

# LEGALIZING EUTHANASIA: WHAT WE CAN LEARN FROM THE NETHERLANDS

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The legalization of euthanasia is increasingly a topic for discussion in countries across Europe. During these discussions, references are often made to the Netherlands, the first country in the world that legalized euthanasia. This publication provides a historical overview, a description of the current state of affairs and an analysis of Dutch euthanasia practice.





#### PREFACE

The European Christian Political Movement (EPCM) and NPV-Zorg voor het leven (NPV-Care for life) noticed that the legalization of euthanasia is being debated in an increasing number of national parliaments and that in some countries legislative proposals have been developed to realize this. Oftentimes, the Netherlands is seen as a positive example of a society in which euthanasia is integrated.



In order to ensure that policy makers and other parties can make informed decisions about euthanasia issues in their countries, this publication provides a historical overview, a description of the current state of affairs and an analysis of Dutch euthanasia practice. Thereby, it shows which lessons can be learned from the Netherlands. This publication is the result of a collaboration between the ECPM, an organization with years of political experience, and the NPV-Zorg voor het leven, a Dutch organization that has built up years of expertise in bioethical reflection around this theme.

Source: Tingey Injury law firm / unspash.com

In 2001, the Netherlands was the first country in the world that legalized euthanasia by adopting the 'Termination of Life on Request and Assisted Suicide Act'. Initially, this act was meant for persons who were in the last stages of life and who were terminally ill. In the

meantime, however, the category of people qualifying for euthanasia kept expanding. Even euthanasia on babies and patients with dementia has become a practice now: euthanasia for defenceless people who do not realize they are being put to death. In a further effort to erode the euthanasia law standards, sustained political pressure is now being carried out to pass 'completed life law' and to legalize a 'kill pill' for those who do not have an unbearable physical or mental disease, but for people that suffer from life itself or think that their life is completed. In the public debate it is often emphasized that euthanasia is about autonomous persons who decide for themselves when to end their life. However, if one digs deeper, one will discover all types of external factors which exert undue influence on what is supposed to be the decision of an autonomous person. Research showed that in 'completed life' cases, loneliness is often the issue. LEGALIZING EUTHANASIA



Or feelings of hopelessness, that things do not matter anymore. Or the fear of being a nuisance to one's own children. Persons who say that their life is completed are often persons who are tired of life or are terribly afraid of continuing to live. Death, therefore, is presented as a solution. Our fear is that a 'completed life law' will put undue pressure on vulnerable people. We fear that our society will find it normal eventually that people who grow old take their own lives; that they will have to defend themselves if they choose to live rather than die.

We believe that we are created in the image and likeness of God. Therefore, life should be protected from the beginning until the natural death, which is the basis for human dignity. It is our responsibility to protect the weak, old, and fragile in our society. Therefore, for many Christians, euthanasia is unacceptable. At the same time, non-Christians recognize that argumentation against legalizing euthanasia is not only religious. Life is sacred and laws that legalize euthanasia have serious and far-reaching consequences: for society, but especially for the vulnerable groups. If someone asks assistance to terminate his or her life, the answer should focus on the underlying causes and on trying to help a person feel that life is worth living. To this end, we advocate for and support palliative care: high-quality, personalized help and care which safeguards the dignity of a person in the last stages of life rather than on terminating it.

This publication describes the Dutch law and its implementation and consequences; it examines the trends, the alternatives for euthanasia and the groups to whom euthanasia is applied. In addition, the issues related to a 'completed life law' are explored. This way, we hope that this publication will provide a real picture of the consequences of the Dutch euthanasia legislation and the dangers related to this. Our wish is that decision makers in Europe and beyond bear the lessons that can be learned from the Netherlands in their mind when working on this matter.

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## INTRODUCTION

The legalization of euthanasia is increasingly a topic for discussion in countries across Europe. During these discussions, references are often made to the Netherlands, the first country in the world that legalized euthanasia in 2001 by adopting the 'Termination of Life on Request and Assisted Suicide Act'.

Euthanasia is understood as the intentional termination of someone's life, at that person's request, performed by a physician. In the case of physician assisted suicide (PAS), the person administers the prescribed lethal medication himself, with the assistance of the physician<sup>1</sup>.

The Dutch so-called 'euthanasia law' states that euthanasia and physician-assisted suicide are not punishable if the physician acts in accordance with the 'criteria of due care'<sup>2</sup>. These criteria stipulate that euthanasia will be performed at the patient's request, that his or her suffering is unbearable and with no prospect of improvement, that the patient has been fully informed, that there are no reasonable alternatives, that another physician is consulted, and that the euthanasia is carried out in a medically appropriate way<sup>3</sup>.

Since the legalization of euthanasia, in practice, the grounds for performing euthanasia in the Netherlands have been broadened: euthanasia is not only allowed for terminally ill persons, but also for patients with psychological problems, persons with severe dementia, and even for children. There is still debate about the grounds for euthanasia: since 2010, there has been a discussion to draft a law that will allow assisted suicide for healthy persons above 70 years old if a person feels they have a 'completed life<sup>4</sup>. And currently, there is a discussion about euthanasia<sup>5</sup> for children 1-12 years old.

#### Arguments used to broaden access to euthanasia

Two main arguments are used in the discussion to legalize or broaden the possibilities to provide euthanasia. First, that death is a private matter and if someone wishes to die, they should have the option to 'die with dignity': the autonomy of people should be respected. The argument of personal autonomy in expanding the grounds for euthanasia plays an important role in the discussion whether persons who think they have a 'completed life' should be able to get assisted suicide or not. Additionally, this argument is also used in the discussion on the legalization of a 'kill pill' (the so called Drion pill).

The second argument used to broaden the access to euthanasia is based on the idea of compassion: that it is better to terminate a person's life if this person is severely suffering. This argument is included in the Dutch law, since it states that euthanasia is only available to people whose suffering is unbearable and shows no prospect of improvement. Although this criterium is open to interpretation, the norm is that a medical condition must be the underlying reason for euthanasia.

The argument of 'compassion' also plays a significant part in the discussion about euthanasia for sick children, people with severe dementia and other people who are incapacitated<sup>6</sup>, since the argument of autonomy does not count for these groups because they cannot always make decisions on their own.

#### **Opposition to broadening access to euthanasia**

An increasing number of physicians, healthcare providers and bioethicists are concerned about the pressure applied on expanding the grounds for euthanasia. Independent research, initiated by the Dutch Government, shows the dangers of expanding access to euthanasia. It also warns policymakers against allowing assisted suicide in cases where people feel they have a 'completed life'. In this publication, we aim to analyse the Dutch law, its implementation, and consequences. We look at trends, the alternatives for euthanasia and the groups to whom euthanasia is applied. We are also reviewing the issues related to assisted suicide when one feels his/her life is complete. By conducting this analysis, we wish to answer the question whether euthanasia is a matter of human dignity or is a danger to our humanity.

## THE DUTCH LAW ON EUTHANASIA

#### **OVERVIEW**

The debate on euthanasia started in 1973, when a Dutch physician, Dr. Postma, gave her mother a lethal injection. As a result, she was sentenced by the highest Dutch court to a week in prison. This case led to the creation of the Dutch Association for the Right to Death (Nederlandse Vereniging voor een Vrijwillig Levenseinde - NVVE), the most vocal pro-euthanasia Dutch association. In 1984, E Wessel-Tuinstra (from the D66 party) presented the first draft law on euthanasia. In 2001, the Netherlands became the first country in the world that legalized euthanasia and assisted suicide. The law on euthanasia came into force on 1 April 2002.

<sup>1</sup> Once it is determined that the person's situation qualifies under the physician-assisted suicide laws for that place, the physician's assistance is usually limited to writing a prescription for a lethal dose of drugs.

<sup>2</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC2781018/

<sup>3</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC2781018/

<sup>4</sup> https://d66.nl/standpunten/voltooid-leven/

<sup>5</sup> In the Netherlands, it is not common to speak about **'child euthanasia**' because the Dutch definition of euthanasia implies a request. Since children can't do official requests, the term **'child euthanasia'** is not used. In these cases, Dutch people use the term **'active termination of life'**. However, for reasons of clarity and because this publication is addressed to an international audience, we will use the term **'euthanasia'**, also in reference to children.

<sup>6</sup> Incapacitated persons are those who are not able to formulate and express their will.



The Termination of Life on Request and Assisted Suicide (Review Procedures) Act (also called: 'euthanasia law') states that euthanasia and assisted suicide are not punishable if the physician acts in accordance with the following criteria<sup>7</sup>:

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- The patient's suffering is unbearable with no prospect of improvement.
- A patient made a request for euthanasia, which was voluntary and persisting over time. The patient must be fully aware of his/her condition, prospects, and options.
- There must be consultation with at least one other independent doctor who needs to confirm the conditions mentioned above.
- There is no other reasonable solution to alleviate suffering. This does not mean, however, that the patient must have tried all possible treatments. For example, when the effect of a treatment is limited or someone thinks the treatment is too heavy, the decision can be made not to start or continue treatment.
- Euthanasia must be carried out in a medically appropriate fashion by the doctor or patient, and the doctor must be present.
- The patient is at least 12 years old (patients between 12 and 16 years of age require the consent of their parents. In patients 16 and 17 years old, parents must be involved in the decision making process, but consent is not needed).

## WRITTEN WILL

An oral request is not mandatory in all euthanasia cases. Physicians are allowed to perform euthanasia on incapacitated persons who do not orally request for euthanasia, but who have stated in a 'written will' (or sometimes called a Euthanasia Statement) that they want euthanasia in a certain -future- situation.



7 Dutch law: Termination of Life on Request and Assisted Suicide Act / wetten.nl - Regeling - Wet toetsing levens¬beëindiging op verzoek en hulp bij zelfdoding - BWBR0012410 (overheid.nl)

#### AN INCREASE IN DEMAND

Euthanasia cases must be reported to one of the five regional euthanasia review committees. These are committees that review the practice of euthanasia after the patient's death. The following euthanasia cases were reported in the period between 2002 (when euthanasia was legalized) and 2020.



Source: Jaarverslagen RTE<sup>8</sup>

Despite some fluctuations, there is a large annual increase in the number of deaths by euthanasia. In 2011, euthanasia or assisted suicide was reported for 3695 people. This figure was 18 percent higher than the previous year and it was double the 2006 figure. In 2012, 4188 cases were reported to the euthanasia review committees compared to 1882 in 2002. More recent information shows that the number kept increasing. In essence, the Netherlands registered an increase in demand for death by euthanasia every single year since the law was passed.

## EUTHANASIA AND COVID-19

In 2020, the number of reported deaths has increased to 6938 persons (which is an increase of 9.2% compared to 2019)<sup>9</sup> This is 4.1% of the total number of deaths in the Netherlands (if we do not consider the 15,000 extra deaths because of the COVID-19, the percentage is 4.5%)<sup>10</sup>. The percentage of persons who died by euthanasia is probably greater since not all cases of euthanasia are reported; the reported rate is 81%<sup>11</sup>.

<sup>8 &#</sup>x27;Jaarverslagen RTE' reports are published annually by the Dutch government.

<sup>9</sup> https://www.rijksoverheid.nl/documenten/rapporten/2021/04/20/regionale-toetsingscommis¬sies-eu-thanasie-jaarverslag-2020

<sup>10</sup> Regionale Toetsingscommissies Euthanasie - Jaarverslag 2020 | Jaarverslag | Rijksoverheid.nl

<sup>11</sup> https://publicaties.zonmw.nl/derde-evalua¬tie-wet-toetsing-levensbeeindiging-op-verzoek¬-en-hulp-

Legalizing euthanasia



The increase during 2020 is especially noteworthy, since the Euthanasia Expertise Centre (the centre responsible for performing euthanasia) suspended its activities for several weeks and the centre's availability of doctors and nurses declined by 20% during the crisis<sup>12</sup>. As a result of that, we should have had a decline in euthanasia reports. However, as the data showed, the euthanasia cases increased compared to the previous year. Another worrisome development during the pandemic is that the physical consultation with a second independent doctor was replaced by a video consultation<sup>33</sup>. Since a video session is less personal than a physical consultation, this should not have been allowed for such an irreversible and difficult decision as euthanasia. Several political parties (SGP, CU, JA21) have rightly asked parliamentary questions about the euthanasia practice during COVID-19<sup>14</sup>.

## THE ISSUE OF THE 'MOBILE HEALTH TEAMS'

Another worrying development in the Netherlands was the establishment of the 'mobile health teams'. Under the name of 'End of Life Clinic', NVVE<sup>15</sup> founded a network of 'mobile health teams' willing to travel to patients who requested euthanasia but there was no available doctor to turn to. The law on euthanasia assumes (but does not require) a stable and trusted relationship between the patient and the doctor. When such a relationship exists, death might be the end of a period of treatment and interaction between them. On the contrary, the doctors of the 'mobile health teams' see each patient on average three times before giving them the drugs needed to end their lives. Therefore, no relationship has been established, and it is not possible to assess what lies behind someone's request to die or to explore alternatives in such a short time.

In 2019, the End of Life Clinic, changed its name to Euthanasia Expertise Centre. In 2020, 899 of euthanasia cases (12,96%) were carried out by a doctor connected to this Centre<sup>16</sup>.



Number of euthanasia cases performed by the Euthanasia Expertise Centre (blue bars) and percentage of these cases compared to the total number of euthanasia cases (red line). Sources: KNMG euthanasia in numbers 2016<sup>17</sup>; KNMG euthanasia in numbers 2020<sup>18</sup>

The table above shows a worrying increase of the percentage of euthanasia that is performed by the Euthanasia Expertise Centre. It shows that euthanasia is becoming a stand-alone act one can ask for, instead of an act taken within and based on a stable doctor-patient relationship, after a period of treatment and interaction.

## EUTHANASIA FOR PSYCHIATRIC PATIENTS

NIVEL (The Netherlands Institute for Health Services Research) presented in 2012 a research showing the change in profiles of persons who requested euthanasia or assisted suicide in the last thirty years<sup>19</sup>. The research showed that the character of euthanasia requests had slightly changed in the last thirty years. Besides pain, the loss of dignity and significance were important reasons for requesting euthanasia. In the Netherlands, the reasons for euthanasia requests are:

| Year | Dementia   | Psychiatric | Accumulation of    | Cancer       | Other        |
|------|------------|-------------|--------------------|--------------|--------------|
|      |            | Disorder    | old age complaints |              |              |
| 2011 | 48 (1.3%)  | 13 (0.4%)   |                    | 2797 (76%)   | 836 (22.3%)  |
| 2013 | 97 (2.2%)  | 42 (1.0%)   | 251 (5.7%)         | 3581 (81%)   | 457 (10.3%)  |
| 2015 | 109 (1.9%) | 56 (1.0%)   | 183 (3.3%)         | 4000 (73%)   | 1351 (24%)   |
| 2017 | 169 (2.6%) | 83 (1.3%)   | 293 (4.4%)         | 4236 (64.3%) | 1804 (27.4%) |
| 2019 | 162 (2.5%) | 65 (1.1%)   | 172 (2.7%)         | 4100 (64.5%) | 1859 (29.2%) |
| 2020 | 170 (2.5%) | 88 (1.3%)   | 235 (3.4%)         | 4480 (64.6%) | 1965 (28.3%) |

Source: KNMG Euthanasia in cijfers 2016; KNMG euthanasie in cijfers 2020 , Jaarverslagen RTE's

17 https://www.euthanasiecommissie.nl/uitspra¬ken/publicaties/infographic/infographic-knmg/infographic-knmg/euthanasie-in-cijfers-2016

<sup>-</sup>bij-zelfdoding/ (Third evaluation of the Termination of Life on Request and Assisted Suicide Assessment Act, Zon Mw Digitale Publicaties, page 182)

<sup>12</sup> https://www.medischcontact.nl/nieuws/laat¬ste-nieuws/nieuwsartikel/expertisecentrum-eutha¬nasie--stopt-met-hulp-wegens-corona.htm

<sup>13</sup> Regional Euthanasia Review Committees - Annual Report 2020 Jaarverslag | Rijksoverheid.nl

<sup>14</sup> Strong increase in the number of cases of euthanasia | Tweede Kamer der Staten-Generaal https:// www.tweedekamer.nl/kamerstukken/kamer¬vragen/detail?id=2021Z07397&did=2021D23768

<sup>15</sup> NVVE is the Nederlandse Vereniging voor Vrijwillige Levenseinde, the Dutch Association for the Right to Death.

<sup>16</sup> KNMG euthanasia in numbers 2020

<sup>18</sup> https://www.knmg.nl/infographic-euthanasie/

<sup>19</sup> https://www.nivel.nl/nl/publicatie/impact¬-dutch-euthanasia-act-number-requests-euthana¬sia-and--physician-assisted-suicide



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Just by looking at these numbers, you can see an increase in psychiatric disorders as a reason for euthanasia. When coupled with the fact that physicians at the Euthanasia Expertise Centre (who do not have a stable relationship with the patient) often provide euthanasia to this vulnerable group, there are legitimate reasons for concern. For example, in 2020, 62 out of the 88 psychiatric disorder- based euthanasia cases were carried out by a physician at the Euthanasia Expertise Centre.<sup>20</sup>.

In 2017, Damiaan Denys, President of the Professional Association of Psychiatrics called for restraint when it came to providing euthanasia to psychiatric patients: "*There is every reason to be careful*". Jim van Os, Head of the psychiatric department at the Academic Hospital of Maastricht and professor in psychiatrics at the Academic Hospital of Utrecht stated that: "*the Euthanasia law is slowly being eroded*. While it used to be about people with untreatable cancer who had only two weeks to live, now it concerns patients with a mental illness who may live for another 20 years." He added that: "If this continues like this, then euthanasia could become the next medical escalation. I find this a worrisome development"<sup>21</sup>. In the Dutch news program 'Een Vandaag', Professor Frank Koerselman mentioned two concrete cases of psychiatric patients who were assisted to be euthanized in the End of Life Clinic in 2016. Neither case was related to 'unbearable suffering' without prospect of improvement. There were a lot of possibilities for treatment, but these were rejected by the patients. One of the cases concerned a patient who refused to take anti-depressive medication because of the side effects. This person, however, was assisted in euthanasia<sup>22</sup>.

#### **EUTHANASIA FOR PERSONS WITH DEMENTIA**

In 2020, a physician who ordered an elderly dementia patient's family to hold her down as she was given a lethal euthanasia injection, has been cleared of any wrongdoing by the Dutch Supreme Court. Before she had developed dementia, the 74-year-old woman had expressed a wish to die 'when the time was right'. She woke up during the procedure despite the sleep-inducing drug she had been given in her coffee and tried to resist the medical provider. This case was referred to as 'coffee euthanasia'<sup>23 24</sup>. After the Dutch Supreme Court ruling, the 'Euthanasia Code' (this code is a guidance for physicians which stipulates the procedures they must follow) was amended. Nowadays, a written will (or sometimes called a Euthanasia Statement) no longer needs to be legally sound, which means that a doctor might pay attention to all circumstances of a case without only leaning on the literal wording of the 'written will'. Additionally, when a patient has severe dementia, the doctor is not obliged to talk to the patient about the time and method of euthanasia in advance. Moreover, a sedative may be given if an incapacitated person is expected to be restless during the act of euthanasia<sup>25</sup>. With these decisions, one of the most vulnerable group of people, namely the incapacitated, have no possibility to resist euthanasia anymore.

## PALLIATIVE SEDATION

There is a steep rise in the number of patients who receive palliative sedation before they die. In 2001 this happened in 6% of the cases; in 2010 it had grown towards 12%, and in 2019 almost a quarter of the people who died at home or in a nursing home received palliative sedation<sup>26</sup>. If sedatives are used correctly, they should diminish the pain for people who are dying. However, they should not be used as a means to intentionally speed up the process of dying or to induce death<sup>27</sup>. There is a rise in the number of people that receive palliative sedation with the intention to hasten or induce death<sup>28</sup>. Both proponents and opponents of euthanasia reject this way of using palliative sedation. Currently, a research is being conducted on the rise in the number of people receiving palliative sedation.<sup>29 30 31</sup>

#### EUTHANASIA FOR CHILDREN YOUNGER THAN 12 YEARS OLD

As mentioned earlier, the two arguments that are mainly used in the euthanasia debate are the 'respect for personal autonomy' and 'compassion'. The latter one is important in the discussion around euthanasia for persons who are incapacitated. Since children aged 12 or under are incapacitated by law, they currently cannot be euthanized.

## EUTHANASIA FOR BABIES – GRONINGEN PROTOCOL

However, there is one exception: since 2007, there is a regulation, namely the 'Regulation late termination of pregnancy and termination of life in newborns' (Regulation LZA/LP), that describes 'criteria of due care' for active termination of life in children aged o-1 (also known as the 'Groningen Protocol'). When physicians abide by

<sup>20</sup> Annual Report 2020 Regional Euthanasia Review Committees (RTE) | Nieuwsbericht | Regionale Toetsingscommissies Euthanasie (euthanasiecom¬missie.nl)

<sup>21</sup> Criticism of psychiatrists on End of Life Clinic | Binnenland | Telegraaf.nl

<sup>22</sup> https://eenvandaag.avrotros.nl/item/zware-kri¬tiek-op-levenseindekliniek-euthanasie-op-patien¬ten-die-nog-niet-uitbehandeld-zijn/

<sup>23</sup> First criminal investigation into doctor after euthanasia | NOS

<sup>24</sup> The Supreme Court gives doctors room to interpreting the death wish of a patient with dementia | Trouw (newspaper)

<sup>25</sup> Adjustment Euthanasia Code 2018 and judgment euthanasia in advanced dementia after Supreme Court judgment Hoge | Nieuwsbericht | Regionale Toetsings¬commissies Euthanasie (euthanasiecommissie.nl)

<sup>26</sup> https://www.trouw.nl/nieuws/27-000-over¬lijdens-per-jaar-met-palliatieve-sedatie¬-dat-schreeuwt-om-onderzoek~b547c9be/

<sup>27</sup> https://publicaties.zonmw.nl/derde-evaluatie¬-wet-toetsing-levensbeeindiging-op-verzoek-en¬-hulp--bij-zelfdoding/ page 129

<sup>28</sup> Third evaluation of the Termination of Life Assessment Act on request and assisted suicide | ZonMw Digitale Publicaties

<sup>29</sup> https://www.nrc.nl/nieuws/2014/11/08/palliatieve-sedatie-is-de-nieuwe-euthanasie¬-1435590-a1343460

<sup>30</sup> https://www.trouw.nl/nieuws/27-000-over¬lijdens-per-jaar-met-palliatieve-sedatie¬-dat-schreeuwt--om-onderzoek~bs47c9be/

<sup>31</sup> https://www.zonmw.nl/nl/over-zonmw/onder¬wijs/programmas/project-detail/palliantie-meer¬-dan-zorg/palliatieve-sedatie-hoe-nu-verder/



these criteria, they will not be punished when they terminate the life of babies. The regulation concerns children who are expected to die within a short period of time after birth and children with a bad prognosis or a 'bad life' perspective. A loophole is thus created: a baby's life may be terminated not only if their suffering is unbearable currently, but also if they are expected to experience unbearable suffering in the future. An analysis of cases for the period 1997-2004 shows that all terminations of life were in babies born with spina bifida<sup>32</sup>. Just like euthanasia with adults, the practice of active termination of life in babies was already ongoing, although there was no formal regulation. Among physicians, there is no consensus on 'when a baby suffers unbearably' or 'if the baby is going to suffer unbearably in future'33. Since 2007, there are 'just' 2 cases reported. The relative low number of cases is attributed to the 20-week ultrasound (since this makes it possible that children with disabilities are already detected before birth and can be aborted). Another reason is that not all cases are reported by physicians (they are not always aware of the fact they must report a termination of life act, since there is a grey area between 'active termination of life' and 'symptom treatment').

## EUTHANASIA INITIATIVE FOR CHILDREN AGED 1-12

Since there is a regulation for children aged 0-1 and a 'euthanasia law' for persons above 12 years old, there is a growing dissatisfaction that there is no regulation for children between 1 and 12 years old (see figure next page). Different parties- among others, the Dutch Association of Pediatricians- plead for a regulation for this age category as well. In October 2020, Dutch Health Minister Hugo de Jonge stated that he would come up with a regulation that would make euthanasia possible for children between 1 and 12 years old. The plan is to implement this regulation in 2022. Although this regulation would only be applicable to children who are terminally ill or face unbearable suffering (with no prospects of improvement) and for whom all forms of palliative care would not work, the scope is much broader. If the process will be based on the pattern of the Groningen Protocol, the expectation is that the scope will expand again within a few years to other categories that do not meet the criteria at this moment.



\* LZA/LP means: Regulation late termination of pregnancy and termination of life in newborns. Source: Brouwer M, van der Heide A, Hein I, Maeckelberghe E, Verhagen E, van de Wetering V. Medical decisions regarding the end of life of children (1-12) UMCG, Erasmus MC, AMC Amsterdam on behalf of VWS. 2019

#### **ALTERNATIVES TO EUTHANASIA**

Most people think that unbearable pain and suffering (witnessed usually by relatives) are strong enough reasons for euthanasia. However, it is known that a lot of people do not know what palliative care implies<sup>34</sup>. The WHO gives the following definition of palliative care:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"<sup>35</sup>.

Good palliative care is important to prevent euthanasia. The view that given the current progress in pain management and palliative care, euthanasia is less necessary, is expressed by many doctors in the Netherlands<sup>36 37</sup>. Therefore, before discussing the legalization of euthanasia, it is always necessary to examine the quality level of palliative care in a country. More specifically, the measures each government takes to increase the number of facilities for palliative care and the accessibility of these facilities must be assessed. Without addressing these concerns, considering increasing access to euthanasia is irresponsible.

In November 2018, the Parliamentary Assembly of the Council of Europe adopted a report titled "The Provision of Palliative Care in Europe". The rapporteur for this report

<sup>32</sup> https://www.ntvg.nl/artikelen/actieve-levens¬be%C3%ABindiging-bij-pasgeborenen-nederland¬-analyse-van-alle-22-meldingen-uit

<sup>33</sup> https://www.ntvg.nl/artikelen/problematische¬-basis-voor-uitzichtloos-en-ondraaglijk-lijden-als¬-criterium-voor-actieve/volledig

<sup>34</sup> Het KOPPEL-Onderzoek (2011) blg122149.pdf (parlementairemonitor.nl)

<sup>35</sup> Palliative Care (who.int)

<sup>36</sup> For example, by the Dutch anaesthesiologist Ben Crul, Professor Emeritus of pain management at the Radboud University of Nijmegen. He is a pioneer in the field of pain management and palliative care.

<sup>37</sup> https://www.volkskrant.nl/nieuws-achtergrond/medische-noodzaak-euthanasie-vervallen~b21b43e2/



was the Irish senator and ECPM Member Ronán Mullen. The report affirms that palliative care is fundamental to human dignity. Not euthanasia, but palliative care is the component of the human right to a dignified death. The Council of Europe asked the Member States to recognize palliative care as a human right, to fully integrate it into their healthcare systems and to dedicate the necessary resources to it<sup>38</sup>.



The importance of palliative care was underlined during the COVID-19 pandemic as the Euthanasia Expertise Centre had to suspend their activities. The former director of the centre Steven Pleiter mentioned: "Our IC nurses and general practitioners are very busy in COVID-19 care and have to set priorities now"<sup>39</sup>. With this remark, the director recognized the validity of what the opponents to euthanasia are saying, namely that trying to keep people alive is more important than euthanasia.

# **UPCOMING INITIATIVES**

# PRESSURE TO WIDEN ACCESS TO THE 'KILL PILL'

In accordance to the principle of 'personal autonomy' regarding end-of-life decisions, the pro-euthanasia lobby in the Netherlands has renewed its push to introduce and legalize the so-called 'kill pill' that would be made available, free of charge and on demand, to people who are older than 70. It was also called the 'Drion pill' from the name of a Dutch judge who advocated this idea in the early '90s. Since such a lethal pill did not exist, the term has come to mean any form of painless, quick, dignified death which the patient wishes to have. It was a metaphor, not an object.

However, in September 2017, the Dutch Cooperative 'Last Will' presented a white powder that people could purchase legally. The powder would enable one to end their life. Since the product was only available in large quantities, the Dutch Cooperative organized groups that supplied the product. In 2018, the Dutch Ministry of Justice started a criminal investigation into this activity and the cooperative discontinued the organization of the supply groups<sup>40</sup>. However, the spread of the powder continues secretly to this day. A survey on the implementation of the 'Last Will' survey shows that around 1500 Dutch persons possess the powder<sup>41</sup>. The former director of the pro-euthanasia lobby group- the NVVE- Robert Schurink<sup>42</sup> claimed in 2015 that '*the society wants this pill*<sup>43</sup>. His claim has no basis, however. He cannot speak for the society at large; he represents only the NVVE members.

The danger of these initiatives which broaden the scope and access to euthanasia is the trivialization of the procedure. As a result, it will stop being a last-resort option for the terminally ill, but instead, people suffering from mental illness, people with dementia or people who simply feel lonely will be able to request euthanasia. A kill pill or a suicide powder that would be easily accessible, no longer controlled by a physician, with the potential to be mis-used or administered to the wrong patient, is even more dangerous.

## PRESSURE TO LEGALIZE ASSISTED SUICIDE FOR PERSONS WITH A 'COMPLETED LIFE'

In 2010 there was a citizens' initiative in the Netherlands that was signed by 116,000 persons<sup>44</sup>.According to this initiative, it should be possible for people who are over 70 years old to ask a therapist's assistance in ending their life if they feel they have a 'completed life'. They argued that a medical reason should not be a prerequisite to assisted suicide anymore. In 2013, the government rejected this proposal because there was not enough consensus on legalizing it.

In 2016, the government set up a committee of experts to investigate the topic of 'completed life'. The committee was led by D66 Senator and Professor Paul Schnabel and consisted of both liberal and conservative experts in the field of health and philosophy. They were asked to investigate the current euthanasia legislation and practice, the legal conditions, and limitations to assisted suicide for persons who consider their life 'completed', indications of these legal conditions, and possible means to avoid that people come to the conclusion that their life is 'completed'. It was concluded that there was no need to make legislation on therapist assistance in ending lives of people that have feelings of a 'completed life<sup>45</sup>.

<sup>38</sup> Resolution 2249 (2018), https://pace.coe.int/en/files/25214

<sup>39</sup> https://www.medischcontact.nl/nieuws/laatste-nieuws/nieuwsartikel/expertisecentrum-euthanasie-stopt-met-hulp-wegens-corona.htm

<sup>41</sup> The hunt for the 'suicide powder' continues, but now underground | De Volkskrant

<sup>42</sup> https://www.volkskrant.nl/nieuws-achtergrond/de-jacht-op-het-zelfdodingspoeder-gaat-door-maarnu-ondergronds-b7c163b74/

<sup>43</sup> https://www.dutchnews.nl/news/2015/11/voluntary-euthanasia-society-renews-calls-for-end-of-life-pill/

<sup>44</sup> http://uitvrijewil.nu/index.php?id=1000

 $<sup>\</sup>label{eq:constraint} \textbf{45} \quad \textbf{160204-adviescommissie-voltooid-leven-voltooid-leven-over-hulp-bij-zelfdoding-aan-mensen-die$ 

Surprisingly, the ministers disagreed. Therefore, the government intended to draft a law that would legalize assisted suicide for persons who feel they have 'completed' their life but are not necessarily terminally ill. In a letter to the Dutch Parliament on 12 October 2016, the Health and Justice Minister underlined that people who "have a well-considered opinion that their life is complete, must, under strict and careful criteria, be allowed to finish their lives in a dignified manner"<sup>46</sup>. In the same letter, the Minister of Health wrote that "because the wish for self-chosen end of life occurs mainly in the elderly, this will be limited only to them", although she did not set a threshold age. According to the Minister, the new law should require "careful guidance and vetting ahead of time with a 'death assistance provider' with a medical background, who has also been given additional training"<sup>47</sup>.

However, things changed in 2017 when the Christian Union (CU) party entered the Dutch Government as part of a coalition with the liberal progressive party D66, liberal VVD and Christian Democrats CDA. The CU was fiercely against a new law on 'completed life' ending and negotiated that this law will not be discussed during that cabinet's mandate, but that a more extensive research will be done on the topic.

To gain more in-depth information about the issue of completed life ending, a new committee was established in 2019 under the leadership of Dr. Els van Wijngaarden. Their aim was to examine the characteristics and the circumstances of elderly persons who have a wish to die while they are not seriously ill: The report produced was called 'Perspectives on the Death Wish of Elderly who are not Seriously ill: The Persons and the Numbers' (also called: PERSPECTIEF-research) and was presented in January 2020<sup>48</sup>. Around 20,000 citizens 55 years and older participated in the research process.

The results showed that 0.47% of the people surveyed had a passive wish to die: a desire for death without undertaking activities to hasten their death. Secondly 0.77% of persons aged 55 and over had an active wish to die. They take concrete steps regarding their wish to die, such as having conversations about euthanasia or seriously considering suicide. The third group identified by the research described their wish to die as: "a wish to end their life". The percentage of this group is 0.18%.

Thereby, the results showed that the group that would benefit from legislation that regulates active termination of life in people who consider their life as completed, is small. Making a law for such a small group would be irresponsible.

In an official reaction to the PERSPECTIEF-Research, Health minister Hugo de Jonge mentioned that the Dutch government will not come up with a law that regulates

46 https://www.tweedekamer.nl/kamerstukken/brieven\_regering/detail?id=2016Z18859&did=2016D38755

48 https://www.uvh.nl/uvh.nl/up/ZejmtegKatN\_E-read\_versie-ZonMw\_A4\_HPO\_def-online-3\_ spread. pdf

active termination of life in people who consider their life as 'completed<sup>49</sup>. However, a few months later, Pia Dijkstra, a member of the House of Representatives for D66, submitted a draft law that would regulate assisted suicide in elderly over 75.

She stated that "this law might comfort people by knowing that assisted suicide is possible when they have the desire to die"<sup>50</sup>. The debate about this draft law had not taken place at the time of writing this publication. However, a new study among elderly over 75 showed again that the group that would benefit from a law is small: only a few thousands<sup>51</sup>. Also, among people over 75; the wish to die might change over time, is ambivalent and those people often suffer from loneliness and physical problems. Dr. Els



van Wijngaarden mentioned: "This shows that the issue of 'completed life' concerns vulnerable people in complex situations. It is not about the self-conscious persons as is often thought'<sup>52</sup>. Therefore, the following conclusion can be drawn: a law for 'completed life ending' affects the vulnerable. Since the government has the task to protect the vulnerable, they must seek solutions to increase the quality of life in people who suffer, not to end their life.

Pia Dijkstra (D66) Source: Wikimedia commons

52 Death wish of over-75's also rare and changeable' - NRC

<sup>-</sup>hun-leven-voltooid-achten.pdf (njb.nl)

<sup>47</sup> https://www.tweedekamer.nl/kamerstukken/brieven\_regering/detail?id=2016Z18859&did=2016D38755

<sup>49</sup> https://www.rijksoverheid.nl/documenten/rapporten/2020/01/30/perspectieven-op-de-doodswensvan-ouderen-die-niet-ernstig-ziek-zijn-de-mensen-en-de-cijfers

<sup>50</sup> https://www.tweedekamer.nl/kamerstukken/wetsvoorstellen/detail?cfg=wetsvoorsteldetails&qry=wetsvoorstel%3A35534

<sup>51</sup> Over-75's with a death wish without being seriously ill | Dutch Magazine for Medicine (ntvg.nl)



## CONCLUSION

When the euthanasia law was adopted in 2001, it focused on persons who were terminally ill. As this publication showed, once the law was introduced, the grounds for performing euthanasia in the Netherlands have been broadened, becoming available to more and more groups of people. The arguments used were: 'compassion' ("it is better for him/her to die than to suffer any longer") and 'personal autonomy' ("death is a personal matter; if someone wants to die, they should be helped").

This situation is, in our view, threatening because:

- 1. legal euthanasia undermines the idea that killing another person is bad. The legalization of the act of killing, shows a kind of justification. Particularly for those who are not able to make decisions for themselves, the following question needs to be answered: can we make life or death decisions and judge about the value of life of another human being?
- 2. legal euthanasia undermines the equality of people. Some groups are considered 'suitable' for euthanasia, while for other groups, we invest money in suicide prevention. What is the message given to the groups that are seen as 'suitable'? For example, the discussions about the 'completed life ending' may indirectly emotionally press the elderly think about the possibility to terminate their lives<sup>33</sup>.
- 3. vulnerable people become even more vulnerable. Having euthanasia as an option can lead people to harbor ideas of death which might be fanned further by the family, causing (indirect) pressure. Applying euthanasia for incapacitated people ignores the right of life for everyone. It also disregards the prerequisite 'on request', which initially was the cornerstone of the Dutch euthanasia law. The role of a government is to protect the vulnerable and to seek solutions to improve the quality of life of those who suffer, not to end their life.
- 4. the 'slippery slope' has become a reality in the Netherlands. The reasoning "it is not fair that euthanasia is available for that group, but not for another group" is often mentioned (e.g., recently in the discussion for children aged 1-12). This shows that once legalized, euthanasia is difficult to be contained to one group of people. Numbers of euthanasia cases are growing every year, also for 'special' groups, like people with dementia or psychiatric disorders.
- 5. euthanasia has become normalized in Dutch culture. 99% of the Dutch citizens know what 'euthanasia' is, while only 53% know what 'palliative care' is<sup>54</sup>. This has far-reaching consequences: 11% of Dutch citizens are afraid to get euthanasia in a secret way<sup>55</sup>.

As a conclusion, we see that, although human dignity arguments were used to legalize or broaden the provision of euthanasia, in reality the human dignity of the vulnerable is in danger. Death is the opposite of life. We should not use the argument for dignity to assist people in dying, but focus on helping people to live. Therefore, it is imperative to invest in initiatives which alleviate loneliness in the elderly or isolated people and to fund good palliative care. It is our duty to protect the vulnerable among us against the dangers stemming from the expansion of access to euthanasia.

<sup>53</sup> https://www.trouw.nl/nieuws/waarom-neemt-zelfdoding-onder-ouderen-toe~ba84d98f/

<sup>54</sup> Report "Knowledge and views of the public and professionals about medical decision-making and end of life treatment - Het KOPPEL-onderzoek" (bijlage bij 32647,nr.2) - Parlementaire monitor

<sup>55</sup> Röling R, Valk N. 2020: Digital poll about the end of life. Amsterdam: DirectResearch commissioned by NPV

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The NPV-Zorg voor het leven (in English: NPV- Care for life) is a Dutch Christian organization with around 50.000 members. Since 1982, this organization stands up for the protection of life. The NPV monitors and reflects on the societal and political discussions around medical-ethical themes. It also built a network of volunteers to support people and to prevent and alleviate loneliness. For more information about the NPV's view on euthanasia, go to <u>www.npvzorg.nl</u>



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