. If they suffer unbearably and lastingly, euthanasia or assisted suicide may be granted to them on the basis of a medical assessment, but it may be questioned whether these possibilities are sufficient. Perhaps even more pressing are the problems that are not limited to the elderly, where individuals who 'suffer from life' are concerned. Their suffering cannot be gauged from a medical point of view, let alone be treated. The physician's role is limited in this respect, since the issues are largely of a non-medical nature and thus require another perspective than the decisive one. This brings with it that individuals have, on the basis of the present legislation, few to no options to have their suffering – and thereby their lives – terminated. By regulating assisted suicide it may become possible to find a solution for the dire cases whose suffering must at present last unabated.

[21] J. VARELIUS, Medical expertise, existential suffering and ending life, in Journal of Medical Ethics, 40(2), 2012, pp. 104-107, 106.

[22] R. YOUNG, 'Existential suffering' and voluntary medically assisted dying, in Journal of Medical Ethics, 40(2), 2012, pp. 108-109, 108.

[23] The idea that suicide itself is not illegal may seem, given that the person involved has deceased, evident, but this appears not to have proven to be an impediment to penalize people in the past (see, e.g., M. MACDONALD, *The secularization of suicide in England 1660-1800*, in *The Past and Present Society*, 111, 1986, pp. 50-100, 52, 53).


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