

## University of Groningen

### At the boundaries of life

Brouwer, Marije

DOI:  
[10.33612/diss.159020586](https://doi.org/10.33612/diss.159020586)

**IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.**

*Document Version*  
Publisher's PDF, also known as Version of record

*Publication date:*  
2021

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*  
Brouwer, M. (2021). *At the boundaries of life: Suffering and decision-making in children with life-threatening conditions (1-12 years)*. University of Groningen. <https://doi.org/10.33612/diss.159020586>

#### Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

#### Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

*Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.*

## **CHAPTER 2**

### **Should pediatric euthanasia be legalized?**

M. A. Brouwer

C. Kaczor

M. P. Battin

E.L.M. Maeckelberghe

J.D. Lantos

A.A.E. Verhagen

Pediatrics. 2018 Feb 1;141(2).

## **Abstract.**

Voluntary active euthanasia for adults at their explicit request has been legal in Belgium and the Netherlands since 2002. In those countries, acceptance of the practice for adults has been followed by acceptance of the practice for children. Opponents of euthanasia see this as a dangerous slippery slope. Proponents argue that euthanasia is sometimes ethically appropriate for minors and that, with proper safeguards, it should be legally available in appropriate circumstances for patients at any age. In this Ethics Rounds, we asked philosophers from the United States and the Netherlands, and a Dutch pediatrician, to discuss the ethics of legalizing euthanasia for children.

Voluntary active euthanasia for adults at their explicit request has been legal in Belgium and the Netherlands since 2002.<sup>1</sup> Euthanasia, voluntary or nonvoluntary, remains illegal in the United States, although several states have legalized physician-assisted aid in dying for adults. No US state permits assisted dying or euthanasia for minors. Opponents of assisted suicide and euthanasia often claim that the legalization of such practices for competent adults will begin a slide down a slippery slope, leading to the legalization of voluntary euthanasia or physician-assisted death for patients who cannot consent.

In Belgium and the Netherlands, acceptance of the practice in adults has been followed by acceptance of the practice for children. But is that a slippery slope, and is it necessarily a bad thing? Proponents argue that euthanasia is sometimes ethically appropriate and that, with proper safeguards, access to it should not be limited by age. Others disagree. In this Ethics Rounds, we asked philosophers from the United States and the Netherlands, and a Dutch pediatrician, to discuss the ethics of legalizing euthanasia for children.

## **Introduction**

Euthanasia for adults has been legal in Belgium and the Netherlands since 2002.<sup>1</sup> It remains illegal in the United States, though many states have legalized physician-assisted suicide for adults. No state permits assisted suicide or euthanasia for minors. Opponents of assisted suicide and euthanasia often claim that the legalization of such practices for competent adults will begin a slide down a very slippery slope, leading to the legalization of voluntary euthanasia or physician-assisted death for patients who cannot consent. That has been the trend in Belgium and the Netherlands, where acceptance of the practice in adults was followed by acceptance of the practice for children. But is that necessarily bad thing? Proponents argue that euthanasia is sometimes ethically appropriate and that, with proper safeguards, access to it should not be limited by age. Others disagree. In this ethics rounds, we asked philosophers from the United States and the Netherlands, and a Dutch pediatrician, to discuss the ethics of legalizing euthanasia for children.

### ***The Case***

Adults and children of 12 years and older can legally request euthanasia in the Netherlands under the 2002 Euthanasia Law. Requests for euthanasia often come from patients experiencing unbearable suffering with no prospect of improvement. Their request must be made earnestly and with full conviction and are only honored if patients and their doctors see euthanasia as the only escape from the situation. Acts of euthanasia are reported to the Ministry of Health and are reviewed to ensure that they comply with the law. In addition, since 2005, neonatal euthanasia for infants <1 year of age has been permitted by a regulation known as the 2005 Groningen Protocol. In the past 10 years, only 2 cases of neonatal euthanasia were reported.

In the last 15 years, seven cases of euthanasia in minors between 12 and 18 years old have been reported. The majority concerned children with terminal cancer. All cases were retrospectively assessed by a multidisciplinary review committee and considered appropriate. Nobody was prosecuted.

Dutch pediatricians and several parent-groups have argued that severely ill children between 1-12 years of age and their families are denied access to the same provisions as newborns and older children without good reasons. They suggest reevaluation of the current

legal situation and propose to extend the newborn regulation to all children 1-12 years of age. The Minister of Health is considering transformation of these propositions into new regulation.

You are asked to advise the Minister of Health. What advice would you give?

***Professor Kaczor comments:***

I would advise the Minister of Health not to expand the range of cases in which intentional killing of innocent human beings is permitted by law.

Defenders of the Dutch law permitting intentional killing of infants as well as adults and children of 12 years and older presuppose an empirical claim: killing a person is “the only escape from the situation” of unbearable suffering. This claim is false. Terminal sedation is a contemporary technique of palliative care in which a person who was suffering is relieved of pain entirely by the continuous infusion of sedatives that entirely relieve all pain. Terminal sedation can be administered to infants, children, or adults who are suffering and cannot be cured of their disease. If we care about suffering people, let us relieve their suffering rather than killing them.

Eventually, terminal sedation leads to death. Over time the dosage of sedatives must be increased. At a certain point, the dosage may be so high that the death of the patient may be foreseen as an unintended but certain side-effect. While it is true that increasing the dosage of the sedatives may be necessary over time to continue to relieve suffering, relieving suffering in this way is ethically permissible, even if death as a side-effect occurs. (For more on why this distinction is legally and ethically important, see the legal philosopher John Keown’s *Euthanasia Examined*, Cambridge University Press).

All people of good will agree that we should alleviate suffering. The legalization of euthanasia and its expansion to new classes of persons, not its criminalization, which hampers achieving this goal. If we kill patients rather than relieving their pain, the practice of euthanasia undermines the practice of palliative care. Why worry about alleviating someone’s pain, when we can simply kill the person? The more people who choose euthanasia and the more euthanasia is non-voluntarily imposed on patients, the less incentive there is to improve methods of palliative care. The more physicians practice euthanasia, the less these physicians practice relieving pain. The more people who die from euthanasia, the fewer people demanding greater palliative care. If demand for palliative care is dampened, there is less financial incentive for

developing new methods of alleviating pain. The more euthanasia is expanded, the less pressure to improve palliative care because killing will be seen as a simpler, cheaper option.

Perhaps worst of all, expanding the scope of legalized euthanasia undermines compassion for those who suffer. Some people will think or even say, “Euthanasia is legal, but this person did not choose it. If she is refusing euthanasia and is choosing to suffer rather than die, that is her problem. Why should we help her when she is not even helping herself?” Legalizing euthanasia endangers and undermines those at the end of life, especially those who choose not to kill themselves.

Moreover, euthanasia is not properly described as “relieving suffering.” A suffering person who is relieved of suffering is in a position to experience the relief of suffering. But a person who is killed is dead, and so such a person no longer has any bodily experiences. The corpse of a person who has been killed does not feel pain nor the relief of the pain. A corpse feels nothing. Indeed, human beings who are killed no longer exist at all, so euthanasia does not ‘relieve’ their suffering.

Moreover, most philosophers draw an important distinction between voluntary and non-voluntary euthanasia. In voluntary euthanasia, a competent patient chooses to die based on his or her own evaluation of his or her life. In non-voluntary euthanasia, no such consent is given. Children under 12 years of age are incapable of giving informed consent for meaningful life decisions. For this reason, we do not permit children under 12 years of age to consent to their own sterilization, to vote in elections, to join the military, to get married, or to have sexual intercourse. The choice to end one’s own life or to authorize another person to end one’s own life is much more serious than the choice to join the military, to get married, or to have sexual intercourse, since these decisions can be reversed and do not complete change an individual’s life in every respect. Current Dutch law does allow for non-voluntary euthanasia of infants, an allowance incompatible with the principles of justice because such infants do not consent to have their lives ended. If all persons are to have equal rights and deserve equal protection of the law, then disabled persons (whether they are infants, children, or adults) deserve the same basic protections from intentional homicide.

***Margaret P. Battin PhD, comments:***

My Dear Minister of Health,

Thank you for asking for my input on this important topic. As you may know, I have long been an advocate for legalized aid in dying in the United States and have published a number of books on the topic. I generally support your proposed change in Dutch law governing eligibility for euthanasia. Given that euthanasia is currently legal for babies under one and children and adults over the age of twelve, I believe that opponents would have to show evidence that at least one and perhaps many of the following propositions are true if they are to persuade you not to support this change in the law:

That children 1-12 don't die.

That children 1-12 don't die badly.

That most prognoses of death in children 1-12 are wrong, so that the law would lead to deaths in children who would have survived.

That parents aren't harmed by seeing their children suffer.

That parents would never allow this; they'd rather see their children suffer.

That pediatricians are in general more interested in their own pocketbooks than in the welfare of their patients.

That pediatricians would be corrupted, and find it easy to terminate the lives of patients they couldn't cure.

That pediatricians can't understand the difference between killing a healthy, curable child and hastening a bad death that is already in progress.

That pediatricians would end the lives of children no matter what the parents said.

That allowing this practice would lead to wholesale killing of children 1-12.

That it is always wrong to end a life. (Proponents of this view would need to address situations such as killing in war, killing in self-defense, killing in defense of others, and (more controversially) capital punishment; they would also need to oppose current laws in the Netherlands that allow euthanasia for children under 1 and adults 18 and over.)

That "euthanasia" is the same as (wrongful) killing, and doesn't refer to helping someone who is already dying die in an easier, gentler way.

That God wouldn't want physicians and parents to help dying children in this way.

My dear Minister, if there is no evidence to support any of these propositions, then the case against extending the age limits of eligibility for euthanasia is not very strong. These questions concern error, abuse, religious objections, consistency, informed consent, physician

integrity, and complacency about the suffering of a child, all the usual objections that are made. I have trouble imagining other ways that opponents of this extension could make a case at all.

But there is, of course, another problem, and one that is not evidence-based. The word “euthanasia” carries important baggage. There in the Netherlands you generally understand it in the Greek sense, *eu-thanatos*, by which it literally means “good death.” But here in the U.S. and in much of the rest of the world, we hear “euthanasia” with overtones of Nazism. Here, the very term euthanasia evokes that legacy of political killing that had nothing to do with the interests of the person killed; for you, it is a term that connotes mercy, compassion, understanding, and the willingness to help someone avoid otherwise intolerable suffering. I mention this only because readers in other countries might come across this letter, and misunderstand the decision you are making.

So, dear Minister, please be as clear as you possibly can that you are only legalizing euthanasia in the Dutch sense. That is, you want to permit the ending of life in a way that, given the unbearably sad circumstances of a child’s dying, can make that gentler, easier, and more humane for both the child and for the parents in whose arms you can help that death to occur.

In sum, I urge you to accept the proposed changes to the regulations. There’s no good argument against doing so and plenty of good reason to say *yes*.

***Drs. Marije Brouwer, Els Maeckelberghe, PhD, and Professor Eduard Verhagen comment:***

We would advise the Minister of Health to consider removing age restrictions from both the Euthanasia Regulation and the Groningen Protocol, and make euthanasia possible both for competent children, and incompetent children who suffer unbearably, when there is no other way to relieve their suffering. It would show trust in mature minors, parents, and doctors to make the right decisions. However, before implementing our recommendation, we would urge the minister to initiate research to monitor and analyze how euthanasia was being used.

Our advice to remove age restrictions is in line with important Dutch values. We believe in self-determination - as manifested by the voluntary request that initiates the procedure— and in the beneficence of physicians to end unbearable suffering when there are no other options.

*Self-determination, parental-determination, and beneficence.*

We believe that the current legal age limit for euthanasia needs to be revised. The current law connects the mental competence necessary for a euthanasia request with a fixed age: twelve

years. This age limit, however practical it might be, is arbitrary. It excludes children capable of discernment at an earlier age. There is evidence that some children up from the age of 8 are competent to make complex choices regarding their treatment.<sup>2</sup> The right of self-determination – one of the two core values of euthanasia– knows no age limit.

Second, we need to consider that many children lack this mental competence. For them the amendment of the Euthanasia Act will not suffice. With the 2005 Groningen Protocol, the Netherlands has an option of euthanasia for incompetent patients younger than one.<sup>3,4</sup> An extension of the Groningen protocol could provide a way out for incompetent children with unbearable and hopeless suffering.

The Groningen Protocol demands parental agreement. This provides a specific extension of the notion of self-determination that we would like to call parental-determination. This parental-determination is a bridge between self-determination and beneficence. For a doctor to act beneficently, he needs to have sufficient understanding of the child's suffering. The parents provide a specific and necessary perspective on the child's suffering, informed by family values, intimate knowledge of the child, and their view on its quality of life. This parental-determination prevents euthanasia for incompetent children to become an out-of-balance decision only based on beneficence.

We would cautiously remind the minister that the group of incompetent patients, who also might suffer unbearably, is not limited to the age of twelve but encompasses patients of all ages.

### *Research*

We would stress that our recommendations should be accepted only in conjunction with a requirement for research. There are at least five reasons why we need to obtain accurate data before we make any permanent change in the existing regulation.

First, in contrast to the extensive data about end-of-life decisions in newborns and over 12-year-old patients, there is hardly any research on end-of-life decisions in the age range of 1-12 years. We need to know what care is provided, which decisions are made for these children and how they died.<sup>5</sup>

Second, because this law would only affect terminally ill children, we would need to study the way such children make decisions. Are they more mature than healthy children and thus more competent to make important health related decisions? Or are they particularly

vulnerable and immature as a result of their illness? There is a lack of scientific knowledge about the decision-making capacities and competence of incurably ill children. We should study that more thoroughly.

Third, the central notion of unbearable suffering needs to be studied. This will help physicians and parents make decisions concerning the end of life. Understanding the suffering of a child is challenging because of its personal nature.<sup>6</sup>

We propose to examine the circumstances around death and dying in that age group, and collect data about 'suffering' using patients experience and parental observations. While an objective description of suffering is out of reach, by collecting experiences from people who encounter unbearable suffering in children, we can obtain a more experience-based understanding of it. Specific (anonymized) cases should be made available to researchers.

Fourth, we need to scrutinize the legal and moral complications of the notion of parental-determination. Are there limits? What happens -in those rare cases-if parents seem to be considering their own needs rather than the needs and interests of the child. Again, detailed case studies would help.

Fifth, we need to better understand the problems that parents and physicians currently face in end-of-life situations. This will help understand the current demand for pediatric euthanasia. In particular, we need to know whether expert palliative care and symptom management are available, and if euthanasia would indeed be the only way to relieve the suffering of these children.

Recently, the minister of Health, Welfare and Sport has made a first step towards acquiring more data by supporting a research-proposal for thorough qualitative research, where parents, physicians and children are interviewed. The aim of the study is to get a better understanding of motivations for and different perspectives on a euthanasia decision and to collect narratives of assessing suffering. This data could be used to make thorough decisions about the amendments in the law and to compare end of life experiences before and after the age limit was removed.

We would add a final bit of advice to the Minister, one from the heart: please do not only provide legal possibilities, but ensure optimal support and care for parents, children and physicians who face such a decision.

*John D. Lantos comments:*

Most philosophical arguments for assisted suicide or euthanasia focus on cases in which people experience intractable pain and suffering. By contrast, most people who choose to end their lives are not motivated by physical pain. Instead, the most common reasons people give for making the choice to end their lives are fears about the loss of autonomy or a desire not to be a burden to others.<sup>7</sup> People who request aid-in-dying also have higher levels of depression, hopelessness, and dismissive attachment (attachment to others characterized by independence and self-reliance), and lower levels of spirituality than comparable terminally ill patients who do not request aid-in-dying.<sup>8</sup>

None of these common rationales for assisted suicide are particularly applicable to children. Instead, as noted in the Groningen Protocol for neonatal euthanasia, the focus of euthanasia eligibility criteria for babies is “unbearable suffering.”<sup>9</sup> This is an important distinction, because unbearable suffering can usually be treated by high-quality palliative care. Patients who are in pain or who have unbearable suffering can be treated with steadily increasing doses of narcotics. Then, either their pain will be relieved or, in rare cases, they go on to respiratory failure and death.<sup>10</sup> Treatment of the sorts of existential suffering and fears about the future that is the more common justification for assisted suicide or euthanasia in adults will require a very different sort of assessment and response. In those cases, the goal is not to relieve current suffering. It is to prevent the possibility of future suffering. Such concerns will generally not be relevant to children. Children generally don’t fear becoming a burden on others. They don’t worry about the loss of future autonomy. Because the circumstances for of and rationales for euthanasia or assisted suicide are so different in children than adults, it seems unlikely that simply extending the legal framework that is used in adults to younger and younger people will be either useful or necessary. Instead, the best approach to the treatment of pain and suffering in dying children would seem to be better palliative care with an understanding that, sometimes, very rarely, such care may lead to situations in which good pain treatment hastens death. To accept that would not require a change in the law.

## References.

Legemaate J, Bolt I. The Dutch Euthanasia Act: recent legal developments. *Eur J Health Law*. 2013;20(5):451-469.

<sup>1</sup> Hein IM, Troost PW, Lindeboom R, Benninga MA, Zwaan CM, van Goudoever JB, et al. Key factors in children's competence to consent to clinical research. *BMC Med Ethics*. 2015;16(1):74.

<sup>1</sup> Ministerie van Veiligheid en Justitie en de Minister van Volksgezondheid WeSMoSaJatMoH, Welfare and Sport]. . Regeling beoordelingscommissie late zwangerschapsafbreking en levensbeëindiging bij pasgeborenen [Regulation Late-term Abortion and termination of lives of Neonates]. *De Staatscourant*. 2016(3145):1-8.

<sup>1</sup> Verhagen AAE, Sauer PJ. End-of-life decisions in newborns: an approach from The Netherlands. *Pediatrics*. 2005;116(3):736-9.

<sup>1</sup> Dan B, Fonteyne C, de Cleyt SC. Self-requested euthanasia for children in Belgium. *Lancet*. 2014;383(9918):671-2.

<sup>1</sup> Cassel EJ. The nature of suffering and the goals of medicine. *The New England journal of medicine*. 1982;306(11):639-45.

<sup>1</sup> Oregon Health Authority. Oregon Death With Dignity Act: Data Summary 2016, <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf>. Accessed April 7, 2017.

<sup>1</sup> Smith KA, Harvath TA, Goy ER, Ganzini L. Predictors of pursuit of physician-assisted death. *J Pain Sympt Management* 2015; 49:555-61.

<sup>1</sup> Verhagen E, Sauer PJJ. The Groningen Protocol – euthanasia for severely ill newborns. *N Engl J Med*, 2005;352; 959-62.

<sup>1</sup> Henderson CM, Fitzgerald M, Hoehn KS, Weidner N. Pediatrician ambiguity in understanding palliative sedation at the end of life. *Am J Hosp Palli Care* 2017;34:5-19.

