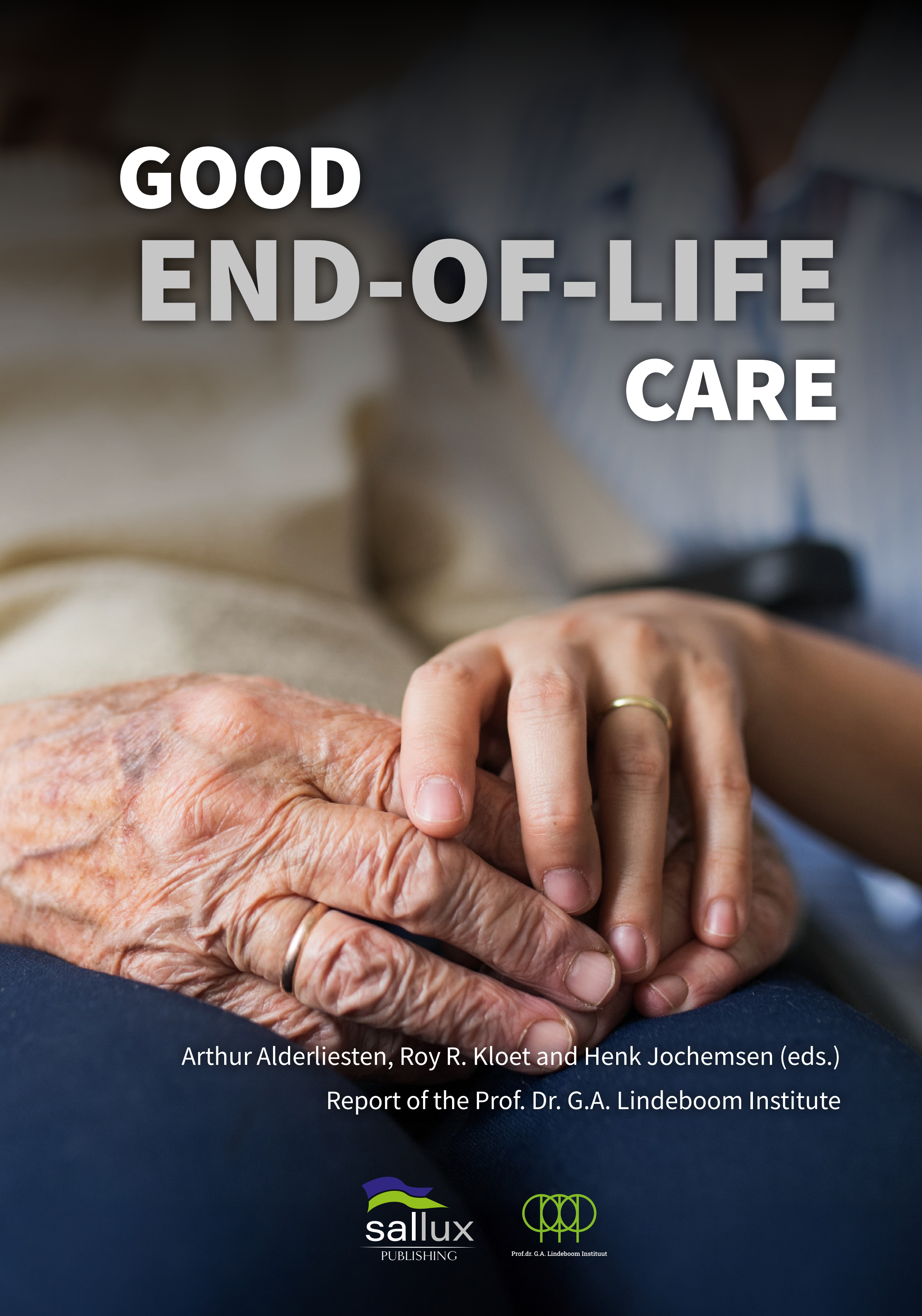

GOOD END-OF-LIFE CARE

Arthur Alderliesten, Roy R. Kloet and Henk Jochemsen (eds.)

Report of the Prof. Dr. G.A. Lindeboom Institute

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Introduction

End-of-life questions, including ethical and medical-ethical ones, have been around since time immemorial. Among (healthcare) organisations, different types of questions are being raised, in particular among those with a Christian identity. This also became clear from a survey among various partners of the Culture for Life platform, which commissioned this literature study. This report presents the combined answers to these questions.

Target

The aim of this literature review is to provide insight into what is and is not known with regard to medical-ethical questions surrounding euthanasia and a 'completed life', applied to a number of subtopics. In Spring 2022, this report formed the basis for determining desirable follow-up research. These follow-up steps will ultimately serve two purposes:

1. Help employees of healthcare organisations deal with medical-ethical questions around euthanasia and a 'completed life' (healthcare workers, staff, management);
2. Provide project partners with input that can add to the public debate.

This report, as a 'knowledge synthesis', lays the foundation for this by presenting the following aspects for each of the issues that are addressed in the different chapters:

1. An overall content summary of what is known and available;
2. Identification of gaps in the scientific literature;
3 Recommendations for follow-up research along the two lines mentioned above.

The organisations that commissioned this study gave two substantive concerns in this regard:

1. Name what we endorse and mention alternatives to euthanasia and the 'completed life' request;
2. Provide perspectives for the work floor.

Three preliminary remarks

First, we would like to note that medical-ethical end-of-life questions have broad social resonance. This was evident at the time this study was completed. Several reports appeared with the message that death should be discussed more. A national (SIRE) campaign has even been been formed to address end-of-life issues.

This is a remarkable trend that runs counter to another tendency, which is to drive back death and make it less visible. Humans continuously seek to relate to the destructive reality of death. Therefore, medical-ethical end-of-life questions are about more than euthanasia and 'completed life'. Answers to medical-ethical end-of-life questions also touch on good care. And this is broader than palliative care, as this report shows. Palliative care itself also has room for improvement.

Secondly, we would like to note that in medical ethics and (palliative) end-of-life care, we observe that more and more attention is paid to spirituality. This development is to be appreciated and is in keeping with the tradition from which the Lindeboom Institute practices ethics, namely from a Christian anthropology in which human beings are also seen as spiritual beings. A major emphasis in this report concerns questions about meaning and significance that are inextricably linked to requests for active life termination.

The third preliminary remark concerns the (Protestant) Christian perspective from which this report is written. Meaningfulness, and certainly spiritual care, is approached from a *Christian* perspective. That means it leads back to Jesus Christ. When it comes to death and dying, Christ's resurrection is decisive. In the *resurrection*, Jesus shows that God, out of love and authority, puts an end to death and brings a new creation into existence, giving new life. The resurrection nourishes Christian hope so that Christians do not face death as helpless victims, but as hopeful pilgrims waiting for God to bring death to its final end. The bodily resurrection of Jesus Christ proves that redemption is redemption of creation, not redemption *out of* material created reality and its order. The eloquence of this new life carries far beyond spiritual care, but also beyond for the (medical) ethical approach from a Christian perspective in general. The redemption of created life realised through the resurrection of Jesus Christ provides a strong argument for providing full protection and care to human beings as physical beings, regardless of their capacities or stage of life.[1] Along this line of thought, in this report we aim to erect a 'dam of care' against the increasing flow of requests for active termination of life in the Netherlands.

Thanks

This report was produced through the cooperation of many people. (Co-)author listed under the various chapters is Roy Kloet. In addition, we thank people who critically 'counter-read' various chapters (in alphabetical order): Colinda Adams

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[1] Henk Jochemsen, "Calvinist spirituality and its meaning for ethics," H. Blommestijn, Ch. Caspers, R. Hofman, F. Mertens, P. Nissen, H. Welzen (ed.), Seeing the seeker. Explorations in the discipline of spirituality. Studies in spirituality Suppl 19, (Leuven: Peeters 2008): 463-474.

(Chapter 5), Yvonne Geuze (Chapters 5 and 7), Stef Groenewoud (Chapter 7), Ewoud de Jong (Chapter 6), Johannes de Jong (Chapter 1), Roy Kloet (Chapters 3, 5 and 8), Lydia van Kralingen (Chapter 8), Sandra van de Langemeen (chapter 6), Jos Leijenhorst (chapters 3, 5 and 7), Wieke Ligtenberg (chapter 5), Gerda de Pater (chapter 7), Hanneke Schaap (chapter 6), Wilma Stoelinga (chapter 5) and Jan Piet Vlasblom (chapter 8).

Reading guide
The report begins with an exploration of the state of euthanasia in Europe to provide a European context for the developments in the Netherlands in this regard. The second chapter defines and explores concepts and issues surrounding active termination of life upon request. Chapter 3 builds a bridge to the past by describing the medieval art of dying (*ars moriendi*) and how it can be actualised today. Chapter 4 explores the relatively new discussion on 'completed life'. Chapter 5, 6 and 7 can be read as a representation of Dutch euthanasia practice, roughly following the outline: active life termination in children (chapter 5), active life termination and crustative care within the mental health care (chapter 6), euthanasia and dementia (chapter 7). The report closes with a chapter on the significance of the spiritual caregiver in requests to end life.
For the pronouns he/him, the feminine form she/her can also be read throughout this document.

Arthur Alderliesten
Henk Jochemsen

Note from editors:

This English version is an adaptation of the original Dutch report by Prof. Dr. G.A. Lindeboom Institute, nr. 21. The report has been adapted for distribution outside the Netherlands. This was done by Sallux, the think tank of the European Christian political party ECPM (www.ecpm.info). This with thanks to Jacoline Waaijenberg, Heather Zeiger, Henk Jochemsen and Arthur Alderliesten.

1 Euthanasia in Europe

Arthur Alderliesten

National legislation and healthcare practices are not isolated from their broader context in Europe. In the first section we argue why it is important to take this into account. The second section discusses how Enlightenment thinking manifests in the euthanasia debate in various European countries through the values placed on equality and autonomy/freedom. Here, the motive of control, including in relation to death, plays a major role. Euthanasia laws, if they exist at all in a particular country, vary widely within Europe. The range of situations is described referring to six countries: Belgium, Germany, Italy, Portugal, Spain and Switzerland. Section 4 briefly outlines the concept of human dignity as a counterbalance to further liberalisation of euthanasia laws. Section 5 describes some end-of life developments in Europe. The chapter concludes with a concluding summary.

1.1 The European context

There are several reasons for including the European context in literature reviews of various medical-ethical questions regarding euthanasia and 'completed life' in the Netherlands. I will mention four of them.

Euthanasia is not only a matter of national politics and public policy, but it also has socio-ethical consequences for national societies and medical-ethical implications for healthcare practices. Although healthcare is not a European, but a national issue, the creation of national legislation increasingly takes place in the European context of directives, treaties and international political relations. Countries also take into account other national legislation, where not infrequently precisely progressive legislation like in the Netherlands and Belgium, serve as inspiration for other European countries.

Moreover, in each EU country healthcare is accessible to citizens of all European Union member states. Those who find euthanasia laws too restrictive in their own countries can move to another country with wider euthanasia practices.

Finally, for those practising medical ethics from a Christian perspective in relation to euthanasia in a European context, it makes sense to share knowledge, exchange arguments and perspectives and deploy them in national contexts. Legislation in the area of active termination of life is profoundly affecting the character of the legal system. Legislation allowing euthanasia exemplifies a major revolution, in Buke's terms: "a revolution in sentiments, manners and moral opinions".[2]

1.2 European Enlightenment thinking

There is also a historical and cultural-philosophical reason to view medical ethics in the European context. The euthanasia debate is unthinkable without European Enlightenment thinking. "In the last 50 years, there has been a striking rise of radical libertarian concepts of personal autonomy. The right to self-determination has been enshrined in a succession of court decisions and changes in primary legislation," writes John Wyatt in a Cambridge Paper.[3] "The concept of autonomy has changed from its roots in the European Enlightenment. Kant conceived it as freedom from coercive influences in order to determine the morally correct path by rational deliberation. But this concept has morphed imperceptibly into an individualistic and narcissistic form of self-determination. To modern thinkers, autonomy has become the freedom to do whatever I wish whenever I wish, without rational or moral justification. And it seems self-evident to many that the right to self-determination must include the right to self-destruction.[4] well-known example is the, especially in liberal circles, still authoritative philosopher John Stuart Mill who stated in his famous book, "Over himself, over his own body and mind, the individual is sovereign."[5]

Autonomy cannot be separated from Enlightenment thinking, although the concept of freedom has transformed since then. Andreas Kinneging, a Dutch philosopher, argues that we are now living in the Age of Enlightenment, by which he says that Enlightenment thinking now dominates:

> [I]t is the dominance of the ideals of freedom and equality in our time, at least in the West. Political decision-making, social discussion, and the personal moral views of the vast majority of people are entirely determined by the basic idea that freedom and equality are the core of morality, the Good that must be promoted. Anything that stands in the way of freedom and equality, on the other hand, is evil.[6]

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[2] Cited in: Matthijs de Blois, Henk Jochemsen, "Een kritisch slotperspectief," in P.J. Lieverse, M. de Blois, Th.A. Boer, et al., Dood gewoon. Perspectieven op 35 jaar euthanasie in Nederland, (Amsterdam: Buijten & Schipperheijn, 2005), Lindeboom series 15, 167.

[3] John Wyatt, "Euthanasia and assisted suicide," in Cambridge Papers. Towards a biblical mind 19 no. 2 (2010): 2; https://lawcf.org/resources/library/app/resource/95/title/Euthanasia-and-Assisted-Suicide.

[4] Wyatt, "Euthanasia and assisted suicide," 2.

[5] John Stuart Mill, On Liberty, (Camebridge: Camebridge University Press, 1989), 13.

[6] Andreas Kinneging, De onzichtbare maat. Archeologie van goed en kwaad, (Amsterdam: Pro-

Kinneging later states, “Enlightenment thinking, which emerged in the 17th century and took hold of the West in the second half of the 20th century, is at its core a radical revolt against the European Tradition, born of a total rejection of it.”[7]

However, Groen van Prinsterer, one of the greatest Dutch statesmen, distinguishes another dimension: that of unbelief, Enlightenment thinking as opposition to God with all its consequences for philosophy, images of God, worldviews and human images. “Revolutionary doctrine is the religion of unbelief, to all that rests on faith in negative relation. In generality also of a false philosophy ‘of the science of divine and human things.’”[8]

The influence of Enlightenment thinking in the euthanasia debate also translates more concretely into views of medicine and death. Of particular importance with regard to medical ethics, is the development of the scientific method and the concomitant mechanisation and mathematisation of the prevailing worldview. In the twentieth century, scientific models and technical mastery increasingly influenced and determined the pervading worldview of the West. This worldviews does not leave room for a common public morality. The biomedical view of the human being and the associated sense of life are accompanied by a strong concentration on the immanent world. Modern medicine, to a large extent, suggests that discomfort, illness and suffering can be controlled and managed. Fear of suffering and deterioration evokes a desire for control. Modern, secularised man needs technology. He cannot do without it, that is, he cannot do without the illusion of ultimate control. Related to this is the tendency to repress death, which is, therefore, included in the pursuit of control. In euthanasia, the human being appears not merely as a manager of life and all that belongs to it (illness, suffering), but as a manager of death.[9] Thus, according to professor of health law H.J.J. Leenen, the human right to self-determination forms the basis of the right to determine one’s own end of life. Leenen continues that the basic value of self-determination “would be affected if others (the state, the physician) were allowed to continue life against the person’s will, making it a life without freedom and self-determination.”[10]

It is this view of human life, this worldview, that underpins current developments

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metheus, 2020), 53

[7] Kinneging, De onzichtbare maat, 75.

[8] G. Groen van Prinsterer, Ongeloof en revolutie, (Franeker: Wever, 1976), 138.

[9] H. Jochemsen, G. Glas, Verantwoord medisch handelen. Proeve van een Christelijke medische ethiek, (Amsterdam: Buijten & Schipperheijn, 1997), Verantwoording nr. 13, chapter 1.

[10] Cited in: De Blois, “Een kritisch slotperspectief,” 171.

regarding the right to active termination of life. Legislation is based on majorities that stand for the right to self-determination. This simultaneously curtails the legal protection of human life. New legislation thus exemplifies the fundamental deficit of the Enlightenment concept of the rule of law, write De Blois and Jochemsen.[11] And self-determination acquires the status of "a legal principle: a supporting (moral) ground for a concrete rule of law."[12]

The view of man that emerges from Enlightenment thinking is based on people having certain characteristics and abilities, such as physical features, character traits, and positive or negative experiences in life. These characteristics diminish or even disappear in the case of severe disability, illness, suffering or existential loneliness. In this view, the concept of human dignity is primarily defined by *experienced* dignity. It is not a person's being, but a person's abilities that are decisive so that the experienced dignity is seen as the defining dignity. This vision of human dignity, which dominates European politics, corresponds to the legal vision in which the right to self-determination takes precedence.[13]

Thus, the cultural-philosophical line runs from the Enlightenment to the euthanasia debate, which is conducted at different stages and with varying intensities in Europe among member states. Medical-ethical conflicts within the various national contexts can often—although not always—be traced back to European Enlightenment thinking.

1.3 End-of-life care in several EU member states and Switzerland

Where do the various member states of the European Union stand in their legislation on active termination of life? This section examines the situation of six European countries. Taken together, they form a representative picture of where Europe stands in its diversity with regard to national euthanasia laws.

1.3.1 Belgium

In 2002, Belgium passed a law decriminalising euthanasia in certain situations.[14] This made Belgium, after the Netherlands, the second country in the world to

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[11] De Blois, "Een kritisch slotperspectief," 169.

[12] De Blois, "Een kritisch slotperspectief," 173.

[13] De Blois, "Een kritisch slotperspectief,", 178.

[14] In 2002 heeft België een wet goedgekeurd die euthanasie in bepaalde situaties uit de strafrechtelijke sfeer haalt," Federale Public Health Service of Belgium, Veiligheid van de voedselketen en leefmilieu, accessed January 15, 2022, https://www.health.belgium.be/nl/gezondheid/zorg-voor-jezelf/levensbegin-en-einde/euthanasie.

legalise conditional euthanasia. At the patient's request, a physician may perform euthanasia if all the conditions outlined in the law are met. This request must be expressed by a competent patient who is conscious (actual request) or by a prior written will (patient who is irreversibly unconscious). In both cases, only the patient himself can request euthanasia. Euthanasia is still punishable if it is not performed by a physician or if the physician does not comply with the conditions and procedure laid out by law.

That law defines euthanasia as "the intentional life-ending (medical) act by a person other than the person concerned (i.e. a physician), at the person's request."[15] However, euthanasia is not a right: making a request does not necessarily lead to the realization of euthanasia. Even if all legal obligations are met, the physician is still free to refuse to administer euthanasial. If the physician refuses to do so, he must inform the patient or any trusted representative of this in a reasonable time frame and provide the reasonswhy he refused. The patient can then go to another physician.

In the case of a current request, at the time of his request the patient must:
- Able to make decisions for himself;
- Be in a medically hopeless condition;
- Experience persistent and unbearable physical and/or psychological suffering where that suffering cannot be relieved and is the result of a serious and incurable condition caused by accident or disease.

This request must be:
- Voluntary
- Deliberated
- Repeatedly expressed;
- Free from any external pressure.

In 2014, euathanasia was extended to non-adopted minors. A minor patient wishing to request euthanasia must be of sound mind, physically suffering (psychological suffering is not considered for minors) and must also be in a medically hopeless situation that would lead to death in the foreseeable future. The minor patient's legal representatives must consent to the request.

Any adult or disenfranchised minor (a person under 18 but who is no longer un-

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[15] "Wet betreffende de euthanasie," Belgisch Staatsblad, June 22, 2002, https://www.ejustice.just.fgov.be/mopdf/2002/06/22_1.pdf#Page16.

der parental authority following a decision by a juvenile court) can also draw up a will. A physician committing euthanasia on the basis of a will must establish beforehand that:

- The patient suffers from a serious and incurable condition caused by accident or disease;
- The patient is unconscious (coma or vegetative state);
- This condition is irreversible according to the state of science.

Non-disenfranchised minors cannot use such a will.

The function of the monitoring and evaluation commission has been criticised. In 2015, for instance, the Dutch ethicist Theo Boer indicated that the committee's chairman, Distelmans, would be untenable in other countries because he interfered with the public debate on euthanasia for mental disorders.[16] The fact that in the commission's first 13 years of operation, only one case was forwarded to the public prosecutor's office also raises questions.[17]

In Belgium, there is debate about 'completed life' as grounds for euthanasia. People in old age who feel that their lives no longer serve any purpose and are 'completed' or grow weary of life when they see their peers dying, sometimes see their lives as not having value and called for assistance in dying. However, the Belgian Advisory Committee on Bioethics ruled in September 2017 that life fatigue or 'completed life' cannot be a basis for euthanasia under the 2002 law. [18]

In a 2021 report, three researchers affiliated with the University of Ghent pointed out a number of shortcomings in the Belgian law, its application and the monitoring of practice.[19] The researchers argue that a broadening of the use of euthanasia is occurring in Belgium and that this can be ethically and legally problematic. This is partly due to the fact that various legal provisions that are intended as safeguards and procedural guarantees often do not work in reality. The study

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[16] Theo Boer, "Positie van Distelmans zou elders onhoudbaar zijn," De Morgen, December 13, 2015, https://www.demorgen.be/meningen/positie-van-distelmans-zou-elders-onhoudbaar-zijn~bbb69391/.

[17] An Haekens, "Ga de dialoog aan, Distelmans!," De Morgen, December 14, 2015, https://www.demorgen.be/meningen/ga-de-dialoog- aan-distelmans~bbde4843/.

[18] Belgisch Raadgevend Comité voor Bio-ethiek, Advies nr. 73 van 11 september 2017 betreffende euthanasie in geval van niet-terminale patiënten, psychisch lijden en psychiatrische aandoeningen, https://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/advies_73_euthanasie.pdf.

[19] Kasper Raus, Bert Vanderhaegen, Sigrid Sterckx, "Euthanasia in Belgium: Shortcomings of the Law and Its Application and of the Monitoring of Practice," The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine 46 no. 1 (2021): 80–107, https://doi.org/10.1093/jmp/jhaa031.

points to shortcomings in theory and practice in three types of safeguards or procedural guarantees:

1. The legally defined standards to qualify for euthanasia;
2. Consulting a second (and sometimes third) physician;
3. Reporting euthanasia cases to the Federal Control and Evaluation Commission for Euthanasia.

1.3.2 Germany

The euthanasia debate in Germany is fraught by history and emotional. In the Third Reich, 'Euthanasia' (or: 'Gnadentod') stood for the systematic killing of races and groups for eugenic reasons.20 This is different from euthanasia as it is discussed in Dutch and Belgian law which assumes 'informed consent' and a request from the patient. Germans, therefore, do not speak of 'Euthanasia' but 'Sterbehilfe'.21

Until December 2015, assisted suicide was not a criminal offence, as suicide did not qualify as a criminally wrongful act.22 The legal situation was basically without problems. This changed after the introduction of section 217 of the Criminal Code: "Geschäftsmäßige Förderung der Selbsttötung"23 , which criminalised assisted suicide. However, this only lasted until February 2020, after years of litigation by euthanasia associations, physicians and seriously ill patients. Just over four years after its introduction, the Federal Constitutional Court declared the law relating to "promoting assisted suicide on a business basis" unconstitutional and null and void.24

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20 Robert Jay Lifton, Nazi-dokters. De psychologie van de rassenmoord in het Derde Rijk, (Utrecht/Aartselaar: A.W. Bruna & Zoon, 1987); Robert N. Proctor, Racial hygiene. Medicine under the nazis, (London: Harvard University Press, 1988).

21 For a German contribution to reflection on euthanasia see: Friedrich-Ebert-Stiftung Gesprächskreis Sozialpolitik, Humane Sterbebegleitung versus aktive Sterbehilfe (Bonn: Wirtschafts- und sozialpolitischen Forschungs- und Beratungszentrum der Friedrich-Ebert-Stiftung, Abteilung Arbeit und Sozialpolitik, 2006). For a reflection of H. Jochemsen on the Dutch euthanasia experience see pages. 56-61. See: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://library.fes.de/pdf-files/asfo/03628.pdf.

22 Jean-Pierre Wills, Sich den Tot geben. Suizid als letzte Emanzipation, (Stuttgart: Hirzel, 2021), 80-89; Marja Verburg, "Rechters: Euthanasiewet in strijd met grondwet," Duitslandinstituut, accessed January 13, 2022, https://duitslandinstituut.nl/artikel/35772/rechters-euthanasiewet-in-strijd-met-grondwet.

23 Bundesministerium der Justiz/Bundesamt für Justiz, Strafgesetzbuch (StGB). § 217 Geschäftsmäßige Förderung der Selbsttötung, accessed January 13, 2022, https://www.gesetze-im-internet.de/stgb/__217.html.

24 BVerfG, Urteil des Zweiten Senats vom 26. Februar 2020 - 2 BvR 2347/15 -, Rn. 1-343, accessed January 13, 2022, http://www.bverfg.de/e/rs20200226_2bvr234715.html.

Many physicians opposed this law from the beginning because their legal position was unclear. The court's ruling allows them to help patients who want to die, but unlike in the Netherlands, physicians in Germany are not allowed to administer lethal drugs to patients. This is laid out in Section 216, which is still enforced. The patient must take the lethal drugs himself.

With the annulment of Section 217 of the Criminal Code, euthanasia associations were also vindicated by the court. They complained against the law because it made it impossible for them to do their work in Germany. Since Section 217 is now no longer valid, the restriction for these organisations is removed.
In connection with the lifting of the ban, the court called on politicians to ensure that assisted suicide is once again regulated by law. However, so far, nothing has happened. Therefore, assisted suicides currently still take place in a legal grey area in Germany.

'Passive' and 'indirect' euthanasia, 'sham' forms of euthanasia, are allowed in Germany. Passive euthanasia is the renunciation of life-extending measures by a competent patient. This includes, for example, waiving nutrition, blood transfusion or artificial ventilation. Indirect euthanasia is primarily aimed at pain relief. In this context, if the patient is administered drugs that make him or her die earlier, this is allowed in Germany and is called 'indirect euthanasia'. This is a confusing term because, providing medication is good when there is no intentional termination of life.

At the time when Section 217 was being debated in Germany politics in 2015, the German public spoke out. A broad survey[25] showed that 38 per cent of respondents were in favour of allowing assisted suicide. 43 per cent were even in favour of allowing active euthanasia. 12 per cent opposed both forms of euthanasia on principle. There is strong opposition to euthanasia (and thus agreement with the nullification of the euthanasia law) by churches. They fear a "normalisation of suicide as a treatment option" and that old or sick people may feel pressured to end their lives. The two largest church denominations spoke out against euthanasia and advocated for human dignity and a focus on palliative care.[26]

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[25] „Schäuble ist beliebt wie nie," Tagesschau, accessed January 13, 2022, https://www.tagesschau.de/inland/deutschlandtrend/deutschlandtrend-339.html.

[26] Bilatere Arbeitsgruppe der Deutschen Biscofskonferenz und der Vereinigten Evangelisch-Lutherischen Kirche Deutschlands, Gott und die Würde des Menschen, (Paderborn/Leipzig: Bonifatius/Evangelische Verlagsanstalt, 2017); https://www.ekd.de/gemeinsame-erklaerung-dbk-und-ekd-zum-urteil-selbsttotung-53539.htm.

1.3.3 Italy[27]

In Italy, there is no specific law on euthanasia. Article 580 of the Penal Code deals with the murder of a competent person, which is always prohibited and punishable. Organisations close to the Partito Radicale (Italian political party) have collected one and a half million signatures in support of a referendum to amend this article so that it will prohibit the killing of consenting persons only in certain cases. On February 2, 2022, the Legal Euthanasia Referendum was declared inadmissible: the Constitutional Court declared that the reform on end of life would not guarantee the necessary protection "of human life."[28]

Italian cultural orientation has now changed profoundly since 2009, and the right to die is more accepted by people, especially young people.

The debate on end-of-life and the right-to-die started about 20 years ago in Italy. It has come up in response to some cases (individual situations of seriously ill or disabled people) in which courts have ruled after lengthy legal disputes. These cases provoked a public debate. The outcomes of these cases have repeatedly changed the cultural and legal framework. The timeline features three names: Piergiorgio Welby, Eluana Englaro, Fabiano Antoniani (known as DJ Fabo). Their histories are long and complex. In this section, we limit ourselves to describing the outcomes of the legal disputes and their impact on this topic.

Piergiorgio Welby was a radical party activist who suffered from muscular dystrophy. In 2006, he publicly asked the president of Italy for euthanasia. He knew this would not be possible. Therefore, he asked for and received suspension of the ventilator that kept him alive. After his death, the removal of the ventilator was recognised as legal and ethical. As a result of this case, the request to withhold or withdraw therapies, in particular life-sustaining treatments (such as artificial ventilation), is generally justified on a moral level when the patient can consciously and freely give his informed consent, even if withdrawing treatment leads to his death.

Eluana Englaro was in a car accident when she was nineteen years old. As a result, she lived in a vegetative state for seventeen years. She was not sick, apparently did not interact with her environment, breathed independently and needed artificial nutrition and hydration. Her parents, especially her father, wanted to stop these life-sustaining treatments. They stated that this would have been Eluana's wish

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[27] With gratitude to Assuntina Morresi.

[28] Maricla Marrone, et al., Italian Legal Euthanasia: Unconstitutionality of the Referendum and Analysis of the "Italian" Problem, Front Sociol. 2022; 7: 898783, doi: 10.3389/fsoc.2022.898783

had she been able to talk. However, she had never written anything on the subject. Her wishes were only reported by her parents and some friends. After a long legal dispute—and after reconstructing Eluana's wishes based on some testimonies—the court allowed her artificial nutrition and hydration to be discontinued. After the court's decision, an important public and political battle began. Several Italian institutional authorities were involved including mayors of cities, presidents of regions, and the entire parliament. In parliament, it was a clash between Prime Minister Silvio Berlusconi and President Giorgio Napolitano. Berlusconi and his ministers wanted to save Eluana (i.e., keep her alive), while Napolitano wanted to enforce the court's ruling. Hydration and nutrition were stopped and, as a result, Eluana died in February 2009. Meanwhile, in an unprecedented quick process, parliament tried to pass a law to save her. Her death was not perceived as a victory by the majority of Italians. After that, no end-of-life law was approved for a long time.

DJ Fabo was a young man who was left paralysed and blinded after a car accident. He requested suicide assistance from a Swiss clinic in February 2017. He went to Switzerland with Marco Cappato, an spokesman of the Partito Radicale, who then self-reported this and started a legal dispute. In December 2017, the Italian parliament passed a law on informed consent and 'advance treatment dispositions', built around the concept of total patient self-determination. With this law, it is possible to refuse and suspend treatments, including life support, even without clinical grounds and only based on the patient's desire. Under this law, withdrawing life support is never considered euthanasia, even if it results in death. During these court proceedings, the Constitutional Court ruled that assisted suicide is not a crime in certain circumstances and the Italian penal code was amended accordingly. In March 2022 the Chamber of Deputies gave the green light to a law based on this ruling, called the "Provisions on medically assisted voluntary death".[29] The proposal will be argued in the Senate.

1.3.4 Portugal

A euthanasia law does not come easily. Because of the deeply entrenched values at stake, the creation of euthanasia legislation can lead to complicated political processes. This is evident in Portugal's recent political history where the process is currently underway to pass more liberal euthanasia legislation. An important step was taken in February 2020 when the Portuguese parliament agreed to legalise euthanasia and assisted suicide of terminally ill patients by physicians. Less than a year later, in January 2021, this assent resulted in the adoption of a euthanasia

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[29] https://www.agenzianova.com/en/news/end-of-life-here-is-what-the-text-approved-by-the-chamber-provides/

law. However, this law could not come into force until the president, Marcelo Rebelo de Sousa, signed it. The president sent the law to the constitutional court before he would sign it. This court declared the law unconstitutional, due to a lack of precision in the eligibility criteria for euthanasia, such as the concept of 'serious condition'.[30] President Rebelo de Sousa already said when the law was submitted to him that the text was "exceptionally vague" about what was to be understood by "unbearable suffering without prospect "; wording that had been copied from Dutch euthanasia legislation. The majority of judges (seven against five) shared the president's doubts. Their criticism came down to the fact that the situations in which life-ending acts would be allowed were not defined precisely enough. According to Presiding Judge Joao Caupers, the grounds must be "clear, precise, predictable and verifiable". The Portuguese constitution calls the right to life "inviolable." The president had requested a special test of this. The court weighed this article heavily, but at the same time said a right to life should not be understood as a "duty under all circumstances". Afterwards, parliament faced the task of amending the law in response to the criticisms made.

A further step was taken on 5 November 2021 when parliament passed a renewed euthanasia law with a majority (60%) of MPs present. The term "serious condition" is defined in the new version of the law as a condition that is "incurable and so disabling that it makes the applicant dependent on others or on technological means in the performance of daily tasks."[31] However, the president vetoed the bill on 30 November 2021, saying the included conditions for allowing "medically assisted death" were too vaguely defined and were also deemed too radical by him.[32] The president stated, "The bill says in one clause that permission for expected death requires a 'fatal illness' but elsewhere broadens it to include 'incurable illness' even if it is not fatal, and only 'serious illness' in another clause. "In addition, he questioned whether the euthanasia law "does not represent a view that is more radical and drastic than the dominant view in Portuguese society."[33]

How does the Portuguese population feel about this? Of the population, 50.5%

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[30] "Portugal: Euthanasiewet ongrondwettelijk verklaard," European Institute for Bio-ethics, accessed January 14, 2022, https://www.ieb-eib.org/nl/nieuws/einde-van-het-leven/euthanasie-en-geassisteerde-zelfmoord/portugal-euthanasiewet-ongrondwettelijk-verklaard-1972.html.

[31] "Portugese parlementsleden keuren nieuwe versie van euthanasiewet goed," European Institute for Bio-ethics, accessed January 14, 2022, The new Spanish law on euthanasia contested against the Constitutional Court a few days before its entry into force - European Institute of Bioethics (ieb-eib.org).

[32] "Portugese president stelt veto tegen euthanasiewet," PaLNWS, accessed January 14, 2022, https://palnws.be/2021/11/portugese- president-stelt-veto-tegen-euthanasiewet/.

[33] PALNWS, "Portugese president stelt veto"; see note 32.

support introduction of legislation and over 25% are opposed.[34] In May 2023 a euthanasia law was finally adopted.[35]

1.3.5 Spain[36]

Since June 2021, Spain has had a law in place regulating medically assisted dying.[37] This made Spain the eighth country in the world to legalise assisted suicide and active euthanasia (and the fourth EU member state), after the Netherlands, Belgium and Luxembourg, Canada, Colombia, New Zealand and some Australian states.[38] As stated in the decree, this law aims to regulate the right of anyone who meets the required conditions to request and receive the necessary assistance in dying, granted the required procedures and safeguards have been observed. The law permits euthanasia ("direct administration of a substance to the patient by the competent healthcare professional") and assisted suicide ("prescription or provision by the healthcare professional of a substance that the patient himself can administer to cause his own death").

In the first twelve months since the introduction of this legislation in Spain, 336 individuals have requested assistance to terminate their lives; 180 of these requests have been carried out.[39]

To qualify for assisted dying, the person must meet all the following requirements:

- Have Spanish nationality or be a legal resident in Spain, be of age, knowledgeable and able to give consent at the time of application;

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[34] Aart Hendriks, "Euthanasie in Zuid-Europa. Nieuwe jurisprudentie en wetsvoorstellen," Nederlands Juristenblad nr. 24 (2020): 1738.

[35] https://www.reuters.com/world/europe/out-vetoes-portugal-president-enacts-law-allowing-euthanasia-2023-05-17/

[36] With gratitude to Christina Montforte en Albert Balaguer Santamaría.

[37] Ministerio de la presidencia relaciones con las cortes y memoria democratie, Ley Orgánica 3/2021, de 24 de marzo, de regulación de la eutanasia," in Boletín oficial des estatdo, March 25, 2021, https://www.boe.es/boe/dias/2021/03/25/pdfs/BOE-A-2021- 4628.pdf.

[38] "Nieuwe Spaanse euthanasiewet enkele dagen voor inwerkingtreding aangevochten voor het Constitutioneel Hof," European Institute for Bio-ethics, accessed January 12, 2022, https://www.ieb-eib.org/nl/nieuws/einde-van-het-leven/euthanasie-en-geassisteerde- zelfmoord/nieuwe-spaanse-euthanasiewet-enkele-dagen-voor-inwerkingtreding-aangevochten-voor-het-constitutioneel-hof- 2025.html?backto=pays-es, "Spanje legaliseert als vierde EU-lidstaat euthanasie," Medisch contact, accessed January 12, 2022, https://www.medischcontact.nl/nieuws/laatste-nieuws/nieuwsartikel/spanje-legaliseert-als-vierde-eu-lidstaat-

[39] Sergio Ramos-Poz´ona et al., "Persons with mental disorders and assisted dying practices in Spain: An overview", International Journal of Law and Psychiatry 87, (March–April 2023), 101871, p.2 https://www.sciencedirect.com/science/article/pii/S0160252723000146

- Have information about his medical care, alternatives to and options of his request, including access to extended palliative care and benefits for dependents;
- Request euthanasia twice in writing (or by other means if the person cannot write), at 15-day intervals and with an explicit statement that the request is not the result of any external pressure. After the initial request, the patient's attending physician must discuss with the requesting patient his diagnosis, possible therapies,palliative care, and make sure that the patient understands the information provided to him. Thereafter, the patient should confirm his intention;
- Suffer from a serious and incurable illness or a serious, chronic and incapacitating condition within the meaning of this Act, certified by the physician in charge;
- Give his informed consent before receiving assisted dying.

The patient must have the agreement of his attending physician. This physician must seek the opinion of another physician that specializes in the patient's condition(s). The second physician must not belong to the same medical team as the attending physician. Subsequently there is an evaluation committee that will appoint two experts, one of whom is a lawyer, to evaluate the approval. If both agree, the process continues. If not, the full committee decides. Once it is decided that the request is justified, the attending physician is informed so that he or she can grant a request for euthanasia or assisted suicide. If the request is denied at any point, the patient can appeal to the committee.

In addition to the ethics of the issue itself, there are at least three legal issues of concern:

1. Lack of clarity without the legal provision of a judge which in Spain is always the guarantor of the law in relevant situations (e.g. inviolability of residence, removal of remains, involuntary hospitalisation, etc.). The presence of a judge is essential in these procedures to protect citizens from possible abuses;
2. A family member or the physician may request euthanasia if they consider the patient incompetent (without going through the usual procedure of 'legal incapacity'). If the physician deems it necessary, he or she may decide to shorten the established time limits;
3. The law provides that "death as a result of assisted dying is legally considered a 'natural death' for all purposes, regardless of the codification carried out. This will make it difficult or impossible to investigate cases of suspected abuse or illegal action.

The soundness of this law has been strongly questioned by certain professional groups, in particular, by the *Consejo General de Colegios Oficiales de Médico* (CGCOM), the general council of official medical associations in Spain and the Bioethics Committee of Spain, an advisory body dependent on the Health Ministry. Both institutions have pointed out the negative consequences of this type of law and the lack of social consensus to enact it.

Other groups have pointed out that the government made unusual haste to get the law passed, taking advantage of the pandemic, without consulting health experts and without having previously enacted a palliative care law or procedures to ensure its widespread application.

1.3.6 Switzerland

Euthanasia is illegal in Switzerland under Article 114 of the Schweizerisches Strafgesetzbuch: “Whoever, out of praiseworthy motives, in particular compassion, kills a person at his or her sincere and insistent request, shall be punished by deprivation of liberty for a term not exceeding three years or by a fine.” The next article of the law prohibits assisted suicide for “selfish motives” (Article 115). Whoever violates this law risks imprisonment for up to five years or a fine. However, this wording also implies that assisted suicide is allowed when the person assisting the suicide has good intentions and does not actually perform the act leading to death (e.g., injecting drugs).

In Switzerland, deliberate killing is not synonymous with murder. A person who intentionally kills another is guilty of intentional killing (‘vorsätzliche Tötung’). This is escalated to murder (‘Qualifizierung’) only if it can be shown that the perpetrator acted from a ‘reprehensible motive’. In certain circumstances, the offender will be guilty of a lesser degree of murder (‘Privilegierung’).[40]
Euthanasia in Switzerland, therefore, amounts to assisted suicide. Euthanasia, in which a physician administers a lethal infusion, is not allowed. Helping someone to kill himself is allowed. Switzerland has six organisations that offer death assistance. They work with physicians who prescribe the lethal drug. Patients themselves take the lethal drink or infusion.[41]

Five of the six (commercial) aid-in-dying organisations in Switzerland have re-

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[40] Christian Schwarzenegger, Sarah J. Summers, “Criminal Law and Assisted Suicide in Switzerland,” Universität Zürich, accessed January 14, 2022, https://www.ius.uzh.ch/dam/jcr:00000000-5624-ccd2-ffff-ffffa664e063/assisted-suicide-Switzerland.pdf.

[41] Marten van de Wier, “In Zwitserland loopt nu een eenvoudige route naar de dood,” Trouw, January 8, 2021, https://www.trouw.nl/buitenland/in-zwitserland-loopt-nu-een-eenvoudige-route-naar-de-dood~b54a473d/.

quirements similar to the Dutch requirements . The sixth, Pegasos, is more liberal and is therefore seen as ‘interesting’ to, for example, Dutch people who wants euthanasia, but for whom the requirements in the Netherlands are too strict.42 Because a Swiss physician often has only one or two conversations with a foreign patient shortly before dying, Govert den Hartogh, professor emeritus of ethics at the University of Amsterdam, describes this process as “ethically problematic”:

“I wonder if that conversation is more than a formality: once Pegasos has taken on the client on the basis of correspondence, the case has actually already been concluded. The Swiss system largely facilitates this course of action. But Pegasos is also pushing the limits of that system.”

Jean-Pierre Wils points out that the number of assisted suicide cases in Switzerland has risen steadily and significantly in recent years and fears that this is “a new normal”.43 The number of assisted suicide cases in Switzerland approached 1 in 50 deaths in 2018. While the total number of suicides has remained stable at just over 1,000 per year since 2010, the number of assisted suicides more than tripled to 1,176 cases in 2018 compared to 2010. Compared to the previous year, the increase was 17%. This cause accounted for 1.8% of all deaths in Switzerland in 2018 and was thus more common than unassisted suicide.44 (By comparison, there were 6,126 reports of euthanasia in the Netherlands in 2018, corresponding to 4.0% of the total number of deaths in the Netherlands.45)

In the canton of Valais, nursing home patients are allowed to request assisted suicide. There is also talk of assisted suicide in prisons.46 The ethical guidelines on dying and death drafted by the Swiss Academy of Medical Sciences (SAMS) determined in June 2018 that assisted suicide is also allowed for non-fatal illnesses.47

The effect of Switzerland’s liberal legal situation is that the aforementioned aid-

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42 Van de Wier, “Eenvoudige route naar de dood.”

43 Wils, Sich den Tob geben, 78.

44 „Häufigste Todesursachen bleiben im Jahr 2018 stabil - assistierter Suizid nimmt stark zu,“ Schweizerische Eidgenossenschaft, accessed February 4, 2022, https://www.bfs.admin.ch/asset/de/15084042

45 KNMG, Euthanasie in cijfers, 2019, https://www.knmg.nl/infographic-euthanasie/.

46 Wils, Sich den Tob geben, 78, 79.

47 Schweizerische Akademie der Medizinischen Wissenschaften (SAMW), Medizin-ethische Richtlinien. Umgang mit Sterben und Tod, 25, https://www.samw.ch/de/Ethik/Themen-A-bis-Z/Sterben-und-Tod.html.

in-dying clinics operate independently, without cooperating with each other.48 Switzerland has become a haven for people from all over the world who want to die, but for whom euthanasia laws in their home country are perceived to be too restrictive. It is not without reason that there is talk of 'death or suicide tourism'.49 Although there are dissenting voices among critics and ethicists, it does not appear that national politics will take restrictive steps.

1.4 European perspective

Critics of euthanasia, especially in southern and eastern Europe, usually oppose the liberalisation of euthanasia and assisted suicide from moral-philosophical positions from a Roman Catholic perspective. Often, an appropriate response can be found in giving more attention to palliative care.[50]

An important ethical principle within the European context is found in the beginning of the Charter of Fundamental Rights of the European Union, signed by Member States on 7 December 2000 in Nice[51] :

> Article 1
> **Human dignity**
> Human dignity is inviolable. It must be respected and protected.
>
> Article 2
> **Right to life**
>
> 1. Everyone has the right to life.
> 2. No one shall be condemned to the death penalty, or executed.

Human dignity as a fundamental right of the European Union can be brought

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48 Anita Kovacevic, Christian Bartsch, „Suizidbehilfe in der Schweiz,“ in Sozialpolitik CH 1 (2017): 9.

49 Saskia Gauthier, Julian Mausbach, Thomas Reisch, Christine Bartsch. "Suicide tourism: a pilot study on the Swiss phenomenon," J Med Ethics 41 (2015): 611-617, DOI: 10.1136/medethics-2014-102091.

50 Palliative care for older people in care and nursing homes in Europe (PACE) project, Palliative care for dignity in old age. Addressing the Needs of Older People in Long-Term Care Facilities in Europe, (2019), https://cordis.europa.eu/docs/results/603/603111/final1-pace-policy-recommendations-booklet-final.pdf.

51 Charter of fundamental rights of the European Union, (2000/C 364/01) signed on December 7, 2000 in Nice by the Member States of the EU, https://www.europarl.europa.eu/charter/pdf/text_en.pdf.

into the euthanasia debate.[52] It thus constitutes an interesting perspective[53] for the coming years when the euthanasia debate will continue to come up in Europe.[54] These articles with which the charter opens align with human dignity in the preambles of the Universal Declaration of Human Rights and in a number of key UN human rights treaties.[55]

In my view, a key for dialogue and actualisation of the concept of human dignity lies in a philosophical, theological and ethical approach that seeks a renewed meaning of human dignity as a key legal principle. This would not be from the secular view of human dignity based on human capabilities, but from the view in which human dignity is seen as inherent to being human. From this perspective, the dignity of human life is not dependent on physical or mental abilities. People—including the unborn and battered at the end of life—possess human dignity and are therefore worthy of protection. In this *given* dignity lies an appeal to promote *perceived* dignity to the best of one's ability and not to use it as a criterion for the worthiness of life.[56] Human dignity is, again in the words of De Blois and Jochemsen, the "articulation of the recognition of the human being as a creature created in God's image and likeness, a starting point of Judeo-Christian morality. Human dignity understood in the light of its historical, religious and philosophical roots, indicates that man deserves respect, because his existence, as such, has meaning, even when that person himself is not convinced of it. (...) For medical ethics and health law, it seems to us of fundamental significance that human dignity and not individual self-determination is paramount in an enumeration of human rights. Human dignity is a given; it is not an acquisition that can be relinquished."[57]

It is of eminent importance that the debate in member states on the relationship between the right to self-determination and human dignity is conducted. How the debate on these sensitive ethical issues is conducted in member states has

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[52] Henk Jochemsen, "Biotech and public policy. The European Debate," in Charles W. Colson, Nigel M. de S. Cameron (ed.), Human Dignity in the Biotech Century. A Christian Vision for Public Policy, (Illinois: Intervarsity Press, 2004), 217-220.

[53] Charles C. Camosy, Losing our Dignity. How Secularised Medicine Is Undermining Fundamental Human Equality, (New York: New City Press. 2021).

[54] "Euthanasia/Assisted Suicide in Europe: Law, Policy & Future," in: A European Pro-Life Strategy, (Amersfoort: Sallux, 2021), 48-91, Sallux, Pro-Life in Ireland and Europe, (Amersfoort: Sallux, 2021).

[55] See, for example, the International Covenant on Civil and Political Rights (1966) and the International Covenant on Economic, Social and Cultural Rights (1966).

[56] De Blois, "Een kritisch slotperspectief," 178.

[57] De Blois, "Een kritisch slotperspectief," 174.

implications for the EU. If the euthanasia debate incites a culture clash, it will not benefit the EU. It is important that the primacy of human dignity does not come under pressure in EU member states. It is rightly argued that the erosion of fundamental rights in member states also promotes erosion of the EU as a community of values. This would undermine how the rule of law functions in the EU. The same applies to the principles on which these fundamental rights rest. If the underlying principles stagger, fundamental rights will be affected. If the primacy of human dignity erodes in member states it will not be without consequences for the EU.

This is all the more true now since the Covid-19 pandemic, and the EU's steps towards a ' European Health Union'.[58] This means that developments in medical ethics are no longer separate from the EU. In this context, an interesting development is the European Commission's commitment to disease prevention and managining cancer. This means that the European Health Union goes beyond, for example, the joint procurement of vaccines. With the Commission taking steps in concrete healthcare, debates in medical ethics are becoming increasingly important for EU policy. In this respect, we are only at the beginning of a development whose course is very much dependent on the political tide in the EU and in the EU member states. This is precisely why it is now necessary to more strongly emphasise the importance of developments in medical ethics for the EU. The initiation of the European Health Union, has made the primacy of human dignity even more important for European policy.

1.5 Developments at European level

Though the direct debate on euthanasia is not currently being conducted at the level of the EU, developments can be identified at the broader level of Pan-European institutions. This applies primarily to developments within the European Court of Human Rights (ECHR) and the Parliamentary Assembly for the Council of Europe.

1.5.1 Resolution against euthanasia in the Parliamentary Assembly for the Council of Europe

The primary function of the Council of Europe (CoE) is the protection of human rights as enshrined in the European Convention for the Protection of Human

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[58] "European Health Union," European Commission, accessed September 21,2023, https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/promoting-our-european-way-life/european-health-union_en

Rights and Fundamental Freedoms (ECHR).[59] Virtually all countries on the European continent are members of the Council of Europe. The CoE has its own Parliamentary Assembly of the Council of Europe (PACE) comprised of parliamentarians from the national parliaments of CoE member countries. [60]

In 1999, a PACE recommendation was adopted calling on member states to reject euthanasia.[61] The following call was part of the recommendation:

> "...recommends the Committee of Ministers encourage the member states of the Council of Europe to respect and protect the dignity of terminally ill or dying persons in all respects:
> (...)
> C. by upholding the prohibition against intentionally taking the life of terminally ill or dying persons, while:
> 9.3.1. recognising that the right to life, especially with regard to a terminally ill or
> Dying person, is guaranteed by the member states, in accordance with Article 2 of the
> European Convention on Human Rights which states that "no one shall be deprived of his life intentionally";
> 9.3.2. recognising that a terminally ill or dying person's wish to die never constitutes any legal claim to die at the hand of another person;
> 9.3.3. recognising that a terminally ill or dying person's wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death."

1.5.2 Resolution on Palliative Care in the Parliamentary Assembly for the Council of Europe

In 2018, PACE adopted a resolution urging member states of the CoE to improve palliative care. This resolution was tabled by Senator Ronan Mullen from Ireland.[62]

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[59] Europa Nu, "Raad van Europa (RvE)", Raad van Europa (RvE) - Europa Nu (europa-nu.nl).

[60] Europa Nu "Parlementaire Vergadering van de Raad van Europa", Parlementaire Vergadering van de Raad van Europa - Europa Nu (europa-nu.nl).

[61] PACE Recommendation 1418 (1999) 'Protection of the human rights and dignity of the terminally ill and the dying' Assembly debate on 25 June 1999 (24th Sitting) (see Doc. 8421, report of the Social, Health and Family Affairs Committee, rapporteur: Mrs Gatterer; and Doc. 8454, opinion of the Committee on Legal Affairs and Human Rights, rapporteur: Mr McNamara). Text adopted by the Assembly on 25 June 1999 (24th Sitting), https://assembly.coe.int/nw/xml/XRef/Xref-XML-2HTML-en.asp?fileid=16722.

[62] PACE resolution, 'The provision of palliative care in Europe' Text adopted by the Standing Committee, acting on behalf of the Assembly, on 23 November 2018 (see Doc. 14657, report of the Committee on Social Affairs, Health and Sustainable Development, rapporteur: Mr Rónán Mullen). https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=25214&lang=en

For the purposes of this publication, the following statements of this resolution are relevant:

> 1. The Parliamentary Assembly recognises that palliative care is fundamental to human dignity and a component of the human right to health.
> [...]
> 3. Echoing its resolution 1649 (2009), *Palliative care: a model for innovative health and social policy*, the Assembly stresses that palliative care should be available not just to the terminally ill, but also to the chronically ill and to persons requiring a high level of individual care who would benefit from the palliative care approach. With an ageing population, living longer and with more years of chronic illness and pain, a substantial increase in palliative care needs can be anticipated in the coming years.
> [...]
> 7. In view of the above, the Assembly calls on the Council of Europe member states to take the following measures with a view to strengthening palliative-care services and ensuring access to quality palliative care for both adults and children who need it:
> 7.1 Recognise palliative care as a human right, define it as part of the health-care system and dedicate the necessary resources to it.

In this resolution, we see that one of the goals of palliative care is to uphold the dignity of patients and their families by alleviating suffering. This underlines the earlier position that the debate around the end of life is ultimately a debate about what it means to uphold human dignity. Therefore, in paragraph 7.1 PACE calls for this vision of palliative care to be implemented in CoE member states. In addition, the resolution calls for palliative care to be expanded as part of chronic care.

1.5.3 ECHR (European Court of Human Rights) judgments

Over the past two decades, attempts have been made to legalise euthanasia and assisted suicide through the mechanism of the European Court of Human Rights (ECHR). So far, all attempts to legalise active euthanasia and assisted suicide for all of Europe through this route have failed. In a number of cases, the ECHR has declared this explicitly.

In the case of Pretty vs United Kingdom, the ECHR ruled in 2002 that there is no right to euthanasia based on the ECHR precedents.[63] The case of Haas vs Switzer-

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[63] CASE OF PRETTY v. THE UNITED KINGDOM Application no. 2346/02 Final Judgement ECHR.

land (2011) confirmed the same line of thinking.[64]

More recently, there has been a development in the ECHR that does not quite point to a reversal of previous rulings, but rather to a more emphatic role in the considerations for why Member States allow euthanasia (Koch v Germany, Gross v Switzerland, Lambert v France).[65] [66] [67] This again shows the interaction between what happens in Europe at the national level in terms of medical ethics and what happens at the European level.

1.6 Concluding summary

Concerning euthanasia, it is important to consider medical ethics in the broader European context in light of what happens between various EU member states. But no less so because of the spirit of Enlightenment thinking, inlfuenced by postmodern subjectivist individualism, which manifests itself dominantly within Europe in the euthanasia debate in values such as equality and freedom/autonomy.

The process of drafting legislation regarding euthanasia varies from one EU member state to another, as does the legislation itself in terms of content. Some countries, such as the Netherlands and Belgium, are progressive and ahead of the rest of Europe, although this is not without criticism. In these countries, further broadening of euthanasia legislation, which now focuses on active termination of life for ‘completed life’, is being considered within the political and social movements. On the other hand, there are countries where (active) euthanasia is banned, and social and political debates are emotional. Sometimes opposition to liberalisation stems from a conservative Christian tradition (e.g., Italy, Portugal), whereas in Germany opposition comes from a sensitive past for the subject. Spain has only very recently legally regulated euthanasia and assisted suicide, but there is still unrest and the first practical data have yet to be published. A special place is held by Switzerland, which leaves so much room for commercial organisations in assisted suicide that it has a pull effect (‘death tourism’) on citizens from other European countries.
An important perspective with which to build a dam against the further liberalisation of euthanasia in Europe is the concept of human dignity, as enshrined in

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[64] CASE OF HAAS v. SWITZERLAND (Application no. 31322/07) Final Judgement ECHR.

[65] CASE OF KOCH v. GERMANY ((Application no. 497/09) Final Judgement ECHR.

[66] CASE OF GROSS v. SWITZERLAND (Application no. 67810/10) Final Judgement ECHR.

[67] CASE OF LAMBERT AND OTHERS v. FRANCE (Application no. 46043/14) Final Judgement ECHR.

the Charter of Fundamental Rights of the European Union: “Human dignity is inviolable. It must be respected and protected.”

Sources

- “Wet betreffende de euthanasie.” in *Belgisch Staatsblad,* June 22, 2002. https://www.ejustice.just.fgov.be/mopdf/2002/06/22_1.pdf#Page16.
- Alderliesten, Arthur. “Dietrich Bonhoeffer en de bio-ethiek van het levensbegin,” Masterthesis, Theological University Kampen, 2021
- Sergio Ramos-Poz´ona et al., “Persons with mental disorders and assisted dying practices in Spain: An overview”, International Journal of Law and Psychiatry 87, (March–April 2023), 101871, p.2 https://www.sciencedirect.com/science/article/pii/S0160252723000146
- Belgisch Raadgevend Comité voor Bio-ethiek. *Advies nr. 73 van 11 september 2017 betreffende euthanasie in geval van niet-terminale patiënten, psychisch lijden en psychiatrische aandoeningen.* Https://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/advies_73_ euthanasie.pdf.
- Boer, Theo. “Positie van Distelmans zou elders onhoudbaar zijn.” *De Morgen,* December 13, 2015. https://www.demorgen.be/meningen/positie-van-distelmans-zou-elders-onhoudbaar- zijn~bbb69391/.
- Bilatere Arbeitsgruppe der Deutschen Biscofskonferenz und der Vereinigten Evangelisch-Lutherischen Kirche Deutschlands. *Gott und die Würde des Menschen.* Paderborn/Leipzig: Bonifatius/Evangelische Verlagsanstalt, 2017.
- Bundesministerium der Justiz/Bundesamt für Justiz. *Strafgesetzbuch (StGB). § 217 Geschäftsmäßige Förderung der Selbsttötung.* Accessed January 13, 2022. https://www.gesetze-im-internet.de/stgb/__217.html.
- BVerfG. *Urteil des Zweiten Senats vom 26. Februar* 2020 - 2 BvR 2347/15 -, Rn. 1-343. Accessed January 13, 2022. http://www.bverfg.de/e/rs20200226_2bvr234715.html.
- Camosy, Charles C. *Losing our dignity. How Secularized Medicine Is Undermining Fundamental Human Equality.* New York: New City Press, 2021.
- Dijk, Diederik van, and Doesburg Leo van. *Legalising euthanasia: what we can learn from the Netherlands.* Amersfoort: Sallux, 2021. https://sallux.eu/Sallux%20-%20Legalizing%20Euthanasia%20WEB.pdf.
- European Institute for Bio-ethics. “The new Spanish law on euthanasia contested against the Constitutional Court a few days before its entry into force.” Accessed January 12, 2022. The new Spanish law on euthanasia contested against the Constitutional Court a few days before its entry into force - European Institute of Bioethics (ieb-eib.org)

- European Institute for Bio-ethics. “Portugese parlementsleden keuren nieuwe versie van
- euthanasiewet goed.” Accessed January 14, 2022. https://www.ieb-eib.org/nl/nieuws/einde-van- het-leven/euthanasie-en-geassisteerde-zelfmoord/portugese-parlementsleden-keuren-nieuwe- versie-van-euthanasiewet-goed-2066.html?backto=pays-pt
- European Institute for Bio-ethics. “Portugal: Euthanasiewet ongrondwettelijk verklaard.” Accessed January 14, 2022. https://www.ieb-eib.org/nl/nieuws/einde-van-het-leven/euthanasie- en-geassisteerde-zelfmoord/portugal-euthanasiewet-ongrondwettelijk-verklaard-1972.html.
- Gauthier, Saskia, Mausbach, Julian, Reisch, Thomas, Bartsch, Christine. “Suicide tourism: a pilot study on the Swiss phenomenon.” *J Med Ethics* 41 (2015): 611-617. DOI: 10.1136/medethics-2014-102091.
- Groen van Prinsterer, G. *Ongeloof en revolutie.* Franeker: Wever, 1976
- Haekens, An. “Ga de dialoog aan, Distelmans!” *De Morgen*, December 14, 2015. https://www.demorgen.be/meningen/ga-de-dialoog-aan-distelmans~bbde4843/.
- Hendriks, Aart. “Euthanasie in Zuid-Europa. Nieuwe jurisprudentie en wetsvoorstellen.” *Nederlands Juristenblad* nr. 24 (2020): 1737-1539.
- Jochemsen, H., Glas, G. *Verantwoord medisch handelen. Proeve van een christelijke medische ethiek.*
  Amsterdam: Buijten & Schipperheijn, 1997. Verantwoording nr. 13.
- Kinneging, Andreas. *De onzichtbare maat. Archeologie van goed en kwaad.* Amsterdam: Prometheus, 2020.
- KNMG, *Euthanasie in cijfers.* 2019. https://www.knmg.nl/infographic-euthanasie/.
- Kovacevic, Anita, Bartsch, Christian. “Suizidbehilfe in der Schweiz.” In *Sozialpolitik* CH 1 (2017): 1-11.
- Lieverse, P.J. , Blois, M. de, Boer, Th. A., et al. *Dood gewoon. Perspectieven op 35 jaar euthanasie in Nederland.* Amsterdam: Buijten & Schipperheijn, 2005. Lindeboom series 15.
- Lifton, Robert Jay. *Nazi-dokters. De psychologie van de rassenmoord in het Derde Rijk.* Utrecht/Aartselaar: A.W. Bruna & Son, 1987.
- Medical Contact. “Spain becomes fourth EU member state to legalise euthanasia”. Accessed January 12, 2022. Https://www.medischcontact.nl/nieuws/laatste-nieuws/nieuwsartikel/spanje-legaliseert-als-vierde-eu-lidstaat-euthanasie.htm?utm_source=twitter&utm_medium=coosto.
- Mill, John Stuart. *On Liberty*. Cambridge: Cambridge University Press, 1989.
- Ministerio de la presidencia relaciones con las cortes y memoria democracy. “Ley Orgánica 3/2021, de 24 de marzo, de regulación de la eutanasia.” In *Boletín oficial des estatdo*, March 25, 2021. https://www.boe.es/boe/

dias/2021/03/25/pdfs/BOE-A-2021-4628.pdf.

- Palliative care for older people in care and nursing homes in Europe (PACE) project. *Palliative care for dignity in old age. Addressing the Needs of Older People in Long-Term Care Facilities in Europe.* (2019). https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=25214&lang=en
- PALNWS. “Portugese president stelt veto tegen euthanasiewet”. Accessed January 14, 2022. https://palnws.be/2021/11/portugese-president-stelt-veto-tegen-euthanasiewet/.
- Proctor, Robert N. *Racial hygiene. Medicine under the Nazis.* London: Harvard University Press, 1988.
- Raus, Kasper, Vanderhaegen, Bert, Sterckx, Sigrid. “Euthanasia in Belgium: Shortcomings of the Law and Its Application and of the Monitoring of Practice.” *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine* 46 no 1 (2021): 80–107. https://doi.org/10.1093/jmp/jhaa031.
- “Euthanasia/Assisted Suicide in Europe: Law, Policy & Future.” In: *A European Pro-Life Strategy*, 48-91. Amersfoort: Sallux, 2021.
- Sallux, *Pro-Life in Ireland and Europe.* Amersfoort: Sallux, 2019.
- Schwarzenegger, Christian, Summers, Sarah J. “Criminal Law and Assisted Suicide in Switzerland.” University of Zurich. Accessed January 14, 2022. https://www.ius.uzh.ch/dam/jcr:00000000-5624-ccd2-ffff-ffffa664e063/assisted-suicide-Switzerland.pdf.
- Schweizerische Akademie der Medizinischen Wissenschaften (SAMW), *Medizin-ethische Richtlinien. Umgang mit Sterben und Tod.* https://www.samw.ch/de/Ethik/Themen-A-bis-Z/Sterben-und-Tod.html.
- Schweizerische Eidgenossenschaft. „Häufigste Todesursachen bleiben im Jahr 2018 stabil - assistierter Suizid nimmt stark zu.“ Accessed September 21, 2023. https://www.bfs.admin.ch/asset/de/15084042
- Tagesschau. „Schäuble ist beliebt wie nie.“ Accessed January 13, 2022, https://www.tagesschau.de/inland/deutschlandtrend/deutschlandtrend-339.html.
- Verburg, Marja. “Rechters: Euthanasiewet in strijd met grondwet.” Duitslandinstituut. Accessed January 13, 2022. https://duitslandinstituut.nl/artikel/35772/rechters-euthanasiewet-in-strijd-met-grondwet.
- *A European Pro-Life strategy*. Amersfoort: Sallux, 2021.
- Wier, Marten van de. “In Zwitserland loopt nu een eenvoudige route naar de dood.” *Trouw,* January 8, 2021. https://www.trouw.nl/buitenland/in-zwitserland-loopt-nu-een-eenvoudige-route-naar-de-dood~b54a473d/.
- Wills, Jean-Pierre. *Sich den Tot geben. Suizid als letzte Emanzipation.* Stuttgart: Hirzel, 2021.
- Wyatt, John. “Euthanasia and assisted suicide.” In *Cambridge Papers. Towards a biblical mind* 19 no. 2 (2010): 1-6. https://cdn2.hubspot.net/hubfs/6674075/Cambridge%20Papers/Euthanasia%20and%20assisted%20suicide.pdf?h-

sCtaTracking=6ad70aa8-39ce-4937-9f50-8f7078a964e6%7Cba625eb8-e505-45a3-9634-3dd15be800a5.

2 Concepts, issues and disciplines involved with life termination upon request

Roy Kloet

2.1 Concepts

What is euthanasia?[68]

In the Netherlands euthanasia is defined as the intentional life-ending act by a someone other than the person concerned, at the person's explicit request. In practice, this means a physician, in compliance with the six standards of care outlined in the law, administers lethal medication to the patient.[69] Like 'assisted suicide', euthanasia falls under the broader concept of 'life termination upon request'.

What is assisted suicide? [70]

Assisted suicide is the deliberate prescription or provision of means by which the person concerned can end his or her own life. In this case, the physician provides a lethal drug to the patient, after which the patient takes the drug himself. Like euthanasia, assisted suicide falls under the broader concept of 'termination of life on request'.

What is palliative sedation? [71]

Palliative sedation is the deliberate lowering of a patient's awarenss in the last phase of life, and is part of palliative care, which provides comfort care for those with terminal or chronic conditions. The aim of palliative sedation is to prevent and relieve suffering. In doing so, much attention is paid to quality of life. If palliative sedation is applied carefully and in the required medical way, it does not shorten life. Thus, someone undergoing this care eventually dies from their

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[68] Bregje Onwuteaka-Philipsen et al, Derde evalutatie Wet toetsing levensbeeindiging op verzoek en hulp bij zelfdoding, (The Hague: ZonMw, 2017), 9-10.

[69] "Euthanasie en de wet: sterven met hulp van een arts," Central Government of the Netherlands, accessed July 20, 2021, https://www.rijksoverheid.nl/onderwerpen/levenseinde-en-euthanasie/euthanasie.

[70] Onwuteaka-Philipsen, Derde evalutatie, 9-10.

[71] Onwuteaka-Philipsen, Derde evaluatie, 9-10.

underlying illness. This distinguishes palliative sedation from euthanasia and assisted suicide.[72]

What does one understand by 'completed life'?
The concept of 'completed life' is the subject of much disagreement. The Advisory Committee on Completed Life,[73] which conducted research on this topic on behalf of the Ministry of Health, Welfare and Sport[74] between 2014 and 2016, speaks of a difficult concept and an unfortunate euphemism.[75] As if life is 'a job to be done' (in line with Den Hartogh).[76]

'Completed life' is used in the context of the social debate on whether it should be possible to provide suicide assistance to elderly people who consider their lives 'completed' without being (seriously) ill.[77] It is always about the subjective, personal experience of the person himself. How can society help people who are 'done with life' and consider life 'completed', and/or are 'suffering from life', and/or are 'tired of life', and/or persistently wish to actively end life (or have it ended)? The concept is understood and interpreted differently by various stakeholders. (See also further detail at the end of this chapter.)

What are common abbreviations in life-ending upon request?

ED	Euthanasia Database
RTE	Regional Euthanasia Review Committee
NVVE	Dutch Association for a Voluntary End of Life
SCEN	Support and Consultation for Euthanasia in the Netherlands
Wtl	Act assessing termination of life upon request and assisted suicide
WGBO	Medical Treatment Contracts Act

What is the main legislation regarding life termination on request?
Ending someone else's life is punishable in the Netherlands, even if a patient

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[72] "Palliatieve zorg and palliatieve sedatie," KNMG, accessed February 28, 2022, https://www.knmg.nl/advies-richtlijnen/dossiers/palliatieve-zorg-en-palliatieve-sedatie.htm.

[73] Schnabel, Voltooid leven, 25, 33.

[74] At the request of ministers, the advisory committee advised on the legal options and social dilemmas regarding assisted suicide for people who consider their lives completed.

[75] Paul Schnabel et al, Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven voltooid achten, (The Hague, Adviescommissie voltooid leven, 2016), 25, 33.

[76] Govert den Hartogh, "Klaar met leven: de open vragen," Podium voor bio-ethiek, 2013 no 20/3, 6, accessed July 21, 2021, https://pure.uva.nl/ws/files/1953339/156157_Hartogh_klaar_met_leven.pdf.

[77] Els van Wijngaarden et al, Perspectieven op de doodswens van ouderen die niet ernstig ziek zijn: de mensen en de cijfers. Het PERSPECTIEF-onderzoek, (The Hague, ZonMw, 2020), 10-17.

requests it from the physician. But the law has guidelines that sometimes allow a physicianto end life upon request without being punished.

The Netherlands has legally regulated life termination on request in the so-called 'Act on the assessment of life termination on request and help with suicide', the Wtl. This law is also popularly known as the 'euthanasia law'. However, in addition to euthanasia, the Wtl also covers assisted suicide.[78] The Wtl came into force in 2002 and has since been reviewed three times.
The aims of the Wtl are:

- Promoting legal certainty for all concerned;
- Increasing the diligence of life-ending acts by physicians;
- Providing an adequate framework for physicians to be accountable for those actions, and
- Promoting transparency and public scrutiny. [79]

The Wtl includes the six so-called 'requirements (citeria) of careful procedure', also called 'due care' or 'due diligence' criteria (see next section). A physician must meet these criteria when carrying out termination of life upon request. Furthermore, the Wtl describes the Regional Euthanasia Review Committees (RTEs). An RTE assesses whether the physician has met the statutory due care criteria.

Another law, the Burial Act (art.7(2)), stipulates that a physician must report to the municipal coroner after carrying out the termination of life upon request. Based on the report that the physician submits, an RTE will assess whether the physician acted in accordance with the Wtl.

What are the 'due diligence' requirements?
The Wtl (art. 2(1) Wtl)[80] sets out six standards of care (due care criteria) against which a physician must assess a patient's request for euthanasia or assisted suicide. A physician has acted correctly in the case of euthanasia or assisted suicide if he or she:

a. Is persuaded that there was a voluntary and deliberate request by the patient;
b. Is convinced that the patient's suffering was hopeless and unbearable;
c. Has informed the patient about his situation and his prospects;
d. Came to the decision with the patient that there was no other reasonable

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[78] There are also other medical courses of action with this purpose and which therefore fall outside the Wtl. These include the intensification of pain and/or symptom control with hastening of end-of-life as a possible side effect; and forgoing potentially life-extending treatment. In addition, an individual can proceed to end life himself by stopping eating and drinking, or taking collected medication.

[79] Onwuteaka-Philipsen, Derde evaluatie, 11.27.

[80] Onwuteaka-Philipsen, Derde evaluatie, 35.

solution for in the patient's situation;
e. Consulted at least one other independent physician, who saw the patient and gave his written opinion on the requirements of care referred to in parts a through d, and
f. Performed the termination of life or assisted suicide in a medically careful way.

The same article contains three more sections that apply to special circumstances:

- Paragraph 2 deals with the possibility of using a 'written will' to meet the requirements of the law. This applies to patients aged 16 and over.
- Paragraph 3 deals with life termination in underage patients between 16 and 18 years of age. They can decide for themselves, but parent(s) or guardian(s) must be involved in the decision-making process.
- Paragraph 4 deals with life termination in underage patients between 12 and 16 years of age. For this group, parent(s) or guardian(s) must agree with the decision.[81]

What are RTEs and how do they operate?
The Wtl (art.3) regulates that there are regional committees, which review reports of cases of life termination upon request and assisted suicide. These are the Regional Euthanasia Review Committee (RTEs). At the time of writing, there are five RTEs.
An RTE consists of an odd number of (appointed) members, including at least:

- A lawyer (as chairman);
- A physician, and
- An expert on ethical or existential meaning issues.

RTEs use a 'Code of Practice' to assess reports. Due to the high number of reports, most RTEs' judgements are highly standardised. This, combined with the high number of reports and the limited reporting per case, sometimes leads to discussions about the transparency and judgment of RTEs. In the case of a judgment 'not in accordance with the standard of care', an RTE always provides an explanation.[82]

Rarely do RTEs conclude that a physician did not comply with due care criteria. Between 2002 and 2015, for example, there were only 76 negative assessments

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[81] "Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding," Central Government of the Netherlands, accessed July 20, 2021, https://wetten.overheid.nl/BWBR0012410/2020-03-19.

[82] There is a tension between reducing the committees' workload and increasing transparency. For highly complex or controversial judgements, ZonMw considers it potentially useful for RTEs not only to publish the judgement, but also to make the underlying considerations visible. (Onwuteaka-Philipsen, Derde evaluatie, 16).

(out of a total of 43,171 reported cases). And in recent years, the likelihood of the judgement 'not in accordance with the requirements of care' has further decreased.[83] Between 2016 and 2018, there were 28 'not compliant' assessments (out of a total of 18,802 reported cases). In 2019, this was still true for four cases out of a total of 6,361 reports.[84] In 2020, RTEs reported a total of 6,938 reports (up 9.1% in 2019). Only two reports were assessed as 'not careful' in 2020.[85]

When an assessment 'not in accordance with the due care criteria' is given, it is usually not about the core requirements of the law (the request, suffering, and possibility of alternatives), but about shortcomings with regard to consultation and medically correct execution. Only cases that are deemed non-compliant reach the Healthcare Inspectorate (IGZ) and the Public Prosecutor's Office (OM) for review. Again, formal steps, such as a disciplinary complaint against the physician, rarely take place. So far, criminal prosecution of a physician by the OM has never come about.

What are examples of current issues around life termination upon request?
Public research conducted by ZonMw[86] on behalf of the third evaluation of the Wlz dated 2017 (p.12) found 'that there is undiminished support among Dutch citizens for the current regulations regarding life termination upon request'. However, there have been 'intensified discussions' in recent years. These are taking place both within the medical profession and society as a whole and concern the boundaries of the Wtl and several specific themes.
Topical issues include, but are not limited to:

- The meaning of a **written will,** and
- Termination of life upon request in people with **psychiatric conditions or dementia**

Since 1 April 2002, it has been legally possible for physicians to follow up on a written euthanasia request from an incompetent patient, for example, in cases of advanced dementia. Physicians can proceed with termination of life if the patient requested it in a written will, written when he/she was still able to exercise his/her will. In implementing a written will, the requirements of care 'apply accordingly'.

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[83] Onwuteaka-Philipsen, Derde evaluatie, 15.

[84] "Jaarverslagen," Regionale Toetsingscommissies Euthanasie, accessed July 20, 2021, https://www.euthanasiecommissie.nl/de-toetsingscommissies/jaarverslagen.

[85] "Jaarverslag 2020," Regionale Toetsingscommissies Euthanasie, accessed July 20, 2021, https://www.euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/jaarverslagen/2020/april/15/jaarverslag-2020.

[86] ZonMw is a state related fund that designs and funds research in the medical sciences, care and welfare

This leads to debate because the question is whether, in the case of euthanasia for an incompetent patient, a physician can still meet the requirements of care. Can the physician still be convinced that the request is voluntary and deliberate? Or of unbearable suffering at that moment? In this situation, can the physician still determine, in consultation, that reasonable other solutions are lacking? A high-profile case illustrative of the complexity is the so-called 'coffee euthanasia case': the case of a nursing home physician who in 2016 granted euthanasia to a 74-year-old woman with advanced dementia. Her written will was not unequivocal and at the time of ending her life, she behaviourly resisted the intervention. The case came before the Supreme Court. It eventually ruled that the physician had acted appropriately.

Postma argues in her recent PhD research[87] that for euthanasia based on a written declaration, the current indication of 'applicable by analogy' in Art. 2(2) Wtl is insufficient. "Euthanasia based on a written will may remain possible, but then the law must - at the time of life termination - accept the 'presumption of an explicit and serious desire to end life'. This may be legally sufficient, but it does result in requirements and criteria that are lacking in the current law," Postma concludes.

- *The possibilities of endling life upon demand in* ***children under 12***

For persons aged 12 and over, there are legal regulations around life termination. There is also a special regulation for children under one year old (the Groningen Protocol), which, incidentally, is rarely used in practice. For children between one and 12-years-old, there is a regulatory gap that has led to debates on how the euthanasia law should be applied. Broadly speaking, this debate is about whether or not there should be (legal) space to actively end the lives of children under 12. The core argument of proponents is compassion: termination of life aimed at removing suffering should also be possible for these children. Opponents fear a slippery slope. Sooner or later, the options for ending life may be stretched beyond hopeless and unbearable suffering. There are fears that a poor prognosis and/or poor prospects of relief and thus the *expectation* of hopeless suffering may become grounds for ending life. The fear of this leading to a slippery slope is not unjustified, in retrospect, given the developments in euthanasia legislation as well as those of the Groningen Protocol.[88]

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87 Liselotte Postma, " Misschien was het nog te vroeg. De regeling van de schriftelijke wilsverklaring euthanasie in artikel 2, tweede lid, Wtl vanuit een strafrechtelijk perspectief," (PhD diss., Erasmus School of Law, 2021).

88 Diederik van Dijk and Leo van Doesburg, Legalising euthanasia: what we can learn from the Netherlands, (NPT, ECPM, 2021), Sallux Report, 14, https://sallux.eu/free/legalizing-euthanasia-what-we-can-learn-from-the-netherlands.html.

- *Termination of life upon request in people who consider their lives complete*

Psychiatrists Tijdink and Naarding aptly articulate how the debate around 'completed life' keeps coming up.[89] What is a 'completed life'? Where does the wish to die come from and how should we deal with it? (See the section 'Zooming in on "completed life"' at the end of this chapter). The most current issues focus on the mutability and psychiatric component of the wish to die.

In an interview about her recent research,[90] Van Wijngaarden was surprised to learn that, in some people who previously considered their lives complete, the desire to exit life has disappeared altogether. She concludes that "a full stop can become a comma".[91] She therefore considers it inappropriate to assume that someone who says they have a 'completed life' means that person is ready to stop living.

Tijdink and Naarding point out that partly because of the variability in the reasons a person wants to die, there is a lack of discussion on the psychological component in the public debates. This component is essential for a nuanced view of a completed life. Depressive disorders are common in the elderly, and thoughts of suicide are common in people with depression. The assumption that elderly people are more likely to have a depressive disorder with related suicidal thoughts is reasonable. These thoughts are expressed in a desire to die. This is ignored in the discussions, which are conducted almost entirely from a social and philosophical perspective. According to the authors, without a psychiatric perspective, nuance is lost and the politicisation of a possible psychiatric problem of a vulnerable fellow human being results. Battles on paper and politics make it likely that the completed-life debate will continue for some time to come.

Other relevant, topical issues are:

- The (moral) acceptability and desirability of assisted suicide by non-physicians;
- (Policy) developments towards greater self-determination for the individual (e.g. availability of suicide drugs such as suicide powder or Drion's pill);

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[89] Joeri Tijdink and Paul Naarding, " Een psychiatrische blik kan perspectief bieden bij 'voltooid leven'. De doodswens kan verdwijnen," Trouw, 2021, accessed August 19, 2021, https://www.trouw.nl/opinie/een-psychiatrische-blik-kan-perspectief-bieden-bij-voltooid-leven-de-doodswens-kan-verdwijnen~be0a06bc/ .

[90] Rianne Oosterom, " Zeven jaar volgde Els van Wijngaarden de doodswens van 25 ouderen. Die kan zeer veranderlijk zijn, blijkt," Trouw, 2021, accessed August 19, 2021, https://www.trouw.nl/zorg/zeven-jaar-volgde-els-van-wijngaarden-de-doodswens-van-25-ouderen-die-kan-zeer-veranderlijk-zijn-blijkt~b079476a/.

[91] Els van Wijngaarden et al, "Still ready to give up on life? A longitudinal phenomenological study into wishes to die among older adults," Social Science & Medicine, 2021.

- The role of the End-of-Life Clinic/Expertise Centre on Euthanasia;[92]
- The increased number of life terminations upon request at the time of COVID-19 (with video consultation as an alternative to physical review by a second expert),[93] and
- The functioning and authority of RTEs and the current system of review and reporting, as well as the relationship between RTEs and prosecutors (who are at odds with each other over this).

The above is just a sample of the current issues regarding the subject. The remainder of this report will elaborate on these.

2.2 The history of euthanasia legislation in the Netherlands in a nutshell

In 2001, the Netherlands became the first country in the world to legalise euthanasia, after approval by the parliament and senate.[94] Before then, euthanasia[95] and assisted suicide were prohibited under all circumstances. This was stipulated in articles 293 and 294 of the Penal Code (Sr.). Case law at the time permitted an exception to that prohibition, under special circumstances. This applied to those cases where 1) a physician acted on the request of a patient and he 2) observed a number of requirements of care. The legal basis for this approach lay in the general criminal ground *of force majeure* (Article 40 of the Criminal Code), caused by a 'conflict of duties'. On the one hand, the physician had a legal duty not to end a life. On the other hand, the physician had a professional duty to remove unbearable suffering. In special cases, the physician could invoke *force majeure* and was discharged from legal action by a judge if this invocation was accepted.

On 1 April 2002, the Wtl[96] ('Wet toetsing levensbeëindiging op verzoek en hulp bij

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[92] In 2020, almost 13% of life terminations were carried out by a physician affiliated with an end-of-life clinic. Interestingly, 62 of the 88 life terminations with a psychiatric motive were carried out by them. In 2020, therefore, there seems to be less and less of a relational component. At least the appearance is that life termination upon request is eroding into a stand-alone, technical (termination) act (see: Van Dijk, Legalising euthanasia, 10-12).

[93] "Sterke toename van het aantal gevallen van euthanasie," House of Representatives of the Netherlands, Parlementary paper 2021Z07397, 1.2.

[94] Van Dijk, Legalising euthanasia, 2,4,6.

[95] The word euthanasia does not appear as such in Article 293 of the Penal Code. This article of the law speaks of intentionally ending the life of another at his or her express and serious desire.

[96] "Wet van 12 april 2001, houdende toetsing van levensbeëindiging op verzoek en hulp bij zelfdoding en wijziging van het Wetboek van Strafrecht en van de Wet op de lijkbezorging (Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding)". Staatsblad van het Koninkrijk der Nederlanden, 2001, 194, accessed July 20, 2021, https://zoek.officielebekendmakingen.nl/stb-2001-194.html.

zelfdoding', also known as 'euthanasiewet') entered into force.[97] The Wtl added a *special ground for exclusion from punishment* to articles 293 and 294 of the Criminal Code. As a consequence, euthanasia and assisted suicide ('termination of life upon request') are no longer punishable if:

- It is carried out by a physician;
- The physician observes the six criteria for due care (Article 2(1) Wtl), and
- The physician reports to the municipal coroner that a termination of life has taken place.

Interestingly, the legal system in the Netherlands does not imply that the termination of life upon request is now formally legalised. Ending another person's life remains punishable, in principle, but it is not punishable if the act has been carried out by a physician and if the conditions set out in the law have been met.[98]

Incidentally, when the bill was being debated in parliament, one option was to add a "duty of referral" in which any physician can refer the patient to another physician (as part of the duty of care) if the attending physician objected to performing euthanasia for conscientious reasons or not. This duty of referral was, due to efforts by the Christian parties, not enshrined in the law. As a result, the lack of this duty of referral, the Levenseindekliniek (end-of-life clinic) was established. This institution opened in March 2012 and is intended for people with a desire to die but their physician cannot or will not provide euthanasia or assisted suicide. After examination by the clinic and review of the request by an independent physician, the legal requirements can still be met and euthanasia or assisted suicide can be performed.[99] In September 2019, the Levenseindekliniek changed its name to 'Euthanasia Expertise Center'.

Since the introduction of the Wtl, there has been a clear increase in the number of deaths due to the termination of life upon request over time, with some fluctuation. The number of deaths in 2020 is more than 3.5 times higher than when the law was introduced. The demand is growing every year.[100]

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[97] Since 1 October 2012, the Wtl has also applied to the BES islands.

[98] Onwuteaka-Philipsen, Derde evaluatie, 34.

[99] "Voorstel van wet van de leden Pia Dijkstra en Voortman tot wijziging van de Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding in verband met de invoering van een verwijsplicht voor de arts," House of Representatives of the Netherlands, Parlementary paper 33778, no.3, 3.

[100] Van Dijk, Legalising euthanasia, 2,4,6.

2.3 Zooming in on 'completed life'

Since 2010, there has been an ongoing, political and social debate on 'completion of life' presupposing the individual's right to end life on rational grounds, even in the absence of illness.[101] Proponents of termination of life upon request in cases of 'completed life', mainly cite an individual's dignity, autonomy and self-determination. The term 'completed life' has now become commonplace, but there are still many differences of opinion on the concept. As mentioned before, the Schnabel advisory commission refers to 'completed life' as a "difficult concept and an unfortunate euphemism.[102] In relation to suicide or euthanasia the connotation is far too positive, according to the committee.

'Completed life' is always about the subjective, personal experience of the individual himself. The theologian F. de Lange, professor emeritus of ethics, believes it is an illusion that we 'bring ourselves to completion' as individuals when we plan our own life project. When terminating life on the grounds of a 'completed life', a physician and loved one must conform to the elder's absolute self-knowledge, when in fact we are not sure what 'self' and 'completed' mean.[103]
In 2011, the KNMG noted that in the public debate physicians and patients used the terms 'finished with life', 'suffering from life' and 'completed life' interchangeably, with distinctions that are difficult to apply in practice.[104]

The following concepts are associated with completed life:

- ***Done with life***

A political description used during the parliamentary treatment of the Wtl (between August 1999 and April 2001) and included in the Code of Practice of RTEs (2015)[105] .
'This generally refers to people who are usually of advanced age and who, without otherwise suffering medically from an untreatable disease or condition associated with severe suffering, have determined for themselves that, for them, the value of life has diminished to such an extent that they prefer death to continuing to live'.[106]

- ***Suffering from life***

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[101] Van Dijk, Legalising euthanasia, 4.

[102] Schnabel, Voltooid leven, 25, 33.

[103] Schnabel, Voltooid leven, 29, 30

[104] KNMG position paper, De rol van de arts in het zelfgekozen levenseinde, 2011, 14-16.

[105] Regionale Toetsingscommissie Euthanasie, Code of Practice van de Regionale Toetsingscommissie Euthanasie, (The Hague, 2015), 31-32.

[106] TK, 1999-2000, 26691, 6, 30.

Used by the Dijkhuis Committee (2004) established by the KNMG. This committee preferred a less neutral concept than 'finished with life', because the committee found it unlikely that (many) people would wish to die in the absence of suffering. This term puts more emphasis on the underlying suffering.

'Suffering from the prospect of having to continue living in such a way that no quality of life or only a poor quality of life is experienced, giving rise to a persistent desire for death, while, as an explanation for the absence or inadequacy in quality of life, a somatic or mental condition cannot or cannot predominantly be indicated'.[107]

- ***Completed life***

1) The Uit Vrije Wil' initiative (2010) uses this term, with Sutorius and Beekman indicating that deciding that one's life is complete is a process and outcome of a longer consideration, in which an elderly person often comes to the conclusion that life is complete based on a combination of (interacting) factors.
'The state in which an elderly person has come to the conclusion that the value and meaning of their life has diminished to such an extent that they begin to prefer death to life'.[108] *(p.28)*

2) Completed life is also used by the Dutch Association for a Voluntary End of Life (NVVE) (2011-2015). The NVVE argues that completed life cannot be equated with 'finished with life', 'suffering from life' or 'tired of life', because people go a step further and want to actively step out of life. According to NVVE, 'completed life' cannot be captured in a definition.
'It is existential suffering: suffering from the meaninglessness and hopelessness of life, a sense of futility, loss of purpose, meaning and lack of perspective. Without a necessary medical basis, where the person perceives the situation as hopeless and there are no more suitable alternative treatment options. Those experiencing a completed life are usually no longer able to participate in society and advocate for themselves. The person mostly affected is at an advanced age, is detached, lives in isolation, is housebound, vision and hearing are poor and is waiting for death'.[109]

3) Defesche, researcher, argues in her study on completed life in the Netherlands (2011) that 'completed life' is akin to 'finished with life', 'life tired' or 'suffering from life', for which there are also no uniform definitions. She identifies complet-

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[107] J.H. Dijkhuis et al, Op zoek naar normen voor het handelen van artsen bij vragen om hulp bij levensbeëindiging in geval van lijden aan het leven, (Utrecht: KNMG, 2004), 15.

[108] Jit Peters et al, Uit Vrije Wil. Waardig sterven op hoge leeftijd, (Amsterdam: Boom, 2011), 27.

[109] Krista Jansen and Nadya Viegas, Rapport Voltooid leven, de ervaring. Een analyse van de rapportages van het NVVE Adviescentrum, (NVVE, 2015), 4.

ed life mainly as a stage of life.
'Completed life means that the life stages of working, of parenting, of self-development and renewal are over; that the phase of winding down is well advanced and that it is not expected that the future will hold substantial valuable new experiences.[110]
This framework is broader than what others in the social discussion understand by 'completed life' and can cover elderly people with and without a desire to die.

4) Van Wijngaarden, Leget and Goossensen conducted qualitative research into the experiences of older people who consider their lives to be completed (2015). They describe the issues as:
'A tangle of inability and unwillingness to connect with his/her real life characterised by a permanently experienced tension: everyday experiences seem incompatible with the life expectations of those involved and their idea of who they are. As one feels more 'disconnected' from life, the persistent desire to end life is reinforced. The experiences are divided into: 1) a sense of painful loneliness; 2) the pain that one does not matter any longer; 3) the inability to express oneself; 4) multi-dimensional fatigue; and 5) a sense of aversion in the face of feared dependency.[111]

- ***Self-chosen end of life by the elderly***

This is the term used in ZonMw's 2014 knowledge synthesis of the same name.[112] In it, the authors note that the terms and concept descriptions used for the group of older people with a desire to die vary in degree of neutrality. This is because there are different interests among those who bring the terms into debate. Recurring aspects in 'finished with life', 'suffering from life' and 'completed life' are:

- Age: it involves older people, often without specifying a precise age limit.
- Desire to die: there is a persistent desire for death over the desire to continue living.
- There is no (serious) illness or condition as a basis for the desire to die.

Sources

- Defesche, Frederique. *Voltooid leven in Nederland. Wat ouderen ervaren, willen en doen als zij het leven voltooid vinden*. Assen: Van Gorcum, 2011.

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[110] Frederique Defesche, Voltooid leven in Nederland. Wat ouderen ervaren, willen en doen als zij het leven voltooid vinden, (Assen: Van Gorcum, 2011), 150.

[111] Els van Wijngaarden et al, "Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living," Social Science & Medicine (2015), 1-8.

[112] Agnes van der Heide et al, "Kennissynthese Ouderen en het zelfgekozen levenseinde," (Rotterdam / Amsterdam / Utrecht / Groningen: ZonMw, 2014), 26.

- Dijk, Diederik van, Doesburg, Leo van. *Legalising euthanasia: what we can learn from the Netherlands.* (NPV/ECPM, 2021). Sallux report. https://sallux.eu/free/legalizing-euthanasia-what-we-can-learn-from-the-netherlands.html.
- Dijkhuis, J.H. et al. *Op zoek naar normen voor het handelen van artsen bij vragen om hulp bij levensbeeindiging in geval van lijden aan het leven.* Utrecht: KNMG, 2004.
- KNMG. "Palliatieve zorg and palliatieve sedatie." Accessed February 28, 2022. https://www.knmg.nl/advies-richtlijnen/dossiers/palliatieve-zorg-en-palliatieve-sedatie.htm.
- Hartogh, Govert den. "Klaar met leven: de open vragen." *Podium for bioethics* 2013 no. 20/3. Accessed 21 July 2021. https://pure.uva.nl/ws/files/1953339/156157_Hartogh_klaar_met_leven.pdf.
- Heide, Agnes van der, et al. *Kennissynthese Ouderen en het zelfgekozen levenseinde.* Rotterdam / Amsterdam / Utrecht / Groningen: ZonMw, 2014.
- Jansen, Krista, Viegas, Nadya. *Rapport Voltooid leven, de ervaring. Een analyse van de rapportages van het NVVE Adviescentrum.* NVVE, 2015.
- Onwuteaka-Philipsen, Bregje, et al. *Derde evaluatie Wet toetsing levensbeeindiging op verzoek en hulp bij zelfdoding.* The Hague: ZonMw, 2017; https://www.zonmw.nl/nl/artikel/derde-evaluatie-wet-medisch-wetenschappelijk-onderzoek-met-mensen
- Oosterom, Rianne. "Zeven jaar volgde Els van Wijngaarden de doodswens van 25 ouderen. Die kan zeer veranderlijk zijn, blijkt. " *Trouw*, 2021. Accessed August 19, 2021. https://www.trouw.nl/zorg/zeven-jaar-volgde-els-van-wijngaarden-de-doodswens-van-25-ouderen-die-kan-zeer-veranderlijk-zijn-blijkt~b079476a/.
- Peters, Jit et al. *Uit Vrije Wil. Waardig sterven op hoge leeftijd.* Amsterdam: Boom, 2011.
- Postma, Liselotte. "Misschien was het nog te vroeg. De regeling van de schriftelijke wilsverklaring euthanasie in artikel 2, tweede lid, Wtl vanuit een strafrechtelijk perspectief." PhD thesis, Erasmus School of Law, 2021.
- Regionale Toetsingscommissies Euthanasie. "Jaarverslagen." Accessed July 20, 2021.
- https://www.euthanasiecommissie.nl/de-toetsingscommissies/jaarverslagen. (English version available.)
- Regionale Toetsingscommissies Euthanasie. "Annual report 2020." Accessed July 20, 2021. https://www.euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/ jaarverslagen/2020/april/15/jaarverslag-2020. (English version available.)
- Regionale Toetsingscommissie Euthanasie. *Code of Practice van de Regionale*

Toetsingscommissie Euthanasie. The Hague, 2015.

- Central Government of the Netherlands. "Euthanasie en de wet: sterven met hulp van een arts." Accessed July 20, 2021. https://www.rijksoverheid.nl/onderwerpen/levenseinde-en-euthanasie/euthanasie.
- Central Goverment of the Netherlands. "Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding." Accessed July 20, 2021. https://wetten.overheid.nl/BWBR0012410/2020-03-19.
- Schnabel, Paul et al. *Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven voltooidachten*. The Hague: Adviescommissie voltooid leven, 2016.
- Tijdink, Joeri, Naarding, Paul. "Een psychiatrische blik kan perspectief bieden bij 'voltooid leven'. De doodswens kan verdwijnen." Trouw, 2021. Accessed August 19, 2021. https://www.trouw.nl/opinie/een-psychiatrische-blik-kan-perspectief-bieden-bij-voltooid-leven-de-doodswens-kan-verdwijnen~be0a06bc/.
- House of Representatives of the Netherlands. "Sterke toename van het aantal gevallen van euthanasie." *Parlementary paper* 2021Z07397. https://www.tweedekamer.nl/kamerstukken/ kamervragen/detail?id=2021Z07397&did=2021D16358.
- House of Representatives of the Netherlands. "Voorstel van wet van de leden Pia Dijkstra en Voortman tot wijziging van de Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding in verband met deinvoering van een verwijsplicht voor de arts." *Parlementary paper* 33778.
- Wijngaarden, Els van, et al. "Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living." *Social Science & Medicine* (2015): 1-8.
- Wijngaarden, Els van, et al. *Perspectieven op de doodswens van ouderen die niet ernstig ziek zijn: demensen en de cijfers. Het PERSPECTIEF-onderzoek*. The Hague: ZonMw, 2020.
- Wijngaarden, Els van, et al. "Still ready to give up on life? A longitudinal phenomenological study into wishes to die among older adults." *Social Science & Medicine* (2021).

3 The ars moriendi as a resource for dying today

Arthur Alderliesten

In this chapter, we seek an answer to the question: what can the tradition of *ars moriendi* (art of dying) mean for dying today from the perspective of those who identify as Christian? It was noted earlier that many of the insights of the ars *moriendi* seem to get covered over, even though they are sorely needed now.[113]

The first section introduces the medieval phenomenon of the *ars moriendi*. This is followed by two paragraphs criticising the medieval art of dying. First by the Dutch humanist Desiderius Erasmus (section 2) and then by the German reformer Martin Luther (section 3). Then, in section 4, some attempts are made to make the *ars moriendi* applicable for the present both broadly within a pluralistic society and specifically within the Christian faith community. Section 5 mentions some relevant ongoing research.

3.1. *Ars moriendi* - the art of dying in the late Middle Ages [114]

Medieval mankind was familiar with death. Wars, famines and epidemics meant people faced large-scale death . The Plague even led to cities being depopulated by more than half. Death came close. Average life expectancy was decades lower than today. For instance, life expectancy in England fell from 35 years to 27 years from the thirteenth to the fourteenth century.[115] The infant mortality rate was also high: 20-to-25 per cent of children died between birth and the fifth year of life. With Huizinga, it can be said that in the fifteenth century, the cry of *memento mori* rang out without ceasing.[116]

People died differently in the Middle Ages from how we die today. This is evident,

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[113] Paul Lieverse, Theo Boer and Dick Mul, "Het medische antwoord op lijden," in Theo Boer and Dick Mul (ed.), Lijden en volhouden. Lindeboom series no 19, (Amsterdam: Buijten & Schipperheijn, 2016), 117.

[114] This paragraph is included as Chapter 1 "Ars moriendi - de kunst van het sterven in Luthers tijd" in Arthur Alderliesten, Stervenskunst bij Luther. Een reformatorisch antwoord op 'voltooid leven', (Apeldoorn: De Banier, 2021), 10-19.

[115] Norbert Ohler, Sterben und Tod im Mittelalter, (Düsseldorf: Patmos, 1990), 28. The average age was strongly influenced by infant mortality.

[116] Johan Huizinga, Herfsttij der Middeleeuwen (Amsterdam: Contact, 1999), 141.

for example, in the words people used to signify dying: ‘stepping out of the world’, ‘going to the Creator freed from the flesh’ or ‘laying down the burden of the brokenness of the body’.[117] These quotes betray a more active attitude towards dying. Moreover, they show that, in line with the Christian tradition, people saw life as a gift from God the Creator to whom life is returned. The role of the physician was subordinate to that of the clergyman.[118] Thus, a physician was not allowed to provide medical assistance until the patient’s soul was secured. This shows that medieval man gave soul care a higher priority than physical care.[119] The time of dying was an intense period as it was believed that eternal salvation of the soul depended on the spiritual condition of the dying person in the hour of death.[120]

People almost never died alone in the Middle Ages. In the Middle Ages the dead belonged to the community. Although in rural areas people could not always be with the dying because they had to work hard to earn a living, at least one person stayed close to the dying. In the last hours, the family or the monastic community gathered around the deathbed, along with physicians and clergy. Death was a public ceremony.[121] This gave the dying a sense of security and prevented him from dying in solitude.[122] The bedroom was no longer a private space, but a place of meeting and public prayer.[123] Rightly, Pope Innocent III in 1207 added the work of ‘burying the dead’ to the six merciful works from Matthew 25.[124]

In particular, the Church had the task of guiding people through (and preparing for) dying, sometimes because doctors sometimes failed in their task. Physicians knew that there was no agent against the Black Death and they were sometimes the first to take refuge when an epidemic broke out.[125]

The church and monastery had the task of managing the ceremony around the

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[117] Ohler, Sterben und Tod im Mittelalter, 52.

[118] B. de Geus et al (ed.), Een scone leeringe om salich te sterven. Een middelnederlandse ars moriendi, (Utrecht: HES, 1985), 9.

[119] De Geus, Een scone leeringe om salich te sterven, 10, 66.

[120] Claudia Resch, Trost im Angesicht des Todes. Frühe reformatorische Anleitungen zur Seelsorge an Kranken und Sterbenden, (Tübingen/Basel: A. Francke, 2006), 24.

[121] Philippe Ariès, Met het oog op de dood. Westerse opvattingen over de dood, van de middeleeuwen tot heden, (Amsterdam: Querido, 1980), 20.

[122] Ohler, Sterben und Tod im Mittelalter, 52.

[123] Philippe Ariès, Het beeld van de dood, (Amsterdam: SUN, 2003), 95.

[124] Arthur Alderliesten, Barmhartig leven. De zeven werken van barmhartigheid, (Amsterdam: Buijten & Schipperheijn, 2016), 23-29.

[125] B. de Geus et al (ed.), A scone leeringe om salich te sterven. Een middelnederlandse ars moriendi. (Utrecht: HES, 1985), 9.

sickbed and the deathbed. When the dying person felt tormented by sin, he needed salvation. It was therefore important that sins were confessed. Anyone who wanted to die a good death asked for forgiveness for the evil he had done in words, thoughts or deeds. He also granted forgiveness to those who had done harm to him.[126] After confession, absolution was granted by the priest with the words, "Ego te absolvo a peccatis tuis. In nomine Patris et Filii et Spiritus Sancti." ("I grant you absolution from your sins. In the name of the Father and of the Son and of the Holy Spirit."). If the condition of the dying person allowed it, the Eucharist was celebrated. As death approached, prayers were said. Here, the seven so-called penitential psalms (Psalm 6, 32, 38, 51, 102 and 143) were particularly used.

Normal burials were hardly possible during epidemics; often thedead were deposited in mass graves without ritual. Because there were so many deaths, there were not enough priests to minister to all the dyingAdditionally, there were fraternities dedicated to counselling the dying. [127] However, there were still not enough to provide pastoral care to the dying, so the help of monastics and even lay people was enlisted.This movement was sparked translating the Latin *artes moriendi,*[128] or books on the 'art of dying', intended as manuals for priests, into the vernacular. Thus, handy 'death books' were created. *Artes moriendi* are thus catechetical, pastoral aid books for dying, written for death counselors, that focused on preparation for death and the afterlife.

Hans-Martin Kirn, professor of church history, points out that medieval people on the one hand repressed the thought of death, but on the other hand could be intensely preoccupied with it (*memento mori*). They were familiar with death.[129] Thus the *ars moriendi*"accommodated the need for orientation towards a 'blissful' death, an answer not only for the individual, but also a guide for counselling the dying." [130]

In the Middle Ages, numerous *ars moriendi booklets* were in circulation. In fact,

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[126] Ohler, Sterben und Tod im Mittelalter, 61.

[127] T.H.M., Akerboom, "'Je moet de dood in het leven zien…' Over het verband tussen de 'Ars moriendi' en Luthers Sermon von der Bereitung zum Sterben," in K. Zwanepol (red.), Luthers erfenis, " (Zoetermeer: Boekencentrum, 1996), 109.

[128] The Latin word "ars" means both "art" and "skill", both "gift" and "theory". (A. Baars, "Pastoraat aan stervenden, lessen voor de levenden. De visie van de vroege reformatie op sterven en stervensbegeleiding," in Documentatieblad Nadere Reformatie 36 (2012): 3.)

[129] Hans-Martin Kirn, „Martin Luther en de ars moriendi," in Sabine Hiebsch, Martin Luther. Zijn leven, zijn werk, Kok: Kampen, 2009, 200.

[130] Kirn, «Martin Luther and the ars moriendi,» 200.

soon after the invention of the printing press, they became the most printed booklets.[131] The booklets usually consisted of a description of dying and of the soul's fight with the devil and hell. The texts were meant to strengthen one's faith when facing these temptations. The most well known booklet on the art of dying is Johannes Gerson's little book *De arte moriendi* (1403). Among other things, his work harkens back to an ancient form (attributed to Anselmus of Canterbury[132]) that listed a number of questions to be put to the dying person, followed by an exhortation (*admonitio*). These questions, which formed the theological heart of the *ars moriendi*,[133] were also sometimes seen as a substitute for sacramental practice, as the priest was often unable to be present with the dying person.[134]

In addition to texts' popular 'Bilder-artes' began to circulate in the mid-fifteenth century. These were block books, with woodcut illustrations of the *artes moriendi*. In their original form, these consisted of 11 illustrations and 11 pages of text, preceded by a two-page introduction. The illustrations not only served to supplement the text, but also had an independent function.[135] These illustrations frightened medieval people - who could not always read - about an important aspect of the *ars moriendi*, the doctrine of the five temptations relevant to salvation in the hour of death: doubts of faith, despair, impatience, complacency and greed.[136] Exalto describes how the whole dying scene is visually displayed on 2x5 + 1 images. "Again and again, the deathbed is surrounded by all sorts of figures: God the Father, Christ, Mary, Moses, Peter, Mary Magdalene, Paul, Stephen, St Lawrence, St Barbara, St Anthony, whole multitudes of saints, the guardian angel, women, children, pagans, beggars, mockers, doubters and bad wives, but also the devil and all sorts of malignant demons; all partakers in this struggle or at least spectators. Everything in this drama focuses on this one soul, in this decisive hour; it will now be Hell or Heaven."[137]

The last judgement and Hell were themes that were often discussed, including in images. Ariès points out that the last judgement and Hell were themes most often depicted on church portals or miniatures from the thirteenth through the sixteenth centuries.[138]

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[131] Resch, Trost im Angesicht des Todes, 17.

[132] K. Exalto, De dood ontmaskerd, (Amsterdam: Ton Bolland, 1979), 6.

[133] Resch, Trost im Angesicht des Todes, 31.

[134] Resch, Trost im Angesicht des Todes, 46.

[135] Akerboom, "'Je moet de dood in het leven zien…'", 112-113.

[136] Kirn, «Martin Luther en de ars moriendi», 200.

[137] Exalto, De dood ontmaskerd, 12.

[138] Philippe Ariès, Het beeld van de dood, (Amsterdam: SUN, 2003), 131.

The *ars moriendi* rules usually contain six sections with the following substantive messages and questions:[139]

1.*Exhortations (exhortationes)*

The sick or dying person must prepare for the end of life. One has earned punishment for their many sins. To receive vindication, one must bear the suffering willingly and patiently. The thought of getting better is only vain hope.

2.*Interrogations (interrogationes)*

The sick or dying person is asked if he sees dying in the Christian faith as cause for joy. Do you believe that our Lord Jesus Christ, God's Son, died for you and thank Him for that?
The dying person repeatedly recites the Apostle's creed.

3.*Prayers (orationes)*

The sick or dying person is urged to pray. This call to prayer occupied a prominent place in books on dying. In addition to the call to prayer, sample prayers can be found that focused mainly on God the Father, Jesus Christ and Mary.

Exalto points out that in the late Middle Ages, people saw Jesus mainly as a strict judge who had to be satisfied no matter what. In Mary, by contrast, people saw goodness, mildness and kindness. Christ alone was not enough on one's deathbed. One also needed the saints and especially Mary.[140]

4.*Duties (observes)*

The sick or dying person receives the sacraments and is empowered with texts and images.
Confession, administration of the Eucharist and the last unction (the anointing of the sick) were seen as decisive sacraments. Confession consisted of three parts. Repentance and confession were followed by reparation. Suffering on the deathbed was seen as vindication.

In addition to performing the sacraments, it was common to read certain psalms, prayers and the story of Jesus' suffering and death to the dying. Sometimes images of Christ, Mary or a patron saint were presented to the sick person. As a sign of contempt, the sick person was sometimes even ordered to spit in the direction where he thought he could detect the devil. Baars says that this is how people

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[139] Exalto, De dood ontmaskerd, 16-29.

[140] Exalto, Death unmasked, 19.20.

experienced judgement being carried out in the dying person's bedroom.[141]

5.Temptations (temptationes or tentationes)
The sick or dying person reflects on temptation and consolation through text and images.
In the aforementioned book of elevent woodcuts, five temptations are depicted. These images represent either temptation or consolation. In the first image (the seduction/ temptation), the devil, demons, doubters and mockers are the extras. In the counter image, we see God, Christ, the Holy Spirit, Mary, Moses and many other saints (the consolation). The themes of doubt versus faith, despair versus hope, impatience versus patience, complacency versus humility and greed versus selflessness are discussed.

6.Community in the Passion of Christ (communicatio passionis Christi)
The sick or dying person may see dying as participating in the suffering of Christ. Imitating Christ was a common practice in the Middle Ages an was the ideal of true devotees and the religious. This imitation extended to dying. Jesus' dying became a model. Johannes von Staupitz, Luther's abbot and spiritual father, even wrote the little book *Von der Nachfolge des willigen Sterbens Christi* in 1515. In it, he has the dying person recite Christ's seven words of the cross to experience death with Christ.

3.2 Erasmus's preparation for death

Desiderius Erasmus (1466-1536) was much concerned with death in his lifetime but did not always think about death in the same way as the traditional ars moriendi did. Based on his writing when he was younger, the adage "Let us eat and drink, for tomorrow we die!" rings true. As a young man, just hearing the word death frightened him. For the elder Erasmus, death is a means to true happiness.[142]

3.2.1. Erasmus on death

Erasmus' most important work on death is about preparing for death (*De praeparatione ad mortem*, 1533). It became a success, as is evident from the publication of twenty editions in six years. We do not find his typically mocking tone in this serious work. Erasmus emphasises the life that precedes death, not the moment of death itself. He does not emphasise the deathbed, but the way of life. The little

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[141] Baars, "Pastoraat aan stervenden", 4.

[142] Manuel Stoffers, "Erasmus en de dood," in Albert van der Zeijden (ed.), Cultuurgeschiedenis van de dood, (Amsterdam: Rodopi, 1990), 76.

work has also been called his spiritual testimony.[143]
It is noteworthy that Erasmus chose the Roman god *Terminus* as his personal logo. Terminus is the personification of death representsthe ultimate limit of earthly life with the motto *concedo nulli*: I give way to no one. Erasmus's great poem on old age (*Carmen de senectute*, 1506) focuses on the brevity and transience of earthly life. Death is a part and conclusion of the *miseria humanae conditiones*: "Only death, which is the greatest evil, puts a stop to all evil."[144]

Erasmus rejects excessive certainty in the face of death. If Christ despaired on the cross, how can ordinary Christians be certain in the face of death? Erasmus, in his work on preparing to die, therefore, turns against Luther's doctrine of *sola fide*, by faith alone. Indeed, for Erasmus virtuous living is central. He believes that a good death can only follow a good life or sincere repentance.[145] Nevertheless, or perhaps because of this, he expects a Christian to have a certain fear of death. Erasmus interprets this fear of death partly as a natural fear of physical death and partly as the well-founded fear of divine judgement.[146] Sincere repentance was sufficient to reverse the judgement, but even the pious could not achieve certainty about this.

Erasmus' critique of rituals and customs surrounding dying

On the basis of an article by Manuel Stoffers, we examine Erasmus' critique of the customs surrounding dying in his time. Stoffers first points to the characteristic difference between popular practices and the humanist educated, intellectual vanguard to which Erasmus belonged. The old *ars moriendi* mainly gave simple, practical guidelines for the last hours. The humanist equivalent became moralistic tracts urging the reader to mend his or her life in the face of death. "The new *artes moriendi* were, therefore, rather *arte vivendi*: their message included that only a virtuous life was proper preparation for death."[147] Death is not only the end of human suffering, but also the gateway to heavenly happiness.

Erasmus attached little value to the outward ceremony of dying. Rather, he preferred a deathbed without a cordon of physicians, priests and acquaintances. This only distracts the dying from necessary repentance. Even physicians, with their professional focus on the medicical aspects, distract from necessary spiritual

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[143] A.H. van der Laan, "Woord vooraf," in Erasmus van Rotterdam, Voorbereiding op de dood. Translation A.H. van der Laan, (Groningen: Rijksuniversiteit, 2011), 9.

[144] Stoffers, "Erasmus en de dood," 79.

[145] Stoffers, "Erasmus en de dood," 74.

[146] Stoffers, "Erasmus en de dood," 74.

[147] Stoffers, "Erasmus en de dood," 70.

preparation (peaeparatione). Erasmus believed that there is no reason to despair if the priest is absent. This is because Erasmus's view of the sacraments, in which they only were effective when they were accepted in faith. In particular, he considered confession a matter between (the conscience of) the dying person and God, rather than between the dying person and the priest. He sharply writes that it is quite conceivable that many did not receive the absolution and sacraments administered by the priest but still rest in peace. And that others who did receive all the spiritual ceremonies andwere even buried in the church next to the altar sailed to hell. However, he considered indulgences a real support and comfort for the dying. The priest's task, according to Erasmus, was not so much in the administration of the sacraments but in what he spoke. He had to encourage desperate dying people and rebuke the carefree.

To put the dying in the right state of mind, Erasmus suggested hanging pictures of saints and of Christ in the dying person's room and reading portions from saints' lives or from the Bible. In the dying person's last hours, he or she had to be free from earthly worries, such as making a testament. As far as Erasmus was concerned, a person's will had to be a civil document settling the inheritance. He opposed the use of testamentary gifts to secure one's soul.

Ideally, according to Erasmus, a Christian died perfectly calmly and willingly, having already prepared himself in life: *Mediation Mortis*. As a result, the Christian was not unpleasantly surprised by death. In his collquium Gerontologie (1542), Erasmus has the elderly Glycion respond to the question of whether or not he is plagued by fear of day of his death as: "No more than for the day of my birth. I know I must die. Worrying about that would perhaps even rob me of a few days of life; in any case, it would not give me any extra days. Therefore, I leave the whole worry to heaven. I myself merely take care to honourably live a pleasant life."[148] Behind this statement is the Christian Epicurean belief that a virtuous life leads to a happy and pleasant life and death. An Epicurean's highest pleasure lies in a good conscience. In *Epicureus* (1533), Erasmus writes that Christ's love makes even death pleasant. For good people, death is the gateway to eternal happiness. In dying, the Erasmian Christian is even more cheerful than many are when feasting.

3.2.2. Summary: Preparing for death[149]

Life is like a ***granted journey***. Man does not perish at death but escapes to a blissful rest. We are travellers; death is the door to eternal life. Life is nothing but a journey

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[148] Cited in Stoffers, "Erasmus en de dood," 73.

[149] Erasmus van Rotterdam, Voorbereiding op de dood. Translation A.H. van der Laan, (Groningen: Rijksuniversiteit, 2011).

to death. God has freely given us life, on condition that we give it back the moment He reclaims it. A Christian does not own his body like a house, but like a tent.

Contemplation of death is a contemplation of true life. The pinnacle of human happiness is to think on and praise his Creator, Saviour and Lord. For this purpose, man was created. ***Contemplation on death*** should be practised over the course of a lifetime.
Those who are healthy and disciplined in contemplating death will not be caught unprepared by death.

Death is fourfold:
Spiritual: spiritual death separates God and soul
Natural: natural death separates body and soul
Eternal: the combination of these two deaths constitutes eternal death, the death of hell
Transforming: transforming death separates spirit and flesh

You don't know when you will die. Therefore, you must be prepared at all times. Only by the grace of Christ does a sinner come to repentance. If we have reconciled with God during our life, then at the time of illness our death will be as our life has been.

Death requires ***practical preparation***. A will achieves a more peaceful death. In good health, you should arrange and settle matters to avoid the need to be haunted by such inconvenient worries in illness.

Forgive and ask forgiveness. It is much more pleasing to God and better for one's piece of mind to do so in health. Not out of fear of death, but out of love for Christ.

That most of us shudder at death is largely due to weak faith. But in the promises of God, we should have rock-solid faith. ***God's promise*** is victory over death, the flesh, the world, the devil and sin. God knows the right time to deliver you from your suffering.

The most effective comfort is to never turn the eyes of faith away from Christ. He is pleading on your behalf with God. Let the sick man hide in the caverns of this rock, let him hide in His wounds and he will be safe from Satan. What Satan barks at us may plunge us into despair. What Christ speaks raises us to hope. ***Contemplating Christ*** crucified for us gives so much strength that despair turns into hope, hope turns into elation.

Take stock of the things we leave behind here on earth: bad and good. Put the pros and cons of this life side-by-side and then weigh the brevity of our life here. What is life other than a moment in eternity that we move to (if we have lived piously) and which escapes us if we were not pious. Seriously contemplating these matters offers no small remedy against revulsion at death. Remember that the Lord died for you and thereby brought about the open door to heaven. Thus, death is not only harmless, but even extremely profitable for those who believe in Christ.

Use of the sacraments

Some wish for full confession, the last unction, and the Eucharist before death. Why do we wish to obtain once for all what should and can be done daily by us? At the moment of death, the main comfort is to contemplate the Lord's death and to contemplate the communion of saints, which is the body of Christ.

A member of the church cannot be abandoned. He is supported by the whole church and countless saints with works and prayers.

If the illness allows, a person should seek healing of his soul rather than of his body through a brief but sincere confession. If there happens to be no priest available, one need not tremble, but should confess one's iniquity to God Himself. God does not necessarily need the sacraments to work in us. However, faith and volition must be openly present.

Certainly, it is good for a Christian to wish for the sacraments. However, it is more holy to desire faith and love because without faith and love, the sacraments do not benefit him. Even with the administration of sacraments one can be dragged to the underworld, and without them one can still move to eternal rest. A brief, sincere confession of wrongdoing should suffice.

Role for those assisting the sick person

The sacraments will not hasten death. A priest should not mislead the sick person with too much flattery, nor drive him to despair with severity at the wrong time. Only allow people to see the sick person that support him with their words. Resist allowing those who can reawaken inclination to sin, for example companions in shameful lust or in dice, to see the sick person. Let the sick person neither despise nor solicit the help of physicians. The greatest hope must be placed in God, who alone removes the soul from the body. Those physicians should be barred who are so concerned with physical health that no time is left for the sick person to give proper attention to spiritual matters.

Role of community/dying support
Reminding the patient of the fellowship of the whole church is a quick remedy for despair. The whole church community, including angels, supports the patient with vows and prayers in anticipation of a wonderful victory. Why would anyone give in when he has such great and powerful helpers?

The devil does his utmost to drive the sick person to despair. Therefore, put up an image of Christ crucified and display paintings of saints in whom God reminds us of His goodness and mercy.
Those sitting at the sickbed should have a range of Bible verses at hand to support the sick person when they falter. He should read aloud and narrate. Appropriately composed prayers are also valuable for this purpose.

3.3 Luther's preparation for dying

Markus Schart, counselor at the court of Frederick the Wise, asked Martin Luther in May 1519 how to prepare for death.[150] Due to an excessive workload, Luther at first rejected the request to write and referred to the writings of his paternal friend Johann Staupitz, who had also written a similar document (*Ein Büchlein von der Nachfolgung des willigen Sterbens Christi*).[151] However, it was not long before Luther wrote his *Sermon von der Bereitung zum Sterben* after all. What is a Sermon (German word)? A sermon resembles a sermon (English word) but is more elaborate in form and content and often longer than a typical sermon (En). It is somewhere between a sermon and a concise theological treatise.[152] Luther's Sermon apparently met a need, because six years after its first publication, it was re-printed twenty-three times. [153]

It was in 1517 that Martin Luther, then thirty-three years old, penned the 95 theses, just two years prior to writing his Sermon on dying and the beginning of the Protestant Reformation. Reformational thinking increasingly permeates Luther's work. It was during these early years of the Reformation that Luther wrote some of his most important works. It is interesting that he calls attention to dying. The discovery of faith as access to God casted evertying, including dying, into a new light.

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[150] This request reaches Luther indirectly, through a letter from Georg Spalatinus (WA Br 1 May 1519).

[151] WA Br 1.13, 17.

[152] Sabine Hiebsch, Luther voor leken. Refomator in een veranderende wereld (Hilversum: De Vuurbaak, 2018), 47.

[153] WA 2, 680-683.

3.3.1. Summary Luther's sermon[154]

A person must say goodbye spiritually in order to turn ***to God***. The dying of the saints is a way through the narrow gate of death from life, like a new birth ('new gepurt'). That celebration is called 'natale' in Latin: day of birth ('tag yhrer gepurt').

The journey out of life requires one to highly regard the ***sacraments***, so that one relies on them to be free ('frey') and joyful ('froelich'). The virtues ('tugend') of the sacraments struggle against vices ('untugent'). The three vices are

1. The image of death - becomes overwhelming and instils fear because in man's weakness, he devotes too much attention to death. The devil thereby sows confusion and doubt. Man forgets God and ultimately disobeys Him;
2. The image of sin - grows when one thinks too much about sin. This is reinforced by our conscience so that we are ashamed of God. While in the moment of death we should only have in mind life, grace and salvation, the evil spirit actually frightens us with images of sin;
3. The image of hell and eternal damnation - becomes too overpowering when one focuses too much on it and thinks about it too deeply. The devil makes man doubt his election by God.

With regard to death, you should only want to see those who have died in God's grace and conquered death, namely ***in Christ*** ('furnemlich yn Christo'), then in all His saints. By regarding Christ's death, you find life.

The flip side of sin is ***grace***. The image of Christ is none other than Christ on the cross and all His dear saints. It is grace and mercy that Christ on the cross took away your sins, bears them and strangles ('erwurget') them. Look at the heavenly image of Christ, rather than hell. For your sake, He descended to hell and was abandoned by God. In this image, your hell has been conquered and your uncertain prospect made certain.

Sin, death and grace flee with all their powers when, in faith, we evoke within us the illuminating images of Christ and His saints. Central to this faith is the crucified Christ. On the cross, He presented Himself as a threefold image. He is the image of life, grace and heaven.

Christ is an ***example*** because He Himself overcame temptations (as expressed in the images). Not by fighting them, but by silencing them. He trusted only in the

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[154] WA 2, 685-697, translation in: Alderliesten, Stervenskunst bij Luther, 47-71.

will of His Father. This is how we should ***do God's will***. When we follow Christ's example, death, sin and hell will not harm us.

3.4 *Ars moriendi* applied today

The time between the discussed *artes moriendi* and today covers more than half a millennium. Not only is death dealt with differently now, society as a whole is more focused on the here –and-now than it was in the Middle Ages. Moreover, the predominance of Christianity has been exchanged for a multi-religious and pluralistic society. This means that the *ars moriendi* is either translated for an application within the Christian church or transformed into a model deployable in pluralistic practices. First, we describe Carlo Leget's *ars moriendi model* for a contemporary pluralistic society. We then make the case for an art of dying oriented on Luther's *ars moriendi* that focuses more on the Christian community of faith.

3.4.1 Carlo Leget: plea for inner space

Carlo Leget published the book *Art of Living, Art of Dying: Spiritual Care for a Good Death* in 2008.[155] In this book, partly based on a previous book of his, *Room to Die*, he develops an *ars moriendi* model for our time. He advances a model for spirituality in palliative care for several reasons even though the spiritual dimension in care seems to cause embarrassment. However, there is no simple model for the sick to prepare for dying, together with loved ones and caregivers..[156]

Leget describes the five themes from the medieval ars moriendi writings as differentiated at the end of life in the form of fields of struggle. In the *ars moriendi,* these themes were called 'temptations'. These fields of struggle pull the dying person between two extremes. The five themes are autonomy, suffering, saying goodbye, unfinished business, and hope, and the respective fields of struggle are (1) me and the other, (2) doing and letting go, (3) holding on and letting go, (4) forgiving and forgetting and (5) believing and knowing (see figure below). In each area, the patient feels pulled between two extremes. According to Leget, fields of struggle can be made manageable by creating inner space. It is always an art to find the right relationship to death between these two extremes. Leget points out that medieval woodcuttings try to calm the dying. The five major themes at the end of life are called upon to achieve acceptance and surrender. The devils try to pin down the sick person; the angels try to offer perspective and space through

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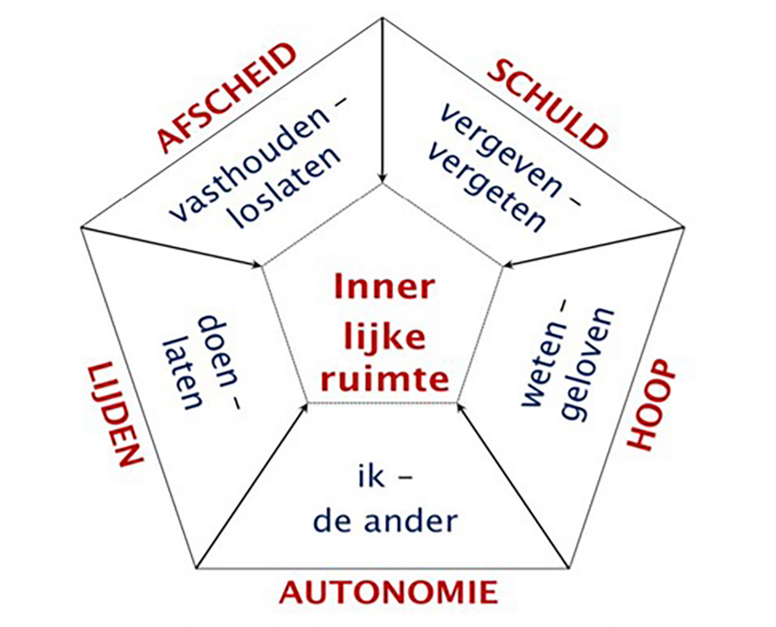
[155] Carlo Leget, Van levenskunst tot stervenskunst. Over spiritualiteit in de palliatieve zorg, (Tielt: Lannoo, 2008). For the English version see: https://archive.org/details/artoflivingartofoooolege/mode/2up

[156] Leget, Van levenskunst tot stervenskunst, 75, 76.

which the dying person can come to surrender.

In the medieval *ars moriendi,* this surrender takes on a very special meaning: it is entrusting oneself to God. In making the *ars moriendi* applicable, Leget interprets entrusting oneself to God as a transformational process resulting in space and surrender: "The whole religious framework of tradition helps to focus man on the invisible mystery from which everything comes and to which everything returns. But in essence it is about a transformation process where out of the distress comes space, relaxation, surrender. There, I believe, lies the spiritual core of medieval dying. There also lies its ancient wisdom of experience and inspiration for our times."[157]



3.4.2 Areas of struggle

Where the medieval *artes moriendi* began with faith, Leget starts with autonomy. "In the Middle Ages, faith was the basis of the *ars moriendi*. In our time, autonomy or self-determination is held in high regard."[158] The five areas of tension are

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[157] Leget, Van levenskunst tot stervenskunst, 84.

[158] Leget, Van levenskunst tot stervenskunst, 94.

meant to facilitate working on inner space. Each pole in the field of tension is of equal importance. It is about a person becoming aware of how both poles play a role at different times and in different situations. It always comes down to finding a (happy) balance between both points of tention. The model is an abstract tool for looking at situations form multiple points of view. What is at stake in the different areas of tension?

1. *Autonomy: I - the other.*

This pole (or theme) asks the question, “is this my illness, my death?” Questions around authenticity, self-determination, identity, autonomy, freedom and the role others play in it are central. Autonomy and dependence belong together. The relationship a person has with their loved ones affects how the dying person sees himself. I and the other are thus intertwined and mutually dependent (patient-neighbour-caregiver).

2. *Suffer: Do - Let*

This struggle is about controlling pain and suffering. Where do we need to become more active physically, psychologically, socially, spiritually? What do we need to accept and let happen? Is there room for receptivity and for that which cannot be planned or made?

3. *Goodbye: holding on - letting go.*

This struggle about saying goodbye to dear people and things of life. Dealing with all that is good in life. Being sick, dying is slowly letting go, but it is also seeking handhold and holding on to the essential. What or who is essential?

4. *Guilt: Forgiving - Forgetting.*

This struggle is about taking responsibility, looking back, taking stock, bringing closure to life. Is there any backlog that needs to be addressed or accepted? Important questions, also for the grieving process of the bereaved.

5. *Hope: Believing - Knowing*

This struggle is about the meaning(s) of suffering and death. Is life seen as an end, a passing phase or a new beginning? Is there continued life in people or things? Do people expect an afterlife? Can you live with questions that have no answers?

In Leget’s *ars moriendi model,* both poles are of equal importance. From inner space, a person can become aware of how each pole can play a role at different times in different situations. Finding a happy balance between the two is the goal. The model is a somewhat abstract tool to clarify the choices within situations.

Contemplating the major themes as fields of struggle enables the dying person to create inner space. Inner space, for Leget, is a metaphor, imagery. Inner space is then "a state of mind that allows a person to freely and calmly relate to immediate emotions and attitudes evoked by a situation."[159] Somewhat pragmatically, he observes that the concept of inner space "can count as the spiritual centre of a new dying art, because it concerns a quality or inner attitude that largely determines how to deal with the questions that are recognised as spiritual (questions around finitude, transcendence, meaning of life, suffering, death, and so on), and as a concept, it connects with the major spiritual traditions."[160]

3.4.3 Arthur Alderliesten: an art of dying oriented on Luther's *ars moriendi*

In *Luther's Art of Dying. A Reformational response to 'completed life'*, Arthur Alderliesten lists nine 'lessons learned' from Luther's art of dying:

1.*Dealing with suffering*

Martin Luther knew what suffering was. He faced many diseases and ailments that sometimes brought him to the brink of death. Therefore, he longed to be delivered from suffering (by an enraged Satan) to be with Christ. The desire to leave this world shows that for Luther, suffering can be unbearable. This recognition takes suffering and the suffering person seriously. It touches on the fundamental question of how we deal with illness, health and suffering. That unbearable suffering can cause people to declare their lives 'completed', demands to be taken completely seriously, including by people who are critical of euthanasia. It is easy to lose sight of this in the heat of the political battle over life and death. Next, Luther focused on what *could* be done. If he couldn't read or write, Luther went about thinking, praying and thereby annoying Satan again; eventually sleeping, doing nothing, joking and singing. Simple actions that keep the mind agile and lead to relaxation, until the time when God determines the moment of death has come. This speaks to the idea of surrender.

2.*Preparing to die*

Luther opens his sermon on preparation to die in a surprising practical way. He calls on people to prepare both physically and spiritually for their farewell.[161] Physically, by taking care of your earthly goods, such as drawing up a will so that after your death there is no cause for quarrelling among the heirs. Spiritually, by coming to terms with people through forgiving and receiving forgiveness. These preparations are necessary so that the dying person can then focus on God in their dying process.

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[159] Leget, Van levenskunst tot stervenskunst, 89.

[160] Leget, Van levenskunst tot stervenskunst, 93.

[161] WA 2, 685.

Saying goodbye physically and spiritually is important for dying well. For Luther, dying well means above all to attain spiritual purity. He considers this necessary for a peaceful dying process.

3.Dying is not something you do alone
Martin Luther argues that a Christian, in particular, need not fear dying alone. The eyes of God, especially those of Christ, angels, the saints and all Christians are on the dying. From this he can draw courage to die because all believers, all saints, together form the community of saints (*sanctorum communio*). They serve as examples and inspirations of faith for the Christian Church.

4.From art of dying to art of living
Luther shifts the focus from the last hours before dying to living before the final stages of life. That is where preparation for dying must take place: "In life, when death is still far away and does not yet corner man, thoughts about it must be brought to mind."[162] In the middle of life, preparation takes place when we learn to trust in Christ.

5.Nuancing death: framing as sleep and overcome by Christ
Luther nuanced the weight of death in two ways. First, by frequently framing it as sleep. This paves the way communicatively and psychologically for radical positive thinking, without dismissing death as a trivial matter.

Secondly, he describes death as having been conquered by Christ. "Nor do we sing songs of mourning or lamentation at our dead and graves, but songs of comfort about the forgiveness of sins and about rest, sleep, life and the resurrection of Christians who have died. So that our faith is strengthened and people are encouraged to true devotion." [163]

6.Radical positive thinking: life, grace and heaven
Characteristic of Luther's art of dying is the strongly Christological tone[164] that even in his hour of death, man should not just focus on himself, but on Christ, Who brings the liberating prospect of redemption and freedom.[165] In the *ars moriendi* writings that were common at the time, many of the images scared the dying. Luther's sermon hinges on a change of perspective that focuses on life, grace, and heaven rather than death, sin and hell often pictured in these writings.

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[162] WA 2, 687.

[163] WA 356, 478, 479.

[164] Akerboom, "'Je moet de dood in het leven zien...'," 132.

[165] Hiebsch, Luther voor leken, 48.

This was radical thinking. Christ Himself is the image of life, grace and heaven. In Christ's death on the cross, for those who believe, a paradigm shift takes place from death-sin-hell to life-grace-heaven.

Luther's Christological thinking is the foundation of his art of dying. Ultimately, according to Luther, a person can only die well, when he believes in Jesus Christ. Here we see a difference with Carlo Leget's *ars moriendi model*. Leget's spiritual model focuses on reaching your 'inner space'. He believes that the medieval *ars moriendi was* essentially about "a process of transformation where out of distress comes space, relaxation, and surrender."[166] Leget thus provides a beautiful and manageable perspective for palliative care. Yet, in doing so, he turns away from what he calls a very special interpretation of: "an entrusting to God." 'Space' becomes a psychological aspect, whereas with Luther it is theologically linked to the assurance one has through faith in Christ (the doctrine of justification). This aspect, the surrender to God and focus on Christ, is so essential to Luther that it cannot be omitted when trying to apply Luther's art of dying today.

Towards a new dying practice

Alderliesten initiates a new dying practice inspired by Luther's *ars moriendi*. It is formed within communities, where relationships are central and has areas of focus: organising the practice, points of concern and spheres of approach.

7.Organising the practice

Luther's Christological emphasis is so fundamental that the application of his *ars moriendi* must start within the Christian church. Alderliesten understands the church as the Body of Christ: *sanctorum communio*, the community of the saints (I Cor. 12; Eph. 5:23-24). The Christian community of faith functions as a serving community,[167] a network of living care.[168] Members of the church can be formed and equipped for the practice of dying. Traditionally, pastors have also had a role as bereavement counselors. Their role can be expanded: Quantitatively by employing more members of a community as bereavement counselors. Qualitatively by paying more attention to the content-practical elements mentioned below in pastoral care.

8.Points of concern

a. The issue of identity plays an important role even amid dying. If our identity

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[166] Leget, Van levenskunst tot stervenskunst, 84.

[167] Stanley Hauerwas, "'The Servant Community: Christian Social Ethics,'" in: The Hauerwas Reader, (Durham, NC: Duke University Press, 2001), 372.

[168] Taylor, Een seculiere tijd, (Rotterdam: Lemniscaat, 2010), 968.

in life is mainly determined by physicality, we will find the process of dying difficult as the body deteriorates. In life, but also towards the end, attention must therefore shift from physicality and physical appearance to spirituality, to solace for the soul;

b. To die well is to die with Christ in view. This starts during life, turning the art of dying into the art of living;
c. Death can be prepared for in practical, spiritual and medical terms (living wills, *advance care planning (ACP*);
d. Especially at the end of life, it is not survival of the fittest that counts. The suffering person is taken seriously. He is not hidden, but,if possible, lovingly cared for and assisted in participating in the full life of the community. One person is allowed to be 'a burden' on another;
e. Surrendering in death: living and dying can not be orchestrated or controlled;
f. A community cannot exist without communication. Communication breaks through loneliness. Even people who lived with a desire to die from the perspective of a 'completed life' showed gratitude when they could talk about their fate.[169]

9. Sphere of approach
The church can be modestly proud of its vision of the the afterlife and how that informs the dying process, as well as how this vision is expressed in an intensified dying practice. This vision matters, also in a plural society that is *post-secular* and *post-Christian*. Using words like 'sleep' for death takes away an oppressive weightiness from death. However, it is in line with Luther that sleep is linked to comfort and assurance of faith in Christ. Without denying the afterlife or the severity of suffering of the dying (which can cause them to characterise life as completed), this can create a helpful perspective.

Radical positive rethinking is possible by focusing not on the dark, suffocating side of sin, death and hell, but on the illuminating, space-creating side of grace, life and heaven. Speaking about dying and death can take on a positive tone by way of belief.

3.4.4 Additional voices

Christoph Jedan: comfort and intelligence of religion in dying
Christoph Jedan, professor of philosophy of religion and ethics at the University of Groningen, wants to address the intelligence of religion.[170] This is in con-

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[169] Paul van Tongeren, Willen sterven, Over de autonomie en het voltooide leven, (Utrecht: Kok, 2018), 109.

[170] Christoph Jedan, Een voltooid leven. Over troost en de intelligentie van religie (oration), (Gro-

trast to a kind of prevailing negativism about religion. According to that negativism, religion is said to be disruptive to society and intellectually irrelevant. Jedan countered that religion actually makes us think. He argues that we should take the intention of religion seriously and see if religion can make a relevant contribution to current issues.[171] There is a long tradition in theology and philosophy of texts that teach how to deal with loss and grief. This tradition dates to Plato continues through the great Christian authors and to today. If we want to take the intelligence of religion seriously, especially in social debates, we need to bring the literature from this long tradition in conversation with the most respected scholarly literature at our disposal. In the case of comfort literature, this is undoubtedly the psychological literature on processing loss.

A comparison between the old comfort literature and the new psychology of grief shows that old comfort texts place a greater emphasis on the worldview of the mourner. The old consolers are convinced that our fundamental views of the world determine the impact of loss, whether they turn out to be destructive for our lives or not. The bottom line is that our answers to deep religious questions about the justice of the world, the purpose of human life and one's view of death determine how well we can cope with loss.

Changes at the level of everyday concrete actions, such as what to do instead of the things we did before with the deceased, get comparatively little attention. However, in the old tradition, much attention is paid to how the memory of the deceased is given a place in our daily lives. In the new grief therapy tradition, this has only been recognised for about 20 years under the heading of 'continuing bonds'.

What the ancient consolation tradition excels at, and what we can still learn a lot from, is the effort to show that the deceased's life was a completed one, that it was finished.[172] The ancient tradition did not focus on ticking off a "bucket list" (a list of things someone definitely wanted to do in his or her life). The old comforters realised how precarious such a list actually is. For example, the Grand Canyon is lovely, but maybe going on a rafting holiday in Montenegro is better; one's best achievements can be surpassed by someone else. What does such a list say about the core of a person's existence? In short, ticking off a bucket list offers little comfort. The old comforters were smarter. They matched the virtues of the deceased. Reformational comforters also belong to this tradition.

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ningen: Rijksuniversiteit Groningen Faculteit Godgeleerdheid en Godsdienstwetenschap, 2017).

[171] Jedan, Een voltooid leven, 11.

[172] Jedan, Een voltooid leven, 14.

Naming the dying person's virtues is more than a rhetorical device; it shows that a biography has an ending and is complete. We see this, for example, in a letter by Jerome (347-420). He writes to the uncle of a young deceased: "Every single virtue was so manifest in him as if he possessed no other." The emphasis on virtues links the Christian consolation tradition with the non-Christian. The Roman philosopher Seneca writes to a grieving mother: "Try to estimate your son according to his virtues and not his years, then he has lived long enough."

We can learn two things from these ancient texts for social discussions today:

1. It is important to recognise that religious traditions give plenty of thought to how a life can be full and, in a sense, completed. The religious traditions need not be pushed into a corner. They can contribute to the discussion of what it means to have a completed life;
2. It is important to see that the ancient texts formulate a positive understanding of a completed life. 'Completed life' is not a euphemism for being life-weary or suffering from life. The ancient texts reveal a blind spot in our contemporary debate: the importance of virtues for experiencing a meaningful life.

A virtues perspective takes a concrete perspective on the abstract terms used in the end-of-life debate (e.g. autonomy, participation, inclusion). For example, when an elderly woman complains that family will pick her up to spend time with her, but no one visits here anymore, it is not about the abstract notions of autonomy or inclusion. After all, she is intentionally included in activities, and she had a choice whether or not to go along. The crux of the issue is that this woman is no longer given the opportunity to be hospitable and show generosity. This deprivation of virtues detracts from her sense of meaning and purpose.

When someone requests termination of life, a sense of isolation, alienation and futility often emerges. This raises the question of how we can structure an affluent and ageing society. And especially how we can change people's mindsets so that we help them practise virtues for a lifetime and reap the benefits - through closer social ties and the experience of a sense of life.

The ancient tradition of comfort literatureillustrates the intelligence of religion, no matter what faith or belief we hold. Religious writers ask good questions and provide challenging answers.

Blaise Pascal: example of ars moriendi

An example of a classic *ars moriendi text* is a prayer text by the French mathematician and physicist, Christian philosopher, theologian and apologist Blaise

Pascal (1623-1662).[173] In this prayer text, Pascal addresses God directly. He does not ask for healing, but for the right way to deal with his illness. The original title of the little work is therefore *Prière pour demander à Dieu le bon usage des maladies* ('prayer to ask of God the right use of diseases'). Pascal wrote the booklet at the end of his life, probably in the last four years of his life, during or at the end of a prolonged period of illness. In this last phase of life, he could hardly publish anymore. Pascal devoted his remaining time to Bible reading, prayer and caring for the poor, both practically and financially.
The prayer was for himself, but was written for the edification ofthe audience.[174] I make some observations relevant in view of 'completed life'.

For Pascal, it is clear that sickness comes from God's hand. The first line of the prayer: "Lord, Your spirit is so good and mild in all things, and You are so merciful that not only the prosperity, but even the adversity that befalls Your chosen people is an outgrowth of Your mercy. "[175]
Insensitivity is to him the greatest of the ills coming along wth illnesss. Sickness as the punishment of the soul's misery. The sorrows are like a medicine: "to cause the sorrows of the soul to be pondered which I did not feel in my soul."[176]

He confessed that he abused his health. His good health allowed him to indulge in life's lavish pleasures with less restraint. He prayed for purification of his desires.[177] He believed he needed it, because he was honour-sensitive, writes Gert van de Wege in his introduction to the prayer text.[178]

Pascal does not ask for healing, to be "free from sorrow", but for consolation added to sorrow. The consolation of God's Spirit by His grace. [179]

"I am not asking you for health, for illness, for life, for death;
But that You dispose of my health and of my illness,
About my life and about my death,
To your honour, to my salvation and to the benefit of the Church and your saints,

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[173] Blaise Pascal, Gebed van een zieke, Translated and introduced by Gert van de Wege, (Kampen: Brevier, 2016).

[174] Gert van de Wege, "Inleiding," in Blaise Pascal, Gebed van een zieke, 19.

[175] Pascal, Gebed van een zieke, 37.

[176] Pascal, Gebed van een zieke, 53.

[177] Pascal, Gebed van een zieke, 57,58.

[178] Van de Wege, "Inleiding," 8.

[179] Pascal, Gebed van een zieke, 61.

of which I am a part."[180]

"For, Lord, you have made the world languish
In natural grief without consolation,
For the coming of your only Son;
Now You comfort Your believers
By the grace of Your only Son;
You fill Your saints with the purest bliss
In the glory of your only Son.
It is in this admirable way that You organise Your works.
You have pulled me from the first stage;
Make me run through the second.
To reach the third.

Lord, that is the grace I ask You for."[181]

He prays to the sovereign God that his will may become conformed to God's.[182] He asks for spiritual equanimity to accept what is happening. He even prays for God to bring him to the point of rejoicing in his suffering:

"So give, Lord,
That I, however I am feeling,
Arrange according to Your will;
That I, sick as I am,
Rejoice in my suffering.
Without suffering, I cannot reach glory;
Without suffering, my Saviour, You Yourself would not have entered glory.
By the scars of Your suffering, You were recognised by Your disciples,
And by suffering You also recognise Your disciples.
Then recognise me as Yours in the suffering I endure
Both in my body and in my mind
For the offences I committed.
(...)
Let my grief become Yours
(...)
Come into my heart and into my soul,
To suffer my suffering there,

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[180] Pascal, Gebed van een zieke, 67.

[181] Pascal, Gebed van een zieke, 62.

[182] Pascal, Gebed van een zieke, 68, 71.

And to endure further in me
What still lies before You
Of thy agony,
Which You complete in Your members.
(...)” [183]

Ineke Visser: plea for just dying

Ineke Visser is president of the *National Expertise Centre for Dying.* In two related publications, the *National Expertise Centre for D*ying pushes back against the social trend that euthanasia must be available.[184] Against the illusion of holding one’s own life and death in one’s hands, Visser argues for a story of surrender and proximity. Euthanasia must not be available, even though the reported number of euthanasia cases has doubled in the past decade. “All the focus on euthanasia (...) quickly creates the impression that almost every deathbed is associated with unbearable suffering without perspective.”[185]

Over the next 10 years, the number annual of all deaths will increase by 14 per cent. We are getting older and old age symptoms are piling up. “The last phase of life has increasingly become a medicalised process. We are dying longer and later.” Visser advocates for exchanging the world of efficiency, care costs and protocols for eyes and ears open to human beings, to compassion and mercy. Along those lines fits what she calls ‘just dying’. “Dying is ordinary, in the sense that it is everyday (...) it happens to us and—contrary to what we like to tell ourselves—cannot be directed.”[186] Dying is an autonomous process of transition in which “we may be able to experience something of the mystery of life.”[187] “Awe and respect for that mystery of life will ultimately determine how we deal with delicate issues surrounding life and death. Do we intervene, ignorantly and unknowingly?”[188]

The ‘other story’ of dying, about which the book speaks, is one that demands surrender rather than anxiously clinging to the illusion that we are in control of life and can direct our dying.[189] Although the term *ars moriendi* does not appear

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[183] Pascal, Gebed van een zieke, 71,72.

[184] Ineke Visser, Sterven – Tijd voor een ander verhaal, (Rotterdam: Landelijk Expertisecentrum Sterven, 2020) and Ineke Visser, Het leven voltooien – Tien persoonlijke verhalen over de waarde van leven met sterven (Rotterdam: Landelijk Expertisecentrum Sterven, 2020).

[185] Visser, Sterven, 12.

[186] Visser, Sterven, 14.

[187] Visser, Sterven, 14.

[188] Visser, Sterven, 32.

[189] Visser, Sterven, 14.

in any of the booklets, the ‘other story’ does have the character of an *ars moriendi*. For one, the booklets serve as practical handouts. The booklets from the National Expertise Centre invite us to think through ‘just dying’ in relation to the *ars moriendi* and by thinking further towards practice.[190]

3.5 Concluding summary

The tradition of the *ars moriendi*, the medieval art of dying, is an inspiring resource for dying today. This ancient comfort tradition recognises the intelligence of religion (Jedan). Back then, people did not die alone but in community. Because many people died, lay people were needed. Initially, *ars moriendi* booklets were written for the layiety to comfort the dying. Later the booklets were also written for the dying themselves. These booklets were mainly spiritual in nature and consisted of a description of the soul’s fight with the devil and hell. Both Desiderius Erasmus and Martin Luther opposed this. Erasmus did not emphasise the deathbed, but the way of life. To him, death was not just the end of human suffering but, for good people, the gateway to eternal happiness. Luther thought dying was so important that he devoted a sermon to it during the height of the Reformation. Dying also came to be seen as access to God for the faithful. For Luther, the usual images of doubting faith, despair, impatience, complacency and greed gave way to life, grace and heaven.

Faith from the Middle Ages gave way to contemporary self-determination. Recently, Carlo Leget developed an *ars moriendi model* for this time in which he makes a spiritual argument for palliative care. In making the *ars mor*iendi applicable, he interprets entrusting oneself to God as a process of transformation in which space and surrender emerge from distress.

Along the lines of Luther’s art of dying, we can now learn to handle suffering, prepare for death (wills and *advance care planning*, ACP), the importance of not dying alone but within the community of family and/or the church, the emphasis on living rather than dying, framing death as sleep (death has been conquered by Christ), and radical positive thinking in terms of life, grace and heaven.

In terms of dying, there is an additional responsibility on the Christian faith community to form a network of living caregivers around dying people. Dying and suffering people are permitted to be ‘a burden’ on one another.

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190 Vries, Huib de, “De wijsheid van normaal sterven”, Reformatorisch Dagblad 20 februari 2023, 18, 19.

Sources

- Akerboom, T.H.M. "'Je moet de dood in het leven zien...' Over het verband tussen de 'Ars moriendi' en Luthers Sermon von der Bereitung zum Sterben." In Zwanepol K. (red.). Luthers erfenis.
- Zoetermeer: Boekencentrum, 1996: 107-133.
- Alderliesten, Arthur. *Barmhartig leven. De zeven werken van barmhartigheid.* Amsterdam: Buijten & Schipperheijn, 2016.
- Alderliesten, Arthur. *Stervenskunst bij Luther. Een reformatorisch antwoord op 'voltooid leven'*. Apeldoorn: De Banier, 2021.
- Ariès, Philippe. *Met het oog op de dood. Westerse opvattingen over de dood, van de middeleeuwen tot heden.* Amsterdam: Querido, 1980.
- Ariès, Philippe. *Het beeld van de dood.* Amsterdam: SUN, 2003.
- Ariese - van Putten, Ariese and Hoek - Burgerhart, Elise. *Van betekenis tot het einde: pastoraat en het levenseinde.* Veenendaal: NPV, 2018.
- Baars, A. "Pastoraat aan stervenden, lessen voor de levenden. De visie van de vroege reformatie op
- sterven en stervensbegeleiding." In *Documentatieblad Nadere Reformatie* 36 (2012): 2-33.
- Erasmus van Rotterdam. *Voorbereiding op de dood.* Vertaling A.H. van der Laan. Groningen: Rijksuniversiteit, 2011.
- Exalto, K. *De dood ontmaskerd.* Amsterdam: Ton Bolland, 1979.
- Geus, B. de e.a. (red.). *Een scone leeringe om salich te sterven. Een middelnederlandse ars moriendi.* Utrecht: HES, 1985.
- Hauerwas, Stanley. "'The Servant Community: Christian Social Ethics'." In: *The Hauerwas Reader.* Durham, NC: Duke University Press, 2001, 371-391.
- Hiebsch, Sabine. *Luther voor leken. Reformator in een veranderende wereld.* Hilversum: De Vuurbaak, 2018.
- Huizinga, Johan. *Herfsttij der Middeleeuwen.* Amsterdam: Contact, 1999.
- Jedan, Christoph, Een voltooid leven. *Over troost en de intelligentie van religie* (oration). Groningen 2017.
- Kirn, Hans-Martin. "Martin Luther and the ars moriendi". in Hiebsch, Sabine, *Martin Luther. Zijn leven, zijn werk.* Kok: Kampen, 2009.
- Leget, Carlo. *Van levenskunst tot stervenskunst. Over spiritualiteit in de palliatieve zorg.* Tielt: Lannoo,2008.
- Lieverse, Paul, Farmer, Theo and Mul, Dick. "Het medische antwoord op lijden." In Boer, Theo and Mul, Dick (ed.). *Lijden en volhouden.* Lindeboom series no. 19. Amsterdam: Buijten & Schipperheijn, 2016.
- Luther, M. *Werke. Kritische Gesamtausgabe.* Weimar, 1883 ff.
- Ohler, Norbert. *Sterben und Tod im Mittelalter.* Düsseldorf: Patmos, 1990.
- Pal voor u. *Wat als je je leven verliest. Themaboekje over keuzes maken in de laat-*

ste levensfase. Tilburg: Zezz.

- Pascal, Blaise. *Gebed van een zieke.* Translated and introduced by Gert van de Wege. Kampen: Brevier, 2016.
- Resch, Claudia. *Trost im Angesicht des Todes. Frühe reformatorische Anleitungen zur Seelsorge an Kranken und Sterbenden.* Tübingen/Basel: A. Francke, 2006.
- Sons, Rolf. *Martin Luther als Seelsorger. Die Freiheit neu entdecken.* Holzergingen: SCM, 2015.
- Stoffers, Manuel. "Erasmus en de dood." In Albert van der Zeijden (ed.), *Cultuurgeschiedenis van de dood.* Amsterdam: Rodopi, 1990, 63-83.
- Taylor, Charles. *Een seculiere tijd.* Rotterdam: Lemniscaat, 2010.
- Timmerman-van Rhee, Ridder-Sneep, J. N.A. de and Jochemsen, H. *Levensvragen... Een christelijke visie op geestelijke zorg in de terminale palliatieve zorgverlening. Met een handreiking voor zorgverleners.* Lindeboom Instituut and the Nederlandse Patiëntenvereniging in cooperation with Buijten & Schipperheijn.
- Tongeren, Paul van. *Willen sterven. Over de autonomie en het voltooide leven.* Utrecht: Kok, 2018.
- Visser, Ineke. *Sterven – Tijd voor een ander verhaal.* Rotterdam: Landelijk Expertisecentrum Sterven, 2020.
- Visser, Ineke. *Het leven voltooien – Tien persoonlijke verhalen over de waarde van leven met sterven.* Rotterdam: Landelijk Expertisecentrum Sterven, 2020.
- Vries, Huib de, "De wijsheid van normaal sterven", *Reformatorisch Dagblad* 20 februari 2023, 18,19
- Wils, Jean-Pierre. *Ars moriendi. Über das Sterben. Insel: Bibliothek der Lebenskunst*, 2007.

4 ‘Completed life’

Roy Kloet

Life expectancy has increased as a consequence of improvements in our standard of living and the advances in medicine and health care. Some people find it difficult to find meaning at an advanced age, and a few even report suffering from life, resulting in a desire to terminate their life without being seriously ill. This is often referred to as ‘completed life’ or ‘life fatigue’.

Suffering due to a ‘completed life’, is real suffering. It is a universal phenomenon, and occurs in non-Western countries, such as China[191] and Brazil.[192] However, unique to the Netherlands is that suffering from life (from a ‘completed life’) is politicised more than elsewhere in the world. This especially applies to the question of whether a request to terminate life for a ‘completed life’ should be made legal, and whether it is or should be considered a right. ‘Completed life’ here is often interpreted ambiguously, and can even be interpreted positively, as a step forward, for example, by the National Expertise Centre for Dying.[193] Or by stating that it is ‘mostly [about] old people looking back on a nice life in which they achieved most of their wishes and in whom there is little or no outlook to the future’, in the words of the Coöperatie Laatste Wil (CLW) [cooperative Last Will].[194] However, a crucial problem remains under-reported in the Dutch debate: there is a lack of robust knowledge on how common these existential issues are and how they relate to a desire to die.[195]

This section deals with these existential issues, specifically the question: what issues lie behind the simple but ambivalent statement ‘my life is complete’? Research into this is still limited and further research is needed.[196]

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[191] Huilan Xu et al, A cross-sectional study on risk factors and their interactions with suicidal ideation among the elderly in rural communities of Hunan, China, BMJ Open, 2016, 6, 4.

[192] Fátima Gonçalves Cavalcante and Maria Cecília de Souza Minayo. Qualitative study on suicide attempts and ideations with 60 elderly in Brazil, Cienc Saude Colet. 2015, 20, 6, 1655.

[193] “Sterven… van angst naar vertrouwen”, Landelijk Expertisecentrum Sterven, accessed October 26, 2021, https://landelijkexpertisecentrumsterven.nl/sterven/.

[194] “Voltooid leven”, Coöperatie Laatste Wil, accessed October 26, 2021, https://laatstewil.nu/menselijk-levenseinde/voltooid-leven/.

[195] As researchers such as Van Wijngaarden and Hartog themselves also argue, see Iris Hartog et al, Prevalence and characteristics of older adults with a persistent death wish without severe illness: a large cross-sectional survey, BMC Geriatrics, 2020, 20, 342, 2.

[196] Iris Hartog et al, Prevalence and characteristics of older adults with a persistent death wish

4.1 Insights from research: prevalence

While political and social debates are vigorous, scientists are only just beginning to unravel what it means to have a 'completed life'. What makes a person suffer from life, how often does this existential suffering occur (prevalence) and what factors are associated with suffering from life?

The PERSPECTIVE survey[197] from January 2020, commissioned by ZonMw, provides insights into the prevalence and nature of desire to die, among other things. With regard to prevalence:

- 1.34% of the approximately 5,600,000 people over 55 in the Netherlands say they have a persistent desire to die without being seriously ill.
- Just under half of this group has a passive desire to terminate their life. These elderly people desire death without taking steps or making plans.
- The remainder (0.77%) have made plans and/or took steps toward terminating their life. These elderly people have an active desire to die. This may be limited to 'seeking information about assisted suicide', or it may go further; for example, from 'considering suicide' to 'drafting a treatment order'.
- 0.18% of over-55s in the Netherlands actually desire (help with) life termination. Extrapolated to Dutch society, this concerns a group of about 10,000 people.

The PERSPECTIVE survey shows that 0.18% of elderly people have a wish to end life without being seriously ill. Note that this refers to a small number of people in the survey: 36 people from a representative sample of 21,294 participants.

4.2 Insights from research: underlying factors and needs

The PERSPECTIVE study, in addition to providing insight into prevalence, also offers insight into factors and needs that underly these people's death wish. Indeed, the researchers asked about characteristics and factors that these people themselves believe reinforce their desire for to die.[198] The reinforcing factors mentioned were:

- Worrying (81%)

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without severe illness: a large cross-sectional survey, BMC Geriatrics, 2020, 20, 342, 2.

[197] Els van Wijngaarden et al, Perspectieven op de doodswens van ouderen die niet ernstig ziek zijn: de mensen en de cijfers. Het PERSPECTIEF onderzoek. The Hague, ZonMw, 2020, 7.

[198] Because of the very small group, these characteristics and factors should be interpreted with caution.

- Physical and/or mental deterioration[199] (61%)
- Loneliness (56%)
- Being a burden (42%)
- Money problems (36%)

These factors can (sometimes, in part) drive a person to say, ‘my life is complete’. Certainly, the last point, money problems, rarely features in the political and social debate. However, even the other factors do not paint the picture sketched by proponents of a healthy elderly person rationally looking back over a life that is ‘complete’. More often, they seem to be a lonely and/or burdened in the present and look toward to a hopeless future. Furthermore, the desire to die often appears reversible, for instance, when (financial or social) circumstances change.

Also, based on scientific research by Hartog et al, the positive image of a group of healthy, elderly people suffering from a ‘completed life’[200] and for whom assistance in dying is the only merciful solution, does not generally seem to hold true. According to Hartog et al.:

‘The findings of our study do not substantiate the positive connotation of the term “completed life”. [It] might obscure the health problems and social and existential struggles some people are dealing with.’ (p.12)[201]

The researchers point out that struggling with a persistent desire to terminate one’s lifewithout any serious illness certainly does not only occur among the very old.[202] Young and old can come to a cry of distress like ‘my life is complete’. Hartog and colleagues identify the following factors as possibly underlying a persistent desire to die in someone without serious illness:[203]

- Undetected health problems (being ill but not recognising this as underlying the desire to die);
- Social problems (loss of social context);
- Existential problems (loss of *meaning*).

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[199] For example, visually impaired, lack of mobility, forgetfulness.

[200] Wouter Beekman, The self-chosen death of the elderly: Public debate in the Netherlands about dying assistance for the elderly who consider their life complete, (America Star Books 2015)

[201] Nor does ‘weariness of life’ capture these social and existential struggles, and thus does not fit, the authors say.

[202] Iris Hartog et al, Prevalence and characteristics of older adults with a persistent death wish without severe illness: a large cross-sectional survey, BMC Geriatrics, 2020, 20, 342, 11.

[203] PDW-NSI: persistent death wish and no severe illness.

According to the researchers, these factors need further investigation.

In addition to quantitative research, qualitative research is also available that sheds light on the research question. These include the studies by Frederique Defesche and by Els van Wijngaarden.

Between 2010 and 2011, Defesche interviewed elderly people who called their lives 'completed', and their relatives.[204] She identified the following factors as potentially underlying this desire to end their life: poor health, lack of mobility, exhausted all coping strategies, physical dependence, loss (of partner and loved ones; of meaningful contacts), damage to self-image and perceived self-worth, a belief that improvement is not possible, pain that cannot be adequately treated, fatigue and apathy, no longer feeling useful, feeling a prolonged and excessive (emotional and financial) burden on loved ones, loneliness, traumatic events and persistent hopelessness. A persistent desire to end one's life was related to the confluence of physical and/or mental health problems on the one hand, and loss of loved ones and social environment on the other. Again, a (romanticised) picture of a deliberate 'completion of life as a project' does not seem to correlate with the research findings.

For her PhD research, Van Wijngaarden conducted in-depth interviews with twenty-five people who had indicated that they considered their lives 'completed' and therefore wanted to end it.[205] The core question of the study was:

"What do older people mean when they say their lives are 'complete'? What world of experience is behind these words?[206]

Complexity, multiple problems and a diffuse but predominantly negative image. THAT is the picture of the world of experience of older people suffering from 'completed life' that emerged from this study. The following five overarching themes are at play for people suffering from 'completed life':[207]

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[204] Frederique Defesche, Voltooid leven in Nederland. Wat ouderen ervaren, willen en doen als zij het leven voltoooid vinden
Van Gorcum, Assen, 2011.

[205] Els van Wijngaarden, Voltooid leven, over leven en willen sterven, Atlas Contact, Amsterdam, 2016.

[206] Els van Wijngaarden, Voltooid leven vraagt ander antwoord dan dood, Medisch Contact, 2016, 37.

[207] Els van Wijngaarden, Voltooid leven vraagt ander antwoord dan dood, Medisch Contact, 2016, 37, 38.

1. Existential loneliness: no longe able to connect with others, there is a deep feeling of being alone.
2. The feeling of no longer having worth: being marginalized, sitting on the sidelines, unable to give or add anything.
3. Inability to express oneself; losing a sense of self by not being able to express yourself in ways that are important to you (due to health problems or no one to talk to).
4. Tired of life: physical fatigue, and/or inability or unwillingness to break from the dullness, drudgery, and monotony of life.
5. Fear of dependence: deep fear, insecurity and shame surrounding physical and cognitive deterioration. Fear of losing control of your abilities, your body and your sense of self. But also a distrust in the care of others.

Van Wijngaarden shows that these elderly people are truly suffering from life. The essence of suffering can be described as "an inability and unwillingness to connect with life any longer". This creates persistent tension and struggles that reinforce the desire to end life, to terminate one's life.

'Completed life' is essentially about becoming disconnected and alienated from the world, from others and from yourself.

Closing

Research suggests that a 'completed life' is mainly about a disconnected life without expectation of improvement, in which underlying factors may include fear of being a burden to others, (fear of) loneliness, deterioration and (accumulation of) old-age complaints, dependency, suffering, the feeling of not being relevant any more, and mental and physical fatigue. It is often accompanied by worrying and financial problems. The combination drives some to say, 'my life is complete'.

This desire to die thus exposes, above all, a social problem. "Behind the blunt, almost rosy term 'completed life' often hides a raw reality of uncertainty, shame and fears."[208] "Paying attention to this and, if possible, seeking a solution to it is (...) better than hastening the end of life." [209]

"The complex and tragic issue of 'completed life' calls for more than just assisted suicide," Van Wijngaarden says. It calls for addressing social issues such

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[208] Els van Wijngaarden, Voltooid leven, over leven en willen sterven, Atlas Contact, Amsterdam, 2016, 181.

[209] Els van Wijngaarden, Voltooid leven vraagt ander antwoord dan dood, Medisch Contact, 2016, 37, 38.

as preventing loneliness and debt problems. It requires providing spiritual care, attention to existential questions, meaning, unnoticed health problems. It calls for connection.

4.3 Society's perception of 'completed life'?

Huib Drion, a former professor of civil law and former justice of the Supreme Court, triggered a public debate in the Netherlands on 19 October 1991 around a self-chosen end of life for the elderly. He set the tone in the debate and the public's imagination.

Drion, in his essay 'The self-intended end of elderly people'[210] , advocated making a medication available to the elderly that would allow them to end their lives in a humane manner. He saw such a means of suicide as a ''right''. And it seemed to him ''subject to no doubt that many old people would find great peace in the possibility of disposing of a means to step out of life in an acceptable manner at the time that—given what is yet to be expected of them—seems appropriate to them.''

A will and a pill

Such a drug, that has since been named 'Drion's pill', is not currently available. The felt need exists and the discussion has been going on, now, for over 30 years. Attempts have been made around the limits of the law, as witnessed by incidents with 'Drug X'. This has not yet been successful, and it has become clear that Drion's wishes have their drawbacks. One objection from the users' perspective is 'Means X' can lead to an inhumane death. On a societal level, a legally available preservative that supposedly could provide in the felt need, and that was distributed illegally, apparently also easily gets into the hands of young people who use it in an act of desperation. Once they take this route, there appears to be no turning back. This raises fears for large-scale legal distribution.

Following from Drion's plea, it *also* seems safe to state that 'there is no doubt that many people find great *disquiet* in it, when people can dispose of such a suicide device'. This because of religious considerations, because of preventing a 'future self' to make its own decision by a decision of a present self who cannot oversee it,[211] and because of social risks, for example. The sense of a 'completed life', in

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[210] Huib Drion, Het zelfgewilde einde van oudere mensen, NRC Handelsblad, October 1991, accessed November 11, 2021, http://retro.nrc.nl/W2/Tegenspraak/Drion/artikeldrion.html.

[211] Drion also argues this himself, and note that the 'I' is quite predominant used in contributions to the debate by the proponents.

addition, seems to reside with a very small group of people, often appears to be born of necessity, cannot be separated from circumstances, and is changeable. Drion's question, which also continues to resonate socially - *If so many people want it, why shouldn't access be be allowed to them?*[212] - has several, equally plausible, possible anaswers.

Framin in politics, reflecting framing and arguments in society
Yet Drion's thought process, a right to die, is alive and well in society. Why are the elderly, if they so choose, not allowed to exit life without question?

A social debate on 'completed life' has been taking place in the Netherlands since the early 1990s.[213] In the secularised and individualised Dutch society, this idea now generates many supporters. Indeed, *assisted suicide* should be allowed in the case of a 'completed life' according to 82-83% of Dutch people. This is shown in the vote guide for the 2021 parliamentary elections, according to CLW.[214] The tone is that people are allowed to desire death, and we should help them to realise it.

'Helping', or 'Giving aid', has a positive connotation. It brings to mind the idea of 'mercy'. Denying help, then, comes across as unmerciful. But what if help is aimed at ending someone else's life? How acceptable is that help? Is that 'help'? Or is it, instead, helpful, merciful, to prevent it? There are different thoughts on what it means to show 'mercy'.

D66, a political party that in 2020 submitted a bill on Completed Life, supports the view that assistence in dying for someone suffering from a 'completed life' should be facilitated. ''People [over 75] who come to the conclusion that their lives are 'completed' should be able to decide for themselves how and when they want to die. Providing a 'last-will pill' under strict conditions of care and verifiability [should] become possible in that situation.'' Because ''next to dignified ageing, there is dignified dying''. The euthanasia law does not suffice for this, because it, in D66's words, assumes a ''strictly medical perspective''.[215] D66 wants ''that

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[212] Huib Drion, Het zelfgewilde einde van oudere mensen, NRC Handelsblad, October 1991, accessed November 11, 2021, http://retro.nrc.nl/W2/Tegenspraak/Drion/artikeldrion.html.

[213] Paul Schnabel et al., Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven voltooid achten. Den Haag, Adviescommissie voltooid leven, 2016, 11.

[214] Coöperatie Laatste Wil, Maar liefst 83% van de mensen is voor hulp bij zelfdoding bij voltooid leven!, accessed November 11, 2021, https://laatstewil.nu/maar-liefst-83-van-de-mensen-is-voor-hulp-bij-zelfdoding-bij-voltooid-leven/ and ProDemos, Recordaantal gebruikers voor StemWijzer: 7,8 miljoen, geraadpleegd 11 november 2021, https://prodemos.nl/nieuws/recordaantal-gebruikers-voor-stemwijzer-78- miljoen/.

[215] D66 Verkiezingsprogramma, geraadpleegd 4 februari 2022, https://d66.nl/verkiezingsprogram-

self-determination becomes leading. Even elderly people who have no medical complaints should be able to decide about their own death with all the care that is necessary and desirable in the process.'' From D66's perspective, ''that fits with our civilization''. [216]

At the other end of the political spectrum (as far as this matter is concerned), there is the sound of, for example, the SGP, which interprets mercy and civilization completely differently. The SGP, a conservative Christian party, argues that when life becomes difficult, we ''should not abandon fellow human beings to death, but should be close to them with attention, love and good care''. This is based on the conviction ''that the life of every human being as a creature of God is valuable and precious''.[217] According to the SGP, the crucial argument in the debate on 'completed life' is the belief that ''autonomous people should be able to decide for themselves whether and when they want to 'step out of life.'' But behind this superficial consideration, there are often deep feelings of loneliness, the feeling of not mattering, and/or the feeling of being a burden to children and society. Countering loneliness and re-evaluating old age are the answer to this; there should be no social climate in which the elderly, or those with high health care costs, experience pressure to end their lives.

The Christian Union, an evangelical-reformed party, also expresses this view. ''We believe that a human life has intrinsic value and does not depend on abilities, limitations, age, or any forms of social contributions.'' The Christian Union stands for a society that recognises the value of older people, affirms them and gives them the best care so that they feel valued and wanted. This also applies to the '' extremely small group of elderly people who have an enduring wish to have their life ended without being seriously ill''. ''Protecting vulnerable groups far outweighs facilitating the suicide of healthy people via a suicide pill, which moreover cannot be safely regulated.''[218]

The other political parties are often less outspoken. 'Completed life' is not mentioned or is included as part of the position on euthanasia. For example, as a paragraph within the euthanasia position, the VVD (liberal party) is largely holds

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ma/voltooid-leven/

[216] D66 position 'Voltooid leven', accessed November 16, 2021, https://d66.nl/verkiezingsprogramma/voltooid-leven/

[217] SGP position 'Voltooid leven', accessed November 16, 2021, https://sgp.nl/standpunten/voltooid-leven.

[218] Christian Union position 'Voltooid leven', accessed November 16, 2021, https://www.christenunie.nl/standpunt/voltooid-leven.

the same position as D66. The VVD states: ''There are people who see their lives as completed. They too have the desire to die with dignity, even though they are not suffering unbearably and hopelessly according to current standards. We want to make it possible to fulfil the sincere wish of these people.''[219] So, according to the VVD, facilitating the termination of life for 'completed life' is also necessary to facilitate '(human)dignified dying'. The CDA (Christian democrat party) is against a Completed Life Act. This party mainly sees this as a societal problem and argues for more attention to people who doubt the meaning of life. ''As a society, we should do everything possible to have these people experience life again.''[220] The PvdA (social democrat party) seems to take the position that people who consider their lives 'completed' should have the right to aid in dying so that they can 'die with dignity', if there is no other way to change their desire to die. ''Dying assistance should always be provided in conjunction with human dignity, good care and protectability of life.''[221] The Green Left does not explicitly mention 'completed life' in its positions, but ''wants to move towards a situation where people can always knock on the door of a professional for suicide assistance. Until that happens, people should feel free to help their loved one with a sustained wish for suicide.''[222]

Christians unfairly quick to be 'left out'

Kevin Yuill, associate professor at the University of Sunderland, notes with regard to the debate around euthanasia in general and 'completed life' in particular, that Christians are 'unfairly quick to be left out of the discussion'. That perception may also arise when superficially considering the various political parties. However, Yuill's *atheistic view* is largely consistent with a theistic view.

Yuill sees a misplaced focus on chosing one's time to die in society. This has emerged from a 'culture of narcissism', due to the rise of individualism since the 1970s. He warns of a 'slippery slope'. 'The degree of suffering cannot be determined by the physician'; suffering is subjective. If so, a Completed Life Act would open a door for all those who believe they are experiencing unbearable suffering. Thus, moral inequality is actually created and ''the protection enjoyed by every member of society is ultimately removed.'' Also for an atheist the rule 'Thou shalt

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[219] VVD position 'Euthanasie', accessed November 16, https://www.vvd.nl/standpunten/euthanasie/.

[220] CDA position 'Euthanasie', accessed November 16, 2021, https://www.cda.nl/standpunten/euthanasie.

[221] PVDA memo 'Levenseinde', accessed November 16, 2021, https://voorne.pvda.nl/wp-content/uploads/sites/344/2020/11/InbrengPvdaVP2021_Levenseinde_Daan.pdf.

[222] Green Left position 'Euthanasie', accessed November 16, 2021, https://groenlinks.nl/standpunten/zorg/euthanasie.

not kill' makes sense; you don't have to be a Christian to believe that. On a right to decide how and when to die, Yuill argues: ''You [also] cannot say, 'I have the right to live'. You live as long as you live. No one has the right to choose the moment of death. Sure, everyone can cause one's own death, but legalising that, giving help in doing so, I think is immoral.''[223]

A medical-specialist perspective

The physicians' federation KNMG also adds substance to the public discussion. ''[Many physicians] fear that a [Completed Life] Act will have unintended negative effects for the elderly people they encounter in the consulting room. (...) Scientific research shows that many of them are vulnerable elderly people who are often less educated and in a weak socio-economic position. The desire to die that these people experience is usually ambivalent and changeable." Sometimes the issues are complex, sometimes they simply have a rental debt or other financial problems.

''The KNMG fears that the introduction of a Completed Life Act will have unintended negative consequences for the elderly. The law may stigmatise old age and send the undesirable signal that the lives of the elderly are less valuable than those of younger people. This may cause and reinforce feelings of insecurity and redundancy among the elderly. The fear is also that the elderly will feel pressed to justify when they do *not* appeal to this law." Incidentally, this already applies to the euthanasia law. Earlier the perception was that the professionalism of the physician was sufficiently resistant to such pressures. There may be indications now that this may not always be the case. [224]

Research

Two studies provide structured insight into the arguments for and against a law or regulation around 'completed life' in the public debate: A survey by the Prof. Dr. G.A. Lindeboominstituut from 2010-2011 and a 2019 survey by De Argumentenfabriek, with the support of VWS.

Viewpoints and arguments in the broad debate - Lindeboom Institute

Different arguments are used in the public debate on 'completed life'. The Prof. Dr. G.A. Lindeboom Institute conducted research between May 2010 and June

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[223] Kevin Yuill, Assisted Suicide: The Liberal, Humanist Case against Legalisation, 2013; Hans-Lukas Zuurman, 'De atheïstische visie van Kevin Yuill op euthanasie: 'de boodschap die van legalisatie uitgaat, klopt niet,' Nederlands Dagblad, October 22, 2021.

[224] KNMG file 'Lijden aan het leven' ('voltooid leven')', accessed November 16, 2021, https://www.knmg.nl/advies-richtlijnen/dossiers/lijden-aan-het-leven-voltooid-leven.htm.

2011 on arguments for and against requests to die because of a 'completed life.'[225] This is in the context of a new bill (alongside the Euthanasia Act) for voluntary termination of life for elderly people aged 70 and over, who consider their lives 'completed'.

Seven perspectives were described: Legal, Medical/Nursing, Social, Ethical/Philosophical, Psychological, Theological and Methodological. From each of these perspectives, experts presented arguments for and against.

Arguments for further facilitating the desire to terminate one's life of people suffering from a 'completed life' that emerged in this study are:

- It is not merciful to leave a group of elderly people in society suffering from a 'completed life' to their fate. Assisted suicide should be facilitated for them too, to prevent them from dying an inhumane death.
- Other than offering death as a way out, there are no alternatives for people who have started, as it were, 'surviving themselves'. At most, sham solutions are possible (sociability or activities), but that is no real solution.[226] These people have run their course, but cannot find the way out.
- Certain problematic conditions such as incipient dementia or chronic psychiatric diseases result in a desire to die because the situation will never improve (chronic, progressive and/or degenerative).
- Not only physicians should be able to provide dying assistance, as in the current euthanasia law. It should also be possible for specialised death aid providers, or relatives, for example.
- If people are willing to assist in suicide, why are they not allowed to do so with those who wish to arrange their own end?
- Elderly care in the Netherlands is frightening. Some people do not want to grow old in nursing homes.
- Old age comes with a loss of dignity. About (this loss of) dignity, people should be able to decide for themselves. ''To me, dying with dignity means dying at a self-chosen time, as gently and easily as possible.'' (p.4)
- It is a burden to know that illness is going to cause you to deteriorate, to change, to know that you are no longer who you were and wanted to be. Or that you will no longer be able to do things and will become dependent on others. Or your life will become meaningless. It cannot be decided by someone

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[225] D.H. Boon-van den Dikkenberg and A.S. Groenewoud, Argumentenonderzoek 'Voltooid leven?!, 2011, accessed November 16, 2021, https://www.npvzorg.nl/wp-content/uploads/2021/02/Argumentenonderzoek-Voltooid-leven.pdf.

[226] In the words of D66: 'This old age problem will not disappear even with the best conceivable elderly care.' D66 position paper 'Completed Life', accessed November 21, 2023, https://d66.nl/verkiezingsprogramma/voltooid-leven/

else how to deal with this.
- Religious believers want to forbid others to stop living, but who are we to impose our faith on others?

Arguments *against* further legal facilitation of the desire to die of people suffering from a ‘completed life’ are:

- The euthanasia law already shows a slippery slope, the same will be true here. Self-determination and compassion already go beyond the original intention; where it started with euthanasia, life-ending for severely suffering newborns followed.[227], [228]
- There is a slippery slope and a process of habituation occurs in public opinion. Theo Boer: ‘If cancer patients are allowed, why not others? Whereas euthanasia was originally meant to give a ‘final push’, now more and more people with a life expectancy of months or even years are going to demand euthanasia for themselves.’
- Living together should be central in a society. We should seek solutions to make and keep life pleasant, rather than looking for ways to facilitate death.
- True self-determination also means doing it yourself, and it can be done in a dignified way [without additional legislation].
- There ís no absolute autonomy in a society. Nobody can make choices in complete freedom. There is relative autonomy, a context within which you make choices and that has to be taken into account.[229]
- Suffering is part of life, so it is also part of dying. All of life is full of surprises, including unpleasant ones. So why should only a ‘dignified death’ suit us?
- Individual self-determination ís *not* a fundamental right; the underlying principle is that of human dignity.[230]
- Value lies in life itself; a person’s life, regardless of health or infirmity, is worthy

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[227] With knowledge of today, we also know that it keeps shifting further and further, to life termination in psychiatric suffering, dementia, teenagers, children, anticipated suffering, ...

[228] We also see this in the argumentation of, for example, the Christian Union: [we see a] creeping shift in euthanasia practice from ‘last resort to prevent a terrible death’ to ‘a possible way out of a terrible life’. Whereas euthanasia used to take place almost exclusively in terminally ill patients, it is now increasingly common in people with dementia, psychiatric disorders, or an accumulation of old age complaints. Christian Union position ‘Completed Life’, accessed November 16, 2021, https://www.christenunie.nl/standpunt/voltooid-leven.

[229] ‘If you want to go by bus, you still depend on whether the bus comes. You can hardly make one yourself.’ Mathijssen in D.H. Boon-van den Dikkenberg and A.S. Groenewoud, Argument research ‘Voltooid leven?!’, 2011, 3, https://www.npvzorg.nl/wp-content/uploads/2021/02/Argumentenonderzoek-Voltooid-leven.pdf.

[230] This is point of debate in health law. Is there a shift in the understanding of autonomy from right to reject to a right ot claim? Does the right of self-determination, fundamental in dignity, take precedence over the legal protection of life?

of protection. (p.4)

- Life is given. It is not at man's disposal: he has received it. Who are we to deprive each other of life?
- To what extent does the argument of an 'autonomous choice' hold if people act because they are tired of the circumstances or act out of fear of what is to come?
- There is no good (material) indication (test criterion) other than the person's own desire.
- Any age limit is arbitrary and offers no solution to elderly people or people below the set limit with similar issues.
- Fear of poor care should not be a guiding motive in cases of 'completed life'.
- For physicians and others involved, assisted suicide in relatively healthy elderly people is difficult and stressful. Unconsciously and unintentionally, suicide causes psychological distress, side effects and sometimes provoke suiscidal thoughts in others.
- 'Completed life' should not be solved by assisted suicide, but with early identification of existential problems (what has made one lose one's meaning of life?), with identification of social problems and by offering help with underlying needs and (health) problems (because the desire to die is mutable, and is often linked to loneliness, brooding, debt or health problems such as depression).

Points of view and arguments in the broad debate - Argument Factory
In 2019, De Argumentenfabriek, with financial support from the Ministry of Health, Welfare and Sport, produced an argument map on making arrangements for a 'completed life'. They investigated the literature and expert opinion to answer the question: *What are arguments for and against an arrangement for assisted suicide for people who wish this because they consider their life completed?*[231] The survey distinguishes five perspectives: welfare, social, principles, legal and economic. The arguments for and against a regulation, listed below, are partly overlapping, partly new or updated.

Welfare perspective
Arguments for:

- People may be better helped with their suicide by facilitating support where they would otherwise have to do it alone and by giving people the freedom to choose who helps them in the process.
- People may suffer less when they are reassured that their death need not be

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[231] De Argumentenfabriek, Argumentenkaart Regeling Voltooid leven, 2019, accessed November 18, 2021, https://www.argumentenfabriek.nl/nieuws/argumentenkaart-regeling-voltooid-leven/.

preceded by suffering and that they can ‘legally end their lives’ whenever they want. Family and friends may also suffer less if their loved one does not have to die or live through a degrading death.

Arguments against:

- An arrangement for suicide may cause people to make end-of-life decisions that are not good, because a desire to die may be mutable and there is no way of knowing in advance whether it applies to someone. However, death is irreversible, and an arrangement does not answer possible existential / meaning questions.
- It can make people more unhappy, for instance, when a desire to die turns out to be impossible to fulfil even with legal regulation. Moreover, when more people choose suicide, more relatives will suffer.

Social perspective

Arguments for:

- It makes death less taboo and easier to talk about as a topic of conversation for the individual with a physician or with family and friends.
- It can reduce loneliness and existential problems in society, by giving suffering people a way out, reducing the group suffering from ‘completed life’.
- It will meet a need; some 116,000 people expressed support for citizens’ initiative Completed Life (Out of Free Will).
- It could potentially relieve pressure on physicians by allowing people to divert to a bereavement counsellor and by allowing a regulation to give physicians better guidance on what is and is not allowed in assisted suicide.

Arguments against:

- It changes the public perception of death and simplifies the choice to die. Older people are increasingly seen as less valuable or costly. A choice to continue living may become something one is held accountable for. Social pressure on a choice to kill oneself may increase, and because a new choice for suicide is added to the scheme, it automatically creates demand for it.
- It may lead to the exclusion of certain groups of people. For some, this choice may be too difficult to understand. It discriminates against older people who can use it, compared to younger people. And it focuses on the individual, leaving family and friends with no role in (co-)deciding on dying.
- It may increase pressure on healthcare and social workers, by creating an additional demand for assisted suicide and potentially getting physicians involved if complications arise.

Legal

It is a legal issue how Dutch law relates to European laws and regulations, such as the European Union's 'Charter of Fundamental Rights'. Does it fit with European law that each person decides how and when to receive assistance in ending life (self-determination)? Or does the (legal) protection of life take precedence over this? Within the Netherlands, additional arguments can be considered.

Arguments for:
- It is needed to legally enable assisted suicide. Without it, people who assist in suicide could face criminal charges.

Arguments against:
- It is legally unnecessary, as the euthanasia law already gives enough space, there are already (legal) options for suicide, and because it concerns a small group of people, a regulation is excessive.
- It potentially detracts from the Euthanasia Act. A new regulation could bypass it, making the rules about dying less clear.

Economic
Arguments for:
- It can reduce social costs because people incur most healthcare costs in the last years of their life, and people will receive pension benefits for a shorter period of time.
- It may create new jobs, possibly growing demand for professional bereavement counsellors.

Arguments against:
- It may reduce the availability of assistance in meaning issues and elderly care and reduce the demand for elderly care (loss of labour).

Perspective from principles
Arguments for:
- An assisted suicide scheme suits a 'civilised society' because it takes people's desire to die seriously, even in the absence of illness, because it allows society to show mercy to those who are suffering, it allows people to appeal to others for help with suicide if they no longer want to live, and because it helps families to legally 'help' their loved one commit suicide.
- It contributes to people's right to self-determination, through a legal way out for people who cannot currently kill themselves humanely and is a possible first step towards free access to a means of suicide (a Drion's pill).

Arguments against:

- It has no place in a civilised society because it is a step toward moral decay where a human life is worth less. It deprives people of the opportunity to show mercy to people who are suffering; money may become a factor in choices about life and death; it runs counter to the medical ethical principles of 'beneficence' and 'do no harm' (if caregivers are involved); it is not up to humans to decide on the moment of death (but to God or nature); and asking for help with suicide is inappropriate because of its controversial and irreversible.
- It impinges on people's right to self-determination because it makes people dependent on the person consenting to assisted suicide and the person providing it.
- It goes against the government's duty to protect human lives, especially those of vulnerable groups. It is not to the government's job to 'help' healthy people with suicide.

Final note
What is merciful for a person suffering from a 'completed life': facilitating death, or surrounding this suffering person with care and perspective, even if he or she does not want to? What is dignity? Is there actually such a thing as an undignified death? How civil is a society, where *self-determination* is the priority? What duty or responsibility does the government have here? The social debate, 30 years after Drion, can still go on for years.

Sources

- Beekman, Wouter. *The self-chosen death of the elderly: Public debate in the Netherlands about dying assistance for the elderly who consider their life complete.* America Star Books 2015),
- Boon-van den Dikkenberg, D., Groenewoud A. *Argumentenonderzoek 'Voltooid leven?!* , 2011, https://www.npvzorg.nl/wp-content/uploads/2021/02/Argumentenonderzoek-Voltooid-leven.pdf.
- Cavalcante, Fátima Gonçalves and Minayo, Maria Cecília de Souza. "Qualitative study on suicide attempts and ideations with 60 elderly in Brazil." In *Cienc Saude Colet.* 2015, 20, 6, 1655.
- CDA. Position 'Euthanasie'. https://www.cda.nl/standpunten/euthanasie.
- Christian Union. 'Voltooid Leven' position. https://www.christenunie.nl/standpunt/voltooid-leven.
- Coöperatie Laatste Wil. 'Voltooid Leven'. https://laatstewil.nu/menselijk-levenseinde/voltooid-leven/.
- Coöperatie Laatste Wil. "Maar liefst 83% van de mensen is voor hulp bij zelfdoding bij voltooid leven! " https://laatstewil.nu/maar-liefst-83-van-de-mensen-is-voor-hulp-bij-zelfdoding-bij-voltooid-leven/.

- D66. Position 'Voltooid Leven', https://d66.nl/verkiezingsprogramma/voltooid-leven/
- De Argumentenfabriek. *Argumentenkaart Regeling Voltooid leven.* October 31, 2019. https://www.argumentenfabriek.nl/nieuws/argumentenkaart-regeling-voltooid-leven/.
- Defesche, F. *Voltooid Leven in Nederland. Wat ouderen ervaren, willlen en doen als zij het leven voltooid vinden.* Van Gorcum, Assen, 2011.
- Drion, Huib. *Het zelfgewilde einde van oudere mensen.* NRC Handelsblad. October 19, 1991. http://retro.nrc.nl/W2/Tegenspraak/Drion/artikeldrion.html.
- Green Left. Position 'Euthanasie'. https://groenlinks.nl/standpunten/zorg/euthanasie.
- Hartog, I., Zomers, M., Thiel, G. van, Leget, C., Sachs, A., Uiterwaal, C., Berg, V. van den, Wijngaarden, E. van. "Prevalence and characteristics of older adults with a persistent death wish without severe illness: a large cross-sectional survey." In *BMC Geriatrics*, 2020, 20, 342, 2.11.
- Landelijk Expertisecentrum Sterven. 'Sterven… van angst naar vertrouwen', 2021. https://landelijkexpertisecentrumsterven.nl/sterven/.
- KNMG. Dossier 'Lijden aan het Leven ('voltooid leven')'. https://www.knmg.nl/advies-richtlijnen/dossiers/lijden-aan-het-leven-voltooid-leven.htm.
- ProDemos. 'Recordaantal gebruikers voor StemWijzer: 7,8 miljoen'. https://prodemos.nl/nieuws/recordaantal-gebruikers-voor-stemwijzer-78- miljoen/.
- PVDA. Memo 'Levenseinde'.https://voorne.pvda.nl/wp-content/uploads/sites/344/2020/11/InbrengPvdaVP2021_Levenseinde_Daan.pdf.
- Raad voor Volksgezondheid en Samenleving. *Stervelingen. Beter samenleven met de dood.* The Hague, 2021, https://www.rijksoverheid.nl/documenten/rapporten/2022/02/21/stervelingen-beter-samenleven-met-de-dood.
- Sallnow, Libby, et al. "Report of the Lancet Commission on the Value of Death: bringing death back into life." *The Lancet commissions* 399, no. 10327 (February 2022): 837-884. https://doi.org/10.1016/S0140-6736(21)02314-X.
- SGP. 'Voltooid leven' position. https://sgp.nl/standpunten/voltooid-leven.
- Schnabel, P., Meyboom-de Jong, B., Schudel, W.J., Cleiren C.P.M., Mevis P.A.M., Verkerk M.J., Heide, A. van der., Hesselmann, G., Stultiëns, L.F. Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven compleet achten. The Hague, Adviescommissie voltooid leven, 2016.
- VVD. Position 'Euthanasie'. https://www.vvd.nl/standpunten/euthanasie/.
- Wijngaarden, Els van. Voltooid leven, over leven en willen sterven. Atlas Contact, Amsterdam, 2016, 181.
- Wijngaarden, Els van. "Voltooid leven vraagt ander antwoord dan dood." In *Medisch Contact*, 2016, 37, 38.
- Wijngaarden, E. van, Thiel, G. van, Hartog, I., Berg, V. van den, Zomers, M.,

Sachs, A., Uiterwaal, C., Leget, C. *Perspectieven op de doodswens van ouderen die niet ernstig ziek zijn: de mensen en de cijfers. Het PERSPECTIEF-onderzoek.* The Hague, ZonMw, 2020, 7.

- Xu, H., Qin, L., Wang, J., Zhou, L., Luo D., Hu, M., Li, Z., Xiao, S. "A cross-sectional study on risk factors and their interactions with suicidal ideation among the elderly in rural communities of Hunan, China." In *BMJ Open*, 2016, 6, 4.
- Yuill, Kevin. *Assisted Suicide: The Liberal, Humanist Case against Legalisation*, Palgrave Macmillan, EAN 9781137487469, March 2013.
- Zuurman, Hans-Lukas. De atheistische visie van Kevin Yuill op euthanasie: "De boodschap die van legalisatie uitgaat, klopt niet.", Nederlands Dagblad, October 22, 2021.

5. End-of-life care for children

Arthur Alderliesten

How is active termination of life in children dealt with in the Netherlands?[232] And to what extent do suffering, quality of life and incompetence play a role in the end-of-life decision-making process in children? This chapter provides an exploration of the (legal) situation for euthanasia in children in the Netherlands. This is followed by two perspectives aimed at preventing the parents' wish for active termination of children's lives: more attention to child palliative care and better understanding on how to cope with suffering in children. This comes together—mutatis mutandis—in a study being performed by the Lindeboom Institute that addresses these ethical questions around suffering and palliative care in children.

5.1 Child euthanasia in the Netherlands

The legal situation around active termination of life in children falls under three categories: For children between birth and one year of age there is the 'Regulation on the Assessment Committee on Late Termination of Pregnancy and Active Termination of Life in Newborns' (LZA/LP)[233], from the age of 12 on, the Termination of Life Act (WTL) applies, and for children between the ages of one and 12, there is no legislation or regulation yet. These three categories are discussed in this section.

5.1.1 Regulation zero to one year ('Active termination of life of newborns')

Through a ministerial regulation it has been established that active termination of life of newborns may be carried out under certain conditions. The regulation came into force in 2007. A revised version came into force on Februaray 1, 2016.[234] This regulation called 'Late Termination of Pregnancy and Active Termination of

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[232] For some lines in this chapter, grateful use has been made of an internal document on child life termination from NPV - Care for Life.

[233] Central Government of the Netherlands, Regeling beoordelingscommissie late zwangerschapsafbreking en levensbeëindiging bij pasgeborenen, wetten.overheid.nl/BWBR0037570/2018-08-01.

[234] This chapter leaves aside the genesis of the regulation. The regulation process can be found in Gerbert van Loenen, Hij had beter dood kunnen zijn. Oordelen over andermans leven, (Amsterdam: Van Gennep, 2009), 75-103 and Theo A. Boer, Ethic comments on pleas for 'child euthanasia'. Speech, given at the farewell as professor by special appointment of the Lindeboom chair 'Ethics of Care' at the Theological University of the Reformed Churches in Kampen, (Amersfoort: Prof. dr. G.A. Lindeboom Instituut, 2020), www.lindeboominstituut.nl/wp-content/uploads/2020/03/Afscheidsrede-Theo-Boer-6-maart-2020- def.pdf.

Life of Newborns' includes the requirements and conditions as they are named in case law, literature and the views of the profession (including the so-called 'Gronings Protocol'). These include the requirement that there is hopeless and unbearable suffering of the newborn and that parents consent to the decision. This ministerial regulation sets out the legal conditions; the well-known 'Gronings Protocol'[235] and aims to provide assistance 'in the decision-making process surrounding active termination of life for the non-intensive care dependent newborn with severe suffering without the prospect of treatment in any other medically responsible way (...) and facilitates its reporting.'

According to common medical opinion, newborns and very young children are divided into three patient groups for which an end-of-life decision is discussed.

1. Group one includes newborns whose death is certain in the very short term, despite maximum intensive therapy. Infants with pulmonary hypoplasia are taken as an example.
   The Groningen Protocol calls treatment of the newborns from this group "medically hopeless" because there is no chance of life.
2. Group two comprises newborns and very young children who can potentially be kept alive with the use of maximum medical technology, but whose future prospects are very bleak. These include, for example, preterm infants in whom very severe brain damage appears to have developed after several days of treatment. Stopping intensive treatment will result in the death of the child. '
   Treating a child from this group is considered medically futile. There are life chances here, but future prospects are extremely bleak. The protocol provides criteria to determine whether it is a futile and hopeless situation. The decision to not begin or to discontinue medically hopeless or futile treatment (abstinence) is seen as part of normal medical treatment.
3. Group three concerns newborns who remain alive even without intensive treatment, but nevertheless face a life of severe suffering without the prospect of relief. These include newborns with disabilities that are so extensive any form of an independent life is impossible and where there is no way to relieve their severe and persistent suffering. Examples of such disabilities are the most severe forms of spina bifida and Epidermolysis Bullosa. The Groningen Protocol focuses on this third group.

Put differently, groups one and two are children who were already going

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[235] Nederlandse Vereniging voor Kindergeneeskunde, Zorgvuldigheidseisen rond actieve levensbeëindiging bij pasgeborenen met een ernstige aandoening. Het Gronings protocol, (Utrecht: Nederlandse Vereniging voor Kindergeneeskunde, 2014), expertisecentrumeuthanasie.nl/app/uploads/2019/09/Het-Gronings-protocol.pdf.

to die, but in whom dying is hastened through active life termination, while group three consists of children who could survive, but whose lives can be ended, provided the requirements are met.

Unlike group two newborns, the group three child, after a well-founded decision to abstain from further treatment, continues to severely suffer despite palliative care. The physician may decide to wait until the child is released from suffering by death. This is unacceptable to most physicians. They feel a conflict of duties: on the one hand, the duty to preserve life and, on the other, the duty to relieve suffering. Later in this chapter, it is emphasised that there are critical questions to be asked when measuring or determining hopeless suffering. In addition, it is also especially important to focus maximally on the use of palliative care rather than active termination of life.

The regulation sets out five due care requirements that must be met for the termination of a newborn's life to be legally acceptable. These requirements are:

a. The child's suffering is hopeless and unbearable according to prevailing medical opinion, which means, among other things, that the decision to abstain must be justified, i.e. it is established according to medical scientific opinion that medical intervention is futile and according to prevailing medical opinion, there is no doubt about the diagnosis and prognosis;
b. The parents consented to the termination of life;
c. The physician fully informed the parents of the diagnosis and the prognosis; this includes the physician, together with the parents, came to the conclusion that there was no other reasonable solutions for the child's situation;
d. The physician has consulted at least one other independent physician who has seen the child and given his opinion in writing on the above-mentioned due care requirements; the opinion of one other independent physician may be substituted for a attending team;
e. The termination of life was carried out in accordance with medical standards.

These standards of care are not without controversy. There is no consensus among the profession on a central component: the 'hopeless and unbearable suffering' of newborns.[236] Before the establishment of the regulation, only *actual* suffering applied. Later, *future, foreseeable* suffering, which is even more difficult to determine, was included. A study on the termination of life of 22 babies between 1997 and 2004 found that all babies suffered from severe forms of spina bifida.[237]

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[236] Van Loenen, Hij had beter dood kunnen zijn, 92.

[237] A.A.E. Verhagen, J.J. Sol, O.F. Brouwer and P.J. Sauer, Actieve levensbeëindiging bij pasgeborenen in Nederland; analyse van alle 22 meldingen uit 1997/'04," Nederlands Tijdschrift voor Ge-

According to the physician-investigators, all these newborns suffered "hopelessly and unbearably". This satisfied the most important criterion in the protocol. However, some critics, including Rotterdam paediatric neurosurgeon De Jong and clinical ethicist Kompanje, argue that babies with spina bifida have no pain at all and if they have pain at all, it can be controlled with painkillers. They conclude that in these 22 cases, it has been stated that they are "suffering hopelessly and unbearably", not because of the pain, but because they are facing a severely disabled life. [238]

So, the questions of what suffering is, when is it hopeless and unbearable and how it can be measured remain crucial questions, even if it is an explicit due care criterion in the regulation. In light of the minister's desire to propose regulations for active termination of life between the ages of one and 12, this is a relevant observation.

5.1.2 From the age of 12 (WTL)

The Act on the Assessment of Termination of Life on Request and Assisted Suicide (WTL) contains specific regulations for minors: for young people aged 16 and over, euthanasia and assisted suicide are allowed under the same conditions as for adults, with the additional condition that parents are involved in the decision-making process. For children aged 12 to 16, euthanasia is allowed when parents are involved in the decision-making process and consent to the termination of life.

In 2014, there was intense debate on whether to extend the options of active life termination to children under 12.[239]

5.1.3 Between one and 12 years

Children under 12 are considered not competent to request euthanasia according to the law. Parents are legal representatives and decide on their behalf. For children in the one- to 12-year age group, there is no regulation or protocol that includes care critera for active termination of life. Therefore, in principle, a re-

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neeskunde 149 (2005):183-188, www.ntvg.nl/artikelen/actieve-levensbe%C3%A Bindiging-bij-pasgeborenen-nederland-analyse-van-alle-22-meldingen-uit/artikelinfo.

[238] E.J.O. Kompanje, T.H.R. de Jong, W.F.M. Arts and J.J. Rotteveel, "Problematische basis voor 'uitzichtloos en ondraaglijk lijden' als criterium voor actieve levensbeëindiging bij pasgeborenen met spina bifida" Nederlands Tijdschrift voor Geneeskunde 149 (2005):2067-2069, www.ntvg.nl/artikelen/problematische-basis-voor-uitzichtloos-en-ondraaglijk-lijden-als-criterium-voor-actieve/artikelinfo.

[239] Paul Brand, "Kinderen hebben recht op een waardig levenseinde," Kinderarts en Samenleving (May 2014), 12-13.

quest for the termination of life from a patient (or parent) in this group cannot be realized. However, an exception can be made when a physician invokes an emergency due to a conflict of duties (art. 40 WvSr). However, as there is no case law on this to date, this feels uncomfortable for physicians.

In a 1997 study by the *Committee on the Acceptability of Life-Threatening Acts*, the KNMG came to the statement with regard to active termination of life in children: "After the initial decision not to treat any more (thereby accepting death), a wait-and-see approach until the child is relieved of suffering by an accidental infection is unacceptable to many physicians. For others, on the other hand, active termination of life is unacceptable because it is a violation of the duty to protect life. Given the difference in normative starting points, consensus on this point is unlikely to emerge any time soon."[240] [241]
More than 20 years later, further steps are being taken in medical-ethical reflection on this topic. In 2019, the Dutch Society of Paediatrics (NVK), commissioned by the Ministry of Health, Welfare and Sport, Ethics Department, released a research report on medical end-of-life decisions for children aged one to 12.[242] The following is a summary of the research findings.

The study on end-of-life medical decisions in children aged between one and 12 sought answers to five questions about its practice. The answers are based on findings from the 2015 National Deaths Survey, in-depth interviews with 66 parents of 44 patients (61% died) and 34 physicians involved, and a survey of 38 physicians who had experience in end-of-life care in children aged one to 12. The researchers came up with the following conclusions, which are quoted here in

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240 Commissie Aanvaardbaarheid Levensbeëindigend handelen KNMG, Medisch handelen rond het levenseinde bij wilsonbekwame patiënten, (Houten/Diegem: Bohn Stafleu Van Loghum, 1997), 67.

241 See also earlier critical studies from the Prof. Dr. G.A. Lindeboom Institute on this matter: H. Jochemsen (ed.), Zorg voor wilsonbekwame patiënten, Lindeboom series volume 5, (Amsterdam: Buijten and Schipperheijn, 1994); H. Jochemsen, "Life-prolonging and life-terminating treatment of severely handicapped new-born babies: A discussion of the report of the Royal Dutch Society of Medicine on: 'Life-terminating actions with incompetent patients: part I: severely handicapped new-borns,'" in Issues in Law and Medicine 1992;8 no.2:167-81 ; H. Jochemsen, "Dutch court decisions on nonvoluntary euthanasia critically reviewed," in Issues in Law and Medicine 1998;13, no.4:447-458.

242 This Dutch report is no longer available on the internet. The summary given in this report is based on that Dutch report. The same researchers published a related article with the results of research in this field: Marije A Brouwer, Els L M Maeckelberghe, Agnes van der Heide, Irma M Hein, Eduard A A E Verhagen, "Breaking bad news: what parents would like you to know," Arch Dis Child 2021;106:276–281. doi:10.1136/archdischild-2019-318398

detail from the abstract.[243] More ethical comments are made later in this chapter.

- There is no evidence that active termination of life and euthanasia in children between the ages of one and 12 has actually happened so far (it is noteworthy that the remainder of the conclusions do show research findings on end-of-life decisions; these probably concern cases of newborn baby's).
- Physicians describe a grey area between palliative sedation and active termination of life in which the boundaries between the two types of action are unclear.

  The mortality survey showed that end-of-life decisions were mostly made because there was no prospect of improvement, an expectation of suffering, and/or the presence of pain and other severe symptoms. Sometimes end-of-life decisions were made (partly) with the aim of hastening the end of life (+/- 15%). In half of the cases, this was discussed beforehand with the parents, in 41% with the child, in 71% with fellow physicians and in 35% with nurses. In the interviews, parents said that they were not always involved in the end-of-life decision and indicated they would like to be more involved. Physicians reported uncertainty about the prognosis as the reason for late involvement of the parents.
- Cases of unbearable suffering without prospect of relief occur in children, and physicians are not always able to end this suffering.

  Suffering plays a major role in what is decided. Physicians and parents mention different forms of suffering in children: physical, existential, and psychosocial. Some of this suffering cannot be treated with medication, so physicians and parents sometimes see children suffering (unbearably or hopelessly) with no relief possible. The survey research revealed that, according to physicians, suffering is caused not only by physical symptoms but also by emotional factors, sadness, lack of positive experiences and hospitalisation. Parents often cite low quality of life as a major cause of their child's suffering. Most physicians felt that parents are often better able to assess their child's suffering than they are. In doing so, 89% of physicians also found that parents are often good at assessing whether life-prolonging treatments for an incompetent child with a serious incurable condition should be continued or discontinued.

  Parents experience severe bottlenecks in end-of-life care in terms of communication, organisation, decision-making and attention to family members, and give examples of this. Many parents would have liked to have had the option of active life termination available to their child. The main reasons for active termination of life for parents are the desire for their child to die with dignity, very low quality of life and the presence of unbearable suffering.

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[243] Brouwer, Medische beslissingen, 66-69.

- There is a clear need among a limited portion of parents and physicians for broadening the possibility of active termination of life in children.

  Some parents report that their child's end of life has been traumatic both because of the suffering of the child and the settings around the end of life. For many parents, the long duration of the bereavement process is a major sticking point. A significant amount of suffering is seen in the dying phase, which sometimes lasted several weeks and was accompanied by many physical symptoms. Physicians explain that the dying process is somties extended due to their fear of hastening the end-of-life in the palliative phase. There are suffering children who are physiologically stable and are not undergoing life-extending treatment. In the eyes of physicians, the decision to end life cannot be made. The prognosis in terms of the expected time of death is too unclear to apply palliative sedation.

5.1.4 Provisional arrangement

On 13 October 2020, minister Hugo de Jonge sent a policy response to the report 'Medical end-of-life decisions' discussed above.[244] In it, he announced that, in consultation with the Public Prosecution Service, he would draw up a 'Regulation on Termination of Life in Children 1-12'. "This regulation will apply to a small group of incurably ill children who are suffering hopelessly and unbearably and in whom all palliative care options are insufficient to relieve their suffering. These are children who are expected to die in the foreseeable future."[245]

5.1.5 Opinions on the active termination of life in children

The third review of the WTL (2017) published the following opinions on active termination of life in children. A public survey first revealed that one in five Dutch citizens mistakenly believe that active termination of life is also possible for children under 12. Citizens were also asked whether they thought that younger children should also be eligible for active life termination. Forty percent of them thought so, but 29% disagreed.[246]

2,500 physicians from different medical specialities who reported euthanasia were presented with the statement: competent children under 12 should be eligible for euthanasia (if they request it). 56% agreed, 16% disagreed and the remain-

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[244] H.M. de Jonge, Beleidsreactie Medische beslissingen rond het levenseinde van kinderen 1-12 jaar, Parlementary paper 32647-82, October 13, 2020, https://zoek.officielebekendmakingen.nl/kst-32647-82.html

[245] H.M. de Jonge, Beleidsreactie, 3.

[246] Bregje Onwuteaka-Philipsen et al, Derde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, (The Hague: ZonMw, May 2017), 90.

ing 28% had no opinion (‘neutral’).

The research report *Medical End-of-Life Decisions 1-12 Years* shows that 84% of these physicians agree with the statement ‘Active termination of life in incompetent children who suffer severely due to an incurable condition may be acceptable under certain conditions if the parents request it’. 5% disagree and 11% neither agree nor disagree. A number of physicians indicate that if physicians acted more proactively in the palliative phase, there would be no need for active termination of life. However, the survey does not specify what this should consist of. Physicians consider consultation with an expert in palliative care in children and multidisciplinary review prior to an end-of-life decision necessaryprerequisites. The table below shows the results of this physician survey.[247]

With the statement that active termination of life in legally incompetent children is only acceptable if there are severe untreatable symptoms, such as pain, shortness of breath or epileptic fits, 47% of physicians agreed.

Great importance is attached to this review. Most respondents (82%) agreed with the statement that an expert in palliative care should be consulted at least once in all cases of children with a serious incurable disease, and 92% would prefer a multidisciplinary committee of (paediatric) physicians, ethicists and lawyers to carry out a pre-assessment in the case of active termination of life. A slightly smaller group, but still a large majority of 71%, felt that retrospective review was necessary.[248]

	Agree	**Agree nor disagree**	**Disagree**
	N (%)		

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[247] Brouwer, Medische beslissingen, 33.

[248] Brouwer, Medische beslissingen, 36.

Active termination of life for incompetent children who are suffering severely due to an incurable disorder may be acceptable under certain conditions if parents request it	32 (84)	4 (11)	2 (5)
Active termination of life for incompetent children is only acceptable if there are serious untreatable symptoms, such as pain, shortness of breath or epileptic seizures	18 (47)	8 (21)	12 (32)
Active termination of life for incompetent children may be acceptable even if there are no serious untreatable symptoms	11 (29)	7 (18)	20 (53)
Active termination of life for incompetent children with the main aim to relieve the suffering of parents and other family members may be acceptable	3 (8)	5 (13)	30 (79)
With good palliative care, active termination of life is never a necessary option with incompetent children	6 (16)	10 (26)	22 (58)

5.1.6 Motives: autonomy and mercy

Professor Theo Boer dwelt on child euthanasia in his farewell address from the Lindeboom Chair in October 2020. He pointed out that when considering active life termination, child euthanasia was never far behind the horizon. “Indeed, behind the idea of euthanasia there are two motives. One can be summed up as ‘respect for autonomy’: I am in charge of my own death, no one can force me to go on living, and expert and legal help is the best guarantee of a humane end to life. It is this narrative that is currently the common thread behind pleas for a completed life. But the second motive is perhaps more important: ‘mercy, compassion, ending heartbreaking suffering through death’. With this motive, Van den Berg started[249] and the churches picked up on this motive in particular.”[250]

Autonomy is at issue in child euthanasia. Some paediatricians argue that children under 12 can indeed actually be considered mentally competent even though legally they are not considered competent.[251] From the perspective of autonomy, Boer believes that “the actual Dutch consensus is this - and if it is not, it should be—that we do not kill people who cannot ask for it.”[252]
Boer additionally asks for understanding for the reasons behind the call for child euthanasia. “It comes neither from laziness nor from eugenic ulterior motives. Those who advocate it have no contempt for life but rather are concerned with it.”[253] [254]

Richard DW Hain, consultant and lead clinician in Peadiatric Palliative Medicine in Wales, argues that no one equates killing a child with treating a child’s illness. It is therefore nothing short of nonsense to equate it with relieving suffering. “To suggest that one way to relieve a child’s suffering is to kill her is like saying that one way to restore a painting is to wash it back to white with bleach and turpentine.”[255] Therefore, according to Hain, the issue is not about whether children should have the choice to die. It is about how society can best care for the vulnerable.

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[249] Boer is referring here to Van den Berg’s controversial book Medische macht en medische ethiek.

[250] Boer, Ethische kanttekeningen, 5

[251] Boer, Ethische kanttekeningen, 13; qoute form paediatrician Martine de Vries, in a blog that is not longer on the internet.

[252] Boer, Ethische kanttekeningen, 14

[253] Boer, Ethische kanttekeningen, 13.

[254] See also: Jochemsen, Zorg voor wilsonbekwame patiënten; Jochemsen, “Life-prolonging and life-terminating treatment of severely handicapped new-born babies.” and Jochemsen, “Dutch court decisions on nonvoluntary euthanasia critically reviewed.”

[255] Richard Hain, “Euthanasia: 10 myths,” Arch Dis Childs, 2014 99;9: 798. DOI: 10.1136/archdischild-2014-306218.

The question that arises is how the two motives of autonomy and mercy relate to each other in practice. In the Netherlands, euthanasia involves a combination of both: there must be unbearable suffering as well as a request. For this reason, euthanasia is only possible in people who are capable of giving their consent. With children, the situation is different. Children between the ages of zero and one year cannot make a request. Therefore, we do not speak of euthanasia, but of active termination of life. This is laid down in the regulation 'Late Termination of Pregnancy and Active Termination of Life of Newborns' discussed above. But even for children between one and 12, there is the question of how willful they are. To what extent are they autonomous and capable of forming and making their will known l (see later in this chapter where it discusses brain maturation)?

5.2 Perspective one: Children's palliative care

This first perspective is that of child palliative care. Active termination of life, be it with or without a request, is, in my view, incompatible with the duty to protect life, with the right to life. Partly for this reason, it requires making the utmost effort to prevent the parents' request for active termination of life.

5.2.1 Relationship of paediatric palliative care and life termination

It is important to consider child palliative care extensively in discussions on termination of life in children. Eduard Verhagen, Dutch paediatrician at UMC Groningen and author of the Groningen Protocol, makes two interesting statements on this subject in an interview. First, he warns: "It is sometimes thought that if you provide optimal palliative care, active termination of life is not necessary to enable dying with dignity. But unfortunately that is not the case. We encounter exceptional situations in which optimal palliative care does not succeed in relieving suffering."

At the same time, he suggests that the provision of paediatric palliative care reduces the demand for active termination of life in children: "I hope that we can also make palliative care even more available, so that the need for active termination of life in practice will decrease further than it did so far." [256] If the latter is indeed the case, it means that those who value the protection of human life and are critical of active termination of life will have to work towards encouraging and improving child palliative care.

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[256] The article refered to in the origin Dutch version of this report is no longer available on the internet; a similar article (in Dutch, 5 July 2022)) can be found here: https://kinderpalliatief.nl/nieuws/details/actieve-levensbee-indiging-in-de-leeftijd-van-1-tot-12-jaar

5.2.2 What is paediatric palliative care?

In the Netherlands, 5,000 to 7,000 seriously ill children need child palliative care every year. About 1,400 children die each year due to a serious illness.[257] Children's Palliative Care Knowledge Centre provides the following information on children's palliative care.[258] Children's palliative care is:

- Care for children with life-threatening or life-limiting conditions;
- A form of care that includes physical, psychological, social, educational and spiritual aspects;
- Care that actively looks at the whole child, not just the medical aspects without forgetting about caring for the family;
- Aimed at the highest possible quality of life, and mainly determined by the individual needs and capabilities of the child and family.

The Knowledge Centre judges that pediatric palliative care should be considered from the moment of diagnosis. In addition, palliative care should continue regardless of changes in where the child is being treated, care providers and/or care perspective. Effective pediatric palliative care requires a coordinated, comprehensive approach by a multidisciplinary team, which includes the family.

Palliative *end-of-life* care for children is part of palliative care for children. Essential in this is the focus on living, even though death is actually approaching. Learning to cope with the immanent end and rounding off the child's life as well as possible, should be a focus in the communication between child/family and care providers involved. Aftercare is an essential part of this care.

Children's palliative care, unlike in adults, starts from *diagnosis* and does not only revolve around the sick child. The whole family may need help and support with care and counselling.[259]

The *European Association for Palliative Care* (EAPC)[260] broadly distinguishes four categories within paediatric palliative care:

1. Children with life-threatening diseases for whom curative treatment exists, but for whom the success rate of this treatment is uncertain (e.g. cancer and

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[257] Van Huizen, Rapportage patient journeys kinderpalliatieve zorg.

[258] "Wat is kinderpalliatieve zorg?" Kenniscentrum Kinderpalliatieve zorg, accessed August 2, 2020, https://kinderpalliatief.nl/over-kinderpalliatieve-zorg/wat-is-kinderpalliatieve-zorg/kinderpalliatieve-zorg

[259] Renate van Huizen and Bianca den Outer, Rapportage patient journeys kinderpalliatieve zorg. Commissioned by foundation pal kinderpalliatieve expertise kenniscentrum kinderpalliatieve zorg, (JB Lorenz, 2018), 4.

[260] See e.g. https://kinderpalliatief.nl/over-kinderpalliatieve-zorg/internationaal/handvest

organ failure);
2. Children with life-threatening diseases in whom there may be long periods of intensive treatment (focused on quality of life) in addition to periods when they can participate in normal life (e.g. cystic fibrosis, severe gastrointestinal infections, severe immune deficiencies and muscular dystrophy);
3. Children with progressive diseases in whom treatment from diagnosis is only palliative in nature and may take many years (e.g. some metabolic diseases such as Batten disease, Gaucher disease and Metachromatic Leukodystrophy, chromosomal disorders such as trisomy 13 and osteogenesis imperfecta);
4. Children with conditions, often neurological in nature, that are usually not progressive but still lead to severe abnormalities. These conditions pose a serious health threat due to an increased risk of complications (e.g. extreme prematurity, cerebral palsy and malformations of the brain).

5.2.3 Bottlenecks in (paediatric) palliative care

The report *Medical End-of-Life Decisions,* discussed above, highlights several bottlenecks that also relate to paediatric palliative care:

a. There is a grey area between palliative sedation and active termination of life;
b. There are bottlenecks in palliative care in terms of communication, organisation, decision-making, attention to relatives and child, and symptom relief;
c. The basic knowledge of physicians should be increased.
d. Basic knowledge on paediatric palliative care and Advanced Care Planning should be increased through training curricula;
e. Awareness and support for the recently established physician support centre of the National Knowledge Centre for Children's Palliative Care should be increased;
f. Some physicians perceive a lack of life-ending options and legal support in ending life;
g. The table below shows the bottlenecks parents experience in caring for children with life-threatening conditions:

Bottleneck 1. Communication
1a. Lack of empathy in communication
1b. Lack of communication about the possibility of the death of the child/ prognosis of the child

Bottleneck 2. Organization
2a. Continuity of care is not guaranteed between healthcare providers
2b. Regulations and organisations create bureaucratic impediments in care
Bottleneck 3. Participation in decision-making
3a. Parents feel insufficiently involved in making decisions
Bottleneck 4. End-of-life decisions
4a. Need for more possibilities to make end-of-life-decisions
Bottleneck 5. Lack of attention for the family
5a. Impact on parents and siblings
5b. Insufficient support for grief
Bottleneck 6. Lack of attention to the child behind the symptoms
6a. Insufficient attention to coping with illness and grief through the child
6b. Complexity of the entire condition is not seen
6c. Attention for the child as a patient but not for the child as a person

Figure 1 Overview of parents' bottlenecks in care and decisions for children with life-threatening conditions

5.2.4 Maturation of the brain

Are children up to the age of 12 sufficiently autonomous and volitional enough to decide whether to actively want to end their life? An interesting approach to this question is from the perspective of brain development. Indeed, a developmental perspective shedslight on a child's ability to make considered decisions. This applies to all kinds of issues includingespecially ending of (one's own) life. This perspective also broadens the scope on suffering. It creates a multidimensional perspective from which to think about coping with life.

One element to consider in children and active termination of life is brain maturation in children. Robert Vermeiren, professor of forensic youth psychiatry at VU University Amsterdam, pointed this out on the television programme 'Zomergasten'. The maturation process of the brain is not complete until the age of 24. "We also have to let the maturation, the ripening of the brain do its work. Know that until the age of 23, young people are still maturing, becoming more stable and emotions fluctuate less. I find it difficult to put an age on it, but I still think we should wait to satisfy the desire [for active life termination, AA] until they are at an age where maturation has done its work."[261]

5.3 Perspective two: Understanding and coping with suffering

We stated at the beginning of the last section that active termination of life without request is incompatible with the duty to protect life, requiring the utmost effort to prevent the parents request. Our second perspective is closely related to pediatric palliative care and focuses on the children's suffering. Little is known so far about suffering in children making this an important area for additional study. It is obvious that, when active termination of life is allowed for a certain degree of suffering, the question of termination of life in cases of a lesser form of suffering comes up. However, once we learn more about suffering in children, better child palliative care can be provided.

In 2019, Colinda Adams conducted research on suffering in children under the supervision of then Lindeboom Chair, Theo Boer. The main question was "How can the dimensions of suffering in young children (0-4 years) be known in a child palliative setting, according to parents and caregivers?" [262]

A semi-structured questionnaire was distributed among informal carers and parents of children under five who stayed at Kinderhospice Binnenveld in 2019, that dealt with signs of (dis)ease/(dis)comfort of the child, possible causes of discomfort and a definition of suffering. Five parents and seven caregivers from the children's hospice participated in the survey. Following Namisango, Adams distinguishes five dimensions of suffering: psychological, social, existential/spiritual, quality of care and practical. However, since all these dimensions influence each other, they cannot be completely separated. The causes of discomfort cannot always be determined and may also be more diverse than assumed. Young children

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[261] "Robert Vermeiren over 24 & Ready to Die", aired August 1, 2021, Zomergasten, 2.22, https://www.vpro.nl/programmas/zomergasten/kijk/afleveringen/2021/robert-vermeiren.html

[262] Colinda Adams, "Suffering in children. The dimensions of suffering in children in palliative care," (Master's thesis, Utrecht University, 2019).

suffer particularly in the physical, psychological and social dimensions. Studies in his field pay little attention to the existential, spiritual dimension in young children who are suffering. Insights regarding end-of-life spiritual care as highlighted in the chapters on *ars moriendi* and the role of the spiritual caregiver may contribute to this.

Awareness of the different dimensions of quality of life can help provide holistic care. Parents and caregivers have different conceptions of suffering, which can complement each other. Parents are particularly focused on short-term physical suffering (e.g., during hospitalisation), while caregivers mention long-term suffering (e.g., daily suffering and outlook) and lack of cognitive challenge. In addition to this, both the child's and the parents' suffering is considered important to caregivers.

5.4 Suffering, meaning and spirituality in paediatric palliative care

Not much is known about 'spiritual suffering' in children, argues Theo Boer. "Do children experience spiritual suffering and if so, is it *at all* fathomable to us?"[263] Four additional comments:

1. Spiritual care is explicitly part of the definition, which is also endorsed in the Netherlands, of paediatric palliative care (see above).
2. Renate Huizen and Bianca den Outer conclude in a 2018 report that the quality of medical and nursing care is generally good. However, "connection to non-medical domains (including education, psychosocial and spiritual care) is often not well established." [264]
3. The practice focuses on the spiritual pillar in various ways:

- A Child Comfort Team[265] is a multidisciplinary team with medical, nursing, pedagogical, psychosocial and spiritual expertise for families whose child receives palliative care. The team accompanies families and organises and coordinates care, and includes a spiritual caregiver who brings spiritual expertise.
- A characteristic of spiritual care in children's palliative care is that support is provided in the first, second and third lines of care. This means that spiritual care is also available in the home situation. A subsidy makes this support, as well as grief and loss counselling, available to families with a child (up to the age of 18) with a serious illness. Families are reimbursed for a certain number of sessions with a spiritual caregiver or grief and loss counsellor through the

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[263] Boer, Ethische kanttekeningen, 15.

[264] Van Huizen, Rapportage patient journeys kinderpalliatieve zorg, 32.

[265] "Kinder Comfort Teams," Kenniscentrum kinderpalliatieve zorg, accessed August 2, 2021, https://kinderpalliatief.nl/ondersteuning/kinder-comfort-teams

regional Integrated Child Care Networks.[266]

4. Caution is needed. For example, Adams' research shows that caregivers and family members sometimes interpret a child's suffering very differently.

5.5 Recommendations

With regard to active termination of life in children, based on a literature review, it is not possible to directly formulate an answer to the question: to what extent do suffering, quality of life and incompetency play a role in the decision-making process in active termination of life in children from zero to 12 years of age?

Follow-up research is needed that focuses on a normative discussion of the aforementioned factors and perspectives in care. It is recommended that research is carried out on at least the two perspectives of commitment to child palliative care and understanding and coping with suffering.

The following list of ethical concerns could potentially enrich such research. This list is not exhaustive (there are many comments to be made on active termination of life in children).

1. Carefuly describe insightful examples of *best practice* paediatric palliative care (England is leading the way in this);
2. Theo Boer does not advocate regulating euthanasia for children between the ages of one and 12, but rather maintaining a twilight zone and trust in the judgement and performance of the attending physician. Boer: "Unlike some who point out to me that the deliberate and active killing of a human being is intrinsically morally problematic, I can imagine active life termination as an exception. But with two caveats. First: heartbreaking suffering in children is not always resolved even with the possibility of child euthanasia. Second: putting life termination in a protocol, complete with a step-by-step plan and a reporting procedure, does not seem to me to be the appropriate signal. We will then turn the exception into a rule, and with every rule we know that it creates new borderline cases."[267] This calls for clarification of the definition of suffering in children, child palliative care and more. It should also be considered that in active life termination, intention plays an important role in medical intervention. High-dose pain relief can sometimes shorten life with

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[266] "Zingeving als je kind ongeneeslijk ziek is," Kenniscentrum kinderpalliatieve zorg, accessed August 2, 2021, https://kinderpalliatief.nl/over-kinderpalliatieve-zorg/wat-is-kinderpalliatieve-zorg/spirituele-zorg

[267] Boer, Ethische kanttekeningen, 15,16.

certainty, but that may be acceptable. The intention is not to shorten life, but to treat the pain.[268]

3. (Literature) research on:
    a. The practice of treatment decisions.
    In particular, the question of how 'quality of life' is dealt with as an important factor in weighing the request of the parents of children aged zero to one year needs further investigation.[269] The Health Council stated in 2007: ''Abroad, there is debate about whether a child's future quality of life may play a role in end-of-life decisions. In the Netherlands, among others, the insight has grown that anyone who rejects the norm that life should always be preserved as long as possible, cannot avoid making judgements about future quality of life in such decisions. However, it is not yet sufficiently clear how such a judgement should be made."[270] Henk Jochemsen points out that the term "quality of life" is in danger of becoming a medicalising term and advocates using the term within healthcare in a comparative sense. How can quality of life be improved or maintained as much as possible in a given patient?" In any case, care must be taken to ensure that quality of life does not become a ground for judging the patient's moral status and thus justifying killing people."[271]
    b. The significance of *future* suffering as a basis for active termination of life, in addition to *actual* suffering, as described in the regulation 'Active Termination of Life of Newborns' (zero to one year).
    c. Making sense of (terminally ill) children:

- The media highlights the most harrowing cases, usually in support of the plea to expand the options for active life termination in children. This results in a one-sided perspective on suffering in children. Both in media and research, medical options remain underreported. For instance, the interaction of medication and meaningfulness could still be researched.
- Multidisciplinary approaches to the topic of children, suffering and active life termination, such as a sociological or psychological study of the parent-child interaction.
- Investigating views of child development in relation to suffering from neuro-

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[268] Cf. Jochemsen, Zorg voor wilsonbekwame patiënten.

[269] Brouwer, Medische beslissingen, does address this, but it could be more expansive.

[270] Gezondheidsraad, Overwegingen bij het beeindigen van het leven van pasgeborenen. Signalering ethiek en gezondheid, (The Hague: Centrum voor ethiek en gezondheid, 2007), 37,38, Centrum voor Ethiek en Gezondheid,
https://www.ceg.nl › signalementen › 2007/05/29, https://www.ceg.nl/documenten/signalementen/2007/05/29/overwegingen-bij-het-beeindigen-van-het-leven-van-pasgeborenen.

[271] H. Jochemsen, "Kwaliteit van leven – een bruikbare term in geneeskunst?" in: Pro Vita Humana 1996:3, no.4:14.

logical and developmental perspectives: what are emotional-cognitive treatment options?

- Some parents, on the basis of their Christian faith and worldview, find it difficult to stop treatment and 'let their child die'. Teaching children to die well and 'letting go' deserves attention, especially from a Christian perspective that includes the idea of God's sovereignty over life's milestones times of life are in God's hand and life is a gift and created.
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5.6 Concluding summary

This chapter provides an exploration of the (legal) situation for euthanasia in children in the Netherlands. The legal situation around active termination of life in children falls into three categories.

1. For children aged zero to one year, there is the 'Late Termination of Pregnancy and Active Termination of Life in Newborns Assessment Committee Regulations' (LZA/LP). This regulation covers the requirements and conditions as they are identified in case law, in the literature and among professionals. These include the requirements of hopeless and unbearable suffering of the newborn and parental consent to the decision. Three groups of children are named in these regulations. Groups one and two are children who were already going to die, but in whom dying is hastened through active termination of life. Group three consists of children who could survive, but whose lives could also be terminated. Children in this group would be seriously and hopelessly suffering, despite palliative care, after a well-founded decision to abstain from life sustaining treatment. After stopping such treatment, the physician may decide to wait and see until death releases the child from suffering. This is unacceptable to most physicians.
   The regulation sets out five requirements that must be met for the termination of a newborn's life to be considered due care. There is no consensus among the profession on a central component: the 'hopeless and unbearable suffering' of newborns. The questions of what suffering is, when it is hopeless and unbearable and how it can be measured remain crucial questions.
2. From 12 years of age and older: The Act on the Assessment of Termination of Life on Request and Assisted Suicide (WTL) contains specific regulations for underage patients: for young people from 16 years of age, euthanasia and assisted suicide are allowed under the same conditions as for adults, with the additional condition that parents are involved in the decision-making process.
3. Children under 12 are legally incompetent. Parents are legal representatives and decide on their behalf. For children in the one- to 12-year-old age group, there is no regulation or protocol with criteria for care for active termination

of life. Therefore, in principle, a request to terminate life from a patient (or parent) in this group will not be realized. However, an exception can be made when a physician invokes an emergency due to a conflict of duties (art. 40 WvSr).

From a research report by the NVK on medical end-of-life decisions for children aged one to 12, the following relevant research findings, among others, follow:

- There is no evidence that active termination of life and euthanasia in children between the ages of one and 12 are currently performed;
- Cases of unbearable suffering without the prospect of recovering occur in children, and physicians are not always able to relieve this suffering;
- There is a clear wish among a limited proportion of parents and physicians for broadening the possibility of active termination of life in children.

Autonomy is at issue in child euthanasia. As such, it is not about whether children should have the choice to die. It is about how society can best care for the vulnerable (Hain).

This chapter outlines two perspectives.

1. Pediatric palliative care
   Because active life termination is incompatible with the duty to protect life, it requires an utmost effort to prevent the parents' desire to actively terminate life. The first perspective is, therefore, that of palliative care for children.
2. Understanding and dealing with suffering
   Little is still known about suffering in children, which means it is important to gain additional insight into this. It is obvious that, when active termination of life is allowed for a certain kind of suffering, the question of termination of life in the case of a lesser kind of suffering comes up. However, when we know more about suffering in children, child palliative care can be used more effectively.

More knowledge is needed on 'spiritual suffering' in children. Spiritual care is explicitly part of the definitionof paediatric palliative care, which is also endorse by the Netherlands. Quality of medical and nursing care is generally good, but the connection to non-medical domains, such as spiritual care, is often not well organised. Caution is needed. For example, Adams' research shows that caregivers and family members sometimes interpret a child's suffering very differently.

With regard to active termination of life in children, based on a literature review, it is not possible to directly formulate an answer to the question: to what extent do suffering, quality of life and incompetency play a role in the decision-making process in active termination of life in children, from zero to 12 years of age? Therefore, three recommendations for follow-up research:

1. Carefuly describe insightful examples of best practice paediatric palliative care (England is leading the way in this);
2. No regulation of euthanasia in children between one and 12 years, but accept a gray area and trust in the professional judgement of the attending physician.
3. Literature review on:
    - The practice of treatment decisions;
    - The significance of *future* suffering, in addition to *current* suffering, as a basis for active termination of life, as described in the regulation 'Active Termination of Life of Newborns' (zero to one year);
    - Experience of meaning in the lives of (terminally ill) children.

Sources

Literature

- Adams, Colinda. "Suffering in children. The dimensions of suffering in children in palliative care." Master's thesis, Utrecht University, 2019.
- Boer, Theo A. *Ethical comments on pleas for 'child euthanasia'. Speech delivered when leaving as extraordinary professor at the Lindeboom Chair 'Ethics of Care' at the Theological University of the Reformed Churches in Kampen.* Amersfoort: Prof. Dr. G.A. Lindeboom Institute, 2020. https://www.lindeboominstituut.nl/wp-content/uploads/2020/03/Afscheidsrede-Theo-Boer-6-maart-2020-def.pdf .
- Brand, Paul. "Kinderen hebben recht op een waardig levenseinde." *Kinderarts en Samenleving* (May 2014), 12-13.
- Brouwer Marije, Heide Agnes van der, Hein Irma, Maeckelberghe Els, Verhagen Eduard and Wetering Veerle van de. *Medische beslissingen rond het levenseinde van kinderen (1-12 jaar).* A research project commissioned by the Ministry of Health, Welfare and Sport, Ethics Department, on behalf of the Dutch Society for Pediatrics. 2019, https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/ rapporten/2019/09/28/medische-beslissingen-rond-het-levenseinde-bij-kinderen-1-12/medische-beslissingen-rond-het-levenseinde-bij-kinderen-1-12.pdf.
- This Dutch report is no longer available on the internet. The summary given in this report is based on that Dutch report. The same researchers published a related article with the results of research in this field: Marije A Brouwer, Els L M Maeckelberghe, Agnes van der Heide, Irma M Hein, Eduard A A E Verhagen, "Breaking bad news: what parents would like you to know," Arch Dis Child 2021;106:276–281. doi:10.1136/archdischild-2019-318398
- Commissie Aanvaardbaarheid Levensbeëindigend handelen KNMG. *Medische handelen rond het levenseinde bij wilsonbekwame patiënten.* Houten/

Diegem: Bohn Stafleu Van Loghum, 1997.

- Gezondheidsraad. *Overwegingen bij het beeindigen van het leven van pasgeborenen. Signalering ethiek en gezondheid.* The Hague: Centrum voor ethiek en gezondheid, 2007. https://www.ceg.nl/documenten/signalementen/2007/05/29/overwegingen-bij-het-beeindigen-van-het-leven-van-pasgeborenen
- Hain, Richard. “Euthanasia: 10 myths.” *Arch Dis Childs.* 2014 99;9: 798-799. DOI: 10.1136/archdischild-2014-306218.
- Huizen Renate van and Outer, Bianca den. *Rapportage patient journeys kinderpalliatieve zorg.* Commissioned by foundation pal kinderpalliatieve expertise kenniscentrum kinderpalliatieve zorg. JB Lorenz, 2018.
- Impact. “Samen praten over zorg en behandeling. Advance Care Planning in de kindergeneeskunde.” Accessed July 30, 2021. www.kinderpalliatief.nl/impact/.
- Jochemsen, H. “Life-prolonging and life-terminating treatment of severely handicapped new-born babies: A discussion of the report of the Royal Dutch Society of Medicine on: ‘Life-terminating actions with incompetent patients: part I: severely handicapped new-borns.’” In *Issues in Law and Medicine* 1992;8 no.2:167-81.
- Jochemsen, H. (ed.), *Zorg voor wilsonbekwame patiënten.* Lindeboom series part 5. Amsterdam: Buijten and Schipperheijn, 1994.
- Jochemsen, H. “Kwaliteit van leven – een bruikbare term in de geneeskunst?” In *Pro Vita Humana* 1996:3, no.4:105-14.
- Jochemsen, H. “Dutch court decisions on nonvoluntary euthanasia critically reviewed.” In *Issues in Law and Medicine* 1998;13, no.4:447-458.
- Jonge, H.M. de. *Beleidsreactie Medische beslissingen rond het levenseinde van kinderen 1-12 jaar. Parliamentary paper* 32647-82, October 13, 2020. https://zoek.officielebekendmakingen.nl/kst-32647-82.html
- Kenniscentrum Kinderpalliatieve zorg. “Active termination of life will soon be possible in The Netherlands for children aged 1-12 who are incurably ill,” Accessed August 2, 2020; www.kinderpalliatief.nl/professionals/detail/active-termination-of-life-will-soon-be-possible-in-the-netherlands-for-children-aged-1-12-who-are-incurably-ill.
- The article refered to in the original Dutch version of this report is no longer available on the internet; a similar article (in Dutch, 5 July 2022)) can be found here: https://kinderpalliatief.nl/nieuws/details/actieve-levensbee-indiging-in-de-leeftijd-van-1-tot-12-jaar.
- Kenniscentrum Kinderpalliatieve zorg. “Wat is kinderpalliatieve zorg?” Accessed August 2, 2020. www.kinderpalliatief.nl/professionals/kennis/over-kinderpalliatieve-zorg/wat-is-kinderpalliatieve-zorg
- Kenniscentrum Kinderpalliatieve zorg. “Kinder Comfort Teams.” Accessed Au-

gust 2, 2021. https://kinderpalliatief.nl/ondersteuning/kinder-comfort-teams

- Kenniscentrum Kinderpalliatieve zorg. “Zingeving als je kind ongeneeslijk ziek is.” https://kinderpalliatief.nl/over-kinderpalliatieve-zorg/wat-is-kinderpalliatieve-zorg/spirituele-zorg Accessed September 9, 2023
- Kompanje, E.J.O., Jong, T.H.R. de Arts, W.F.M. and Rotteveel J.J. “Problematische basis voor ‘uitzichtloos en ondraaglijk lijden’ als criterium voor actieve levensbeëindiging bij pasgeborenen met spina bifida.” *Nederlands Tijdschrift voor Geneeskunde* 149 (2005):2067-2069. https://www.ntvg.nl/artikelen/problematische-basis-voor-uitzichtloos-en-ondraaglijk-lijden-als-criterium-voor-actieve/artikelinfo
- Loenen, Gerbert van. *Hij had beter dood kunnen zijn. Oordelen over andermans leven.* Amsterdam: Van Gennep, 2009.
- NPV. *Source document active termination of life in children 1-12*. Not published.
- Nederlandse Vereniging voor Kindergeneeskunde. *Zorgvuldigheidseisen rond actieve levensbeëindiging bij pasgeborenen met een ernstige aandoening. Het Gronings protocol.* (Utrecht: Nederlandse Vereniging voor Kindergeneeskunde, 2014. https://expertisecentrumeuthanasie.nl/app/uploads/2019/09/Het-Gronings-protocol.pdf
- Onwuteaka-Philipsen, Bregje, et al. *Derde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding.* The Hague: ZonMw, May 2017. Regulatory evaluation series: volume 40. https://www.zonmw.nl/nl/artikel/derde-evaluatie-wet-medisch-wetenschappelijk-onderzoek-met-mensen
- Central Government of the Netherlands. *Regeling beoordelingscommissie late zwangerschapsafbreking en levenbeeindiging bij pasgeborenen.* https://wetten.overheid.nl/BWBR0037570/2018-08-01 .
- Utrecht University. “Promotie: Advance care planning in paediatrics.” Accessed July 30, 2021. www.uu.nl/agenda/promotie-advance-care-planning-in-pediatrics.
- Verhagen, A.A.E., Sol, J.J., Brouwer O.F. and Sauer, P.J. “Actieve levensbeëindiging bij pasgeborenen in Nederland; analyse van alle 22 meldingen uit 1997/’04.” *Nederlands Tijdschrift voor Geneeskunde* 149 (2005):183-188. https://www.ntvg.nl/artikelen/actieve-levensbe%C3%ABindiging-bij-pasgeborenen-nederland-analyse-van-alle-22-meldingen-uit/artikelinfo .

Interviews

- Colinda Adams, researcher Lindeboom Institute, July 27, 2021.
- Wieke Ligtenberg, researcher Lindeboom Institute, July 27, 2021.
- Wilma Stoelinga, director Kinderhospice Binnenveld in Barneveld, March 19, 2021 and September 7, 2021.

6. Active life support and crustative care in mental health care

Arthur Alderliesten

This chapter focuses on the possible application of crustative care in the Netherlands as an approach to provide palliative care to psychiatric patients with an active request for termination of life.[272] In the first section, we explore how active termination of life is dealt with within the mental health care sector: legislation, figures and a focus on the role of the care recipient and caregiver. The treatments currently offered to psychiatric patients is discussed in section 2, after which the third section explores crustative care as a palliative care approach. The chapter closes with a concluding summary.

6.1 Mental health care and active life termination

What is known about how euthanasia and assisted suicide are dealt with in the mental health sector?[273] And what do we know about psychiatric patients with a persistent desire to die and how do psychiatrists view this? Where does (Christian) mental health care stand on active termination of life upon request, including in its ethical considerations? With these questions, we explore the field of active life termination within psychiatry.

6.1.1 Figures

The question of how mental health practice should treat patients with a request for active termination of life due to psychological 'unbearable suffering without the prospect of relief', is relevant and topical because the number of people in this category is increasing.[274] Estimates of requests for euthanasia submitted to psychiatrists were included in the third evaluation of the Act on the Assessment

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[272] Thanks to Sandra van de Langemeen, mental health social worker at Eleos.

[273] Here I draw on Roeljan de Weerd, "Euthanasie in praktijk" (master's thesis, Utrecht Hogeschool, 2020).

[274] S.M.P. van Veen, F.W. Weerheim, M. Mostert, J.J.M. van Delden, "Euthanasie van Nederlandse psychiatrische patiënten in 2015-2017," Tijdschrift voor psychiatrie 61(2019)4, 241-247, https://www.tijdschriftvoorpsychiatrie.nl/nl/artikelen/article/50-11908_Euthanasie-van-Nederlandse-psychiatrische-patienten-in-2015-2017.

of Termination of Life on Request and Assisted Suicide (WTL).[275] These run from 320 requests in 1995, to 500 in 2008, to 1,100 in 2016. The number of requests for euthanasia actually carried out is 2-5, 30 and 60, respectively. In percentages of all requests for euthanasia: 0.6-1.6%, 6% and 5.4% respectively.

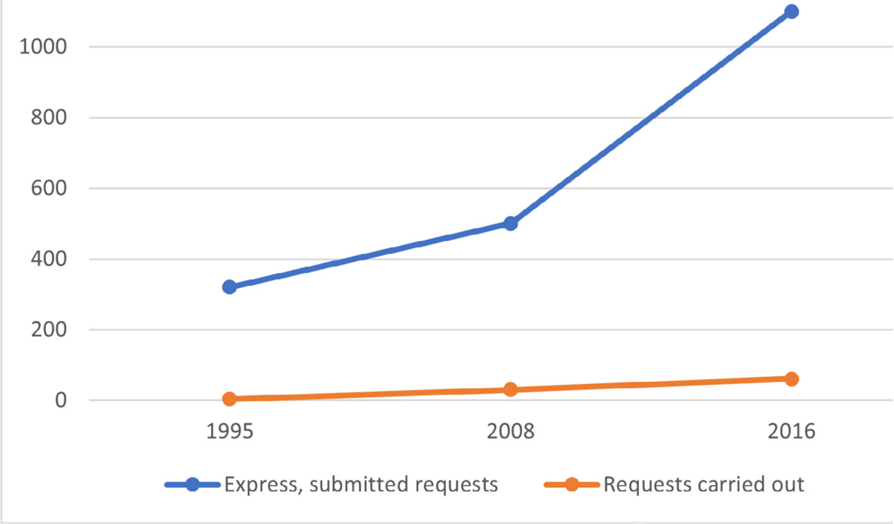

Figure 2 Number of euthanasia requests submitted and carried out for mental suffering.

It is notable that despite the increase in requests, the relative number of (estimated) euthanasia requests carried out between 2008 and 2016 did not increase as much as between 1995 and 2008, but actually decreased by 0.6%. The number of psychiatrists unwilling to perform euthanasia for a psychiatric patient has increased. While this percentage was 53% in 1995, in 2016 it was found to have increased by 10% to 63% who are unwilling to perform euthanasia for a patient.[276] Have psychiatrists become more critical over time?

A broader survey of the profession shows that the percentage of physicians who think it is conceivable to perform euthanasia or assisted suicide on persons with psychiatric conditions ranged from 20% among medical specialists, 39% among

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[275] Bregje Onwuteaka-Philipsen, et al, Derde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding , (The Hague: ZonMw, May 2017), Regulatory Evaluation Series: Vol. 40, 137, 138.

[276] Derde evaluate WTL, 138.

psychiatrists, 45% among gerontologists and 47% among general practitioners.[277]

We draw the circle even wider: how does the Dutch population view euthanasia due to mental suffering? Recent research shows that 53% of the population believes people with psychiatric disorders should be eligible for euthanasia and assisted suicide. Fifteen percent are against, with the remaining portion of respondents neutral on this issue.[278]

Euthanasia for mental suffering is apparently still a controversial topic.

6.1.2 Laws and regulations

The Assessment of Termination of Life at Request and Assisted Suicide Act also applies to psychiatric patients, although psychiatry is not explicitly mentioned. This means that the six criteria of due care listed in the introductory chapter also apply to psychiatry. And that is the rub, especially with regard to 'hopeless and unbearable suffering'. Whereas physical suffering is objective and measurable to a significant extent, determining the extent of psychological suffering relies more subjective criteria.[279] In response to the lack of objective and quantifiable measurements of unbearable suffering without the prospect of relief, is a multidisciplinary approach, as indicated in the guideline 'Termination of life on request in patients with mental disorders'.[280]

In Belgium, where the debate on euthanasia for mental suffering is more intense than in the Netherlands, an open letter by more than 60 experts was published stating that mere mental suffering should no longer be grounds for granting a request for euthanasia.[281] This group of experts argues that euthanasia due to psychological suffering is causing a medical-cultural shift in the mental health sector. Stockman et al. point out that considering intolerable suffering untreata-

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[277] Kirsten Evenblij, "End-of-life care for patients suffering from a psychiatric disorder," (PhD thesis, Vrije Universiteit Amsterdam, 2021), 163.

[278] Evenblij, "End-of-life care," 163.

[279] René Stockman et al, Euthanasie bij psychisch lijden. Het hellend vlak dat overslaat? Fracarita series 9. (Antwerp/Apeldoorn: Garant 2018), 9, An Haekens, "Euthanasie bij uitzichtloos psychisch lijden," in Timothy Devos (ed.), Euthanasie: een ander verhaal, (Kalmthout: Pelckmans, 2021), 93ff.

[280] Federatie Medisch Specialisten, Levensbeëindiging op verzoek bij patiënten met een psychische stoornis, (2012-2022), https://richtlijnendatabase.nl/richtlijn/levensbeeindiging_op_verzoek_psychiatrie/startpagina_-_levensbe_indiging_op_verzoek.html.

[281] Ariane Bazan, Gertrudis van de Vijver, Willem Lemmens, "Schrap euthanasie op basis van louter psychisch lijden uit de wet," De Morgen, 8 December 2015, https://www.demorgen.be/meningen/schrap-euthanasie-op-basis-van-louter-psychisch-lijden-uit-de-wet~b277b650/).

ble reflects a narrow view of psychiatry.[282] Patients, such as thosewith depressive disorder or borderline personality disorder, may experience immediate suffering as intolerable, but this does not mean that all suffering is untreatable over time. The experts also raise the question of whether there are measurable parameters to determine the unsolvable nature of mental suffering. Is it not characteristic of mental suffering that a patient no longer believs there is the prospect of recovery? The experience of hopelessness in itself says little about the prognostic expectations of mental suffering.[283] Conditions that play an important role in the demand for euthanasia because of psychological suffering, such as depression, bipolar disorder and personality disorders, are known to change unpredictably in the future. Many of these conditions tend to move toward a favorable direction over time, whether thanks to pharmacotherapy or psychotherapy or not, as shown in a study published in 2016 in the *Journal of the American Medical Association*. In 56% of Dutch patients who underwent euthanasia for psychiatric reasons, there were still treatment options that had not been tried (for various reasons).[284] With psychiatric disorders, the degree of severity fluctuates. What is hopeless today need not be in three- or six-months' time. In short: who determines on what basis that someone is beyond treatment?

6.1.3 Around the euthanasia request

The aid applicant

Retrospective file research by the Expertise Centre for Euthanasia shows that the application of euthanasia involved people with complex, long-term and mostly chronic psychiatric problems. The majority of patients had been through counselling for mental health for 10 years or more.[285] Within this group, 'depressive mood disorder' was the most common main diagnosis, followed by disorders in the schizophrenia spectrum and trauma and stress-related disorders.[286] Patients were often reluctant bring up a request for active life termination to their

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[282] Stockman, Euthanasie bij psychisch lijden, 10.

[283] Stockman, Euthanasie bij psychisch lijden, 11.

[284] S.Y.H. Kim, R.G. de Vries, J.R. Peteet, "Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014," JAMA Psychiatry 73 no. 4 (2016):362-368, doi:10.1001/jamapsychiatry.2015.2887.

[285] Veerle Beel and Ine Renson, "'Wie zijn wij om te bepalen hoeveel een ander moet lijden?'" The Standard, November 4, 2017, https://www.standaard.be/cnt/dmf20171103_03168722.

[286] Monique Kammeraat, Pieternel Kölling, Psychiatrische patienten bij Expertisecentrum Euthanasie. Retrospectieve dossierstudie naar de achtergronden en het verloop van euthanasieverzoeken op grond van psychiatrisch lijden bij Expertisecentrum Euthanasie. Period 2012-2018, (The Hague: Expertisecentrum Euthanasie), 60, https://expertisecentrumeuthanasie.nl/app/uploads/2020/02/ Onderzoeksrapportage-Psychiatrische-Pati%C3%ABnten-Expertisecentrum-Euthanasie.pdf.

caregiver out of fear of hospitalization.[287] Patients prefer to discuss a request for euthanasia with their own general practitioner. Trust and respect are important aspects for them in their contact with the caregiver.[288]

Karin Evenblij received her PhD in December 2021 for research on end-of-life care for patients suffering from a psychiatric disorder. Part of her research involved nine psychiatrists who described a case study in which they granted a request for euthanasia or assisted suicide from a patient with a psychiatric disorder. These patients included five men and four women. Their ages ranged between 42 and 82 years. Five of them had a mood disorder, three had a somatic co-morbidity. The main reasons for requesting euthanasia or assisted suicide were suffering with no prospect of improvement and depression. In addition, 66 psychiatrists described a case in which they refused a psychiatric patient's request. Of these 66 patients, 82% were under 65 years, 63% were women, 59% had a personality disorder and 19% had a somatic co-morbidity. The main reasons for requesting euthanasia or assisted suicide were feelings of depression and being stuck in multiple areas of life (such as work, finances, and relationships). Most of the requests were refused because, according to the psychiatrist, the due care criterion that there no reasonable treatment alternatives were left, was not met.[289]

The psychiatrist

The figures mentioned above have already shown that over time, psychiatrists have become more reluctant to honour their patients' requests for euthanasia. This could be explained by a number of reasons cited in third evaluation of the WTL. "For example, countertransference could affect the objectivity of the assessment and psychiatrists experience a conflict between treatment goals and carrying out life termination on request. " There are also counterarguments related to due care criteria. For example, sometimes doubts exist about the extent to which a psychiatric patient's request can be voluntary and deliberate, because the desire to die can vary greatly in psychiatric patients. In addition, psychiatrists sometimes experience difficulties in assessing whether there is unbearable suffering without the prospect of improvement because of uncertainty about possible new treatments or recovery in the future. Furthermore, some feel insufficiently competent to perform life termination. Finally, there is dissatisfaction with the quality

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[287] A. Callebert, Herstel als antwoord op euthanasie? (Leuven: Acco, 2017), CBO Kwaliteitsinstituut voor de gezondheidszorg, Evidence-based Richtlijnontwikkeling voor werkgroepleden (2007), https://docplayer.nl/8157534-Evidence-based-richtlijnontwikkeling-handleiding-voor-werkgroepleden.html.

[288] Emily M Woltmann, Rob Whitley, "Shared decision making in public mental health care: Perspectives from consumers living with severe mental illness," Psychiatric Rehabilitation Journal, 34(1), 2010: 29-36, https://doi.org/10.2975/34.1.2010.29.36.

[289] Kirsten Evenblij, "End-of-life care," 85-110.

of mental health care. Psychiatrists question whether to cooperate with life termination upon request if the quality of care is not sufficient.[290]

Another argument common among psychiatrists is that discussing euthanasia would lead to a fixation on death. Psychiatrists, furthermore, experience resistance against a multidisciplinary approach to a euthanasia request because the physician bears ultimate responsibility.[291]

Yet, several arguments are put forward that support a positive view of life termination upon request by psychiatric patients. The third evaluation of the WTL writes: "For instance, according to some psychiatrists, it is unjust to exclude psychiatric patients on the basis of their condition when this patient group can meet the law's due care requirements. In addition, some feel that psychiatric suffering is perhaps worse than somatic suffering since the latter is finite in many cases, unlike psychiatric suffering, which can last for years. In some cases, mercy may be a reason for wanting to cooperate with life termination upon request. Other arguments that support life termination upon request for psychiatric patients include: the argument of self-determination, providing a dignified end for patients who might otherwise commit suicide and the belief that cooperating with termination of life upon request is part of the physician's responsibilities to ensure a good end of life."[292]

Rosalie Pronk suspects that the difference in views on active life termination among psychiatrists stems from differing views on mental illness: "A difference in views seems related to a difference in views on what mental illnesses are. Some psychiatrists emphasise the difference, while others name the similarities between somatic and mental disorders." [293]

The treating physician has a special responsibility and position of power. This is reflected in the reasoning cited above for taking a position on active life termination in cases of mental suffering. Although the medical paternalism of the past has largely disappeared and the physician-patient relationship has changed, in the euthanasia process the physician is driven to a new kind of paternalism.

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[290] Derde evaluatie WTL, 178.

[291] Dennis Demedts et al, "The attitudes, role & knowledge of mental health nurses towards euthanasia because of unbearable mental suffering in Belgium: A pilot study," Journal of Psychiatric and Mental Health Nursing 25 (September 2018): 400-410, https://doi.org/10.1111/jpm.12475.

[292] Derde evaluatie WTL, 178.

[293] Rosalie Vonk, "A dialogue on death. On mental illness and physician-assisted dying," (PhD. diss., University of Amsterdam, 2021), 182.

Willem Lemmens states, in sharp terms about the physician, “He decides about life and death, honours the patient’s request or not. He seemingly knows when suffering is truly unbearable or not. When a psychiatric patient is beyond treatment or not. Surely one should realise (...) that patients’ free choice can always be influenced. That some patients resort to death out of a kind of desperation, a blind conviction that in that way everything is ‘solved’. That it may not be a manifestation of compassion at all if one neutrally follows and honours that belief. That as a physician, one can really make a mistake and become a co-perpetrator to something that is irreparable.”[294]

Active termination of life, including in cases of psychological suffering, thus calls for an ethics of restraint and caution.

“Dying or living?” - an existential perspective

Thinking about euthanasia in psychiatry is tangentially related to thinking about ‘completed life’. One of the critical questions raised in the ‘completed life’ debate relates to the reason for the desire to die. Does the person really want to die, or does he or she want to end the suffering? Ann Callebert conducted extensive research on the requests to die among people with mental illness: “The request to be allowed to die often masks an inability to live, the desire for the desire for a different and better life. Actually, people do not want to die, but they do want to be relieved of horrible suffering.”[295] She made this observation in the context of the need to really listen carefully to the patient.

This observation gives the issue of euthanasia for mental suffering an existential perspective involving issues of meaning and spiritual needs. Machteld Huber showed that people suffering from a serious illness seek meaning, hope for the future and ultimately acceptance of their situation.[296] The movement Huber initiated emphasizes a more positive healthcare that can be of added value to the issue euthanasia for psychiatric suffering. This seems to call for a perspective shift in psychiatric care from a purely therapeutic orientation on the part of the caregiver to the existential-spiritual dimension of the person seeking help.

In 2010 the psychiatrist Herman van Praag called loss of meaning a neglected topic in psychiatry. “Need for meaning can be experienced as ‘self-generated’ or

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[294] Quoted in: Stockman, Euthanasie bij psychisch lijden, 54.

[295] Callebert, Herstel als antwoord op euthanasie, 84.

[296] M. Huber, M. van Vliet, M. Giezenberg et al, “Towards a ‘patient-centred’ operationalisation of the new dynamic concept of health: a mixed methods study,” BMJ 2016;5:e010091, doi:10.1136/bmjopen-2015- 010091.

as metaphysically inspired, i.e., prompted by an supernatural authority. Sense deficiency is a psychological state that is hardly recognised, let alone treated, in psychiatry."[297] He ends his essay by noting that psychiatry has increasingly focused on the why question, at the expense of the question of purpose. "While the why question is primarily asked by philosophers and theologians, even the psychiatrist cannot avoid it. If an individual has no answer to the meaning question, there is no prospect of a future, in fact no reason to exist anymore and the lust for life evaporates. The truth question has been ignored by the psychiatrist. This no longer seems acceptable."[298] And more recently, Ann Haekens, psychiatrist and psychotherapist, in a discussion on euthanasia and psychological suffering, opined that the mental health system is guilty of therapeutic doggedness, persistent pressure to treat and that the existential dimension in mental health has long been underexposed.[299]

6.1.4 Euthanasia within psychiatry from a Christian perspective

From an explicitly Christian perspective, no exhaustive thought and writing has yet been done on dealing with euthanasia in psychiatric patients. In the literature, I nevertheless distinguish four–perspectives that are not mutually exclusive:

1. Palliative psychiatry is the most obvious approach, because palliative care—with its emphasis on care for the whole human being, relief of pain and a dignified dying process—fits with an ethics of care from a Christian perspective. Gerrit Glas, philosopher and psychiatrist, advocates for this.[300] Rosalie Vonk, who got her PhD on 'mental illness and phyisician-assisted dying' in late 2021, also argues for this perspective, although not from an explicitly Christian view of care.[301] Palliative care within health care for physical pain for terminally ill patients is widely respected and valued. It is therefore striking that it is still only sporadically used within psychiatry. The uniqueness of palliative care in psychiatry compared to somatic care is discussed later in this chapter.
2. Dealing with psychiatric patients with request to terminate their liferequires a pastoral approach. A Christian view of euthanasia and psychiatry should begin with an open-minded recognition of psychiatric suffering. For instance,

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[297] H.M. van Praag, "Zinverlies; een verwaarloosd onderwerp in de psychiatrie," Journal of Psychiatry 52 no. 10 (2010): 705-714, https://www.tijdschriftvoorpsychiatrie.nl/assets/articles/TvP10-10p705-714.pdf.

[298] Van Praag, "Zinverlies," 712.

[299] Ann Haekens, "Euthanasie bij uitzichtloos psychisch lijden," 96, 97.

[300] Parliamentary Papers II 2013/2014, 32647, 28.

[301] Vonk, "A dialogue on death," 161, 162, "Euthanasie in de psychiatrie: een dubbel taboe," Folia, accessed February 3, 2022, https://www.folia.nl/wetenschap/148891/euthanasie-in-de-psychiatrie-een-dubbel-taboe.

Theo Boer can imagine “that if God does not answer our prayer to die, that also implies a certain comfort: apparently He will stand by me as long as I am alive; apparently the difficulties I am living through now will eventually lead to a greater gain, in whatever form, after all. I also draw from the observation that suffering before death will ‘never be meaningless’.” Boer therefore also comes out in favour of using palliative psychiatry.[302] “For people with chronic psychiatric illness, euthanasia is not settlement with death,” Boer argues, “but settlement with life. That is a head-on collision with our duty to protect life.”[303]

Bart van den Brink, psychiatrist at Eleos, identifies the pastoral nature of the Christian approach with the words ‘hope’ and ‘compassion’. About hope[304] Van den Brink writes that in psychiatry it belongs to ‘neglected notions, perhaps also because from a scientific point of view we prefer to limit ourselves to that which has been proven. From a Christian perspective, however, there is yet every reason to work on bringing hope beyond what we see.’ Compassion in his view, is an even trickier notion, although compassion, sympathy, are empathy are basic psychiatric competencies. ‘Underneath that, I think there is an even deeper Christian notion: God in Jesus Christ has given us a compassionate Substitute. His compassion calls us to go the next mile with the other person. Even when illness calls for someone’s life to be ended, you may still look for a way to support that neighbour. By thinking and working creatively, with a directive for palliative psychiatry, perhaps you can even carry your neighbor on your own donkey, even when the inn still seems miles away.’[305]

3. Social environment and church should be involved with someone suffering severely from their mental health problems. It worries Ewoud de Jong, Hanneke Schaap-Jonker and Femmeke van den Berg, all three involved at Eleos, how clients’ network deal with his or her desire to die, both in the case of euthanasia and suicide. “Close relatives sometimes indicate that they do not

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[302] Theo Boer, “Euthanasie bij psychiatrische patiënten: de christelijke tegenstem,” Psyche & geloof 30.2 (2019): 132-133.

[303] Theo Boer, “ Euthanasie bij psychiatrische patiënten: de christelijke tegenstem: Observaties vanuit een protestantse-christelijk Perspectief,” Psyche & geloof 30.2 (2019): 118.

[304] Cf. Theo Boer, Eind goed. Een protestantse kijk op euthanasie in Nederland, (Utrecht: Kok-Boekencentrum, 2021), 81, 82.

[305] Bart van den Brink, “ Euthanasie in psychiatrie vraagt om christelijk antwoord,” Reformatorisch Dagblad, February 16, 2018, https://www.rd.nl/artikel/891006-euthanasie-in-psychiatrie-vraagt-om-christelijk-antwoord. The metaphores are from Jesus’s parabel on the good Samaritan (Luke 10:25-37)

seek professional help because they believe that their mentally ill relative has the right to decide whether or not he or she wants to live. Recently, someone with an office in the church did not consider it necessary to report that someone with suicidal intentions was unreachable, because he could understand when that person would end his life. Therefore, we want to make an emphatic appeal to those in client's circle to remain supportive, possibly point out alternatives, ease the suffering wherever possible and, above all, not to give up on someone because God is powerful enough to do more than we pray or think."[306] Especially when the other person no longer sees hope and the sight of the cross of Christ is obscured, the person's close contacts, together with counselling, has the job of maintaining hope. Thus, the connections, family and church, can form a network of living care[307] for people with such severe mental health problems that they have a desire to die. Yet this is a perhaps too idealistic representation, which means that realising such a commitment will hardly prove feasible in practice. Instead, many psychiatric patients are distant from their families and have a social network limited to fellow patients and caregivers.[308] Loved ones, such as family and church, face a considerable challenge to play a meaningful role in the existential questions of psychiatric patients with a desire to die.

4. Of a different order is the assertion by Belgium's René Stockman et al. that it is socially important to have institutions that continue to resist euthanasia. "The *ethical* question in relation to euthanasia," they argue, "is whether the patient's judgment can be a sufficient reason for euthanasia, for the healthcare provider to break the radical prohibition against killing (even if it involves killing in response to the patient's urgent wish). No healthcare provider or healthcare institution can or should disregard that question."[309] They speak of "euthanasia-free institutions" that are indicators of resisting further stretching of the (Belgian) law. "Not responding to the request for euthanasia, especially from purely mentally ill people, does not mean that patients are abandoned. On the contrary, it has to do with the very willingness not to abandon the other person, however hopeless the situation may look to that other person."[310]

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[306] Ewoud de Jong, Hanneke Schaap-Jonker, Femmeke van den Berg, " Kerk en familie hebben taak ter voorkoming van euthanasie," Reformatorisch Dagblad, November 18, 2016.

[307] Arthur Alderliesten, Stervenskunst bij Luther, (Apeldoorn: De Banier, 2021), 118.

[308] Heidi de Kam, Hennie Kievit, De helikopter van Viktor. Palliatieve zorg in de psychiatrie, (Amersfoort: GGz Centraal, 2020), 28, 30.

[309] Stockman, Euthanasie bij psychisch lijden, 57, 58.

[310] Stockman, Euthanasie bij psychisch lijden, 59.

6.1.5 Palliative psychiatry

Palliative care and psychiatry are not two spearate phenomena. Since a significant proportion of patients receiving palliative care suffer from anxiety, depression, delirium or other psychological symptoms, psychiatry and palliative care already work closely together for somatic conditions. Despite this involvement of psychiatrists in palliative care, psychiatry currently provides little explicit palliative care for patients with mental disorders outside the context of a terminal medical condition. This leads to, for instance, mental health nurses feeling inadequately equipped to attend to patients in the last phase of life.[311]

What is meant by palliative psychiatry (PP)? Trachsel et al. formulate the following working definition based on the WHO definition. Palliative care is seen as "an approach that enhances the quality of life of patients and their families in coping with the problems associated with life-threatening severe persistent mental illness (EPPA) by preventing and alleviating suffering through timely assessment and treatment of associated physical, mental, social and spiritual needs. PP focuses on harm reduction and on avoiding some psychiatric interventions with questionable effect."[312]

Trachsel et al. assign PP the following characteristics:

- Provides support in dealing with and accepting distressing, psychological symptoms;
- Affirms life but recognises that EPPA can be incurable;
- Does not aim to hasten or delay death;
- Integrates the physical, psychological, social and spiritual aspects of patient care;
- Provides a support system to help patients live as actively as possible until death;

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[311] De Kam, De helikopter van Viktor, 11. A Spanish study of 534 nurses found that more than half (61%) of nurses reported feeling competent in dealing with patient bereavement (based on CDS score). Nurses with male gender, higher age and more work experience reported being better able to cope with the death of a patient. Analyses using regression models showed that more fear of death, psychoticism (by which is meant a pattern of personality traits characterised by acting out of self-interest, insensitivity towards others and little compassion) and more anxiety caused nurses to feel less competent in dealing with death. In contrast, higher age and more work experience are related to being more competent in dealing with death. (M. Povedano-Jiménez, C. Ropero-Padilla, M. Rodriguez-Arrastia and M.P. García-Caro, "Personal and Emotional Factors of Nursing Professionals Related to Coping with End-of-Life Care: A Cross-Sectional Study," International journal of environmental research and public health 2021 18(18); 9515, https://doi.org/10.3390/ijerph18189515.

[312] Trachsel et al, "Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks," BMC Psychiatry (2016) 16:260, DOI: 10.1186/s12888-016-0970-y.

- Provides a support system to help family members cope with patients' EPPA;
- Uses a multidisciplinary approach to meet the needs of patients and their families;
- Improves quality of life and may also have a positive impact on the course of EPPA and
- Is applicable in combination with other therapies aimed at prevention, cure, rehabilitation or recovery.

The last feature is interesting. Palliative psychiatry does not compete with other important concepts in psychiatry, such as the recovery model or crustative care, but can go hand in hand with them. On the contrary, as an approach, it cannot do without therapies aimed at prevention, cure, rehabilitation or recovery. There are hopeful signs that better palliative care for people with EPPA is leading to fewer requests for active life termination.[313]

The differences between palliative care in somatics or in psychiatry are not minor. This is shown by Heidi de Kam and Hennie Kievit in their 2020 book *Viktor's helicopter: Palliative care in psychiatry*.[314] They combine literature reviews with real-life cases and show that the consequences of a psychiatric condition make care more complex on the physical, psychological, social and existential level.[315] However, palliative care in psychiatry differs from palliative psychiatry because palliative care involves impending death. Moreover, palliative psychiatry lacks the physical component.

6.1.6 Five interfaces of mental health and end-of-life care

We zoom out a little to survey the field of end-of-life care within the mental health sector in order to zoom in on crustative care later. In Flanders (Belgium), at the interface of end-of-life care and psychiatry, five intersections are defined.[316] These are intersections where the two worlds of psychiatry and end-of-life care meet. This gives an overview of the field of active termination of life and psychiatry. The various intersections, while quantitatively modest, are complex in nature for (psychiatric) care. These groups are not mutually exclusive; patients can be part of several groups at the same time.

1. Palliative psychiatry refers to palliative care for psychiatric patients. However,

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[313] M.C Jansen-van der Weide, B.D. Onwuteaka-Philipsen, G. van der Wal, "Requests for euthanasia and physician-assisted suicide and the availability and application of palliative options," Palliat Support Care 2006;4(4):399-406, DOI: 10.1017/s1478951506060494.

[314] De Kam, De helikopter van Viktor.

[315] De Kam, De helikopter van Viktor, 20.

[316] Loïc Moureau, personal interview with author, January 28, 2022.

psychiatric care facilities often lack the knowledge to provide palliative care for their patients;
2. Psychiatric care and support in persons in palliative stage;
3. Individuals who, because of their condition, find themselves in a life-threatening situation (e.g., refractory anorexia nervosa) and therefore require palliative care;
4. Crustative care, as a palliative care approach. This often concerns EPPA patients, whose situations seem hopeless and do not qualify for a regular euthanasia project;
5. Individuals with psychiatric disorders requesting euthanasia or other forms of medically assisted dying on the grounds of psychological suffering. In Flanders, this includes recovery-oriented work and experiential expertise. One example is the Reakiro project in Leuven.[317]

The remainder of this chapter focuses on the fourth intersection or interface, crustative care, including the question whether it meets the needs of patients in the fifth intersection. How can crustative care take shape? And how does crustative care relate to current treatment offerings? Current treatments and therapies focus on (belief in) recovery, while palliative psychiatry recognises that EPPA can be incurable. It has been concluded from the literature that there are patients who do not experience ‘progress’ with current treatment and retain a persistent desire to die. It is therefore recommended palliative psychiatry is applied to supplement the current treatment offer. An example of this is crustative care, which is in development in Flanders.

6.2 Crustative care

6.2.1 Introduction]

In somatic care, when one runs up against the limits of medicine and the patient is beyond treatment, i.e., ‘untreatable’, palliative care is initiated in most cases. However, in (mental health) care, there is no similarly recognised form of careeven though there are psychiatric patients in whom therapy resistance occurs and in whom there are no longer any treatment options to alleviate their unbearable psychological suffering. In particular, these are patients with severe persistent psychiatric disorder (EPPA). To date, a specific programme, recognition and funding of psychiatric palliation for this target group is lacking.[318] In Bel-

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[317] “Visie,” accessed February 3, 2022, https://reakiro.be/visie/.

[318] R. de Rijke, “ Crustatieve zorg: een nog ontbrekende schakel in de geestelijke gezondheidszorg,” Artsenkrant, December 13, 2017, https://www.artsenkrant.com/actueel/crustatieve-zorg-een-nog-ontbrekende-schakel-in-de-geestelijke-gezondheidszorg/article-column-30507.

gium, healthcare providers and researchers have been searching for a palliative response to unbearable psychological suffering, which led to the development of of crustative care. Crustative care focuses on 'dignified living' as a counterpart to euthanasia with the goal of 'dignified dying'. Crustative care is a form of care aimed at alleviating the psychological suffering and the physical, psychosocial and existential problems EPPA patients face using a palliative approach. This section focuses on current knowledge and research on crustative care.

6.2.2 Origin crustative care

The current social climate and care system seems unfavourable to protcting seriousand chronic mentally ill patients.[319] In the Netherlands the Social Support Act (WMO) and the Participation Act (PW), have emphasized the concepts of 'empowerment', 'own power' and 'participation in society'. EPPA patients cannot be held accountable for their own strength and responsibility, or at a reduced level. They are at risk of being left out in terms of good, appropriate and long-term care. This can also be seen in the increasing number of incidents involving 'paranoid delusional' and 'disorderly conduct' in news coverage since the start of this century. The 'retreating' government no longer considers the safety issue for psychiatric patients as its responsibility. This is evidenced by the fact that initially, mental health patients were not admitted for care according to the Long-Term Care Act (LTC). From the moment psychiatric patients were granted access (January 2021) to healthcare, the number of applications for this turned out to be significantly higher than expected.[320] In the search for how appropriate care can be delivered to the invisible, vulnerable EPPA patient, the term 'crustative care' was born. Crustative care was developed in Flanders as an innovative model of care and is still evolving. [321] The starting point here is to provide quality care to non-terminal EPPA patients. Because mental illness has a wide variety of causes, care for these patients and providing for their needs is complex. Palliative elements are added to recovery, although, this does not focus on the end of life. [322]

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html?cookie_check=1695298117.

[319] Armand Höppener, "Op de bres voor kwetsbare psychiatrische patiënten," Medisch Contact, October 19, 2017, https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/op-de-bres-voor-kwetsbare-psychiatrische-patienten.htm#:~:text=There%20is%20a%20appropriate%20form,if%20that%20is%20of%20the%20society.

[320] CIZ, " Vertraging ggz-aanvragen," March 9, 2021, https://www.ciz.nl/nieuws/vertraging-ggz-aanvragen.

[321] Françoise Verfaillie, "Interview met dr. Françoise Verfaillie," in Afrit 8 no. 3 (Sept-Nov 2016): 4-6, https://www.pzonzelievevrouw.be/sites/pzolv/files/files/Afrit8NS201603.pdf.

[322] K. Sweers, M. de Hert, J. Detraux, "Een menswaardige palliatieve zorgverlening voor patiënten met een (ernstige) psychiatrische stoornis: utopie of noodzaak? Een systematisch literatuurstudie," Psychiatrie en Verpleging 87/3 (2011): 156-170.

6.2.3 Defining crustative care

Crustative care is a term derived from the Latin word ‘crusta’, meaning shell. Caregivers create a ‘shell’ in which EPPA patients can live. This ‘external structure’ is needed because the ‘internal structure’ of the patient’s capacities is too weak to function.[323] In English, the term is translated as ‘oyster care’. The shell protects the oyster, which inhabits the shell. The pearl arises as a reaction to a foreign object entering the shell. The oyster then resists the threat by hardening the foreign object. The pearl is thus the result of a coping mechanism of the oyster. In EPPA patients, their original coping behaviour fails. They are threatened in their vulnerability. Caregivers accept them with their deviant behaviour, value their coping mechanisms as a pearl and protect them from harmful behaviour with a shell. In crustative care, the shell may close around the vulnerable patient and their pearl for protection if care needs increase or if the patient’s choices and behaviour cause harm to themselves or others. When care needs are minimal and the person’s behaviour is not harmful, the shell can open more. Thus, caregivers can help patients realise their autonomy, or they can take responsibility when their choices and behaviours are harmful to themselves or others.

6.2.4 Theoretical concept

Crustative care involves an integrated approach with the aim of relieving the pain of suffering, helping to bear the burdens of life, managing symptoms, limiting the side effects of medication, preserving and restoring human dignity and finding ways to make life meaningful for EPPA patients. Crustative care begins only after the completion of other stages of care in which (re)diagnosis was central. Symptom treatment and acceptance of chronic symptoms are paramount.[324] The aim of interventions is no longer to remove the disruptive behaviour so that the patient can live in society again, but to create an environment in which he can exist with his deviant behaviour. This treatment is not as much future-oriented as it is living in the here and now. So this approach is not aimed at symptom improvement, but rather at controlling symptoms that are bothersome to the client and interfere with a better quality of life. In other words, the goals are to reduce suffering and increase well-being. In addition, crustative care is characterised by providing external structures in which the client can be himself or herself to the maximum extent. The living environment is adapted to the client and not vice versa. It is a dynamic approach that responds to individual needs and possibilities

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[323] I. Decorte, et al, “Oyster Care: An Innovative Palliative Approach towards SPMI Patients,” Frontiers in Psychiatry 11 (2020): 509, doi.org/10.3389/fpsyt.2020.00509.

[324] I. Decorte, et al, “Schelpzorg: een palliatief zorgmodel voor patiënten met een ernstige, persisterende psychiatrische aandoening,”
Tijdschrift voor Geneeskunde (2021/2): 136, doi: 10.47671/TVG.77.20.177.

and acts as a counterbalance to the chaos a client often experiences.

Crustative care is a holistic care approach, which, like the palliative care approach, is based on the four pillars of physical, psychological, social and existential care, as described below. This holistic care approach requires counsellors to take a multidimensional approach with a range of interventions, such as a highly personalised approach. A good rapport between caregiver and patient is required. In addition, extensive expertise in somatic care is needed such as integrating a GP and a nurse trained for such care into the care team. Creativity and out-of-the-box thinking cannot be missed. It turns out that the development of this care model in a number of care units in Flanders increased the well-being of patients and created significant positive dynamics among care providers. An example of the realisation of this care model was seen in ward 52 of the Onze-Lieve-Vrouw psychiatric hospital in Bruges.[325]

Physical pillar
Research shows that EPPA patients have a much lower life expectancy due to comorbidities and multiple (chronic) conditions.[326] Major causes include an unhealthy lifestyle, eating disorders, side effects of medications, a increased incidence of diabetes, increased incidence of metabolic syndrome and increased risk for cardiovascular disease. Responding appropriately to somatic limitations is important. Optimising and properly adjusting medication is also important. Attention is paid to balancing taking over general daily living (ADL) and allowing the patient to do things himself. The orientation toward the future has disappeared. As in palliation, crustative care approaches pain and the perception of pain multidimensionally, i.e., by taking into account a combination of somatic, psychological, social and existential factors.[327] Pain is not always expressed by the patient or self-inflicted through self-mutilation. The care unit of crustative care works like a shell: it provides as much safety as possible to, as best as possible,preserve physical integrity. This requires much more intervention from caregivers and often one-to-one counselling.

Example: Liz (66) often falls for unclear reasons. She incurs fractures but expresses no pain symptoms. Fractures go unnoticed or are treated too late. Destructive behaviour

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[325] " Langdurige intensieve psychiatrische behandeling (afdeling 52)," Psychiatrisch Ziekenhuis Brugge Onze Lieve Vrouw, accessed February 5, 2022, https://www.pzonzelievevrouw.be/langdurige-intensieve-psychiatrische-behandeling-afdeling-52.

[326] M. de Hert, et al, "Physical illness in patients with severe mental disorders: prevalence, impact of medications and disparities in health care," World Psychiatry (2011/10): 52-77.

[327] B.S. Wanrooij, et al, Palliatieve zorg in de dagelijkse praktijk, (Houten: Bohn Stafleu van Loghum, 2010), 13.

results in permanent fractures. In addition, the patient regularly refuses to eat. After another vertebral fracture, protection as an external structure was used within the care framework of crustative care. With consent, it was decided to restrain the patient for six weeks until the fractures healed. This took place in an easy chair in a cosily furnished room with continuous care from caregivers. There was proximity and recognition of suffering. There was also a joint search for what could help. Finally, the patient felt treated as a human being. 'I am worth being cared for'. This resulted in contact being made with a healthy, functioning part of the client for the first time in a long time. Positive behavioural changes took place.[328]

Psychological pillar

The care relationship in crustative care is even more important and often more challenging than in other care approaches. Many patients have failed to build trusting relationships because they have suffered from hurt relationships, have little or no trust in other people or have not developed stable and safe attachments. Social workers provide safety and structure as a 'shell'. They protect patients from external or internal overstimulation, such as anxiety or severe psychological distress. Taking an 'emotionally available' position, as in Baart's 'presence theory'[329] , enables the patient to connect with the caregiver. The ideas of Tielens[330] and Prouty[331] can be important inspirations for building supportive relationships with patients who lack relational skills.

The example below also shows a certain way of dealing with the EPPA patient's autonomy. The caregiversdo not always do what the patient wants, especially when the harm to the patient is too great. On the other hand, healthcare providers always seek the patients' underlying autonomy. Who are they, what values need to be respected and protected, and how can these values be protected in times when the patient is not capable of independent decision-making?

Example: The purpose of confinement of a patient (Liz, 66) was to prevent unstable vertebral fracture resulting in paresis of lower limbs. Paradoxically, the recovery of the relationship happened not despite but because of the patient's confinement. The patient could no longer avoid care and caregivers. Confinement, in this case, acted as a

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[328] I. Decorte, et al, "Oyster Care."

[329] A. Klaver, A. Baart, "How Can Attending Physicians Be More Attentive? On Being Attentive versus Producing Attentiveness," Med Healthcare Philosophy (2016/19): 351-359, doi: 10.1007/s11019-015-9669-y.

[330] J. Tielens, In gesprek met psychose: Verbindende gesprekstechniek, praktische handleiding om in verbinding te komen en blijven met psychotische mensen, (Utrecht: De Tijdstroom, 2012).

[331] G. Prouty, D. van Werde, M. Pörtner, Pre-Therapy: Reaching contact-impaired clients, (Ross-on-Wye: PCCS Books, 2002).

kind of boundary that offered protection or safety. It allowed the caregiver to be available in a reassuring way. That (intensive) presence allowed a therapeutic relationship to be reestablished.

Social pillar
Patients often suffer from a lack of social skills, and their social network is usually very limited. Due to a long history in psychiatric care, their relationships with family members are usually damaged or lost. For many EPPA patients, contact with society is broken. They feel alienated and often rejected by society. The care unit acts as a shell that provides safety because the patient is familiar with the expectations and rules there. On the one hand, the care workers create a safe environment where encounters can take place and are encouraged. On the other hand, they also protect the patient from negative interactions and societal misunderstandings. There is tolerance for 'strange' behaviour, provided it remains safe for all involved. At the same time, the social behaviour of the caregiver is a model for patients. Within this care framework, supervision and intervision around the dynamics of distance and proximity is essential for the caregiver. The patient is dependent requiring personal care. This is assumed by the caregiver, but at the same time professional distance is needed to make correct decisions.

Existential pillar
'Existential' refers to the basic need to seek and discover meaning and purpose in existence. This pillar is closely related to 'spirituality': the way individuals seek and express meaning and purpose, and the way they experience their connection to the moment, to themselves, to others, to nature or to God.[332] Due to experiencing severe loss, patients confront the fragility and brokenness of their existence, risking an existential crisis. At the same time, EPPA patients (mostly) have a strong will to live; they still want to 'be here'. Looking for and recognising the strength and will to live is very important. At the heart of crustative care is the search in word and deed for the essence of the human person—for the remaining bit of meaning and self-worth—and encouraging growth in this area. Connection through relationship is important here. Despite the care givers' powerlessness in the face of the patient's suffering, they should still remain present. There should be attention to themes of grief, loss, faith and meaning.

6.2.5 Requirements for psychiatric care

Crustative care makes a special appeal to psychiatric care, including the following:

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[332] C. Puchalski, et al, "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference," Journal of Palliative Medicine (2009/12): 885-904, doi: 10.1089/jpm.2009.0142.

1. A trusting relationship between caregiver and patient is crucial. The personal care relationship based on a bond of trust assumes attention and respect for the whole person. The person-centred approach is important. When the caregiver and patient do not ‘click’, it is better that care is taken over by a fellow caregiver;
2. The care framework requires a different view of autonomy. Autonomy should be seen from the perspective of *ability* rather than a *right*. The caregive looks at whether the patient has the capacity to make an independent decision at that moment, and if not, then the caregiver can take over decision-making for the patient. This need not harm the patient’s autonomy because the caregiver takes into account independent decisions made by the patient at the time when the patient had the ability to make those decisions;
3. The infrastructure where care is provided requires particular attention because good infrastructure can promote good care. For instance, single rooms should be available, if possible, in small residential units. Good lighting, attention to greenery, homely furnishings can create a feeling of home;
4. More focus on conversations about death and the desire for euthanasia.[333] The Reakiro project in Leuven also gives attention to this.
5. This care framework requires trained staff and more FTE per patient than other care frameworks.

6.3 Concluding summary

We return to the research question on the possible application of crustative care as a palliative care approach to provide a care option to psychiatric patients with desire to end their life. By exploring the situation between caregiver and care recipient, there is a variety of reasons to opt for an ethic of restraint. Patients with an request to terminate their life often appear not to be ‘untreatable’ (in the sense of cure) and therefore ineligible for euthanasia. The number of psychiatrists willing to execute a euthanasia request is decreasing for numerous reasons.

Behind a desire to die is often an existential perspective, involving issues of meaning and spiritual needs. Hence, a plea for palliative psychiatry that includes the spiritual dimension as an important component makes sense. Loss of meaning and sense of purpose have long been understudied in psychiatry. Palliative care for psychiatric patients is more complex than palliative (somatic) care in the terminal phase and requires specialised attention. Mental health services with a Christian identity founded on Christian notions such as mercy and hope should be able to respond to the spiritual dimension of palliative psychiatry, although

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[333] Cf. Roeljan de Weerd, “ Euthanasie in de praktijk” and the Reakiro project in Leuven.

palliative psychiatry as a dignified alternative to euthanasia does not yet seem to gain momentum. EPPA patients, in particular, would qualify for a palliative care approach, such as what crustative care offers. This approach does not compete with other important treatments but goes hand in hand with them. As an approach, crustative care cannot do without therapies aimed at prevention, curation, rehabilitation or recovery.

'Crusta' is the Latin word for shell. In crustative care, the shell may close around the vulnerable patient and their pearl, their innermost identity, for protection. When care needs diminish (or behaviour and decisions are less harmful), the shell can open more. Caregivers help patients realise their autonomy or, on the contrary, for a certain time take over responsibilities from the patient. Crustative care aims to reduce suffering and increase well-being. This requires a flexible, multidisciplinary and, above all, personalised approach. Psychiatric care is hereby challenged to accommodate the questions of meaning, significance, and the 'why' in patients seemingly 'beyond therapy' with a desire to die. This is how hope can be kept alive. The need exists, the vision is presented. Who is willing to take responsibility?[334]

Sources

- Alderliesten, Arthur. *Stervenskunst bij Luther*. Apeldoorn: De Banier, 2021.
- ART. "Het model." Accessed February 3, 2022. http://art-psy.nl/het-model/.
- Anthony, W.A. "Recovery from mental illness. The guiding vision of the mental health service system in the 1990s." *Psychosocial Rehabilitation Journal* (1993)16: 11-23.
- Bazan, Ariane Pond, Gertrudis van de, Lemmens, Willem. "Schrap euthanasie op basis van louter psychisch lijden uit de wet." *De Morgen*, December 8, 2015. https://www.demorgen.be/es-b277b650.
- Beel, Veerle, Renson, Ine. "'Wie zijn wij om te bepalen hoeveel een ander moet lijden?'". *De Standaard*, November 4, 2017. https://www.standaard.be/cnt/dmf20171103_03168722.
- Boer, Theo. "Euthanasie bij psychiatrische patiënten: Observaties vanuit een protestants-christelijkPerspectief." *Psyche & Geloof* 30.2 (2019): 114-124.
- Boer, Theo. "Euthanasie bij psychiatrische patiënten: de christelijke tegenstem." *Psyche & Geloof* 30.2 (2019): 132-133.
- Boer, Theo. *Eind goed. Een protestante kijk op euthanasie in Nederland*. Utrecht: KokBoekencentrum, 2021.

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[334] „Nicht der Gedanke, sondern die Verantwortungsbereitschaft ist der Ursprung der Tat." (Dietrich Bonhoeffer, Widerstand und Ergebung, DBW 8, (Gütersloh: Chr. Kaiser/Gütersloher Verlagshaus: 1998), 433).

- Bonhoeffer, Dietrich. *Widerstand und Ergebung.* DBW 8. Gütersloh: Chr. Kaiser/Gütersloher Verlagshaus: 1998.
- Brink, Bart van den. “Euthanasie in psychiatrie vraagt om christelijk antwoord.” *Reformatorisch Dagblad,* February 16, 2018. https://www.rd.nl/artikel/891006-euthanasie-in-psychiatrie-vraagt-om-christelijk-antwoord.
- Callebert, A. “De herstelvisie als antwoord op de euthanasievraag bij ondraaglijk psychisch lijden?” *Tijdschrift Klinische Psychologie*, 2014, 44(1), 35-41.
- Callebert, A. *Herstel als antwoord op euthanasie?* Leuven: Acco, 2017.
- CBO Kwaliteitsinstituut voor de gezondheidszorg. *Evidence-based Richtlijnontwikkeling voor werkgroepleden.* 2007. https://docplayer.nl/8157534-Evidence-based-richtlijnontwikkeling-handleiding-voor-werkgroepleden.html.
- CIZ. “Vertraging ggz-aanvragen.” March 9, 2021. https://www.ciz.nl/nieuws/vertraging-ggz-aanvragen.
- Decorte, I., Verfaillie, F., Moureau, L., Meynendonckx, S., Van Ballaer, K., De Geest, I., & Liégeois, A. “Oyster Care: An Innovative Palliative Approach towards SPMI Patients.” *Frontiers in Psychiatry* 11 (2020): 509. doi.org/10.3389/fpsyt.2020.00509.
- Decorte, I, Verfaillie, F., Moureau, L., Ballaer, K. van, Geest, I. de Liegeois, A. “Schelpzorg: een palliatief zorgmodel voor patiënten met een ernstige, persisterende psychiatrische aandoening. *Tijdschrift voor Geneeskunde* (2021/2): 133-140. doi:10.47671/TVG.77.20.177.
- Demedts, Dennis et al. “The attitudes, role & knowledge of mental health nurses towards euthanasia because of unbearable mental suffering in Belgium: A pilot study.” *Journal of Psychiatric and Mental Health Nursing* 25 (September 2018): 400-410. https://doi.org/10.1111/jpm.12475.
- Evenblij, Kirsten. “End-of-life care for patients suffering from a psychiatric disorder.” PhD, VU Amsterdam, 2021.
- Federatie Medisch Specialisten. *Levensbeëindiging op verzoek bij patiënten met een psychische stoornis.* (2012-2022). https://richtlijnendatabase.nl/richtlijn/levensbeeindiging_op_verzoek_psychiatrie/startpagina_-_levensbe_indiging_op_verzoek.html.
- Folia. “Euthanasie in de psychiatrie: een dubbel taboe,” Accessed February 3, 2022. https://www.folia.nl/wetenschap/148891/euthanasie-in-de-psychiatrie-een-dubbel-taboe.
- Frankl, Viktor E. *De zin van het bestaan. Een inleiding tot de logotherapie.* Rotterdam: Ad. Donker, 2020.
- Haekens, An. “ Euthanasie bij uitzichtloos psychisch lijden.” In Devos, Timothy (ed.), *Euthanasie: eenander verhaal.* Kalmthout: Pelckmans, 2021, 89-104.
- Deer M. de, Correll C.U., Bobes J, et al. “Physical illness in patients with severe mental disorders: prevalence, impact of medications and disparities in health care.” *World Psychiatry* (2011/10): 52-77.

- Höppener, Armand. "Op de bres voor kwetsbare psychiatrische patiënten. *Medisch Contact*. October 19, 2017. https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/op-de-bres-voor-kwetsbare-psychiatrische-patienten.htm#:~:text=There%20is%20a%20appropriate%20form,if%20that%20is%20of%20the%20society
- Huber, Machteld, Knottnerus, J André, Green, Lawrence, Horst, Henriëtte van der, Jadad, Alejandro R., Kromhout, Daan, Leonard, Brian, Lorig, Kate, Loureiro, Maria Isabel, Meer, Jos W M van der, Schnabel, Paul, Smith, Richard, Weel, Chris van, Smid, Henk, "How should we define health?" *BMJ*. 2011 Jul 26;343:d4163. doi: 10.1136/bmj.d4163.
- Huber, M., Vliet, M. van, Giezenberg, M. et al. "Towards a 'patient-centred' operationalisation of the new dynamic concept of health: a mixed methods study." *BMJ* 2016;5:e010091. doi:10.1136/bmjopen-2015- 010091.
- Jansen-van der Weide, M.C., Onwuteaka-Philipsen, B.D., Wal, G. van der. "Requests for euthanasia and physician-assisted suicide and the availability and application of palliative options." *Palliat Support Care* 2006;4(4):399-406. doi: 10.1017/s1478951506060494.
- Jong, Ewoud de, Schaap-Jonker, Hanneke. "Herstel georiënteerde zorg binnen de christelijke ggz." *Psyche en geloof* 2016 (4): 197-205.
- Jong, Ewoud de, Schaap-Jonker, Hanneke, Berg, Femmeke van den. "Kerk en familie hebben taak tervoorkoming van euthanasie." *Reformatorisch Dagblad*. November 18, 2016, https://www.rd.nl/artikel/686054-kerk-en-familie-hebben-taak-ter-voorkoming-van-euthanasie.
- Comb, Heidi de, Kievit, Hennie. *De helikopter van Viktor. Palliatieve zorg in de psychiatrie*. Amersfoort: GGz Centraal, 2020.
- Kammeraat, Monique, Kölling, Pieternel, *Psychiatrische patiënten bij Expertisecentrum Euthanasie. Retrospectieve dossierstudie naar de achtergronden en het verloop van euthanasieverzoeken op grond van psychiatrisch lijden bij Expertisecentrum Euthanasie. Periode 2012–2018*.The Hague: Expertisecentrum Euthanasie. https://expertisecentrumeuthanasie.nl/app/uploads/2020/02/Onderzoeksrapportage-Psychiatrische-Pati%C3%ABnten-Expertisecentrum-Euthanasie.pdf.
- Kim, S.Y.H., Vries, R.G. de Peteet, J.R. "Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014." *JAMA Psychiatry* 73 no. 4 (2016):362-368. doi:10.1001/jamapsychiatry.2015.2887.
- Klaver, A., Baart, A. "How Can Attending Physicians Be More Attentive? On Being Attentive versus Producing Attentiveness." *Med Healthcare Philosophy* (2016/19):351-359. doi: 10.1007/s11019-015-9669-y.
- Leamy, M., Bird, V., Le Boutillier, C., Williams, J., Slade, M. "Conceptual

framework for personal recovery in mental health: systematic review and narrative synthesis." *Br J Psychiatry* 2011 Dec;199(6):445-52. doi:10.1192/bjp.bp.110.083733.

- Marivoet, Dirk. "The plaats van het lijden in de psychotherapie." Bodypsychotherapy. Accessed February 5, 2021. https://www.bodypsychotherapy.info/wp-content/uploads/2017/03/ De_plaats_van_het_lijden_in_de_psychotherapie.2009.pdf
- Onwuteaka-Philipsen. Bregje, et al. *Derde evaluatie Wet toetsing levensbeëindiging op verzoek enhulp bij zelfdoding.* The Hague: ZonMw, May 2017, Regulatory Evaluation Series.
- Povedano-Jiménez, M., Ropero-Padilla, C., Rodriguez-Arrastia M., and García-Caro, M.P. "Personal and Emotional Factors of Nursing Professionals Related to Coping with End-of-Life Care: A Cross-Sectional Study. *International journal of environmental research and public health* 2021 18(18); 9515. https://doi.org/10.3390/ijerph18189515.
- Prague, H.M. van. "Zinverlies; een verwaarloosd onderwerp in de psychiatrie." *Tijdschrift voor Psychiatrie* 52 no. 10 (2010): 705-714. https://www.tijdschriftvoorpsychiatrie.nl/assets/articles/TvP10-10p705-714.pdf.
- Prouty G., Werde D. van, Pörtner, M. *Pre-Therapy: Reaching contact-impaired clients.* Ross-on-Wye: PCCS Books, 2002.
- Psychiatrisch Ziekenhuis Brugge Onze Lieve Vrouw. "Langdurige intensieve psychiatrischebehandeling (afdeling 52)." Accessed February 5, 2022. https://www.pzonzelievevrouw.be/langdurige-intensieve-psychiatrische-behandeling-afdeling-52.
- Puchalski C., Ferrell B., Virani R., Otis-Green S., Baird P., Bull J., et al. "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference." *Journal of Palliative Medicine* (2009/12): 885-904. doi: 10.1089/jpm.2009.0142.
- Reakiro. "Visie." Accessed February 3, 2022. https://reakiro.be/visie/.
- Rijke, R. de. "Crustatieve zorg: een nog ontbrekende schakel in de geestelijke gezondheidszorg." *Artsenkrant*, December 13, 2017. https://www.artsenkrant.com/actueel/crustatieve-zorg-een-nog-ontbrekende-schakel-in-de-geestelijke-gezondheidszorg/article-column- 30507.html?cookie check=1634059859.
- Stockman, René et al. *Euthanasie bij psychisch lijden. Het hellend vlak dat overslaat?* Fracarita series 9. Antwerp/Apeldoorn: Garant 2018.
- Sweers, K., Hert, M. de, Detraux, J. "Een menswaardige palliatieve zorgverlening voor patiënten meteen (ernstige) psychiatrische stoornis: utopie of noodzaak? Een systematisch literatuurstudie." *Psychiatrie en Verpleging* 87/3 (2011): 156-170.
- Tielens, *J. In gesprek met psychose: Verbindende gesprekstechniek, praktische handleiding om in verbinding te komen en blijven met psychotische mensen.*

Utrecht: De Tijdstroom, 2012.

- Trachsel et al. “Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks.” *BMC Psychiatry* (2016) 16:260. doi: 10.1186/s12888-016-0970-y.
- Veen, S.M.P. van, Weerheim, F.W., Mostert, M., Delden, J.J.M. van. “Euthanasie van Nederlandsepsychiatrische patiënten in 2015-2017. *Tijdschrift voor Psychiatrie* 61(2019)4, 241-247. https://www.tijdschriftvoorpsychiatrie.nl/nl/artikelen/article/50-11908_Euthanasie-van-Nederlandse-psychiatrische-patienten-in-2015-2017.
- Verfaillie, Françoise. „Interview met dr. Françoise Verfaillie.” In *Exit 8* no. 3 (Sept-Nov 2016): 4-6. https://www.pzonzelievevrouw.be/sites/pzolv/files/files/Afrit8NS201603.pdf.
- Vonk, Rosalie. “A dialogue on death. On mental illness and physician-assisted dying.” PhD thesis, University of Amsterdam, 2021.
- B.S. Wanrooij, Graeff A. de, Koopmans, R.T.C.M., Leget, C.J.W., Prins, J.B., Vissers, K.C.P., Vrehen H., Zuurmond, W.W.A. *Palliative care in daily practice.* Houten: Bohn Stafleu van Loghum, 2010.
- Weerd, Roeljan de: “Euthanasie in de praktijk”. Master’s thesis, Hogeschool Utrecht, 2020.
- Woltmann, Emily M, Whitley, Rob. “Shared decision making in public mental health care: Perspectives from consumers living with severe mental illness.” *Psychiatric Rehabilitation Journal*, 34(1), 2010: 29-36. https://doi.org/10.2975/34.1.2010.29.36.

7. Euthanasia and dementia

Arthur Alderliesten

More and more people are requesting euthanasia because of (advanced) dementia. Living with dementia can be understood as a very distressing experience: the individuals involved enter a very uncertain, unpredictable period of life and a dreaded future they are trying to control through euthanasia.[335]

Dementia also turns out to be a fear for many healthy people and a reason many make a living will. Ever since the introduction of the euthanasia law (2002), physicians have struggled with the dilemma of how to deal with written euthanasia declarations from people with severe dementia. Most physicians are reluctant to end the life of someone with whom they can no longer communicate, but the first euthanasia executions are a reality. Developments following the so-called 'coffee euthanasia' from which a broadening of the due care criteria followed, are, understandably, causing social unrest. It is therefore important to carefully, and thusrather comprehensively, address this issue.

The first section considers the functioning of the living will in dementia. Both in the debate and in euthanasia practice, (complying with) a number of due care criteria play a crucial role. These criteria are discussed in section 7.2. Section 7.3 shows how the spectre of dementia translates into wider perceptions. Section 7.4 deals with the 'coffee euthanasia' case, which has put the subject of euthanasia and dementia on edge of people's minds and on the social agenda. The question arises of whether there is a trend of normalising euthanasia. This question is discussed in the fifth section of this chapter. Section 7.6 discusses the increasing role of the family in caring for a person with dementia, an obvious aspect in care for these people. An overview of ongoing relevant research is included in section 7.7. Ethical perspectives on previous findings are given in section 7.8.

7.1 Living will and dementia

A euthanasia declaration is a specific form of a will in which a person states the circumstances under which he/she wants a physician to end his/her life. The status of living wills is not always clear, as evidenced by the existence of positive and

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[335] E. van Wijngaarden, M. Alma, A-M The, "'The eyes of others' are what really matters: The experience of living with dementia from an insider perspective," PLoS ONE 14(4), 2019: e0214724, https://doi.org/10.1371/journal.pone.0214724.

negative declarations.

Euthanasia declarations are sometimes called ‘positive’ wills, while declarations in which a patient states which medical treatment he no longer wants to undergo, are called ‘negative’ wills. ‘Negative’ living wills are in principle binding: a physician may ignore a ‘negative’ living will only on the basis of well-founded reasons. Euthanasia declarations are ´positive’ wills, which are not binding. A physician is never personally obliged to carry out a euthanasia request expressed in a written will, as it is not a normal medical act.[336] Moreover, the physician is always allowed to make his own assessment based on normative and professional arguments.[337]

At the request of the Minister of Health, Welfare and Sport (VWS), a working group of the Ministry of Security and Justice, the physicians’ federation KNMG and the Ministry of Health, Welfare and Sport published a guide in 2016. This was prompted by the lack of clarity in society about the possibilities of euthanasia in cases of dementia. This *Guide to Written Euthanasia Requests* states the following: “Patients with advanced dementia sometimes give the impression of not suffering unbearably from the dementia. However, it may be clear that a patient with advanced dementia is suffering unbearably from additional conditions, such as severe shortness of breath or pain, but anxiety, aggression or agitation may also contribute to unbearable suffering. In these cases, a physician may perform euthanasia, even if a patient can no longer make this clear by word or gesture. However, this requires a written euthanasia request, previously drawn up by the patient. This has happened a few times so far in the Netherlands. If a physician can no longer check with a patient whether the wish for euthanasia still exists at that time, there is a high chance that the physician will not carry out the euthanasia. That is why it is important for people to have regular discussions with their physician about their wishes at the end of life and about how their physician thinks about euthanasia in situations where someone can no longer clearly express their will.”[338]

7.1.1 How elderly people think about a living will in the case of dementia

Not infrequently, (the fear of) dementia plays a role in the drafting of a will. For example, the 2013 ZEMBLA/ANBO survey of over 10,000 elderly people found

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[336] Euthanasia is reserved for a physician and in that sense does qualify as ‘medical’.

[337] C.P.M. Akerboom, J.C.J. Dute, J.K.M. Gevers, et al, Thematische Wetsevaluatie. Wilsonbekwaamheid en vertegenwoordiging, (The Hague: ZonMw, August 2011).

[338] Central Government of the Netherlands, Handreiking schriftelijk euthanasieverzoek, (2016), 7, www.rijksoverheid.nl/documenten/brochures/2015/12/17/handreiking-schriftelijk-euthanasieverzoek-publieksversie.

that fear of the diagnosis of dementia was a reason for 52% of the respondents with a euthanasia declaration, to draw up a will. For 73%, dementia would be a reason to ask the physician for euthanasia. The main reasons were loss of grip on thinking and acting (53%), becoming incontinent/responsive/aggressive (13%), not recognising loved ones anymore (13%), or having to go to a nursing home (10%).[339]

What do respondents to this survey think about performing euthanasia? Many expect the euthanasia declaration to be implemented: 91% of respondents thought that a physician should implement a written euthanasia declaration from a patient with dementia if the patient is no longer able to repeat his or her wishes; 46% assumed that a physician would implement a self-prepared written euthanasia declaration. Regarding the legal status of a euthanasia statement, 13% thought that euthanasia is a patient's right, 6% that the physician must cooperate, 55% that the physician does not have to cooperate, and 26% did not know.

7.1.2 How the profession feels about living wills in cases of dementia

A literature review from 2014[340] showed that most physicians have dealt with patients with a euthanasia declaration should they become demented or incompetent. The physicians were predominantly sympathetic to the wish to end life and believed that advanced dementia could sometimes result in unbearable suffering. They rarely proceeded to euthanasia in the studies consulted until 2014. This was partly because they were not convinced of unbearable suffering, and partly because they felt it was necessary for the patient himself to confirm that he perceived the suffering as unbearable.

As for nurses and carers, it appears that they do not always agree with physicians not following the euthanasia declaration of a patient with dementia.[341]

In her 2011 PhD thesis M.E. de Boer showed that written euthanasia declarations are still rarely followed by geriatric specialists working in nursing homes, and

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[339] Quoted in Agnes van der Heide, Eric Geijteman, Judith Rietjes, Schriftelijk vastgelegd euthanasiewensen van wilsonbekwame patiënten. Een literatuuroverzicht van opvattingen, praktische ervaringen en knelpunten, (Rotterdam: Erasmus MC, Department of Social Healthcare, October 2014), 12.

[340] Van der Heide, Schriftelijk vastgelegd euthanasiewensen, 18.

[341] J.J.M. van Delden, A. van der Heide, S. van de Vathorst, H. Weyers, D.G. van Tol, Kennis en opvattingen van publiek en professionals over medische besluitvorming en behandeling rond het einde van het leven. Het KOPPEL-onderzoek. , (The Hague: ZonMw, 2011). Possibly, reluctance among physicians is greater than among nurses because the physician has final responsibility and can also be sued.

never when a patient is struggling with advanced dementia. “The crucial role in non-compliance with written euthanasia declarations of patients with advanced dementia seems to lie in the fact that the patient’s current desire and the possibility of communicating it are leading factors in the consideration made by specialists in geriatrics to proceed to life-ending action.”[342]

7.1.3 Who is who?

A broad spectrum of views on the meaning of euthanasia declarations of incompetent patients can be found in the international ethics literature.[343] At one end of that spectrum is the view that a euthanasia declaration of a person who has become incompetent cannot be acted upon because the incompetent person is no longer the same person as the one who made the declaration in the person’s will. This view is taken by Parfit (1984).[344] The former person should not make decisions about the current person, especially if it is a far-reaching decision where the current person cannot indicate whether he still stands by his will.

At the other end of the spectrum is the view that the will of a person who is capable of a reasonable appreciation of his interests should also extend to the period in that same person’s life in which he has become incompetent. This view is taken by Dworkin (1986).[345] According to this view, the previously expressed will fits the life, interests and values of the person in question and therefore has more weight (‘critical interest’) than the fact that the current person can no longer indicate whether he still stands behind that expression of will. Some have a nuanced view, arguing that expressions in a will are by no means always well-considered and thought-out. A euthanasia declaration would therefore carry more weight if it were clearly worded and based on good information. Incidentally, some say it is difficult, if not impossible, to determine in advance the circumstances under which life would no longer be liveable once the capacity to consent has been lost.[346] In addition, a request for euthanasia by an incompetent person should only be followed if it does not harm the interests of the current person (‘experi-

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[342] M.E. de Boer, “Advance directives in dementia care: perspectives of people with Alzheimer’s disease, elderly care physicians and relatives” (PhD thesis, Vrije Universiteit Amsterdam, 2011), 165.

[343] Van der Heide, Schriftelijk vastgelegde euthanasiewensen, 5, 6.

[344] D. Parfit, Reasons and Persons, (New York: Oxford University Press, 1984).

[345] R. Dworkin, “Autonomy and the demented self,” The Milbank Quarterly 64, suppl. 2, (1986): 4-16.

[346] R.S. Dresser, J.A. Robertson, “Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach,” Law, Medicine and Health Care 17, no. 3 (1989): 234-244, doi:10.1111/j.1748-720X.1989.tb01101.x.

ential interest').[347] If a person with dementia still seems to take some pleasure in life, termination of life would not be an acceptable act. This is elaborated below in the discussion on the legal requirements of care.

7.2 Due care criteria

The debate on euthanasia and dementia, especially advanced dementia, revolves around the interpretation of the due care criteria/requirements of the Euthanasia Act. It should be emphasised that at the time the law was drafted, situations with dementia were not considered.

The due care requirements in people with and without dementia are the same. When it comes to euthanasia for people with dementia, three-of-six due care requirements are much debated:
1. The physician was convinced that there was a voluntary and deliberate request by the patient;
2. The physician was convinced that the patient's suffering was hopeless and unbearable;
3. The physician has come to the conclusion with the patient that there is no reasonable other solution for the situation of the patient.

7.2.1 The first due diligence requirement: the request

An important point of discussion concerns the question of whether a previously written euthanasia request should be confirmed by the patient at the time when the decision was made and when euthanasia was performed. The Euthanasia Act states that the patient's request may consist of a recent oral request but can also consist of a written declaration of will by a patient who is no longer capable of oral communication if this declaration was drawn up at a time when the patient was competent. The law does not specify that the patient should be able to repeat this written wish at the time when their life would be terminated.[348] On this ba-

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[347] A. Jaworska, "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value," Philosophy and Public Affairs 28 (1999): 105-138, doi.org/10.1111/j.1088-4963.1999.00105.x.

[348] The Euthanasia Code, a guideline that describes physicians should act with due care when performing euthanasia, does say the following about the performance of euthanasia and the living will: "Art. 2(2) WTL stipulates that a patient aged 16 years or older, who is capable of exercising his or her will, may draw up a written statement in which he or she requests euthanasia (hereinafter referred to as: written will). If the situation subsequently arises that the patient can no longer express his will (e.g. as a result of advanced dementia, aphasia, reduced consciousness or palliative sedation), the physician may interpret the written will as the request as referred to in section 2(1) under a WTL. This gives the written will the same status as a verbal request for euthanasia.

The law does not require that a written will, once drafted, has a certain period of validity or must be updated at regular intervals. However, the older the will is, the more doubt there is as to whether sis, Chabot argues that the practice of euthanasia is out of control "because the legal requirements met by physicians in physically ill citizens have been declared applicable, without limitation, to vulnerable patients with incurable neurological diseases (...) In dementia cases, such a limitation disappeared by equating the written will with a current oral request."[349]

In addition to the problem of the timing of the desire to terminate life, many believe it is difficult, if not impossible, to determine in advance the circumstances under which one would want to see one's own life ended. Keizer believes, for example, that "there has never been anyone who has been able to draw up a will in which a stage of suffering from advanced dementia was described in such a way that one could later unambiguously conclude from it: this is what she meant and now her life must be ended."[350] According to Wijsbek, this is indeed possible, and he cites the case of the patient with advanced Alzheimer's assessed by the review committees as an example.[351] Hertogh agrees with Keizer. He points out, for example, that patients often adapt to their changing situation and often do not seem to suffer from their dementia in the way they expected beforehand.[352] Van Delden believes that even a repeated conditional written euthanasia request ("when I become demented, I want euthanasia") is very different from a repeated unconditional topical request ("I want euthanasia now because I am suffering un-

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it still reflects what the patient really wanted. In cases where the patient has updated the living will, or verbally reaffirmed its contents after it was drafted, more value can be attached to the will than when this is not the case. It is important that the patient describes as much as possible the concrete circumstances in which he wants the termination of life to be carried out. It is the patient's responsibility to discuss the living will with the physician at the time of drafting and updating it. The physician should include this information in the record. A personally drafted statement by the patient, giving a description in the patient's own words, usually has more meaning than a pre-printed form." (Regionale Toetsingscommissies Euthanasie, EuthanasieCode. De toetsingspraktijk toegelicht. Aangepast naar aanleiding van de arresten van de Hoge Raad van 21 april, (April 2018), 38, www.euthanasiecommissie.nl/uitspraken/brochures/brochures/euthanasiecode/2018/euthanasiecode-2018-herziene-versie-2020.) The section on euthanasia in 'later stage dementia' in an earlier version of the Euthanasia Code has disappeared in the latest one.

[349] Boudewijn Chabot, De weg kwijt. De zorgelijke staat van de euthanasiewet, (Amsterdam: Nijgh & Van Ditmar: 2017), 45.

[350] A.A. Keizer, "Euthanasie bij gevorderde dementie: een morele onmogelijkheid," Nederlands Tijdschrift voor Geneeskunde 157 (2013): A6407, https://www.ntvg.nl/artikelen/euthanasie-bij-gevorderde-dementie-een-morele-onmogelijkheid.

[351] H. Wijsbek, "Euthanasie bij gevorderde dementie. Wilsverklaring is wel nuttig," Nederlands Tijdschrift voor Geneeskunde 157 (2013): A6440, https://www.ntvg.nl/artikelen/euthanasie-bij-gevorderde-dementie-wilsverklaring-wel-nuttig.

[352] C.M.P.M. Hertogh, "The role of advance euthanasia directives as an aid to communication and shared decision-making in dementia," Journal of Medical Ethics 35 (2009): 100-103, dx.doi.org/10.1136/jme.2007.024109.

bearably “). People change and can adapt to new situations. Van Delden feels that the law’s provision regarding a written euthanasia declaration relies too heavily on the principle of respecting the patient’s wishes and does not adequately take into account the principle of compassion, a key pillar of the euthanasia law. Based on the principle of compassion, the physician must always make his own judgement on the patient’s wish, and this cannot be done soley on the basis of a written statement.[353]

It is good to guard against the situation in which “the living will becomes a substitute for the independent requirement of unbearable suffering. Indeed, the latter requirement refers to suffering that is more objectively ascertainable and not suffering that reveals itself through a will, a subjective representation of a daunting prospect.”[354]

Tim van Iersel, spiritual caregiver and ethicist, characterises the ethical conflict at play here as a conflict between “past autonomy” and “today’s autonomy”. “In weighing up dilemmas in dementia around past autonomy, it is important to give the most weight to the individual’s autonomy at the moment. That means letting the current wishes of the person with dementia be guidigng as much as possible, even if those wishes clash with past lifestyle or choices. A limit is reached when the patient puts themselves or others at risk, or infringes upon the dignity of others.”[355] For Van Iersel, current autonomy becomes the decisive factor, and human dignity (see the following) and due care requirements are not sufficiently being taken into account.

People who only know the current person with dementia and not the person before the onset of dementia, such as caregivers in the nursing home, tend to take the present condition of the patient as a starting point. Perhaps this is the only person they know; whereas family, and GPs sometimes also, take into account the image of the past.

7.2.2 Dementia and autonomy

To what extent can a request for euthanasia be seen as an independent decision, a decision based on adequate arguments/knowledge and a reasonable deliberation process? Declining competence in dementia stands in the way of an autonomous

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[353] J.J.M. van Delden, “The unfeasibility of requests for euthanasia in advance directives,” Journal of Medical Ethics 30 (2004): 447-452, dx.doi.org/10.1136/jme.2002.002857.

[354] E.F. Kamphorst-Helsloot, H. Jochemsen, “Euthanasie bij dementerende mensen?” Tijdschrift voor Gezondheidszorg en Ethiek 15, no. 2 (2005): 49-53.

[355] Tim van Iersel, Dilemma’s bij dementie, (Bohn Stafleu Van Loghum: Houten, 2019), Nursing-dementia series, 14.

request, gradually requiring people other than the patient to make more and more decisions for the patient.

In principle, as many decisions as possible are left to patients, even if they have dementia. This respects their autonomy. But once patients can no longer make decisions on their own, others will have to decide for them.[356] Whether the situation is unacceptable can only be determined indirectly, argues the Committee on Acceptability of End-of-Life Treatment. This is done either through a request that must be taken very seriously, or through a third-party with appreciation of the situation. In the latter case, there must be disenchantment and loss of human dignity. Because the patient himself is no longer able to exercise his will, at this point the judgement on life termination shifts to bystanders: physicians and family. When dementia has progressed, ultimately the attending physician, possibly together with someone acting on behalf of the patient, determines when the patient's situation is such that his or her euthanasia declaration will be carried out. "The actual decision about the patient's death is thus in the hands of someone else," Kamphorst-Helsloot and Jochemsen write.[357]

Kamphorst-Helsloot and Jochemsen describe that suffering from the *prospect* of dementia provides a second perspective on dementia.[358] "When people suffer from the prospect of becoming demented, we are dealing with two perspectives on dementia. On the one hand, those people are spectators of the dementia: people suffer what others are going through. On the other hand, they put themselves in the demented person's shoes and because of this, they suffer as if they were demented. People thus want to imagine what it is like to live in the incompetent state of dementia, but do not yet live in that state and do not want to enter it. However, one cannot be both the demented person and the observer. These perspectives do not exist at the same time and therefore cannot be taken at the same time. Especially for the spectator, dementia means suffering. For yet another reason, autonomous decisions about life termination before some degree of dementia manifests itself is problematic, to say the least. We could understand the process of decision-making as follows. The starting point of autonomous decision-making is the freedom to choose something. The setting of the choice to be made has an if-then relationship. So, if my dementia is at that stage, then I want euthanasia. But free, autonomous choice is not a matter of 'would want'.

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[356] Commissie Aanvaardbaarheid Levensbeëindigend handelen (KNMG), Medisch handelen rond het levenseinde bij wilsonbekwame patiënten, (Houten/Diegem: Bohn Stafleu Van Loghum, 1997), 118-119.

[357] Kamphorst, "Euthanasie bij dementerende mensen?" 49-53.

[358] Kamphorst, "Euthanasie bij dementerende mensen?" 49-53.

Freedom takes place in present circumstances and implies adequate knowledge to base a choice. A second aspect of this is that we cannot say much about ourselves in future situations that are still far away from us. We do not know what it will be like to be in a hypothetical future situation, let alone what we would decide about it. To assume that the decision can already be made is an overestimation of the human capacity to choose freely."[359]

A similar line of thought can be found with philosopher Paul van Tongeren who, in considering the themes of autonomy and completed life, wonders whether you can want to die if you cannot imagine it. "By closing my eyes, I can still experience something of what it means to be unable to see as a blind person. The same goes for the other senses. But then always I am still there as the one who experiences not being able to do something. But how can I imagine that 'I' is no longer there? And if it can't be, how can I want it to be?"[360]

Theo Boer points out that signing a living will is seen by some as an act of ultimate autonomy, but such a declaration actually does the opposite. You give physicians and bystanders the key to being allowed to kill you.[361] Boer does not hesitate to write: "what some will see as the ultimate tribute to the woman she used to be, I see mainly as a deep contempt for the woman she is now."[362] The highly-stated right to self-determination has here, by putting the decision in the hands of the other, degenerated into sham autonomy.

Moreover, the more the drum is beaten that severe dementia is unbearable suffering, the more readily the family thinks that lethal injection is not only the only possible solution, but also the best solution. This no longer has anything to do with *self-determination*.[363]
M.E. de Boer conducted interviews among twenty-four elderly people living at home with early stages of Alzheimer's disease and asked how these people think about the future. De Boer's research revealed that the participants interviewed live day to day and tend to leave planning for the future to others. Thinking about the future and planning for future care was of little or no concern to these participants. For planning for future care (Advance Care Planning), they depend

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[359] Kamphorst, " Euthanasie bij dementerende mensen?" 49-53.

[360] Paul van Tongeren, Willen sterven. Over de autonomie en het voltooide leven, (Utrecht: Kok, 2018), 42.

[361] Theo Boer, "Waarom de "koffie-euthanasie" weinig met patiëntenautonomie te maken heeft. Een ethisch commentaar op de uitspraak van de Hoge Raad," Radix 46, no. 3 (2020): 234.

[362] Boer, " De 'koffie-euthanasie'," 235.

[363] Chabot, De weg kwijt, 52.

on interventions by others.[364] This is also the conclusion of Sascha R. Bolt in her 2021 PhD study. She therefore “stresses the importance of an inclusive society, in which we facilitate people with dementia to fulfil a basic human need. Namely to live a meaningful life and to feel seen, involved and valued as a human being until the end of life.”[365]

7.2.3 Second and fourth due care criterion: unbearable suffering without prospect and reasonable alternatives

A major point of discussion in the debate on the meaning of a euthanasia declaration by patients with dementia relates to unbearable suffering without the prospect of relief and without reasonable alternatives. Section 2(2) of the Euthanasia Act states that in the case of a written euthanasia request by an incompetent person, the requirements of care ‘shall apply accordingly’. The key questions, then, are whether and how a physician can arrive at the determination of unbearable suffering without the prospect of relife. And whether and how the physician can establish with the patient that there is no reasonable solution for the patient’s situation.

Can you establish unbearable suffering without the prospect of relief in the current situation of an incompetent patient? According to Keizer[366] and Wijsbek[367] , it is possible to establish that a cognitively impaired patient with dementia is suffering unbearably based on facial expression, body language and behaviour.

Others, such as Hertogh[368] and Van Delden,[369] counter that unbearable suffering cannot be established when the physician cannot communicate with the patient. They believe that having dementia in and of itself does not qualify as a form of unbearable suffering, due to the lack of insight into the disease and lack of the conscious experience of being ill. When a patient cannot confirm that the situation he feared when he made the euthanasia declaration corresponds to the current situation, ‘unbearable suffering’ cannot be established in that patient. In 2003, the KNMG also pronounced that establishing that the patient was expe-

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[364] De Boer, “Advance directives,” 161.

[365] Sascha R. Bolt, “The fundamentals of a DEDICATED palliative approach to care for people with dementia,” (Thesis, Maastricht University, 2021), 187-188. https://www.awolimburg.nl/userfiles/files/proefschriften/proefschrift-dedicated-palliatieve-zorg-bij-mensen-met-dementie_sascha-bolt.pdf.

[366] A.A. Keizer, “Euthanasie bij gevorderde dementie: een morele onmogelijkheid, “157.

[367] H. Wijsbek, “ Euthanasie bij gevorderde dementie. Wilsverklaring is wel nuttig,” 157.

[368] Hertogh, “The role of advance euthanasia,” 100-103.

[369] Van Delden, “The unfeasibility of requests for euthanasia,” 447-452.

riencing intolerable suffering and also the absence of any alternatives in such a situation is almost impossible.[370] Nevertheless, attempts are being made to include dementia in the legal frameworks. One option put forward by the KNMG[371] is to accept that the *prospect* of increasing dementia can be seen as unbearable suffering without the prospect of relief within the meaning of the Life Termination Review Act, as has been similarly applied to Huntington's disease or AIDS. Kamphorst-Helsloot and Jochemsen point out that it has not been established whether the person concerned is actually suffering, which is the case with the aforementioned diseases. "Even in early dementia, it is not the dementia itself that is the cause of hopeless and unbearable suffering, but is assessed based on suffering evoked by the prospect of the future."[372]

To what extent does a person with dementia suffer unbearably? Based on her literature review, De Boer argues that there is no unequivocal answer to the question of whether dementia necessarily leads to a situation of severe suffering. It clearly emerges that the impact of dementia on daily life is great and is accompanied by various experiential losses. At the same time, De Boer sees evidence that people with dementia do not passively undergo their illness, but are constantly coping and adapting to the changing situation. Regarding the aspect of 'suffering' in dementia, the stories of people with dementia seem to give a more nuanced picture than the assumptions made by the general public.[373] Importantly, additional qualitative research reveals that the gradual deterioration that characterises Alzheimer's disease also allows room for adaptation. As a result, current perceptions of the disease may differ favourably from patients' perceptions of the disease in the past. Such differences are important in the discussion of living wills and highlight the importance of letting people with dementia have their own say.[374]

7.3 Imaging dementia

The concepts of human dignity and suffering are decisive in dealing with dementia. This can be seen, for example, in the different reactions of the Health Council and the KNMG at the beginning of this century to a court case dismissed by the

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[370] KNMG, Een nadere uitleg van het standpunt Euthanasie, (2003), https://www.knmg.nl/actualiteit-opinie/nieuws/nieuwsbericht/nieuw-knmg-standpunt-geeft-houvast-bij-euthanasie-bij-dementie#:~:text=De%20KNMG%20vindt%20het%20belangrijk,de%20wet%20die%20ruimte%20wel.

[371] KNMG, Knelpunten bij levensbeëindiging, (2004), 16.

[372] Kamphorst, "Euthanasie bij dementerende mensen?" 49-53.

[373] De Boer, «Advance directives,» 28-42.

[374] De Boer, «Advance directives,» 60,61. See also Bolt, "DEDICATED palliative approach."

Board of Procurators General in which a GP provided assisted suicide to a man suffering from the prospect of dementia.

The KNMG believes that physicians and bystanders should at least recognise that there is pronounced loss of disenchantment. The loss of experience of dignity stems from the consequences of severe dementia. After all, there may be incontinence and bedriddenness. Patients no longer recognise their own partner and children, there are often sleep disturbances, and so on. [375]
The Health Council, on the other hand, takes a different approach to dementia. Society's perception of a disease determines the way people with the disease are treated as well as a person's attitude towards any future situation in which they themselves have the disease. "Demented people are less than others", "dementia is humiliating" and "the nursing home is the worst outcome for people with dementia". People with dementia are no less human and deserve the best possible care. Substandard care in institutions sensitises a large public to the view that nursing home admission is humiliating and should be avoided.[376] The KNMG calls dementia "contrary to human dignity". The Health Council says: "people with dementia are no less". The difference of opinion seems to boil down to different conceptions of human dignity. On the one hand, one can, as the KNMG apparently does, base human dignity on certain characteristics people have, such as a certain capacity voluntary actionor continuity of personal character traits. Such characteristics do indeed disappear with dementia. Human dignity is then primarily the perceived dignity of a person based on existing abilities, with cognition being highly valued.[377] As a result of this, there is a collective fear of dementia "spreading like a contagious disease."[378]

It is clear from the above that human dignity is mostly seen in society as a *perceived characteristic* of human life. This opinion is partly fuelled by the high value placed on health. At the same time, with the increase in medical-technical possibilities to reduce pain and suffering, it is becoming increasingly difficult to deal with the loss of health. A 'degraded' life is no longer worth living, brining into sight the idea of terminating life. Kamphorst-Helsloot and Jochemsen point to another approach: the approach underlying our rule of law. For instance, Article 1 of the Charter of Fundamental Rights of the European Union, signed by member states on 7 December 2000 in Nice, reads: "Human dignity is inviolable. It must

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[375] Commissie Aanvaardbaarheid Levensbeëindigend handelen (KNMG), Medisch handelen rond het levenseinde bij wilsonbekwame patiënten, 134.

[376] Gezondheidsraad, Dementie, (The Hague: Gezondheidsraad, 2002), 20.

[377] Kamphorst, " Euthanasie bij dementerende mensen? " 49-53.

[378] Chabot, De weg kwijt, 25.

be respected and protected."[379] It has been stated within the Council of Europe that the right to self-determination has its roots in human dignity.[380] The legal principle of human dignity is more fundamental than self-determination. In relation to euthanasia and dementia, this could mean that the right to self-determination could be curtailed when there are other options for care.[381]

7.4 The 'coffee euthanasia'

A much-discussed case study in euthanasia and dementia is what has come to be called 'the coffee euthanasia'. The ethical dilemmas mentioned above come up in a salient way in this case. A 74-year-old patient with dementia stated in her living will that she wanted euthanasia should she end up in a nursing home and it is deemed the appropriate time for euthanasia. When she did indeed end up in a nursing home, she wasincompetent and gave varying indicators: most of the time she did not want to live, but sometimes she enjoyed her life. The physician judged that her suffering was unbearable enough for euthanasia. Because she sometimes reacted violently to touch, the physician placed a sedative in her coffee prior to euthanasia. However, the woman awoke at the moment the euthanasia was about to take place and physically resisted. Nevertheless, the physician carried out the euthanasia.

The Hague court and later the Supreme Court held that the physician had acted correctly by taking this patient's declaration of will as a guide and no longer relied on her ambiguous expressions from the onset of her advanced dementia.

Theo Boer weighs the statement from an ethical perspective:
"With its ruling in the 'coffee euthanasia' case, the Supreme Court made history: a first judgment on a euthanasia case under the Act on the Assessment of Termination of Life on Request and Assisted Suicide (Wtl). This decision goes beyond the confines of the review committees but is not a judgment that provides clarity: where the Brongersma judgment closed a door, this judgment unlocks one. Al-

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[379] Europees Parlement, Charter of fundamental rights of the European Union, (2000/C 364/01) signed on December 7, 2000 in Nice by the Member States of the EU, www.europarl.europa.eu/charter/pdf/text_en.pdf.

[380] M.A.J.M. Buijsen, "De keuze voor een geen bezwaarsysteem: een kwestie van principe," Pro Vita Humana 11, nr. 1 (2004): 3, https://provita.nl/nieuws/publicaties_nieuw/de-keuze-voor-een-geen-bezwaarsysteem-een-kwestie-van-principe/; M. de Blois, "Persoonlijke autonomie en de heiligheid van het leven," Pro Vita Humana 9, nr. 6 (2002): 137, https://provita.nl/nieuws/publicaties_nieuw/persoonlijke-autonomie-en-de-heiligheid-van-het-leven/.

[381] H. Jochemsen, G. Glas, Verantwoord handelen. Proeve van een christelijke medische ethiek, (Amsterdam: Buijten & Schipperheijn, 1997), Accountability Series No 13, 85.

though proponents of acquittal speak of a victory for the autonomy of the patient with dementia, she has in fact surrendered her autonomy to others: her 'former self', interpreted by physicians and family members. Autonomous euthanasia in dementia, ethically speaking, calls for an earlier moment in life of the patient. With this verdict, *mercy killing* also comes back into view."[382]

We outline the importance of this case in six points:

1. Never before has there been a judicial review since the existence of the Euthanasia Act in 2002;
2. On a positive note, Theo Boer points out that the Supreme Court did not give a general ruling that wills always prevail. However, the living will of someone who is no longer capable of giving his or her consent takes precedence over someone's current expressed will. But apart from that request, there must also be unbearable suffering;[383]
3. That the written statement can take precedence over confused indicators from an incompetent patient leads to new questions: how clear should the person's intentions be? Where is the line to consider someone's current expressed will? Boer warns that the Supreme Court ruling opens the door to an unknown practice;[384]
4. Boer points to four limits to autonomy, as the Supreme Court placed high stakes on autonomy in its judgment:
    a. For a major and irreversible decision, the patient must have a sufficient degree of competence;
    b. Autonomous decisions must be compatible with similar freedoms in others;
    c. Freedoms are sometimes curtailed because, when things go wrong, society obliges itself to pick up the pieces;
    d. In many cases, especially in healthcare, autonomy is a freedom right, but not a positive claim right. The rights of an autonomous person are primarily rights of non-interference. The question is whether this right to non-interference also implies that the physician should be expected to actively cooperate with the request to termainate life. Ton Vink and Boudewijn Chabot, therefore, argue that an autonomous decision to stop living should be carried out as much as possible by the person himself. Theo Boer accuses the Supreme Court of ignoring this aspect.
5. The highest court has stated unequivocally that it is up to the physician to

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[382] Boer, "De 'koffie-euthanasie'," 229.

[383] Boer, "De 'koffie-euthanasie'," 230, 231.

[384] Boer, "De 'koffie-euthanasie'," 231.

interpret a written will, where in order to assess the intentions ofthe drafter, not only the wording matters;[385]

6. The Supreme Court has said that in assessing whether the medical actions of the physician conducting euthanasiawere in agreement with the due care criteria, the insights and standards of medical professionals should apply. This sent a signal to the criminal court to exercise restraint and to the public prosecutor not to pursue criminal proceedings lightly. Buijssen points out that it is curious that this Supreme Court's statement was also presented to the disciplinary judge. After all, medical disciplinary judges do not punish but make rulings on the quality of the actions of individual members of the profession. In doing so, their own professional standards are used as the yardstick that is measured by a judge ruling on behalf of the profession. The physicians in question were thus told that they should have applied their own standards more broadly.[386]

7.4.1 Amended euthanasia code RTE

In line with the Supreme Court ruling on the 'coffee euthanasia' discussed above, the RTE updated its Euthanasia Code in November 2020.[387] This code sets out when physicians act with due care in euthanasia.[388] There are four salient changes[389] :

1. The written will underlying the euthanasia granted must be interpreted with a view to ascertaining the patient's intention. In doing so, the physician must pay attention to all the circumstances of the case and not just to the literal wording of the written will. Indeed, a written will no longer has to be legally

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[385] Martin Buijssen, "Van overeenkomstige toepassing Over levensbeëindiging op verzoek bij gevorderde dementie," in Radix 46, no. 3 (2020), 226.

[386] Buijssen, ""Van overeenkomstige toepassing…," 226.

[387] Eva Nyst, "RTE brengt EuthanasieCode in lijn met arrest Hoge Raad," Medisch Contact, accessed July 26, 2021, www.medischcontact.nl/nieuws/laatste-nieuws/nieuwsartikel/rte-brengt-euthanasiecode-in-lijn-met-arrest-hoge-raad-.htm.

The RTE: Regional Euthanasia Review Committee, see p 27.

[388] Regionale Toetsingscommissies Euthanasie, EuthanasieCode. De toetsingspraktijk toegelicht. Aangepast naar aanleiding van de arresten van de Hoge Raad van 21 april 2020 (April 2018), www.euthanasiecommissie.nl/uitspraken/brochures/brochures/euthanasiecode/2018/euthanasie-code-2018-herziene-versie-2020.

[389] Regionale Toetsingscommissies Euthanasie, "Aanpassing EuthanasieCode 2018 en oordeel euthanasie bij vergevorderde dementie na arrest Hoge Raad," accessed January 8, 2022, https://www.euthanasiecommissie.nl/actueel/nieuws/2020/11/20/aanpassing-euthanasiecode-2018-en-oordeel-euthanasie-bij-vergevorderde-dementie-na-arrest-hoge-raad; Diederik van Dijk en Yvonne Geuze, "Makkelijker euthanasie bij diep demente patiënten. Het hellend vlak wordt werkelijkheid," Nederlands Dagblad, November 27, 2020, https://www.nd.nl/opinie/opinie/1005280/makkelijker-euthanasie-bij-diep-demente-patienten-het-hellend-v#closemodal.

binding, giving a physician more room to interpret it.
This increases the chances of misinterpretation and even abuse. Already, physicians must deal with the influence of family around euthanasia (see below). Here the question of patient autonomy, discussed above, comes into play.

2. Determining whether there was in fact unbearable suffering without prospect of relief in the case of progressive dementia is a medico-professional judgement reserved for the physician. The RTE must therefore review that medical-professional judgement with restraint and ask itself whether the physician could reasonably come to the conclusion that the suffering was unbearable.
3. When granting euthanasia to a patient who is incompetent due to advancing dementia, it is not necessary for the physician to consult with the patient about when and how the euthanasia will be performed. Such a conversation is pointless because the patient lacks understanding on these issues.
4. If there is evidence that while performing euthanasia the incompetent patient will become agitated or aggresive, the observed medical standards may lead the physician may to conclusde that premedication is desirable.

In July 2021, it was revealed that the Public Prosecution believes the RTE misinterpreted the ruling in their euthanasia code, resulting in more patients qualifying for euthanasia than legally permitted.[390] The public prosecutor's office, supported by the physicians' organisation KNMG, believes it is not in line with the law to state that in the case of an unclear written will, the verdict is primarily up to the physician. The RTE and the public prosecutor's office discussed the euthanasia code, and it was revised in 2021.[391]

On 1 December, as a partial outcome of the Euthanasia for Dementia project, the KNMG came forward with an updated position paper entitled *KNMG position paper: End-of-life decisions*. In it, KNMG formulates the position of euthanasia for dementia as follows: "The KNMG's view is that the life of a person with advanced dementia is worthy of protection, regardless of what the patient has previously written about it. The actual wishes, interests and preferences of a person with advanced dementia deserve to be respected. That said, the previous written eu-

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[390] Marten van de Wier, "Conflict tussen OM en euthanasiecommissies: wie bepaalt de regels?", Trouw, July 20, 2021, www.trouw.nl/verdieping/conflict-tussen-om-en-euthanasiecommissies-wie-bepaalt-de-regels~b9961199/.

[391] Simone Paauw, "Ondanks verschillen van inzicht is nieuwe EuthanasieCode nu klaar", Medisch Contact 6 juli 2022 https://www.medischcontact.nl/actueel/laatste-nieuws/nieuwsartikel/ondanks-verschillen-van-inzicht-is-nieuwe-euthanasiecode-nu-klaar. See also https://english.euthanasiecommissie.nl/the-committees/euthanasia-code-2022

thanasia request can be respected in exceptional situations. This, then, is only justified if the performance of the euthanasia corresponds to the earlier written euthanasia request and if there are no contraindications for this (such as clear signs that the patient no longer wants euthanasia). In addition, there must be actual intolerable suffering of the patient. If there is doubt in a legally incompetent patient with advanced dementia as to whether one or more of the due care criteria for euthanasia have been met, the physician must refrain from performing euthanasia and alleviate the suffering in some other way."[392]

In this updated position, the physicians' organisation distances itself from the previous requirement that physicians may only perform euthanasia after verifying shortly before the execution that the patient still has a desire to die. This duty no longer applies to patients with advanced dementia who made a written request for euthanasia when they were still able to express their will but are now unable to express their will.

7.4.2 Normalising euthanasia in dementia?

Since 2012, RTEs have been registering termination of life for dementia as a separate category. In 2012, 42 reports were made (1% of the total number of reports that year); in 2020, this rose to 170 (2.45% of the total number of reports that year). So, both in absolute numbers and in relative terms, the number of the reports in this category has increased. In 2020, 168 reports involved early-stage dementia and 2 reports of advanced-stage dementia in an advanced stage.[393] In 2021, the number of reports of advanced-stage dementia was 6.

Number of reports of euthanasia for dementia 2012-2021

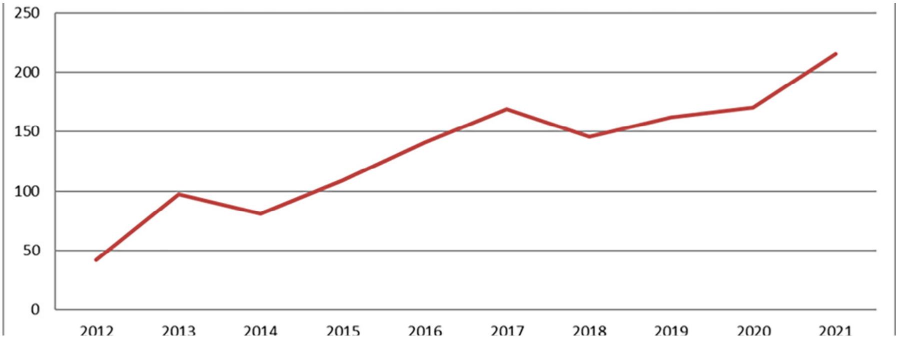

Figure 3 Number of reports to the review board 2012-2020 of euthanasia in patients with dementia.

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[392] KNMG, KNMG-standpunt. Beslissingen rond het levenseinde, (Utrecht, 2021), 36,37 , https://knmg-standpunt.maglr.com/knmg-standpunt-levenseinde/standpunt-levenseinde.

[393] Regionale Toetsingscommissies, Jaarverslag 2020, 12.

In 2017, the debate over euthanasia for dementia was sparked even before the 'coffee euthanasia'. A 65-year-old man with dementia signed a written will three years before his death.[394] Two years before his death, he considered his life worth living; he was not suffering unbearably and did not want to die. Two years later, an SCEN physician interpreted the severely demented man's anger and frustration as unbearable suffering. One day, the man was given a sleeping pill mixed in apple sauce without his knowledge. Then he taken home, without resistance and was administered a lethal injection by the end-of-life clinic physician. Did this man with advanced dementia still know that his life was going to be terminated? The review committee, which assessed this euthanasia as tentaive, put it as follows: "It was not entirely clear whether at the time of administrating euthanasia the patient had awareness of what was going to happen." Boudewijn Chabot's verdict is that this crossed a fundamental moral boundary in the Netherlands.[395]

In this, Chabot was not alone. Thirty-three physicians endorsed his concern. They feared pressure from family members and a climate in which problems in healthcare are solved by making it easier to talk about euthanasia for defenceless patients.[396]

Resistance from the profession intensified after the 'coffee euthanasia'. A total of 450 physicians—via the website www.nietstiekembijdementie.nl—expressed their concern "that killing defenceless people is becoming commonplace in the Netherlands."[397] They wrote, "Giving a lethal injection to a patient with advanced dementia on the basis of a will? To someone who cannot confirm that he wants to die? No, we are not going to do that. Our moral repugnance toward ending the life of a defenceless human being is too great."[398]

Anne-Mei The, professor of Long-Term Care and Dementia, objects that "the debate on euthanasia is too obviously focused on making euthanasia procedurally permissible and that there is little attention to developing possible alternatives. If people with dementia fear losing their grip on reality, burdening their loved ones and being at the mercy of meagre care, surely we should look at how we can sup-

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[394] Chabot, De weg kwijt, 21,22.

[395] Chabot, De weg kwijt, 22.

[396] Eva Nyst, "Artsen worstelen met euthanasie bij gevorderde dementie", Medisch Contact, accessed May 24, 2021, www.medischcontact.nl/nieuws/laatste-nieuws/artikel/artsen-worstelen-met-euthanasie-bij-gevorderde-dementie.htm.

[397] Chabot, De weg kwijt, 26.

[398] www.nietstiekembijdementie.nl, accessed May 25, 2021.

port them?"[399] And: "Isn't it strange (...) that there is more debate about euthanasia for dementia than about living with dementia? As long as we do not have the latter debate, euthanasia is an embarrassment and perhaps the easiest route."[400] Chabot fears that "if good care becomes scarce, it is not inconceivable that problems in care will be solved by making it easier to talk about euthanasia in helpless patients."[401] People fear dementia even more than cancer, Chabot writes.[402] Care is diminished, and better quality of life is desired. Chabot, therefore, expects a sharp increase in euthanasia for severe dementia based on a written will.[403] Physicians have their moral boundaries to guard. Chabot points physicians who do not want to grant euthanasia to patient autonomy in which he argues for authoritative, legal rulings that provide a safe possibility for self-determination to end of one's life without the help of a physician.[404] For many physicians and nurses/carers, getting involved in euthanasia and assisted suicide feels like solving a non-medical problem.

7.5 Increasing role of the family

When patients with dementia are increasingly unable to express themselves, the role of the family expands. Family members' considerations and social context influence both patients and physicians when considering a request for euthanasia. According to a 2019 study, in the practice of euthanasia, the triad model of patient-physician-family gives a better description of the situation than the diadem model of patient-physician, which the euthanasia law assumes.[405] This study incorporates all the elements of the role of family members that may be relevant to Dutch practice before, during and after euthanasia. The researchers define several themes, some of which are relevant to this chapter:

1. Family-related reasons for (not) requesting euthanasia or assisted suicide. Several studies show that patients ask for euthanasia when they no longer recognises family members. On the other hand, some people actually postpone the request because of the meaningful contact they have with grandchildren, for example.

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[399] Anne-Mei The, „Ten geleide. De zorg bij dementie," in Chabot, De weg kwijt, 11.

[400] The, "Zorg bij dementie," 12.

[401] Chabot, De weg kwijt, 26.

[402] Chabot, De weg kwijt, 31.

[403] Chabot, De weg kwijt, 31, 56.

[404] Chabot, De weg kwijt, 35.

[405] B. Roest, M. Trappenburg, & C. Leget, The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review, BMC Med Ethics 20, 23 (2019), doi.org/10.1186/s12910-019-0361-2.

2. Roles and responsibilities of family members during decision and implementation of euthanasia.
   Both qualitative and quantitative studies show that once a patient has made a request for euthanasia to a physician, a process of consultation, decision-making and eventual implementation begins. Family members are often involved in this process. Many physicians discuss with family members how the euthanasia statement was drafted by the patient and consult the family to reach a judgement regarding 'unbearable suffering'. Even in the case of patients with dementia, family members are usually involved in the conversation about the euthanasia policy.

The patient-physician-family triad that is emerging in practice raises ethical questions, in addition to empirical ones, that have not been sufficiently addressed, so far.[406] Roest et al. identify several ethical issues. For instance, several researchers featured in the study emphasise the moral significance of family members in medical decision-making based on the existence of important shared values and beliefs and the profound influence of familial relationships. These relationships are dynamically involved in independent decision-making and a person's identity.

In 2019 and 2020, Reliëf, an association of Christian health care institutions, conducted research commissioned by the Coalition of Meaning to the End for the benefit of the social debate around termination of life for people with dementia. Regarding the role of the family in euthanasia, one of the conclusions is that it is *formally* marginal and also undesirable under the law. "The legal due care criteria do not allow this either."[407] In practice, an increasing role for the family is viewed positively in the Relief report. "Care professionals and, to a greater extent, informal caregivers/family see a greater role for the family than is currently allowed in the process and decision-making on euthanasia for people with dementia. This raises the question of whether we should give the relational aspect a more explicit place in euthanasia, especially where people with dementia are concerned."[408] Elsewhere, the author of the Relief report, Trijntje Scheeres-Feitsma, writes: "The loss of a loved one irrevocably affects the lives of those left behind. Your life and destiny are linked, either by kinship or by choice. With a self-chosen end of life, the impact of the loss is perhaps even greater. It is, therefore, important—in addition to medical and legal due care—to pursue relational due care. This does not mean the final decision should rest with loved ones. But it does mean we

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[406] Roest et al, The involvement of family, 15.

[407] T.M. Scheeres-Feitsma, Onderzoek ten behoeve van het maatschappelijk debat rond levensbeindiging bij mensen met dementie, (Woerden: Reliëf, 2020), 5.

[408] Scheeres-Feitsma, Onderzoek, 59.

should see people in conjunction with their environment and significant others, rather than as separate and isolated individuals.”[409] The question may be asked here whether this serves the interests of the patient himself or the loved ones.

One of the main ethical issues is whether the interests of individual patients should always prevail or whether the interests and needs of family members should weigh equally or at least be recognised. Moreover, the question is how a voluntary request for euthanasia is both authorised and safeguarded when family members are closely involved in the decision-making process. The concept of relational autonomy could help explore the various links between relationships and an autonomous choice for euthanasia. Involving the family in decision-making may obscure the perspective of the patient making the request. The family may pressure the patient toward direction of the request. In that case, legal options can put relationships between people on edge, sometimes leaving patients to fear their families.

7.6 Ethical perspectives

Several perspectives emerge from the literature about euthanasia and dementia that provide a way out of the ethical dilemmas outlined above. They are starting points for an answer that deserve further elaboration.

1. Verenso, an association of geriatric specialists, in an exploration of euthanasia in patients with dementia, points out the importance of conversation with the patient. “One of the most important professional activities of specialists in geriatrics is advance care planning, which involves having regular conversations with the patient about his health situation. Preferably, in the presence of a legal representative. Timely mapping of views and wishes gives direction to what may be appropriate care and treatment if, in due course, the person with dementia is no longer able to articulate this himself. These conversations can also address anticipatory medical decisions around the end of life. We find that there is a lot of ignorance in society about dying in general. Out of fear of dying, and the possible suffering that may precede it, requests for active termination of life are often madeeven though most people die, for example, with palliative care. So, a good explanation about dying and palliative care options is hugely important.”[410]

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[409] Trijntje Scheeres-Feitsma, “Luister naar de stem van de naaste. Onderzoek naar het denken over euthanasie aan mensen met dementie,” Denkbeeld 33, 8-11 (2021): 11, https://doi.org/10.1007/s12428-021-0892-4.

[410] Verenso, Euthanasie bij gevorderde dementie. Een verkenning, (Verenso: October 2018), 8,9.

2. Because dementia has a progressive course, it is advised to keep the request for euthanasia up to date by reconfirming or modifying the patient's living will in discussion with the physician concerned and repeatedly dating it.[411] This will certainly become of great importance when the RTE's Euthanasia Code gives physicians more room for interpretation. Along these lines, it may also be wise to return to advance care planning (the palliative care quality framework uses the term 'proactive care planning') on a regular basis and/or even to re-date a living will on a regular basis.[412]
3. Theo Boer argues for the option for a timely cessation of curative treatment, i.e. medical intervention aimed at cure. Boer: "The actual reason why we euthanise people with advanced dementia is not primarily their autonomy, but our concern for the severe suffering of these people. This is a very humane thought. At the same time, this thought is so risky that I advocate we explore all options to avoid this scenario. Rather, let us stop curative treatment in time."[413]
4. M.E. de Boer concludes in her thesis that:
    a. "the experiences of people with early-stage Alzheimer's disease are not necessarily as negative as the widespread assumption of the general public suggests. The gradual progression of dementia (which is characteristic of Alzheimer's disease), allows those affected to adapt to their changing situation, which can also lead to changing previous ideas about living with dementia. This can create a situation where a person with dementia considers a previously written living will no longer applicable to the situation for which it was intended, without being able to revoke or adapt the living will (anymore) due to incapacity.[414] It is, therefore, important to provide more accurate and nuanced information to patients and families. Information on living with dementia should be available not only to (potential) dementia patients and their loved ones, but also to professional caregivers and the general public."[415]
    b. "People with early-stage Alzheimer's disease tend to live day-by-day and not think about the future, which implies limited initiative on their part to engage in early care planning." This leads to the conclusion that the help and support of others is needed to encourage people with early Alzheimer's disease to participate in planning for future care. However, it should be noted that there is a limited opportunity for this involve-

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[411] Van Iersel, Dilemmas bij dementia, 12.

[412] De Boer, "Advance directives in dementia care," 142.

[413] De Boer, "De 'koffie-euthanasie'," 237.

[414] De Boer, "Advance directives in dementia care," 140.

[415] De Boer, "Advance directives in dementia care," 141.

ment in early care planning, as active participation of the person with dementia declines over the course of the disease.[416] It is recommended that people with dementia are guided in planning their future through 'advance care planning'. However, this requires the development of adequate models for implementing early care planning in dementia care." [417]

5. The third evaluation of the Euthanasia Act (WTL) states that concerning euthanasia for advanced dementia, resistance from the profession seems to be increasing. "Formally, this is not a problem, as physicians are not obliged to make full use of the space provided by the law. But it is a point of concern, in order to avoid the law and practice growing apart or confusion among physicians about what is allowed by law and what does not allow." This leads the researchers of the evaluation to the following recommendation: "As a government, make it clear that physicians are not obliged to perform euthanasia, but at the same time emphasise the legal space that exists with regard to euthanasia requests from people with dementia."[418] A side note here is that emphasising the legal space that exists in relation to dementia contributes to the perception that living with dementia is difficult. This image does not seem to match practice, as this chapter has shown, and the care for people with dementia deserves different attention from the government than connecting dementia to euthanasia.
6. The strong emphasis on autonomy and living wills stems from the secular-liberal view of man. Life is worth living only when the balance of positive-to-negative experiences is still favourable. Human dignity shows itself, above all, in the right to self-determination. If that right can no longer be exercised, then dignity is diminished. A care ethic, even independent of underlying beliefs or world views, comes up with a completely different approach, namely, an approach to humane care where people in their relationships are central. Such an approach is in line with Anne-Mei Thei's plea quoted above by which she intends to shift the focus from dementia and euthanasia to living with dementia.
7. The issue of the autonomy of a person with dementia, the former self and the present self, deserves a biographical approach, as revealed, for example, in Psalm 71 in the Bible. You remain the same person (autonomous, rational), but not the same. "For you have been my hope, Sovereign Lord, my confidence since my youth. From birth I have relied on you; you brought me forth from my mother's womb. I will ever praise you. [...].Do not cast me away

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[416] De Boer, "Advance directives in dementia care," 140.

[417] De Boer, "Advance directives in dementia care," 141.

[418] Bregje Onwuteaka-Philipsen et al, Derde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, (The Hague: ZonMw, May 2017), 244,245.

when I am old; do not forsake me when my strength is gone. [...].Since my youth, God, you have taught me, and to this day I declare your marvelous deeds. Even when I am old and gray, do not forsake me, my God, till I declare your power to the next generation, your mighty acts to all who are to come."[419]

8. What is the role of nurses and caregivers in the practice of euthanasia involving persons with dementia? Previously cited research showed that nurses and caregivers create a supportive social network in cases where family is absent.[420] The nurse knows the patient, and even if the nurse does not participate in euthanasia, the nurse can meaningfully contribute to humane care and making life bearable for the patient with dementia. However, research also shows that nurses are actually more inclined to proceed to euthanasia for dementia than physicians. For physicians, family and relatives[421] there are protocols and handbooks, but are nurses adequately equipped? Do they need information on how to talk to persons with dementia about their end of life, and do they need information on how to care for patients with dementia until the end? In light of this, advance care planning can play an important role. An early approach to advance care planning, discussing both medical and non-medical preferences, is consistent with the needs of people with dementia and their loved ones.[422]
9.

7.7 Concluding summary

Increasingly people are requesting euthanasia because of (advanced) dementia. Living with dementia can be understood as a very distressing experience: the individuals involved enter a very uncertain, unpredictable period of life and a dreaded future that the individual tries to control through euthanasia.

Not infrequently, (the fear of) dementia plays a role in the drafting of a living will. Most physicians have dealt with patients with a declaration of euthanasia in case they become demented or incompetent. Physicians are overwhelmingly sympa-

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[419] Psalm 71:5-6, 9, 17-18 (New International Version, NIV).

[420] Roest, "The involvement," 12.

[421] Zorg rond het levenseinde. Voor mensen met de ziekte van Alzheimer of een andere vorm van dementie. Een handreiking voor familie en naasten. Published (and translated) by VU medical centre - EMGO Instituut voor onderzoek naar gezondheid en zorg, Amsterdam, www.unoamsterdam.nl/wp-content/uploads/2018/07/Boekje-Zorg-rond-het-levenseinde.pdf.

[422] Bram Tilburgs, "Advance care planning in dementia. Development and evaluation of an educational intervention in primary care," (Thesis, Radboud University Nijmegen, 2020), 169, 170, https://www.ukonnetwerk.nl/media/1489/bram-tilburgs-advance-care-planning-in-dementia-1.pdf.

thetic to the desire to terminate life and believe that advanced dementia can sometimes result in unbearable suffering. Yet, the studies show physicians rarely proceed to euthanasia. This is due, in part, because they were not convinced of unbearable suffering, and partly because they found it necessary for the patient himself to confirm that he perceived the suffering as unbearable.

A broad spectrum of views on the meaning of euthanasia declarations of incompetent patients can be found in the international ethical literature. At one end of the spectrum is the view that a euthanasia declaration of an incompetent person cannot be acted upon because the incompetent person is no longer the same person as the one who made the declaration. At the other end of the spectrum is the view that the will of a person who is capable of a reasonable appreciation of his interests should also extend to the period in that same person's life in which he has become incompetent.

The debate on euthanasia and dementia, especially advanced dementia, revolves around the interpretation of the due care criteria of the euthanasia law. A key point of debate concerns whether a previously written desire for euthanasia should be in line with the patient's behaviour at the time the decision was made and/or when euthanasia is performed. To what extent can a request for euthanasia be seen as an autonomous decision, a decision based on adequate arguments/knowledge and a reasonable deliberation process? Declining competence in dementia stands in the way of an autonomous request, gradually requiring someone other than the patient to make more and more decisions on behalf of the patient. Research shows that interviews with those who have dementia live day-to-day and tend to leave planning on the future to others.

A major point of discussion in the debate on the meaning of a euthanasia declaration from patients with dementia relates to 'unbearable suffering without prospect of relief' and without reasonable alternatives. Can one establish intolerable suffering without prospect of relief in the current situation of an incompetent patient? Additional qualitative research suggests that the gradual deterioration characteristic of Alzheimer's disease also allows room for adaptation. As a result, current perceptions of the disease may differ favourably from patients' perceptions of it in the past. Such differences are important in the discussion of living wills and highlight the importance of letting people with dementia have their own say.

The so-called 'coffee euthanasia' case is much discussed because the main dilemmas stand out. It led to judicial review by the Supreme Court and then to an amended euthanasia code by the RTE.

When patients with dementia are increasingly unable to express themselves, the role of the family gains importance. Several researchers emphasise the moral relevance of family members in medical decision-making based on the importance of shared values and beliefs and the profound influence of family relationships. Relationships are dynamically involved in independent decision-making and the formation of people's identity.

I conclude with eight perspectives providing a way out of the ethical dilemmas surrounding euthanasia and dementia:

1. The importance of talking to the patient, especially about advance care planning (or proactive care planning) and explaining dying and palliative care options;
2. Keeping the patient's living will up-to-date;
3. Stopping curative treatment in time;
4. Persons with dementia are capable of adapting to their situation, such that a previously written living will is not applicable. This information should be shared with patients, healthcare professionals, family and the general public to counteract false perceptions about dementia;
5. The government overemphasises the scope for euthanasia in cases of dementia. The government would do well to pay less attention to this connection and work to change the perception of living with dementia;
6. Great emphasis on autonomy and living wills stems from the secular-liberal view of man where human dignity is expressed especially in the the right to self-determination. This calls for a different approach, namely approaching the human being with humane care in which people in their relationships are central;
7. The issue of the autonomy of a person with dementia, the former self and the present self, deserves a biographical approach: one may not remain the same, but one remains the same person (autonomous, rational);
8. In the absence of family, nurses and caregivers form a supportive social network. It is a question whether they are sufficiently equipped to make decisions about care on the patient's behalf.

Sources

Literature

- Akerboom, C.P.M., Dute, J.C.J., Gevers, J.K.M., et al. *Thematische Wetsevaluatie. Wilsonbekwaamheid en vertegenwoordiging.* The Hague: ZonMw, August 2011.
- Blois, M. de. "Persoonlijke autonomie en de heiligheid van het leven." *Pro*

Vita Humana 9, no. 6 (2002). provita.nl/publications/personal-autonomy-and-the-sanctity-of-life-annotations-at-pretty-v-united-kingdom-dr-matthijs-de-blois/.

- Boer, M.E. de. " Waarom de "koffie-euthanasie" weinig met patiëntenautonomie te maken heeft. Een ethisch commentaar op de uitspraak van de Hoge Raad." PhD thesis, Vrije Universiteit Amsterdam, 2011.
- Farmer, Theo. "Why 'coffee euthanasia' has little to do with patient autonomy. An ethical commentary on the Supreme Court ruling." In *Radix* 46, no. 3 (2020), 229-238.
- Bolt, Sascha R. "The fundamentals of a DEDICATED palliative approach to care for people with dementia." Thesis, Maastricht University, 2021. https://www.awolimburg.nl/userfiles/files/proefschriften/proefschrift-dedicated-palliatieve-zorg-bij-mensen-met-dementie_sascha-bolt.pdf.
- Buijsen, M.A.J.M. "De keuze voor een geen bezwaarsysteem: een kwestie van principe." *Pro Vita Humana* 11, no. 1 (2004). https://provita.nl/nieuws/publicaties_nieuw/de-keuze-voor-een-geen-bezwaarsysteem-een-kwestie-van-principe/.
- Buijssen, Martin. "Van overeenkomstige toepassing Over levensbeëindiging op verzoek bij gevorderde dementie." In *Radix* 46, no. 3 (2020). 216-228.
- Chabot, Baudouin. *De weg kwijt. De zorgelijke staat van de euthanasiewet.* Amsterdam: Nijgh & Van Ditmar, 2017.
- Commissie Aanvaardbaarheid Levensbeeindigend handelen (KNMG). *Medisch handelen rond het levenseinde bij wilsonbekwame patiënten.* Houten/Diegem: Bohn Stafleu Van Loghum, 1997.
- Delden, J.J.M. van, Heide, A. van der, Vathorst, S. van de, et al. *Kennis en opvattingen van publiek enprofessionals over medische besluitvorming en behandeling rond het einde van het leven. Het KOPPEL onderzoek.* The Hague: ZonMw, 2011.
- Delden, J.J.M. van. "The unfeasibility of requests for euthanasia in advance directives." *Journal of Medical Ethics* 30 (2004): 447-452. dx.doi.org/10.1136/jme.2002.002857.
- Dijk, Diederik van, Geuze, Yvonne. "Makkelijker euthanasie bij diep demente patiënten. Het hellend vlak wordt werkelijkheid." *Nederlands Dagblad*, November 27, 2020. https://www.nd.nl/opinie/opinie/1005280/makkelijker-euthanasie-bij-diep-demente-patinten-het-hellend-v.
- Dresser, R.S., Robertson, J.A. "Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach." *Law, Medicine and Health Care* 17, no. 3 (1989): 234-244. doi:10.1111/j.1748-720X.1989.tb01101.x.
- Dworkin, R. "Autonomy and the demented self." *The Milbank Quarterly* 64, suppl. 2, (1986): 4-16.

- European Parliament. *Charter of fundamental rights of the European Union* (2000/C 364/01) signed on December 7, 2000 in Nice by the Member States of the EU. www.europarl.europa.eu/charter/pdf/text_en.pdf. Dutch translation: www.europarl.europa.eu/charter/pdf/text_nl.pdf.
- Gezondheidsraad. *Dementie*. The Hague, Gezondheidsraad, 2002.
- Groenewoud A.S., E. Leijten, S. van den Oever, J. van Sommeren & T.A. Boer. "The Ethics of Euthanasia in Dementia. A qualitative content analysis of case summaries (2012-2020)." In: *Journal of the American Geriatric Society* (20 February 2022): 1-13. https://doi.org/10.1111/jgs.17707.
- Heath, Agnes van der, Geijteman, Eric, Rietjes, Judith. *Schriftelijk vastgelegde euthanasiewensen van wilsonbekwame patiënten. Een literatuuroverzicht van opvattingen, praktische ervaringen en knelpunten.* Rotterdam: Erasmus MC, Department of Social Care, October 2014.
- Iersel, Tim van. *Dilemma's bij dementie*. Bohn Stafleu Van Loghum: Houten, 2019, Nursing-dementia series.
- Jaworska, A. "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value." *Philosophy and Public Affairs* 28 (1999): 105-138. doi.org/10.1111/j.1088-4963.1999.00105.x.
- Jochemsen, H., Glass, G. *Verantwoord handelen. Proeve van een christelijke medische ethiek.* Amsterdam: Buijten & Schipperheijn, 1997. Series Accountability no. 13.
- Hertogh, C.M.P.M. "The role of advance euthanasia directives as an aid to communication and shared decision-making in dementia." *Journal of Medical Ethics* 35 (2009): 100-103. dx.doi.org/10.1136/jme.2007.024109.
- Kamphorst-Helsloot, E.F., Jochemsen, H. "Euthanasie bij dementerende mensen?" *Tijdschrift voor Gezondheidszorg en Ethiek* 15, no. 2 (2005): 49-53.
- Keizer, A.A. "Euthanasie bij gevorderde dementie: een morele onmogelijkheid." *Nederlands Tijdschrift voor Geneeskunde* 157 (2013): A6407. www.ntvg.nl/system/files/publications/a6407.pdf.
- KNMG. *Een nadere uitleg van het standpunt Euthanasie.* 2003. www.knmg.nl/web/file?uuid=4039069e-49bc-4f56-a210-74f8749b0898&owner=5c945405-d6ca-4deb-aa16-7af2088aa173&contentid=259.
- KNMG. *Knelpunten bij levensbeëindiging.* 2004.
- KNMG. *KNMG-standpunt. Beslissingen rond het levenseinde.* Utrecht, 2021. https://knmg-standpunt.maglr.com/knmg-standpunt-levenseinde/standpunt-levenseinde.
- Nyst, Eva. "Artsen worstelen met euthanasie bij gevorderde dementie." *Medisch Contact*, accessed May 24, 2021. www.medischcontact.nl/nieuws/laatste-nieuws/artikel/artsen-worstelen-met-euthanasie-bij-gevorderde-dementie.htm.
- Nyst, Eva. " RTE brengt EuthanasieCode in lijn met arrest Hoge Raad." *Me-*

disch Contact, accessed July 26, 2021. www.medischcontact.nl/nieuws/laatste-nieuws/nieuwsartikel/rte-brengt-euthanasiecode-in-lijn-met-arrest-hoge-raad-.htm.

- Onwuteaka-Philipsen. Bregje, et al. *Derde evaluatie Wet toetsing levensbeëindiging op verzoek enhulp bij zelfdoding*. The Hague: ZonMw, May 2017.
- Parfit, D. *Reasons and Persons*. New York: Oxford University Press, 1984.
- Regionale Toetsingscommissies Euthanasie, Jaarverslagen; zie https://www.euthanasiecommissie.nl/de-toetsingscommissies/jaarverslagen
- Regionale Toetsingscommissies Euthanasie. *Euthanasia Code. De toetsingspraktijk toegelicht. Aangepast naar aanleiding van de arresten van de Hoge Raad van 21 april 2020.* (April 2018). www.euthanasiecommissie.nl/uitspraken/brochures/brochures/euthanasiecode/2018/euthanasiecode-2018-herziene-versie-2020.
- Regionale Toetsingscommissies Euthanasie. “Aanpassing EuthanasieCode 2018 en oordeel euthanasie bij vergevorderde dementie na arrest Hoge Raad.” Euthanasia Committee. Accessed January 8, 2022. https://www.euthanasiecommissie.nl/actueel/nieuws/2020/11/20/aanpassing-euthanasiecode-2018-en-oordeel-euthanasie-bij-vergevorderde-dementie-na-arrest-hoge-raad.
- Central Government of the Netherlands, Handreiking schriftelijk euthanasieverzoek. (2016). https://www.rijksoverheid.nl/documenten/brochures/2015/12/17/handreiking-schriftelijk-euthanasieverzoek-publieksversie.
- Roest, B., Trappenburg, M. & Leget, C. “The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review.” *BMC Med Ethics* 20, 23 (2019). doi.org/10.1186/s12910-019-0361-2.
- Scheeres-Feitsma, T.M. Onderzoek ten behoeve van het maatschappelijk debat rond levensbeëindiging bij mensen met dementie. Woerden: Reliëf, 2020. https://www.relief.nl/wp-content/uploads/2021/08/Onderzoek-dementie-en-euthanasie-eindverslag-aangepast-1.pdf.
- Scheeres-Feitsma, Trijntje. “Luister naar de stem van de naaste. Onderzoek naar het denken over euthanasie aan mensen met dementie.” Denkbeeld 33, 8–11 (2021): 8-11. https://doi.org/10.1007/s12428-021-0892-4.
- Tilburgs, Bram. “Advance care planning in dementia. Development and evaluation of an educational intervention in primary care.” PhD thesis, Radboud University Nijmegen, 2020. https://www.ukonnetwerk.nl/media/1489/bram-tilburgs-advance-care-planning-in-dementia-1.pdf.
- Tongeren, Paul van. *Willen sterven. Over de autonomie en het voltooide leven.* Utrecht: Kok, 2018.
- Verenso. *Euthanasie bij gevorderde dementie. Een verkenning.* Verenso: October 2018. www.verenso.nl/_asset/_public/Nieuws/Nieuws_2017_2018/VER-002-

14_euthanasie-bij-gevorderde-dementie_web3.pdf.

- Wier, Marten van de. " Conflict tussen OM en euthanasiecommissies: wie bepaalt de regels?" July 20, 2021. www.trouw.nl/verdieping/conflict-tussen-om-en-euthanasiecommissies-wie-bepaalt-de-regels~b9961199/.
- Wijngaarden E van, Alma M., The A-M. "'The eyes of others' are what really matters: The experience of living with dementia from an insider perspective." *PLoS ONE* 14(4) 2019: e0214724. https://doi.org/10.1371/journal.pone.0214724 .
- Wijsbek, H. "Euthanasie bij gevorderde dementie. Wilsverklaring is wel nuttig." 157 (2013): A6440. https://www.ntvg.nl/artikelen/euthanasie-bij-gevorderde-dementie-wilsverklaring-wel-nuttig.

- *Interviews*

1. Dr Ir Jenny van de Steen, associate professor at LUMC, 12 May 2021.
2. Reference evening research group Lindeboom Chair, 1 June 2021.

8. The significance of the spiritual caregiver in requests to end life

Arthur Alderliesten

In this chapter, we explore the role of the spiritual caregiver[423] in requests for active life termination. This chapter does not address the theological-ethical weight of euthanasia. Its content touches on the *ars moriendi*, covered in a prior chapter,but focuses on the contemporary meaning of the role of spiritual care. To address this topic, we conducted four interviews with spiritual caregivers from various Protestant Christian nursing homes and processed the interviews anonymously. Additionally, we conducted a literature review on the topic.

After defining the key concepts, we consider the *task* of a spiritual caregiver in the dying phase and in dealing with indicators from the patient[424] indicating a desire to end their life. Then, in the second section, we look at the relationship between the work of the (palliative) nurse and the spiritual caregiver. Subsequently in the third section, we look at the spiritual caregivers' *possible handling of* end-of-life indicators. In the fourth section, we consider the role of the patient's family through the eyes of spiritual caregivers.

8.1 Definitions and demarcation

In the Netherlands, the Association of Spiritual Caregivers in Care Institutions (VGVZ), adopted a professional standard in 2015 defining spiritual care as follows[425] :
"Spiritual care is professional guidance, assistance and counselling on meaning and world view.
Four dimensions can be distinguished for meaning and world view:
a. The existential dimension refers to the experience of existence as such, in

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[423] This is a translation of the common Dutch word nowadays used for this function. In English the traditional word used here was chaplain/chaplaincy.

[424] The word for the person who receives spritual or pastoral care is, in Dutch called pastorant. However, this word is not used in English. Since we speak about palliative care in this chapter we will use the word patient also in de context of spiritual care

[425] VGVZ, Professional Standard of Spiritual Caregiver, 2016, https://vgvz.nl/wp-content/uploads/2018/07/Beroepsstandaard-2015.pdf.

its everydayness as well as with its (contingent) experiences of horror and wonder and everything in between;

b. The spiritual dimension refers to transcendent meaning and experience;
c. The ethical dimension refers to the field of values, norms and responsible actions;
d. The aesthetic dimension refers to the formative significance of experiences of beauty in both culture and nature."

Spiritual caregivers, especially in a healthcare institution, are increasingly faced with a huge plurality of worldviews among residents, clients and patients. As in a two-stream country, there is the professional stream that advocates general spiritual care, and there is the the traditional stream that guards the pastoral character of spiritual care. With Heitink, I stand for an integrative approach that does justice to both the philosophical and professional aspects of the spiritual caregiver.[426] Spiritual care should not be corporatised and pastoral care should not be 'churched'.[427] Spiritual care that does not get its content from a world view remains an empty concept.[428] Heitink points out that spiritual caregivers, whether a Christian or a representative of another religion or worldview, like humanism, are challenged to develop their own identity and articulate it more clearly. "At a first level, one can be a spiritual caregiver for all, but deepening a relationship will, as a rule, require differentiation in world view/beliefs to avoid remaining in a role of passive mirroring. The latter seems insufficient to me. If God is mentioned in a conversation or a prayer is said, then world view/religious identity plays an increasingly important role."[429]

In this chapter we have chosen to discuss how (in care institutions) the role of spiritual caregiver can be fulfilled from a Christian perspective in spiritual counselling and assisting people with a desire for euthanasia. Here, the first task is to bring up God, the Father of Jesus Christ, and the second to address questions of meaning. This does not mean that in time or stage of conversation it should *first be* about God and *then* about meaning. In practice, these subjects will often come up in spiritual conversation in reverse order: from meaning to world view, to God. That which has the primacy, speaking about God, cannot be done without the secondary, the question of meaning. Talking about meaning, the secondary, without talking about God is, in line with the VGVZ's definition mentioned above,

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[426] G. Heitink, "Geestelijk verzorger: een ambt en een ambacht," in: J.J.A. Doolaard et al (ed.), Nieuw Handboek Geestelijke Verzorging, (Kampen: Kok 2006), 161-169.

[427] Heitink, "Geestelijk verzorger," 166.

[428] Heitink, "Geestelijk verzorger," 167.

[429] Heitink, "Geestelijk verzorger," 167.

possible under the heading of spiritual care. This means that in the plurality of spiritual care, meaning issues are connected to the world view of the person receiving spiritual care. But if the primary, God, is left out, the Christian perspective and the age-old and global Christian tradition is short-changed.[430] Talking about God precedes talking about meaning; not chronologically, but in significance and importance. After all, meaning is *received* from God. He gives meaning, meaning to our existence. God serves man, to give his life meaning.[431]

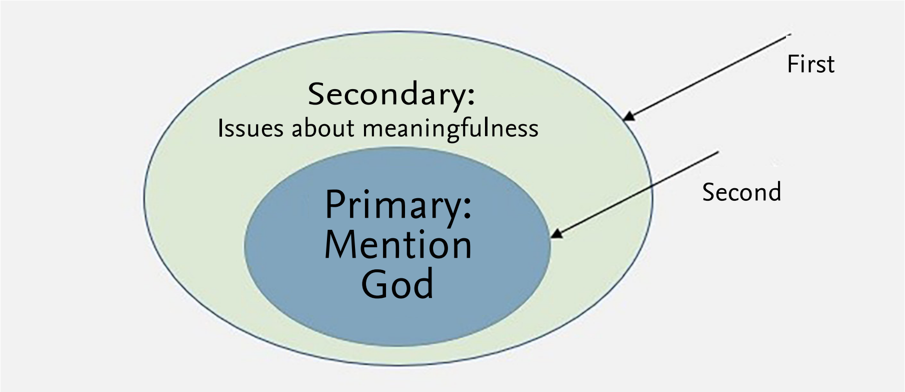

Figure 4 Model spiritual care around the end of life

By pastoral care, I mean spiritual care in which the caregiver addresses the 'patient' pastorally in the name of Christ.[432] The approach of this chapter is to let the hope that exists in Christ be central to spiritual care, particularly in the context of to end-of-life issues.

The WHO's definition of palliative care testifies to the fact that spiritual care unmistakably belongs to the dying phase:
"Palliative care is an approach that improves the quality of life of patients and their loved ones coping with a life-threatening condition by preventing and relieving suffering through early identification and careful assessment and treatment of pain and other problems of a physical, psychosocial and spiritual nature."[433]

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[430] Cf. Jan Piet Vlasblom, Martin N. Walton, Henk Jochemsen, "Ministry in spiritual care", in: Jan Piet Vlasblom, Spiritual care by nurses and the role of the chaplaincy in a general hospital. PhD thesis (Amsterdam: VU University, 2015), 105-126; https://research.vu.nl/en/publications/spiritual-care-by-nurses-and-the-role-of-the-chaplaincy-in-a-gene.

[431] Bram van de Beek, Ego. Een cultuuranalyse van het ik, (Utrecht: KokBoekencentrum, 2022), 93.

[432] GKN/NHK, Euthanasie en pastoraat, (The Hague: Boekencentrum, 1998), 40.

[433] "Definition of palliative care," World Health Organization, accessed January 5, 2021, https://www.who.int/health-topics/palliative-care.

If this is the vision of care for the last phase of life, it also applies to a patient with a (persistent) desire for active termination of life. The question is not *whether* care includes spiritual care, but *how*.

The English ‘spiritual’, can be translated in Dutch as either mental or spiritual. Spiritual care is usually ‘spiritual care’ in Dutch, but nowadays spiritual care is also often used in this context. With Jochemsen, I understand that by spiritual care, “the world viewis and possibly religious functioning of human beings, to which we include the questions of meaning experience and sense-making.”[434]

This definition stems from a broad *functional approach* to spirituality in which it is seen as a function that can be discerned in human existence, as Henk Jochemsen *et al*. argue. “By an approach in which spirituality is described as an anthropological structure. Such a functional approach to religion is not uncommon in anthropology, and without equating religion with spirituality, an anthropological definition of religion may well provide a good starting point for our reflection on spirituality.”[435]

“It further means that spirituality is not a *separate area of* human existence, (e.g. participating in certain rituals at certain times) but is an *aspect* of *all* existence. So an *attitude to life* rather than an *area of life*.”[436]

This vision is in line with Machteld Huber who advocates for ‘positive health’, which is echoed in the WHO definition.[437] With this term, she emphasises people’s strength and puts less focus on the absence of disease. From this perspective, health is seen in terms of resilience, functioning and participation rather than just in a somatic or psychological sense. She defines positive health in six dimensions, one of which is spiritual/existential dimension.[438] Additionally, she points out that experiential meaning is associated with greater well-being.[439]

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[434] Henk Jochemsen, “Behoort aandacht voor spiritualiteit tot de medische zorg?” in H. Jochemsen and E. van Leeuwen (ed.), Zinervaring in de zorg, (Assen: Van Gorcum, 2005), 13.

[435] H. Jochemsen, M. Klaasse-Carpentier, B.S. Cusveller, et al, Levensvragen in de stervensfase. Kwaliteit van spirituele zorg in de terminale palliatieve zorg vanuit patiëntenperspectief. Report of the Prof. Dr. G.A. Lindeboom Institute. no. 16 (2002), Ede, 11, 12.

[436] Jochemsen, Levensvragen in de stervensfase, 13.

[437] Huber’s work leans on the impressive thinking of Viktor Frankl. See: Viktor E. Frankl, De zin van het bestaan, (Rotterdam: Ad Donker, 2020).

[438] M. Huber, M. van Vliet, M. Giezenberg, et al, “Towards a ‘patient-centred’ operationalisation of the new dynamic concept of health: a mixed methods study,” in BMJ Open 2016;5:e010091. doi:10.1136/bmjopen-2015- 010091.

[439] “Machteld Huber verovert met positieve gezondheidszorg de zorg,” ZorgenZ..., accessed Octo-

8.2 The spiritual caregiver...

8.2.1 ... as an ethicist

Ethics is about the question of the moral good in concrete situations (i.e., conflict). So it is the ethicist in the spiritual caregiver who asks the reflective questions to help the patient arrive at (perspectives on) an answer when a dilemma arises in care. But does this role suit the spiritual caregiver? Or is the role limited to those in (silent) proximity, like the father in Judith Herzerg's poem *Ziekenbezoek (Visiting the Sick)*, which is especially well-known among spiritual caregivers?

My father had sat silent by my bedside for a long hour.
When he had put on his hat
I said, well, this conversation
is easy to resume.
No, he said, not really,
Just give it a try.

Is the role of the spiritual caregiver limited to bringing up God (the 'traditional stream'), to guidance on questions of meaning (the 'professional stream') or should he/she as an ethicist also seek the good together with the patient?[440] Theo Boer explicitly qualifies the spiritual caregiver also as an ethicist. In medical-ethical end-of-life issues, he believes the spiritual caregiver can play an important role. And for two reasons: without world view, ethics becomes rudderless and risks becoming cynical. In addition, accorind to Boer, spiritual care is *itself an* ethical activity.[441]

Ethics, and with it the conversation about active termination of life, cannot exist without a world view, which involves a normative view of reality. Christian theology, with its notions of 'creation', 'fall', 'redemption' and 'completion', has sought to untangle the knot between 'good' and 'bad'. A world view also offers additional factual considerations with an evaluative element (value facts). A person's views

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ber 26, 2021, https://zorgenz.nl/machteld-huber-verovert-met-positieve-gezondheid-de-zorg/ and M. Huber, B. Garssen, "Relaties tussen zingeving, gezondheid en welbevinden," in Wijgergangs, L., Ras, T., Reijmerink, W., Zingeving in zorg. De mens centraal. ZonMw, 2016: 17-21, https://www.iph.nl/assets/uploads/2020/12/ZonMw_zingeving_herdruk_totaal.pdf.

[440] Since ministry ceased to be a requirement for the profession of spiritual caregiver in 2013, and membership of the professional organisation and inclusion in the quality register has been open to both recognised and non-recognised spiritual counsellors, a lot of attention has been paid to the task and role of the spiritual caregiver.

[441] Theo Boer, "De moderne geestelijke verzorger als ethicus: een toevalstreffer?" in: J.J.A. Doolaard et al (ed.), Nieuw Handboek Geestelijke Verzorging, (Kampen: Kok 2006), 735-746.

on the origin and purpose and essence of being human, for example, imply a particular view of and approach to ageing. World view beliefs form a leading framework within which we make ethical decisions. The spiritual caregiver with explicit attention to spiritual care is ideally placed to reflect on decisions and desires of a moral nature.

Boer also points out that one can derive from faith "a certain cheerfulness and ability to put things into perspective. Faith keeps morality alive, it offers ('if functioning well', we should add) an antidote to moral cynicism and pessimism."[442]

Thus, the role of the spiritual caregiver is not limited to being a loving, empathetic listener. According to Don Browning, the pastor's role is "[to facilitate] a mode of enquiry that will help the members of the church to develop a framework of meanings relevant to all aspects of their lives."[443] While he expresses this within a church context, it is more broadly applicable. When a spiritual caregiver is 'consulted', it should not be seen as an afterthought, but as a request for help to ensure that ethics and meaning are properly aligned.

Theo Boer points to the task of the spiritual caregiver, which he rightly has rooted in the broad Christian tradition, although, in practice, many spiritual caregivers have become more disconnected from these roots: "The spiritual caregiver does his work partly in the face of an ancient and global community and is called to help present the values of that shared tradition, as best he can, in complex ethical decisions."[444] This keeps the ethical task of spiritual care linked to its 'classical content'.

It is also interesting to connect modern-day spiritual care to the practice of caring for the soul as seen in classical antiquity beginning in the fifth century BC. Therapy of the soul was part of everyday life and was rumoured to be about the good life, *eudaimonia*, or happiness. Insights from antiquity can be discerned today in various forms of cognitive therapy within a broad ethical setting.[445]

There is no easy answer to the question of what it means to live in line with Jesus Christ in the face of euthanasia. Nevertheless, the Bible, as God's Word, is an important source, even in issues related to a self-chosen end of life. "The 'ship of the church' may sail on the compass of the Bible, but a compass is not an auto-

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[442] Boer, "De moderne geestelijke verzorger als ethicus," 740.

[443] Quoted in: Boer, "De moderne geestelijke verzorger als ethicus," 740.

[444] Boer, "De moderne geestelijke verzorger als ethicus," 741-742.

[445] Heitink, "Geestelijke verzorger," 167.

matic pilot. It is a necessary tool for setting a course, including on euthanasia."[446]

In the context of a dying person and a desire for euthanasia, the gospel is salutary in three directions:

1. Past: reconciliation and forgiveness;
2. Present: the fear of death, we may be sustained by the faith that God's recreating hand guides us through death;
3. Future: death does not have the last word; after all, Christ has been raised! Therefore, we can look to the future with confidence.[447]

8.2.2 ... as a euthanasia counsellor or end-of-life counsellor?

Is it also part of the spiritual caregiver's job to act as a euthanasia counsellor or end-of-life counsellor? First, what is a euthanasia counsellor? In the Act on Assessment of Termination of Life on Request and Assisted Suicide, articles 1.d and 8.d refer to a counsellor. This is defined in section 1.d as 'the physician who has been consulted about another physician's intention to administer life termination on request or help with suicide'. What is meant here is the SCEN physician, or the second independent physician, who is necessary for a rigorous process under the Act on the Assessment of Termination of Life at Request and Assisted Suicide. It was somewhat confusing when the Albert Schweitzer Hospital (ASZ) in Dordrecht in 2014 announced that they also have a 'euthanasia consultant'. This role is usually filled by spiritual care. At ASZ, the euthanasia counsellor is called once the patient has submitted the request for euthanasia to the physician. One of the ASZ's euthanasia consultants then supervises the entire process from request, to decision-making, to performing the act and to the aftercare, and the euthanasia counsellor serves as the point of contact throughout the procedure. [448] All this is done in consultation with the patient, his family, the physician and the nurse. The euthanasia counsellor informs all those involved and brings them together for a meeting. On its website, the hospital writes: "The spiritual caregiver at Albert Schweitzer hospital believes it is important that patients can make a well-considered choice in all areas, including euthanasia. She therefore fulfils the subsidiary function of 'euthanasia consultant' within the hospital. She is knowledgeable on the medical, legal and human aspects of euthanasia."[449]

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[446] GKN/NHK, Euthanasie en pastoraat, 11.

[447] GKN/NHK, Euthanasie en pastoraat, 41

[448] Albert Schweitzer Ziekenhuis, Euthanasie, April 4, 2019, https://www.asz.nl/specialismen/euthanasieconsulent/folders/euthanasie.pdf.

[449] "Euthanasie consultant," Albert Schweitzer Ziekenhuis, accessed October 4, 2021, https://www.asz.nl/specialismen/euthanasieconsulent/.

A similar role, but under the heading of ‘end-of-life counsellor’ is provided for in the ‘completed life’ initiative bill submitted by D66 to the House of Representatives (Second Chamber of parliament) on 17 July 2020.[450] Article 1 describes an end-of-life counsellor as one “ who is registered as such in a register as referred to in section 3(1) of the Act on individual healthcare professions, the BIG law.” This means that such a counsellor will have to be BIG-registered. The work of the euthanasia counsellor is described in the WTL as testing the due care criteria for euthanasia. It is notable that in article 2.e, the end-of-life counsellor must have obtained the conviction with the person being counseled that “ addressing the background of the request, is not desirable.” Thus, as far as D66 is concerned, in this bill, the end-of-life counsellor does not have the task of ethically reflecting and exploring alternative options other than the current request for assisted suicide. The end-of-life counsellor prescribes the means, is present at the suicide and reports to the RTEs. In the bill, only five professional groups have access to the training of end-of-life counselors: physicians, psychiatrists, health psychologists, psychotherapists, and nurses. [451] But other voices are also heard. Joachim Duyndam, professor of humanism and philosophy, for instance, argues precisely that end-of-life counselling is a task for spiritual care.[452] In politics yet another way exists of speaking about end-of-life counsellors. Following from, or in response to, the ‘completed life’ act, end-of-life counsellors were created precisely to coach the elderly in their existential questions. It is up to the minister to flesh this out. The confusion of definitions makes it necessary to carefully monitor what any legislative proposal will entail. Spiritual caregivers should not be obliged to cooperate to counsel someone toward euthanasia or assisted suicide. People deserve to be helped with their spiritual needs and existential questions, not to have their dying wishes honoured outright.

We return to the initial question in this section: Is it part of the spiritual caregiver’s role to act as a euthanasia counsellor when it has been decided to perform euthanasia or suicide? The Association of Spiritual Caregivers (VGVZ) held an ‘open platform meeting’ in April 2017 on the possible role of the spiritual caregiver as a life coach.[453] Spiritual caregivers spoke about the then imminent ‘completed life’ bill. A mixed picture emerges from the report. On the one hand, agreement with

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[450] House of Representatives of the Netherlands, Legislative Proposal, 35 534-2, https://www.tweedekamer.nl/kamerstukken/wetsvoorstellen/detail?id=2020Z14112&dossier=35534.

[451] House of Representatives of the Netherlands, Explanatory Memorandum, 35 534-3, 41, https://www.tweedekamer.nl/kamerstukken/wetsvoorstellen/detail?id=2020Z14112&dossier=35534.

[452] Joachim Duyndam, “Geestelijke begeleiding bij voltooid leven,” in Waardenwerk, 72 May 2018: 131-136, Duyndam_Waardenwerk_Voltooid_Leven.pdf (humanistischverbond.nl).

[453] “Discussion members on ‘Completed life’”, Vereniging van Geestelijk VerZorgers (VGVZ), accessed October 11, 2021.

the role of the spiritual caregiver, but on the other hand, predominantly reticence in the role as consellor of a euthanasia process. According to the report, some of those present recognised that the spiritual caregiver has a role to play because the issues at stake are existential and ethical. These go beyond a purely clinical dimension. Furthermore, these issues are of social importance.

Interviews conducted as a part of this study reveal a similar response. One interviewee would be willing to be present during a euthanasia or assisted suicide in distressing situations. The others set a limit when reflecting on the underlying questions behind the desire for euthanasia and assisted suicide. One respondent indicated that he would not want to be present for a religious ritual, such as a prayer, at the end of life, but would consider being present in cases of fear and loneliness.

Should the euthanasia counsellor's job description include being critical of the patient's decision? Do spiritual caregivers have a duty to speak critically about euthanasia? The interviews reveal that some do make it clear in conversation with the patient that they do not support the choice for termination of life. Another indicated being direct, but only when the patient is in doubt. A third said accept the choice and connect with the patient at the point at which the patient finds himself.

I conclude that the task of the spiritual caregiver excludes the role of euthanasia counsellor and end-of-life counsellor as understood within the WTL and the Bill on Completed Life. After all, these roles presuppose that the decision has already been made after euthanasia has been presented as a seemingly medical act. However, it is expressly up to the spiritual caregiver to connect to the patient's spiritual dimension, to his or her existential questions and to reflect ethically on the request for a termination of life. In terms of critical reflection on the process, there may therefore be overlap in the roles of spiritual caregiver and those of the euthanasia counsellor/ end-of-life counsellor. However, the functions cannot be the same.

It should also be noted that the spiritual caregiver's attitude is partly determined by the notion of 'helping', 'assisting' (which, by the way, does not override the task of ethical reflection!). Someone who is about to die is *supported*. This means, as much as possible, making that person's needs and questions a priority.[454] In 2015, the Anglican pastor and theologian Samuel Wells wrote the fascinating book *A Nazareth Manifesto: Being with God*. In it, he argues mortality is not humanity's

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[454] GKN/NHK, Euthanasie en pastoraat, 13.

biggest problem, but isolation is. Partly for this reason, he contends that it is best to be involved with other people in terms of 'being with'. This he distinguishes from 'working for', 'working with' and 'being for'. According to Wells, this is the heart of theology. Being with God and each other is inherent in creation, disrupted by the fall, restored with the coming of Christ in the flesh (Immanuel - God with us) and ratified in the resurrection.[455]

Going along with a decision, request or wish for active termination of life conflicts with spiritual care conducted from the conviction that human beings are created in God's image, that God is focused on life, and has our times in His hand (Ps 31.16). One of the mental health workers in the study stresses that the task is not to "bring someone to the end, but [to bring them], in accordance with Christian tradition, to Christ." And that, in turn, does not contradict the fact that the pastor "must indicate (not only at the deathbed, but during all his work) that even highly controversial issues are up for discussion within the space of the church without the expectation of immediate approval or disapproval."[456]

Spiritual guidance "presupposes a willingness to think along with the other person in their concrete situation. This does not mean answering every question, not even with the Bible in hand. It does mean listening, showing solidarity (e.g., when 'medical authority' manifests itself at the patient's expense), clarifying insights, unmasking false certainties, confronting other opinions, discussing what bothers or frightens someone, encouraging, comforting, helping and much more."[457]

When a spiritual caregiver accompanies someone with a non-Christian world view, their presence is less 'proclamation' and more accompaniment in the broader sense of spiritual care. Unless the patient is clearly open to this proclamation. In that case, it should never "be hidden that pastoral care is provided from the church's confession that God's word is 'a lamp to our foot and a light to our path". From this, pastoral care, [i.e., spiritual care in the context of the church], derives its identity." The power of the Gospel is great: it comforts; it speaks of freedom from guilt; it edifies; it opens up a future; and it speaks of a "peace that passes all understanding". Spiritual care here presents itself as a proclamation. At the same time, we cannot and should not foist or impose hope on a dying person. "Better no gospel than a cheap gospel. Imposing an opinion does not lead one to commit oneself to Christianity. The point, however, is to help the other person go

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[455] Samuel Wells, A Nazaret-manifest. Met God zijn, translated by Zwany Kamerman (Franeker: Van Wijnen, 2020).

[456] GKN/NHK, Euthanasie en pastoraat, 14.

[457] GKN/NHK, Euthanasie en pastoraat, 14.

their own way and help them make the decisions necessary to do so. If circumstances permit, the persom may make decisions in light of the Gospel, and they may make a choice to be dedicated to Him who sees the heart in Christ Jesus who justifies the sinner. "[458]

8.3 Relationship to palliative care

How does the work of the spiritual caregiver relate to the palliative nurse's[459] attention to the spiritual dimension of the human being?[460] Palliative care is characterised by attention to the whole person, as shown in the chapter on *ars moriendi*. This means that a palliative nurse has time for to address all of the person's needs, is equipped to do so and does not need to consult or have a spiritual caregiver come by for every spiritual and/or existential question. Both literature and field research from 2007 at Rotterdam's Ikaziaz hospital show –that training in spiritual care increases the competences of nursing staff, and patients experience better spiritual support during their illness.[461] Patients experienced more receptivity and support in their questions about the purpose and meaning of their lives and of their illness. Nurses changed their behaviour in several aspects, such as better recording and asking about patients' needs.[462] Other research shows that a number of factors are crucial for spiritual care: time to listen, availability, empathy, being open to other opinions and a good trust relationship.[463] Moreover, the research underscores the above definition of spiritual care.[464]

Regarding the role of management of care institutions regarding spirituality in care practice, Lucas Tiesinga presented the following recommendation in regards

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[458] GKN/NHK, Euthanasie en pastoraat, 15.

[459] "The palliative care expert is qualified through recognised training in palliative care, work experience and substantive deepening and broadening and has specific knowledge and skills in complex palliative care and crisis situations. From his position, the palliative care expert works in a field where palliative care is the sole focus of the work" (IKNL/Palliactief, Kwaliteitskader palliatieve zorg Nederland, 2017, https://palliaweb.nl/getmedia/02b81c30-d9be-4c51-83bf-deb1260c-cf7b/Kwaliteitskader_web-240620.pdf).

[460] See also J.P. Vlasblom, "Spiritual care by nurses and the role of the chaplaincy in a general hospital," (PhD thesis, Vrije Universiteit Amsterdam, 2015).

[461] Jan P. Vlasblom, Jenny T. van der Steen, Dirk L. Knol and H. Jochemsen, "Effects of a spiritual care training programme for nurses," in Nurse Education Today 31 (8):790-796, DOI: 10.1016/j.nedt.2010.11.010.

[462] Vlasblom, "Effects of a spiritual care training programme for nurses," 795.

[463] Jan P. Vlasblom, Jenny T. van der Steen, Henk Jochemsen, "Spiritual care in a hospital setting: nurses' and patients' perspectives," in Nurse Reports 2012:2e7: 39-45, http://dx.doi.org/10.4081/nursrep.2012.e7.

[464] Vlasblom, "Spiritual care in a hospital setting: nurses' and patients' perspectives," 43.

to the role management can play in spirituality and care practice: "Management can do this by creating a space and atmosphere within the institution where attention to spiritual issues is legitimised and not limited to the private world of users or care providers, by discussing and establishing the institution-wide identity or mission statement regarding the spiritual functioning of users and care providers, and by stimulating (further) training of care providers who are not qualified or competent in the field of world view and spiritual care, although they should be qualified on the basis of good professional functioning."[465] Henk Jochemsen formulated quality criteria at the management level, beginning with identity policy, along three strategies: culture, structure and personnel management. He also formulated a list of criteria related to spiritual care for the management of institutions. Listed here are some of the themes he mentions:

- Conditions for providing spiritual care;
- Faith and worldview;
- Experiences and emotions;
- Courage, hope and growth;
- Religious customs and habits;
- Relationships and social connections.[466]

The Research Group Zorg en Zingeving [Care and sensemaking] of Viaa University for professional education in Zwolle, conducted research on spiritual care support and the role of nurses.[467] In general, spiritual care is seen as an aspect of nursing care. They also stress the importance of education to develop these competences. As an explanation for why nurses are sometimes somewhat reluctant to focus on the spiritual dimension, they mention that spiritual care is often not sufficiently embedded at the 'meso level' (i.e., at the ward or team level) of the organisation. One way to focus more also on spiritual aspects is by appointing a so called 'liasionf nurse' within the team. This is someone who understands individual cases, draws attention to the theme and also understands how management considers policy. The research group studied the implementation of such a liasion nurse in a hospital context. During the intervention, the nurses' competence in spiritual care increased and there were more referrals to spiritual caregivers. A similar intervention could be applied and used in other contexts. Furthermore, the *spiritual care competence scale* could be used in contexts where nurses may

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465 Lucas Tiesinga, "Levensbeschouwing en spiritualiteit in wetenschappelijk onderzoek en zorgpraktijk," in Jochemsen, Zinervaring in de zorg, 86.

466 Henk Jochemsen, "Verantwoordelijkheid van het management voor spirituele zorg," in Jochemsen, Zinervaring in zorg, 54-61.

467 B. Cusveller, A. Damsma-Bakker, T. Streefkerk, R .van Leeuwen, "Implementing 'Link Nurses' as Spiritual Care Support in a General Hospital," Religions 2020, 11(6), 308, https://doi.org/10.3390/rel11060308.

be more focused on physical care, and investigators want to determine whether sufficient attention is given to spiritual aspects.

The spiritual caregivers interviewed as part of this study indicated differences in how they interacted with other caregivers in practice:

- The timing of referrals depended on the personal relationship with the person accompanying them and was not determined by protocol. The spiritual caregiver was involved with patients/residents when they knew the palliative nurse, but not when there was not a personal relationship;
- One interviewee indicated that—together with the attending physician—he is structurally involved in palliative sedation;
- One interviewee emphasised Effective Interdisciplinary Collaboration (EIS) by stating that he was part of the team that cares for nursing home residents: physicians, nurses, psychologists, etc;
- Two of the four spiritual caregivers reported being involved with patients and residents because they have more time for spiritual attention than the palliative nurse. This indicates a more practical than substantive boundary between the spiritual duties of the two professionals;
- One spiritual caregiver observed that in his professional work he asks more probing questions about sources of strength, comfort and perspective than his palliative nurse colleague;
- One spiritual caregiver indicated that she did not actually know what the palliative nurse does about spiritual care;
- Some nurses felt that a spiritual caregiver was only needed with religious people. This misses the opportunity to be more broadly relevant to people struggling with questions of meaning;
- One spiritual caregiver is structurally involved with everyone in the hospice;
- One spiritual caregiver, involved in a traditional Reformed nursing home, indicated a fairly clear boundary: as soon as spiritual questions arise that relate to the patient's personal relationship with God, the spiritual caregiver is involved. Discussing these questions is not up to the (palliative) nurse.

Although the data are limited, this list shows ambiguity around roles and tasks of the palliative nurse and spiritual caregiver. This confusion does not benefit spiritual care. The functional approach to spirituality mentioned in the introduction may be of help. The functional approach differs from a substantial approach because a substantial approach to spirituality focuses on the content of what a person believes. The functional approach focuses on the role spirituality has in the person's life. The (palliative) nurse has a role in spiritual care when there is room for asking existential questions, regardless of which religion or worldview one adheres to. The Protestant spiritual caregiver can—but not exclusively! —ful-

fil the task of counselling patients/residents with corresponding religious convictions in their questions concerning, for instance, personal salvation. This requires connecting with the patient's experience and language, i.e. the professional field of the spiritual caregiver. This is where the substantial approach comes in.
In other words, a distinction can be made between spiritual care as an aspect of care (nurses) and spiritual care as a practice (spiritual caregivers).[468] Instead of "spiritual care", terms such as "dealing with life questions" or "helping with meaning" can also be used.

8.4 Dealing with indicators

The great strength of the spiritual caregiver with regard to dealing with a desire for termination of life is recognising and anticipating indicators of a patient's desire to request termination of life. In practice, it may be the nurses who can pick up on these indications (or "red flags"), and then respond or involve the spiritual caregiver.[469] Furthermore, it is possible that spiritual needs arise that the patient himself did not foresee but the nurse identifies.

The spritual caregivers interviewed indicated that about four times a year they encounter someone who specifically expresses a desire to die. Indications of a wish to die come up more frequently. They come up more casually, in a conversation about someone's life, for example. These indicators manifest themselves in statements such as:

"I don't need to live further."
"Life is done for me."
"I don't want to be a burden to my family any longer."
"For me, it has been enough."

These cues enable the spiritual caregiver to ask and reflect further. What are the underlying questions? "In the case of a euthanasia request, it is necessary to find out why someone says they want to die and whether such a person would still want that if the impetus for expressing such a indicator could be (partially) removed. Is it a persistent desire or is it a decision based on fear?"[470] What are one's

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[468] H. Jochemsen, M. Klaasse-Carpentier, B.S. Cusveller, et al, Levensvragen in de stervensfase. Kwaliteit van spirituele zorg in de terminale palliatieve zorg vanuit patiëntenperspectief. Report of the Prof. Dr. G.A. Lindeboom Institute no. 16 (2002), Ede, 15, 16.

[469] Henk Jochemsen, "Spiritualiteit en spirituele zorg in de gezondheidszorg," Tijdschrift voor Gezondheidswetenschappen 86, no. 2: 72.

[470] GKN/NHK, Euthanasie en pastoraat, 30.

sources of strength? This is, as it were, a search for value, for what is important to the person. Patients who lack quality of life are anxious and in pain. From which sources does the patient draw comfort and strength? What would motivate the person to get out of bed?

The spiritual caregiver can anticipate this search for what is valuable to a patient. For example, one of the spiritual caregivers recounted how a person with somewhat of a desire to die, told her she was actually still alive for her granddaughter but hardly saw her. Reconnecting the grandchild with the elderly lady gave the woman a renewed sense of worth and the latent desire to terminate her life abated. Another had a desire for euthanasia that was fuelled by a disturbed mother-daughter relationship. Once the relationship was re-established, thanks to intervention by the spiritual caregiver, the need for an active termination of life fell away. For good reason, Dr Alfred Sachs, family physician and researcher, characterises the needs of someone with a desire to die as a need for 'spiritual intimacy'.[471]

In the case of a more concrete desire to die, spiritual caregivers can adopt more of a position as discussed in the section on the spiritual caregiver as ethicist. In this role, they also look for sources of meaning, comfort and strength. One of the spiritual caregivers interviewed emphasised reflecting on biblical frameworks: what does God ask of us?

8.5 Role of the family

In daily practice, spiritual caregivers also recognise a role for the family in the decision-making process. The family can play a role in four ways:

1. The person with the desire to die does not want to be a burden on their family. It matters how the family responds to this. The family may, intentionally or unintentionally,affirm the person's life, or conversely the family may signal that the person may be 'a burden';
2. The family opposes the request for active termination of life;
3. The family is resistant to the way the person is suffering and consider it not a life worth living. As a result, they do not see, for example, that father or mother (the patient who wants to die) also enjoys life, fosters the feeling of 'being a burden' and can thus influence the decision-making process;
4. The family can respond positively to existential issues by pointing to sourc-

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[471] Dr Alfred Sachs at the symposium "Levenseindewet, summum van vrije wil? Een juridische, ethische en medische verkenning" organised by Juristenvereniging Pro Vita (JPV) on October 2, 2021.

es of strength and give the person's life meaning by being at the bedside (more), being present as a source of strength or providing practical support in meaningful activities.

It may be the role of the spiritual caregiver to address the wishes of the patient in a conversation with the family.

8.6 Concluding summary

Spiritual caregivers, especially in a healthcare institution, increasingly must deal with a plurality of worldviews among residents, clients and patients. This report takes an integrative approach that does justice to both the spirituality and the profession of the spiritual caregiver. The spiritual caregiver is rooted in the Christian tradition, as broadly understood.

In a care facility that identifies as Christian, the role of spiritual caregiver can be fulfilled through counselling and assisting people with a request for euthanasia where the *primary* task is to bring up God, the Father of Jesus Christ, and where the *secondary* focus is on issues of meaning. This does not mean that the timing or stage of conversation must be about God *first* and *then* about meaning. In practice, the spiritual conversation will take place in reverse order: from meaning to the philosophical, to God. The primary cannot be addressed without the secondary. End-of-life issues in the spiritual care context outlined above are about presenting the hope that is in Christ.

The WHO definition of palliative care attests to the fact that spiritual care is unmistakenbly linked to the dying phase. By spiritual care we mean "the world view and possibly religious functions of the human being, to which we include the questions of meaning experience and sense-making." This definition stems from a broad *functional approach* to spirituality in which this is seen as a role to be discerned in human existence; in other words as an anthropological structure. Spirituality is not a separate area of human existence, but an aspect of the whole of existence.

The spiritual caregiver is also as an ethicist. When a spiritual caregiver is 'consulted', it should not be seen as an afterthought, but as a request for help for a proper alignment of ethics and meaning.

In the light of political developments, spiritual caregivers should be prevented from having to participate in compulsory counselling that promotes euthanasia or assisted suicide.. People deserve to be helped in reflecting on their spiritual needs and existential questions rather than responding to their desire to die without question.

The task of the spiritual caregiver excludes the role of euthanasia counsellor and end-of-life counsellor, in line with the above meanings within the WTL and the Bill on Completed Life. After all, these roles assume the decision for euthanasia after which act is carried out as an appropriate medical act. . In terms of critical reflection on the process, there may be overlap in the roles of spiritual caregiver and those of the euthanasia counsellor/ end-of-life counsellor. However, as a whole, their rolescannot coincide.

The pastor's attitude is partly determined by the notion of 'helping', 'assisting' (which, by the way, does not override the task of ethical reflection!). Someone who is about to die is *supported*. This means that as much as possible keeping the person's questions and needs central.

Going along uncritically and unreflectively with a decision, request or wish for active termination of life conflicts with spiritual care conducted from the conviction that man is created in God's image, that God is focused on life and He has our times in His hand (Ps 31:16).

It is important for the management of healthcare institutions to feel partly responsible for the optimal spiritual functioning of both carers and caregivers.

A limited number of interviews revealed a lack of clarity around the roles and tasks of the palliative nurse and spiritual caregiver. This confusion does not benefit spiritual care. In practice, it may actually be nurses who can pick up on the signs of a desire to die, act on them or involve the spiritual caregiver.

Indicators of a desire to die are more often given than concrete expressions of a death wish. Those indicators come up more casually, in a biographical conversation, a conversation about someone's life course, for example. Together with the patient, the spiritual caregiver can look for sources of strength, for what is of value to someone.

Regarding the role of the family, it may be the role of the spiritual caregiver to explicitly address the wishes of the patient in a conversation with the family.

Sources

Literature

- Albert Schweitzer Ziekenhuis. *Euthanasie*. April 2019. https://www.asz.nl/specialismen/euthanasieconsulent/folders/euthanasie.pdf.

- Albert Schweitzer Ziekenhuis. “Euthanasieconsultant.” Accessed October 4, 2021. https://www.asz.nl/specialismen/euthanasieconsulent/.
- Beek, Bram van de. *Ego. Een cultuuranalyse van het ik*. Utrecht: KokBoekencentrum, 2022.
- Boer, Theo. “De modern geestelijk verzorger als ethicus: een toevalstreffer?” In: J.J.A. Doolaard et al (ed.), *Nieuw Handboek Geestelijke Verzorging*. Kampen: Kok 2006.
- Cusveller, B., Damsma-Bakker, A., Streefkerk, T. , Leeuwen, R. van. “Implementing ‘Link Nurses’ as Spiritual Care Support in a General Hospital. “ *Religions* 2020, 11(6), 308. https://doi.org/10.3390/rel11060308.
- Duyndam, Joachim. “Geestelijke begeleiding bij voltooid leven.” In *Waardenwerk*, 72 May 2018: 131-136.
- Duyndam_Waardenwerk_Voltooid_Leven.pdf (humanistischverbond.nl); see https://files.humanistischverbond.nl/app/uploads/2019/04/12095056/Duyndam_Waardenwerk_Voltooid_Leven.pdf.
- Frankl, Viktor E. *De zin van het bestaan*. Rotterdam: Ad Donker, 2020.
- GKN/NHK. *Euthanasie en pastoraat*. The Hague: Boekencentrum, 1998.
- Heitink, G. “Geestelijk verzorger: een ambt en een ambacht.” In: J.J.A. Doolaard et al (ed.). *Nieuw Handboek Geestelijke Verzorging*. Kampen: Kok 2006, 161-169.
- Huber, M., Vliet, M. van, Giezenberg, M., et al. “Towards a ‘patient-centred’ operationalisation of the new dynamic concept of health: a mixed methods study.” In *BMJ Open* 2016; doi:10.1136/bmjopen-2015- 010091.
- Huber, M., Garssen, B. “Relaties tussen zingeving, gezondheid en welbevinden.” In

  Wijgergangs, L., Ras, T., Reijmerink, W. *Zingeving in zorg. De mens centraal*. ZonMw, 2016: 17-21, https://www.iph.nl/assets/uploads/2020/12/ZonMw_zingeving_herdruk_totaal.pdf.
- IKNL/Palliactief. *Kwaliteitskader palliatieve zorg Nederland*. 2017. https://palliaweb.nl/getmedia/02b81c30-d9be-4c51-83bf-deb1260ccf7b/Kwaliteitskader_web-240620.pdf.
- Jochemsen, Henk. “Spiritualiteit en spirituele zorg in de gezondheidszorg.” *Tijdschrift voor Gezondheidswetenschappen* 86, no. 2: 71-72.
- Jochemsen, H., Klaasse-Carpentier, M., Cusveller, B.S., Scheur, A. van de, Bouwer, J. *Levensvragen in de stervensfase. Kwaliteit van spirituele zorg in de terminale palliatieve zorg vanuit patientperspectief.* Report by the Prof. Dr. G.A. Lindeboom Institute. no 16 (2002), Ede.
- Jochemsen, H. and Leeuwen, E. van (ed.). *Zinervaring in de zorg. Over de betekenis van spiritualiteit in de gezondheidszorg.* Assen: Van Gorcum, 2005.
- Timmerman - Van Rhee, J., Jochemsen, H. *Levensvragen… Een christelijke visie op geestelijke zorg in de terminale palliatieve zorgverlening met een handreiking*

voor zorgverleners. Prof. Dr. G.A. Lindeboom Institute.
- House of Representatives of the Netherlands. *Legislative Proposal.* 35 534-2. https://www.tweedekamer.nl/kamerstukken/wetsvoorstellen/detail?id=2020Z14112&dossier=35534
- House of Representatives of the Netherlands. *Explanatory Memorandum.* 35 534-3. https://www.tweedekamer.nl/kamerstukken/wetsvoorstellen/detail?id=2020Z14112&dossier=35534
- VGVZ, *Beroepsstandaard Geestelijk Verzorger*. 2016. https://vgvz.nl/wp-content/uploads/2018/07/Beroepsstandaard-2015.pdf.
- VGVZ . "Discussion members on 'Voltooid leven'." Accessed October 11, 2021. https://vgvz.nl/2017/05/01/discussie-leden-voltooid-leven/.
- Vlasblom, Jan P., Steen, Jenny T. van der, Knol, Dirk L. and Jochemsen, H., "Effects of a spiritual care training programme for nurses." In *Nurse Education Today* 31 (8):790-796. DOI: 10.1016/j.nedt.2010.11.010.
- Vlasblom, Jan, P., Steen, Jenny T. van der, Jochemsen, Henk. "Spiritual care in a hospital: nurses' and patients' perspectives." In *Nurse Reports* 2012:2e7: 39-45. http://dx.doi.org/10.4081/nursrep.2012.e7.
- Vlasblom, J.P. "Spiritual care by nurses and the role of the chaplaincy in a general hospital." PhD thesis, Vrije Universiteit Amsterdam, 2015.
- Wells, Samuel. *Een Nazaret-manifest. Met God zijn*. Translated by Zwany Kamerman. Franeker: Van Wijnen, 2020.
- World Health Organization. "Definition of palliative care." Accessed January 5, 2021. https://www.who.int/health-topics/palliative-care.
- ZorgenZ.... "Machteld Huber verovert met positieve gezondheid de zorg". Accessed October 26, 2021. https://zorgenz.nl/machteld-huber-verovert-met-positieve-gezondheid-de-zorg/.

Interviews

- Four anonymised spiritual caregivers affiliated with Protestant Christian nursing homes and also deployed - through centres for life questions - in non-hospital (spiritual) care;
- Jaap Gootjes, director hospice Kuria, Amsterdam.

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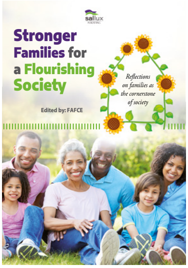

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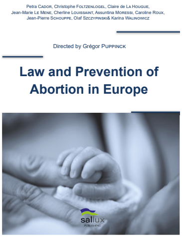

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Law and Prevention of
Abortion in Europe

Law and Prevention of Abortion in Europe

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“Sallux has provided substantial and very valuable support to our promotion of the rights of the family in Europe at the Council of Europe, a 27 Member States wide European institution that rules over Human Rights in Europe.”
Maria Hildingsson, former Director, FAFCE, Brussels

“Sallux has supported us to find our way in the European Union and to reach out to European decision makers, and to create our common declaration with the Yezidi and the Turkmen. We thank Sallux for their work.”
Rima Tüzun, Head of Foreign Affairs, European Syriac Union

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