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## Dying to be normal

Snijdewind, M.C.

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1

# General introduction



## INTRODUCTION

This thesis studies the question whether or not euthanasia and physician-assisted suicide (EAS) in the Netherlands has become subject to normalization. It might seem that the question of normalization in relation to EAS only came up a few years ago.(1-4) However, to begin this thesis, I'll briefly show that already before the legal regulation of EAS in the Netherlands, questions of this sort and the worries that come along played a role.

### **History of physician-assisted dying in the Netherlands: an overview**

When medical opportunities increased in the twentieth century, questions about quality of life (and death) followed. Where dying had previously been a natural process, death and dying now made its entrance to the medical field — something for physicians to meaningfully intervene in. Making the patient comfortable in the end of life was sometimes done by giving the patient 'a little push', although it was definitely not talked about in the open.(5-7)

The publication of Admiraal's booklet(8) on how to perform euthanasia in a correct manner, combined with a more open attitude to inform patients about their disease and upcoming death(5), and the prosecution of the family physician Postma who performed euthanasia on her mother(9), sparked the debate on physician-assisted dying and the question if it should be permissible under certain conditions. The petition of Postma's patients to back their physician in the process in its turn led to the foundation of the NVVE, the Dutch Right-to-Die movement.(10) Also, in the decision of the Postma-case, the court formulated four requirements that needed to be met for euthanasia to be justifiable. These requirements are the foundation of the later due care criteria. More prosecutions followed(11) and in 1984 the Supreme Court accepted that a request for euthanasia can cause a situation of 'force majeure'(12) for a physician, because the physician experiences a conflict of the duty to relieve suffering and the duty to preserve life.(13-14) If someone commits a crime as a result of force majeure, he/she is not criminally liable according to the criminal code. This meant physicians from then on could be acquitted when they had performed EAS in a prudent way, following the then known conditions.

During that same time period, the State Commission on Euthanasia was appointed to answer the question if EAS should be legally regulated(6), the Royal Dutch Medical Association published a position paper on euthanasia(15), and D66 — a Dutch political party — presented a proposal for a bill on euthanasia.(16) The discussion of EAS was on fire. The majority of people were of opinion that EAS should somehow be regulated;

however, there was no consensus on how exactly. This discussion is interesting in the context of normalization, as it came down to the question if euthanasia was a normal medical act or not.

In this discussion, Enschedé, was convinced that EAS should fall under the medical exception.(17) Within the medical exception, physicians can harm their patients if this is necessary for the treatment of the patient. Think for instance about amputation of a leg. Enschedé argued that euthanasia was part of the medical domain and should follow the medical professional standards — there was no need to regulate this by law.(18) This point of view meant that EAS would be a normal medical act. He also was of opinion that a physician could issue a certificate of natural death in case of performing EAS while following the medical standards.(17-18) Leenen opposes the idea of euthanasia falling under the medical exception, and is of opinion that euthanasia should follow societal norms, not medical ones.(19)

More than a decade later, the discussion whether or not EAS was a normal medical act or not was repeated. This time Griffiths and van Dantzig defended the position that EAS should fall under the medical exception.(20-21) According to them, the distinction between EAS, stopping treatment, and pain relief was vague, morally irrelevant, and a mere construct. The latter two acts do not fall under the criminal code and therefore neither should EAS. EAS could then be regulated by the medical profession itself and incidents would be handled by disciplinary law. Den Hartogh thought otherwise. He was of opinion that EAS should be regulated by law.(22) In the end, it was decided that EAS should be legally regulated by criminal code. With this in place, performing euthanasia was an exceptional medical act (in Dutch: ‘niet-normaal medisch handelen’) — not to be confused with the medical exception.

To be clear: normal medical practices are acts which have a medical indication and patients have a right to receive these treatments if they meet the requirements. In contrast, an exceptional medical act is something which does not, or not solely, belong to the medical domain: next to the norm of the medical profession, it is also shaped by societal norms, and it falls within the legal domain, as explained before. Therefore, from the outset of the legal regulation, there is no indication for EAS. Even if a patient meets the requirements, he/she does not have a right to receive EAS — a physician is never obliged to perform EAS. The law that came into effect in 2002 protects the physician from prosecution. Therefore, the physician’s compassion is seen as the cornerstone of the Euthanasia Law, with the patient’s autonomy following in second place.(23)

The legal due care criteria as mentioned in the law are the following(24):

1. The physician is convinced that the request of the patient is voluntary and well considered.
2. The physician is convinced that the suffering of the patient is unbearable and without prospect of improvement.
3. The physician has informed the patient about his/her situation and prognosis.
4. The physician and the patient have concluded that there is no reasonable alternative.
5. The physician has consulted at least one other, independent, physician, who has visited the patient. This physician has provided a written report, based on the due care criteria 1-4.
6. The physician has performed euthanasia or assisted-suicide with due medical care.

### **Current practice of physician-assisted dying in the Netherlands**

When the law came into effect in 2002, not much changed in daily practice. However over the years a few noteworthy changes — in light of normalization — made their entry. I will not go into detail about these, since they will also be addressed in the upcoming chapters.

Firstly, although physicians are never obliged to perform EAS, voices of those who advocate the option of EAS, or even a right to die, grew stronger in Dutch society. ‘Of Free Will’ (Uit Vrije Wil) filed a bill in 2010 in which persons older than 70 years without serious medical problems would get a right to assisted suicide.(25) The bill ended up being debated in parliament, but was rejected.

Secondly, in 2012, the End-of-Life Clinic was established by the NVVE, an organization that helps patients whose request is rejected by their own physician. The clinic also specializes in more uncommon requests for EAS.(26) Their founding idea, that a patient should be able to receive EAS if the due care criteria can be fulfilled, seems to interfere with the fact that EAS is not a patient’s right. There was much ado about their foundation: people worried the treatment relationship between doctor and patient would be compromised and wondered if without this a careful performance of EAS would be possible. This relates to the concern that EAS might become too easy. Next to this, the End-of-Life Clinic is a form of specialization. By specializing in something, you acknowledge its established status, which in turn might be seen as normalization. In the beginning the clinic was dependent on donations for financing their costs, nowadays their service is covered by insurance companies — a sign that it

has been integrated in the care system, another form of establishment, and with that, of normalization.

Then, in 2012, an Advisory Committee was appointed by the Dutch government to give advice on the juridical and societal dilemmas regarding people who consider their life completed. Their report on this issue was presented in 2016; stating they saw no reason to change the current law. The committee was of opinion that the group of people suffering from a completed life was small and that most people who consider their life completed also suffer from an accumulation of diseases of old age. If a physician is willing to grant an EAS request from this last group of people, it falls within boundaries of the current law.(27) Despite this report, a draft law proposal for a new law, next to the euthanasia law, was put forward by Dijkstra in order to accommodate people whose wish to die is not based on medical grounds, and who are over 75 years of age.(28)

Last, in 2017 and 2018, an organization called Cooperative Last Will (Coöperatie Laatste Wil) received extensive media attention.(29-31) This initiative advocates the option of assisted suicide without intervention of physicians or other professionals: assisted suicide should be available for anyone without any form of review beforehand or afterwards.(32) The idea that review is no longer necessary might reflect the normalization of assisted suicide. Also, the de-medicalization and de-professionalization of assisted suicide can be interpreted as normalization of the choice to actively end your own life.

Where do we stand today? From 1990 onwards, there has been an evaluation of the practice of EAS every five years. The support of the general public for the option of EAS was first studied in 2001-2002 and has stayed high since then. In 2001-2002, 82% of the respondents agreed with the view that a physician may end the life of a severely ill person on his/her request(33), and in 2016 88% thought it was positive that there is an Euthanasia Law in the Netherlands.(34)

The last evaluation showed a clear increase of the incidence of euthanasia compared to the ones before: from 1.7%-2.8% of all deaths between 1990-2010 to 4.5% in 2015. Physician-assisted dying has stayed between 0.1-0.2% of all deaths throughout the years.(35) The increase of euthanasia can be explained by a higher percentage of people requesting euthanasia (6.7% in 2010, 8.4% in 2015), and by an increased granting rate (45% in 2010, 55% in 2015). Looking at the underlying medical conditions of the patient whose request was granted in 2016, 67% suffered from cancer, another 21% suffering from another physical condition, 4% had a psychiatric condition, 3% suffered from dementia, and in 6% the physician indicated there was no severe physical or psychiatric suffering.(34) This last group was probably suffering from an accumulation of

diseases due to old age. These last three groups have gained special attention throughout the years, with people again fearing EAS has become too easy and saying that the Euthanasia Law was never intended for these groups of more vulnerable people.

When physicians were asked if they had experienced pressure to come to a decision in a request for EAS in the past five years, 56% of the general practitioners reported they had experienced pressure either from the patient or their relatives to grant a request for EAS.<sup>(34)</sup> An explanation might be that patients and relatives think EAS is a normal part of the job as a physician and they don't empathize with the hesitation a physician might have.

### **Normalization?**

Normalization is an ambiguous concept. When opening a dictionary, and searching for 'normal', you'll find "ordinary or usual; the same as would be expected".<sup>(36)</sup> Normal can also refer to the 'natural', or just 'what is.' Normalization in turn, can then be understood as 'the process of becoming normal'. Normalization in sociology can refer to power structures and social control, or it can refer to the way that acts or practices become incorporated in everyday life.

In describing how the Euthanasia Law came to be and what the present state of affairs in the practice of EAS is, we have seen several aspects of what might be understood as (contributing to) normalization: more openness, broad support of the general public, willingness of physicians, positive acknowledgement of the issue by the medical association, a political climate that was ready to agree upon legal regulations, and — after implementation of the law — specialization of EAS by the End-of-Life Clinic, and de-medicalization of assisted dying. We have also already seen the two main concerns related to normalization of EAS: the fear that there will be pressure on vulnerable groups and the fear that EAS will become too easy. Just as normalization is ambiguous, its counter concept is as well. To give you some ideas, the opposite of normalization could be that EAS is demanding, not simple, complex, and exceptional.

In the studies presented in this thesis, I chose to not define normalization beforehand, because exploring what my respondents understood by normalization was part of the research, as well as exploring the aforementioned aspects and fears without pinpointing in advance that those aspects truly *are* aspects of normalization.



## This thesis

The aim of this thesis is to explore the concept of normalization in relation to euthanasia and physician-assisted suicide in the Netherlands.

Each chapter in this thesis studies one or more possible aspects of normalization that are described above. In all chapters a certain duality can be found: elements of normalization combined with elements that show the opposite. Throughout the thesis we will gain a better understanding of normalization of EAS and developments which play a role in this. I used different methods, both qualitative as quantitative, to study the developments in the practice of EAS and the concept of normalization: in-depth interviews with physicians, bereaved, and experts, an observational study of consultation hours on advance directives including (future) patients and their relatives, and a study of application forms and registration files of the End-of-Life Clinic.

Below, the research questions, their connection with normalization, and the methods are presented per chapter.

The second chapter of this thesis studies normalization as related to de-professionalization. It answers the question what the aims and expectations of people visiting consultation hours on advance directives are, what advice is given by the consultants, and how is acted upon this advice. This study is connected to the topic of normalization because the consultations happen outside the professional medical context. This de-professionalization can be seen as part of normalization. To answer the question I conducted an observational study on consultation hours on advance directives and looked into the way people are managing their end of life. This study, conducted in 2016, resulted in the observation of 29 appointments with 36 members and eight consultants.

The third chapter shows insights into the possible normalization of EAS from the physicians' perspective: what changes have they encountered, (how) have they experienced developments in the practice of EAS? Also, it addresses the issue of pressure on physicians. The research question is the following: what are important developments in the field of euthanasia or physician-assisted suicide, according to physicians. The chapter presents the results of a semi-structured in-depth interview study among 28 physicians who have experience with complex cases of EAS. It was conducted in 2011-2012.

The fourth chapter explicitly focusses on the question whether EAS is becoming a normal act in the medical domain. This chapter also answers the same question as the third chapter, namely what important developments in the practice of EAS are,

however now from the perspective of Dutch experts in the field of euthanasia. Twelve semi-structured in-depth interviews were conducted in 2015 to answer this question.

Chapter five addresses the fear that because of normalization, EAS has become too easy. It describes complex cases of euthanasia and answers the question what causes a case of EAS to be more complex than another. Results were based on the same data used for chapter three, combined with in-depth interviews with 26 relatives of patients who had died by EAS.

Chapter six studies normalization in the context of specialization. It shows the results of a study into the End-of-Life Clinic, a facility for people whose own physician is not willing to grant their euthanasia request. It answers the question which patients register themselves at the clinic, what the outcome of these EAS requests are and which factors are associated with granting or rejecting a request. The clinic can be seen as a sign of normalization, because it is a specialization of the practice, while the opposite is also true: it is a sign that EAS remains so exceptional and difficult for physicians that they are often not willing to perform it. All application forms and registration files of the first year of the clinic, March 2012 to March 2013, were analyzed, which came down to a total of 645 requests.

## REFERENCES

- (1) Medisch Contact. Is euthanasie normaler geworden? Available from: <https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/is-euthanasie-normaler-geworden.html>. Accessed August 7, 2018.
- (2) NRC. Verblind door euthanasiame. February 25, 2017. Available from: <https://www.nrc.nl/nieuws/2017/02/25/verblind-door-euthanasiame-6476764-a1547640>. Accessed August 7, 2018.
- (3) Trouw. Euthanasie mag je niet vergelijken met een blindedarmontsteking. June 15, 2018. Available from: <https://www.trouw.nl/opinie/euthanasie-mag-je-niet-vergelijken-met-een-blindedarmontsteking~a93740cf/>. Accessed August 7, 2018.
- (4) Handelingen Tweede Kamer. 2013-2014. Bijlagen 32 647, nr. 28. Available from: <https://zoek.officielebekendmakingen.nl/kst-32647-28.html>. Accessed August 7, 2018.
- (5) The A. Verlossers naast God. Dokters en euthanasie in Nederland. 2009. Thoris.
- (6) Weyers H. Euthanasie. Het proces van rechtsverandering. 2004. Amsterdam: Amsterdam University Press.
- (7) Kennedy J. Een weloverwogen dood. Euthanasie in Nederland. 2002. Amsterdam: Uitgeverij Bert Bakker.
- (8) Admiraal, PV. Verantwoorde euthanasie; handleiding voor artsen. 1981. Amsterdam: Nederlandse Vereniging voor Vrijwillige Euthanasie.
- (9) Rechtbank Leeuwarden 21 februari 1973. NJ 1973, nr. 183.
- (10) NVVE. Organisatie. Available from: <https://www.nvve.nl/over-nvve/organisatie>. Accessed August 7, 2018.

- (11) van der Wal G, Dillmann RJM. Euthanasia in the Netherlands. *BMJ*. 1994;308:1346.
- (12) Wetboek van Strafrecht, artikel 40 (wet van 3 maart 1881).
- (13) Hoge Raad 27 november 1984, NJ 1985, nr. 106.
- (14) Gevers S. Euthanasia: law and practice in the Netherlands. *British Medical Bulletin*. 1996;52(2):326-333.
- (15) KNMG. Standpunt inzake euthanasie. *Medisch Contact*. 1984;31(3):990-1003.
- (16) Handelingen Tweede Kamer. 1983-1984. Bijlagen 18 331, nr 3.
- (17) Enschedé Ch J. De Doodsbriefjes. *Ned Tijdschr Geneeskd*. 1986;130:1411-1412.
- (18) Enschedé Ch J. *De Arts en de Dood*. 1985. Deventer: Kluwer.
- (19) Leenen HJJ. De Overlijdensverklaring. *Ned Tijdschr Geneeskd*. 1986;130:1430-1431.
- (20) Griffiths J. Euthanasie: legalisering of decriminalisering? *Nederlands Juristenblad*. 1997;72(14):619-627.
- (21) van Dantzig A. Doodgaan is doodgewoon: een pleidooi voor de medische exceptie. *Medisch Contact*. 1999;54(2):63-64.
- (22) Den Hartogh G. Euthanasie onder de medische exceptie? *Medisch Contact*. 1998;53(48):1539-1540.
- (23) Pans E. *De normatieve grondslagen van het Nederlandse euthanasierecht*. 2006. Nijmegen: Wolf Publishers.
- (24) Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding. Hoofdstuk II. *Zorgvuldigheidseisen*. Available from: <http://wetten.overheid.nl/BWBR0012410/2014-02-15#HoofdstukII>. Accessed August 7, 2018.

- (25) Peters J, Sutorius E, van Baarle Y, Beekman W, Daniels S, de Fauwe L, et al. *Uit Vrije Wil. Waardig sterven op hoge leeftijd*. 2011. Amsterdam: Boom.
- (26) de Jong P. *Haalbaarheidsonderzoek levenseindekliniek (fase 2)*. 2010.
- (27) Schnabel P, Meyboom-de Jong B, Schudel WJ, Cleiren CPM, Mevis PAM, Verkerk M. *Voltooid Leven: Over hulp bij zelfdoding aan mensen die hun leven voltooid achten*. 2016. Den Haag.
- (28) D66. *Dijkstra publiceert initiatiefwet Waardig Levenseinde 2016*. Available from: <https://d66.nl/wet-voltooid-leven-pia-dijkstra/>. Accessed August 7, 2018.
- (29) Nieuwsuur. *Coöperatie Laatste Wil vindt middel voor levensbeëindiging*. September 1, 2017. Available from: <https://nos.nl/nieuwsuur/artikel/2190853-cooperatie-laatste-wil-vindt-middel-voor-levensbeëindiging.html>. Accessed August 7, 2018.
- (30) NRC. *Laatste Wil stopt definitief met verspreiden dodelijk poeder*. March 26, 2018. Available from: <https://www.nrc.nl/nieuws/2018/03/26/laatste-wil-stopt-definitief-met-verspreiden-dodelijk-poeder-a1597108>. Accessed August 7, 2018.
- (31) Nieuwsuur. *Leden Coöperatie Laatste Wil kopen zelfdodingspoeder op eigen houtje*. July 8, 2018. Available from: <https://nos.nl/nieuwsuur/artikel/2240550-leden-cooperatie-laatste-wil-kopen-zelfdodingspoeder-op-eigen-houtje.html>. Accessed August 7, 2018.
- (32) *Coöperatie Laatste Wil*. Available from: <https://www.laastewil.nu/>. Accessed August 7, 2018.
- (33) Van der Wal G, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ. *Medische besluitvorming aan het einde van het leven. De praktijk en de toetsingsprocedure euthanasie*. 2003. Utrecht: Uitgeverij de Tijdstroom.

- (34) Onwuteaka-Philipsen B, Legemaate J, van der Heide A, Delden H, Evenblij K, El Hammoud I, et al. Derde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding. 2017. The Hague: ZonMw.
- (35) van der Heide A, van Delden JJM, Onwuteaka-Philipsen BD. End-of-Life Decisions in the Netherlands over 25 years. *N Engl J Med.* 2017;377(5):492-494.
- (36) Cambridge Dictionary. Available from: <https://dictionary.cambridge.org/>. Accessed August 7, 2018.