


# Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care

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on behalf of the board members of the EAPC

## Abstract

**Background:** In recognition of the ongoing discussion on euthanasia and physician-assisted suicide, the Board of Directors of the European Association for Palliative Care commissioned this white paper from the palliative care perspective.

**Aim:** This white paper aims to provide an ethical framework for palliative care professionals on euthanasia and physician-assisted suicide. It also aims to provide an overview on the available evidence as well as a discourse of ethical principles related to these issues.

**Design:** Starting from a 2003 European Association for Palliative Care position paper, 21 statements were drafted and submitted to a five-round Delphi process

**Participants:** A panel with 17 experts commented on the paper in round 1. Board members of national palliative care or hospice associations that are collective members of European Association for Palliative Care were invited to an online survey in rounds 2 and 3. The expert panel and the European Association for Palliative Care board members participated in rounds 4 and 5. This final version was adopted as an official position paper of the European Association for Palliative Care in April 2015.

**Results:** Main topics of the white paper are concepts and definitions of palliative care, its values and philosophy, euthanasia and physician-assisted suicide, key issues on the patient and the organizational level. The consensus process confirmed the 2003 European Association for Palliative Care white paper and its position on the relationship between palliative care and euthanasia and physician-assisted suicide.

**Conclusion:** The European Association for Palliative Care feels that it is important to contribute to informed public debates on these issues. Complete consensus seems to be unachievable due to incompatible normative frameworks that clash.

## Keywords

Euthanasia, physician-assisted suicide, palliative sedation, consensus process, online survey

### What is already known about the topic?

- The European Association for Palliative Care (EAPC) published a position paper on euthanasia and assisted suicide in 2003, with concepts and definitions.
- Changed legislation in some countries and an ongoing public discussion in many European countries indicate a broad range of ethical norms and values underlying these discussions.

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**What this paper adds?**

- This paper provides an overview where there is consensus among European palliative care professionals and points out controversies where there is no consensus.
- The paper provides a clear stance by experts and representatives of national organizations on palliative care and an official position of the Board of Directors of the EAPC with 21 statements on euthanasia, assisted suicide and palliative care.

**Implications for practice, theory or policy**

- Individual requests for euthanasia and physician-assisted suicide (PAS) are complex in origin and may include personal, psychological, spiritual, social, cultural, economic and demographic factors. Such requests require respect and careful attention, together with open and sensitive communication in the clinical setting.
- The EAPC position paper states that the provision of euthanasia and PAS should not be included into the practice of palliative care.
- Individuals requesting euthanasia or PAS should have access to palliative care expertise. This should be achieved by the establishment of palliative care within mainstream healthcare systems of all European countries supported by appropriate finance, education and research.
- Within Europe, several approaches to euthanasia and PAS are emerging, and open and respectful debate surrounding this is to be encouraged.

**Background**

In 1991, a debate at the European Parliament on euthanasia stimulated discussion at all levels in Europe. Subsequently, the European Association for Palliative Care (EAPC) produced a first statement, *Regarding Euthanasia*,<sup>1</sup> in order to clarify the position the organization should adopt towards euthanasia. In 2003, the EAPC task force on ethics published a more detailed and updated statement.<sup>2</sup> The editors published a series of 53 comments from different experts from the fields of medicine, philosophy, theology and ethics describing a broad range of different attitudes towards euthanasia and the EAPC position statement.

Subsequently, there have been major developments and achievements in the field of palliative care, as well as much discussion, some of it controversial, on euthanasia and physician-assisted suicide (PAS). There has also been new legislation in some countries. Euthanasia has been legalized in the Netherlands (2001), Belgium (2002) and Luxembourg (2009), and legislation allowing PAS exists in Switzerland as well as outside of Europe in three federal states in the United States: Oregon, Vermont and Washington.

The complexity of debate is also highlighted by an ongoing discussion on treatment withdrawal or withholding of treatment (non-treatment decisions (NTD)) in some European countries such as France, where an expert commission recently reported to the government that although NTD have been legal since 2005, physicians do not use the full range of options, whereby needs and priorities of patients related to end-of-life care are often ignored.<sup>3</sup>

The EAPC feels that it is important to contribute to informed public debates on these issues. This is no straightforward task, as euthanasia and PAS are two of the most frequently debated and most sensitive ethical issues in the

field of health care today. Complete consensus on these topics seems to be unachievable due to incompatible normative frameworks that clash. This paper builds on current debates and develops a viewpoint from the palliative care perspective, which is sensitive to the manifold cultural and legal differences across European countries.

**Historical trends and current situation**

Around the world some important changes relating to euthanasia and PAS have been taking place. In 1996, for the first time in history, a democratic government enacted a law that made both euthanasia and PAS legal acts, under certain conditions as described in the Rights of the Terminally Ill Amendment Act 1996, Northern Territory, Australia.<sup>4</sup> The law was, however, made ineffective by the Euthanasia Laws Bill of the Parliament of Australia in 1997.<sup>5</sup>

In the same year, PAS (but not euthanasia) was legalized through the Oregon Death with Dignity Act.<sup>6</sup> This has been followed by similar legislation in Washington (2008), Vermont (2013) and California (2015) and is currently being debated in New Jersey. In Montana, a court ruling finding no constitutional objection to assisted suicide has opened the way for similar practices in 2009, and a similar court ruling in New Mexico in 2014 is currently under appeal. In contrast to the legal requirements in European countries, in Oregon, Washington and Vermont, patients must have a terminal physical illness in order to qualify for PAS. Data on frequencies of euthanasia and PAS are presented in Table 1.

**Table 1.** Prevalence of euthanasia and physician-assisted suicide in countries with legislation allowing these practices.

Country	Year	Deaths	Percentage of all deaths
United States			
Oregon <sup>7</sup>	1998	16 (24 people with prescriptions)	0.31
	2014	105 (155 people with prescriptions)	
Washington <sup>8</sup>	2009	36 (63 people with prescriptions)	0.23
	2013	119 (173 people with prescriptions)	
Vermont		n.a.	
Montana		n.a.	
California		n.a.	
New Mexico		n.a.	
New Jersey		n.a.	
Switzerland			
	2009 <sup>9</sup>	Approx. 300	0.48
	2010 <sup>10</sup>	353 (slow increase in the last decade) <sup>9</sup>	0.56
The Netherlands			
	2001 <sup>11</sup>	All	2.6
		Without explicit request of the patient	0.7
	2005 <sup>11</sup>	All	1.7
		Without explicit request from the patient	0.4
	2010 <sup>11</sup>	All	2.8
		Without explicit request from the patient	0.2
	2014 <sup>12</sup>	4188	
	2015 <sup>12</sup>	4829	3.4
		4501 euthanasia	3.2
		286 physician-assisted suicide	0.2
		42 both	<0.1
Belgium			
	2003 <sup>13</sup>	235	
	2011 <sup>13</sup>	1133	
	2012 <sup>14</sup>	1432	
	2013 <sup>14</sup>	1807	1.7
		1454 in Flanders	
		353 in Wallonia	
	2013 <sup>15</sup>	Physician survey in Flanders	4.6
Luxemburg			
	2011–2012 <sup>16</sup>	14	0.18

n. a.: not available.

Switzerland has a long tradition of assisted suicide, not only for Swiss citizens but also for foreigners. Swiss law, which dates back to 1942, is not specifically related to medical illness. Right-to-die organizations are involved in the majority of cases. The lethal drugs are prescribed by physicians, but these do so at the request of the organizations. In contrast to the regulations in the Netherlands, Belgium or Luxemburg, the process is not one of PAS, as a doctor–patient relationship is not required.<sup>10</sup> The physician is generally not present when the patient commits suicide.<sup>17</sup>

The Netherlands, following a long public discussion and a policy of tolerance, introduced the Termination of Life on Request and Assisted Suicide (Review Procedures) Act in 2001,<sup>18</sup> suspending prosecution of euthanasia and PAS if certain criteria are fulfilled: the patient's suffering is unbearable with no prospect of improvement; the patient is fully aware of his condition and prognosis, and the request is voluntary and persisting over time; a second independent physician has confirmed the conditions; and

the procedure is performed in a medically appropriate way. A combination of first barbiturate (to induce coma) and then a muscle relaxant (causing respiratory arrest) is used most often for euthanasia. After the death of the patient, the doctor must report the procedure to the Regional Euthanasia Review Committees (RERCs) which assess whether or not the criteria have been met.

Euthanasia can be performed in adults and in adolescents older than 16 years. Children between 12 and 16 years require parental consent if they want to receive euthanasia. The legislation also recognized the validity of a written advance directive specifying conditions where the patient might want to receive euthanasia.

Belgium also introduced legislation of euthanasia with similar regulations to those in the Netherlands in 2002.<sup>19</sup> Physicians will not be prosecuted if they provide euthanasia for competent patients of legal age, who have expressed a repeated and consistent request made under no external pressure who are subject to persistent and intolerable

physical and/or mental suffering due to an irreversible medical condition (accident or disease) with no prospect of improvement, and if the physician follows the procedures detailed in the law. Requests expressed in a written advance directive are acceptable in the case of patients in an irreversible state of unconsciousness.

According to the legislation, a patient requesting euthanasia has to be of age >18 years or an emancipated minor (being married or in exceptional cases with a judge's verdict). Euthanasia was performed only very rarely in young people. In a recent parliamentary debate, the relevance of age was regarded as less important than the capacity for discernment of involved issues and implications, and in consequence a new bill was approved in February 2014, which rests on the same fundamental principles as the 2002 legislation, but which incorporates no reference to any age limit, contrasting sharply with the Dutch legislation. However, although the Belgian legislation extends its application to children, it restricts its scope by excluding psychiatric disorders. More importantly, the new bill also specifically addresses the issue of discernment, which has to be assessed by a multidisciplinary team including a clinical psychologist or psychiatrist. Parents or guardians must agree with the request.<sup>20</sup>

New ethical questions have emerged, for example, when patients in Belgium wish to be organ donors. For several patients euthanasia has been performed immediately before organs were removed for transplantation, although care was taken that the transplantation team acted independently.<sup>21</sup> The establishment of a virtual 'life's end clinic' in the Netherlands, for people whose euthanasia request was not met by their own physician, providing euthanasia for 134 cases in 2013 and 232 cases in 2014,<sup>22</sup> has raised concerns as this mobile team exclusively services euthanasia requests.

In 2009, Luxemburg also introduced euthanasia and PAS.<sup>23</sup> Similar to the criteria in the Netherlands and Belgium, patients must be suffering unbearably, with no prospect of improvement, but the illness does not have to be terminal.<sup>10</sup>

Across Europe as a whole, however, there is little evidence in the last 10 years of concerted attempts to bring about the legalization of euthanasia through parliamentary processes. Indeed, in many European countries, the legalization of euthanasia is opposed by a wide range of professional associations representing doctors, nurses and others, groups representing disabled or older people and also by palliative care organizations.

Assisted suicide is not prosecuted under the criminal law of many European states. In Switzerland, assisted suicide is a crime if and only if the motive is selfish according to Article 115 of the Swiss penal code. The German legislation is even more permissive, and assistance or encouragement is not punishable according to Article 216 of the penal code. However, prosecution is possible for other

reasons such as neglected duty to rescue or homicide by omission.

In the United Kingdom, assisted suicide is a criminal offence in England and Wales according to the Suicide Act 1961 and in Northern Ireland through sections 12 and 13 of the Criminal Justice Act (Northern Ireland) 1966. It does not apply to Scotland. Several attempts have been made in recent years to introduce bills that would legalize assisted suicide in England and Wales, but all have been rejected by Parliament. In 2010, the Director of Public Prosecutions has published a policy for prosecutors describing public interest factors tending in favour or tending against prosecution.<sup>24</sup> The policy indicates that prosecution is less likely if the victim had reached a voluntary, clear, settled and informed decision to commit suicide and the suspect had been wholly motivated by compassion. An assisted dying bill has been introduced to the House of Lords by Lord Falconer of Thoroton in June 2015, but has been turned down as in previous years.

Outside of Europe, most recently the Supreme Court of Canada has extended the constitutional right to autonomy by ruling that the criminal code has no force to prohibit PAS for a competent adult person who clearly consents to it and has a grievous and irremediable medical condition (including illness, disease or disability) that causes enduring suffering that is intolerable to the individual.<sup>25</sup> However, this is not yet put into laws or rules.

## Aims

This paper aims to provide an ethical framework for palliative care professionals on euthanasia and PAS. It also aims to provide an overview on recent research as well as a discussion of ethical principles related to these issues. The paper takes into consideration the broad range of cultural settings and attitudes in different European countries. It provides clear recommendations where there is consensus and points out controversies where there is no consensus. It seeks to stimulate a broad discussion within the health-care system about the role of medical professionals, goals of care, epistemology of a medical indication and ethical implications which strengthen the benefit of palliative and end-of-life care for society and political decision-making. The white paper does not discuss advance care planning (ACP), attitudes towards euthanasia or PAS nor societal changes in these attitudes.

## Methods

A Delphi procedure was used to produce consented statements on euthanasia and PAS from the palliative care perspective. This section outlines the process followed. More information can be accessed in the online Supplementary Material.

The work group met on four occasions: in Frankfurt, Germany (August 2012), in Munich, Germany (April 2013), at the 13th EAPC Congress, Prague, Czech Republic (June 2013) and in Bonn, Germany (September 2014).

The EAPC position paper on euthanasia and PAS from 2003<sup>2</sup> was used to produce a white paper draft with 21 statements as the starting point for the consensus procedure. The draft has been used in a consensus procedure using a five-round Delphi process. The first round included feedback from a number of palliative care or medical ethics experts. The second, third, fourth and fifth rounds of the survey were performed with an online survey tool (SurveyMonkey©). The respondents were able to choose between different levels of agreement for each statement presented on a five-step Likert scale. The second and third rounds of the Delphi process involved the board members of the national palliative care and hospice associations that are collective members of the EAPC. The fourth round included the expert panel from the first round and round five the board members of EAPC.

After each of the five Delphi rounds, those statements that did not reach consensus were revised in accordance with the comments of the participants. Although some statements did not reach the high level of agreement required for consensus in the third round, no statement had to be deleted from the draft as the lowest rate of agreement still was 68% (agreement/complete agreement). For each of these statements (2, 6, 11, 14, 15 and 16), the lack of full consensus was documented in the text. The final version of the paper has been adopted as an official position paper of the EAPC in April 2015.

## Concepts and definitions

This section presents, in turn, definitions of palliative care, euthanasia, PAS, withholding or withdrawing futile treatment and palliative sedation:

1. Following the definition of the World Health Organization (WHO), 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>26</sup>

According to the WHO definition, palliative care affirms life and regards dying as a normal process, and it intends to neither hasten nor postpone death. Palliative care offers a support system to help patients live as actively as possible until death.

Across Europe, palliative care is an expanding and acknowledged part of health care. At the same time, there are continuing debates over what palliative care includes

and where it begins and ends (stage and type of disease, prognosis and care setting).<sup>27,28</sup> Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. Regional, national and cultural differences exist in the approach to and organization of palliative care.<sup>29</sup> These different viewpoints are also reflected in professional practice.<sup>30</sup>

2. Euthanasia is defined as follows: a physician (or other person) intentionally killing a person by the administration of drugs, at that person's voluntary and competent request.

When the expression 'killing on request' is used in connection with euthanasia, this is a technical description of the act, based upon the procedure used usually: an injection of a barbiturate to induce coma, followed by the injection of a neuromuscular relaxant to stop respiration causing the patient to die. Whether or not euthanasia may be *justified* killing on request is another matter, addressed below. A sharp distinction, therefore, exists here between what 'is' and what 'ought' to be.<sup>31</sup>

Medicalized killing of a person without the person's consent, whether non-voluntary (where the person is unable to consent) or involuntary (against the person's will), is not euthanasia: it is murder. Hence, euthanasia can be voluntary only.<sup>32</sup> Accordingly, the frequently used expression, 'voluntary euthanasia' should be abandoned since it by logical implication, and incorrectly, suggests that there are forms of euthanasia that are not voluntary. In the literature, as well as in the public debate, a distinction is sometimes drawn between so-called 'active' and 'passive' euthanasia. It is our view that this distinction is inappropriate. In our interpretation, as well as according to the Dutch understanding,<sup>33</sup> euthanasia is active by definition, and so 'passive' euthanasia is a contradiction in terms (an oxymoron).

While this statement received high agreement in the Delphi process, it did not reach consensus among the board members of national palliative care associations in Europe according to the strict definition used in this study. Disagreement seemed to focus on the choice of the word 'killing'; in addition, some comments maintained that it should only be a physician who is entitled to perform euthanasia, no other persons.

3. Assisted suicide is defined as follows: a person intentionally helping another person to terminate his or her life, at that person's voluntary and competent request.

In contrast with euthanasia, where the authority of action lies with the other person administering the lethal drugs, for

assisted suicide the authority of action lies with the person who wants to terminate his or her life. The decision-making process remains with the person who wishes to end his or her own life and is not different from euthanasia.

If a patient voluntarily stops eating and drinking, this would not be considered assisted suicide as it would require no assistance from another person.

4. PAS is defined as follows: a physician intentionally helping a person to terminate his or her life by providing drugs for self-administration, at that person's voluntary and competent request.

Physicians may be urged to assist suicide as their medical expertise is wanted for the prescription or advice in the use of lethal drugs. However, there are also specific challenges with PAS. Physicians usually have relief or cure as their only goal, but if the ending of life becomes another option, this might jeopardize the relationship between patient and physician.

In contrast, the largest physician federation of the Netherlands (KNMG) has produced a position paper on the role of the physician in euthanasia and PAS, describing clearly tasks and responsibilities in performing these acts.<sup>34</sup>

The medicalization of PAS has also been criticized as part of a transformation of medicine from a caring profession into a business designed to serve demands for medical services.<sup>35</sup> Alternative concepts where euthanasia and PAS are performed by non-physicians have been described.<sup>36</sup> Differences between Switzerland as a non-medical legal model and Oregon as a medical legal model concerning the capacity of the person providing assistance in suicide and the state of health of the person committing suicide have also been described.<sup>37</sup> In the Netherlands, the role of the physician in the current forms of assisted dying has been challenged in recent years by a public campaign advocating for special, non-medically trained workers educated as counsellors to help clarify the person's wish to die and administer a lethal drug that would be provided by a physician. Also, the concept of auto-euthanasia has been suggested, where patients would end their own lives with the support of their children.<sup>38</sup>

Not only the ethical dimension but also specific legal aspects may be relevant for PAS: For example, in Germany, physicians (similar to parents, spouses or police officers) are in a position as warrantor for the well-being of their patients and are obliged to exert more than usual efforts to prevent suicide and might be liable for homicide by omission if they assist the patient. In addition, PAS may be penalized by civil law.

5. NTD are defined as follows: withholding or withdrawing medical treatment from a person either because of medical futility or at that person's voluntary and competent request.

NTD are not euthanasia within the definitions used here because NTD do not intend to hasten death, but rather accept death as a natural phenomenon through omission of ineffective, futile, very burdensome or unwanted life-prolonging procedures.<sup>39</sup>

NTD can be related to medical futility, for example, deciding against antibiotic treatment in an imminently dying patient with pneumonia and lung cancer. Another example would be deciding against fourth-line chemotherapy in a patient with rapidly progressive cancer and inadequate response to previous courses, if this chemotherapy carries a high risk of side effects or increased treatment-related mortality. NTD for futile medical interventions should be discussed with the patient and relevant caregivers. Problems may arise with patients persisting in their wish for futile treatments, either out of tenacity or out of desperation.

Different from medical futility, NTD may also be related to a patient's decision to withhold or withdraw medical therapies. This may lead to moral challenges with the healthcare team, for example, when a patient with renal failure decides to discontinue haemodialysis treatment or if a patient with motor neuron disease (MND) and complete respiratory failure requests withdrawal of mechanical ventilation. However, these NTD do not end life (as euthanasia does), but rather allow imminent death from the underlying condition, which is prevented by life-prolonging measures. Patient's requests for NTD require open and sensitive communication, in order to ensure that the patient and his caregivers are adequately informed and understand the implications and consequences of the NTD.

6. Palliative sedation is defined as the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and healthcare providers.<sup>40</sup>

Palliative sedation is an accepted, ethical practice when used in the appropriate situations.<sup>40</sup> The EAPC white paper on sedation considers sedation to be an important and necessary therapy in the care of selected palliative care patients with otherwise refractory distress. However, this approach requires attention to proportionality and good clinical practice and attention to potential risks and problematic practices that can lead to harmful and unethical practices.

Potential ethical conflicts or problems should be duly considered, and the indication, planning and administration of sedation should be based on consensus in the team and between team, patient and at least in most cases also caregivers. Detailed guidance is provided in the EAPC framework for palliative sedation.<sup>40</sup>

The definition of palliative sedation has been the focus of much debate, considering aspects of medical indication, decision-making, ethical norms, goals, forms and philosophical questions. This debate is also related to different cultural and organizational settings. There is, for example, an ongoing debate on whether the ethical precondition in the last part of the EAPC definition<sup>40</sup> is appropriate or should be deleted.

While this statement received high agreement in the Delphi process, it did not reach consensus among the board members of national palliative care associations in Europe according to the strict definition used in this study. The ethical precondition caused much discussion, among the participants in the consensus panel as well as among the authors of this paper.

### Palliative care values and philosophy

7. In palliative care, the intrinsic value of each person as an autonomous and unique social individual is acknowledged and respected. Ideally, the patient preserves his or her self-determination regarding the power of decision on place of care, treatment options and access to specialist palliative care.<sup>28</sup>

A discourse analysis of the definition of palliative care found that the main goals were relief and prevention of suffering and improvement of quality of life.<sup>41</sup> This was based on common core values such as respect for autonomy. Power of decision-making on place of care, treatment options and access to specialist palliative care receives special emphasis, and patient's empowerment is assigned an important role. The human being is the focus of care. Palliative care should be provided in a respectful, open and sensitive way – sensitive to personal, cultural and religious values, beliefs and practices as well as the law of each country. Palliative care is foremost patient-centred and contingent upon individual and familial needs. A salutogenic orientation with emphasis on the resources and competencies of clients, and not simply on their difficulties, might be preferable.

### Key issues on the patient level

8. Individual requests for euthanasia and PAS are complex in origin and may include personal, psychological, spiritual, social, cultural, economic and demographic factors.

The use of euthanasia or PAS has an inherent danger of misinterpreting the patient's preferences by failing to acknowledge this divergence of underlying meanings and ambivalence or changing priorities of the patients. In a large survey of terminally ill patients, 10.6% reported seriously considering euthanasia or PAS for themselves, but

the follow-up interview showed that 50.7% of these patients had changed their mind after 6 months, while a nearly equal number had started to consider it.<sup>42</sup> Ultimately, in this survey, only 5.6% of the deceased patients had discussed asking the physician for euthanasia or PAS.

In-depth evaluation found many meanings and uses of the expression of desire for hastened death, ranging from a manifestation of the will to live and a gesture of altruism to a despairing cry depicting the misery of the current situation and to a manifestation of the last control the dying can exert.<sup>43</sup> The expression seems to be an important tool of communication for the patients.

In a similar study, being a burden to others was a most important motivation for the desire for hastened death.<sup>44,45</sup> Suffering was described as a reason as well, although most often it was anticipated suffering rather than suffering right now: patients were very afraid of disease-related deterioration in the future.

In clinical practice, patients often show major ambivalence, with the wish for hastened death, on one hand, and the will to live, on the other, often in parallel or with short-term fluctuations. This coexistence of opposing wishes has been explained as part of authentic, multi-layered experiences and moral understandings at the end of life.<sup>46</sup>

9. Requests for euthanasia and PAS require respect and careful attention, together with open and sensitive communication in the clinical setting.

Palliative care staff should acknowledge and listen carefully to these requests and be able to enter an open dialogue about this request with patients, caregivers and staff members. A request for euthanasia should lead to an exploration with the patient and the family of the burdensome experiences that are underlying the question. In Germany, patients explained that the intention to address their wish for hastened death to palliative care staff was associated with the need for information and reassurance and the perception of staff competence in symptom control.<sup>44</sup>

10. Individuals requesting euthanasia or PAS should have access to palliative care expertise.

Requests for euthanasia and PAS may be altered by the provision of comprehensive palliative care. Suffering from physical symptoms can be alleviated, and psychosocial and spiritual care can improve well-being of patient and caregivers. Information about the available palliative care options may provide reassurance and diminish anxieties about the subsequent disease trajectory.<sup>44</sup>

11. Palliative sedation may offer an option for many conditions in which patients may request euthanasia or PAS.

Sedation is potentially indicated for patients with intolerable distress due to physical symptoms, when there is a lack of other methods for palliation within an acceptable time frame and without unacceptable adverse effects (refractoriness). The specific intolerable symptoms should be identified. The most common symptoms include agitated delirium, dyspnoea, pain and convulsions. Emergency situations may include massive haemorrhage, asphyxiation, severe terminal dyspnoea or overwhelming pain crisis. Continuous deep sedation should only be considered if the patient is in the terminal phase as defined in the Australian Palliative Care Phase definition (Death is likely within days).<sup>47</sup> Palliative sedation may in this stage also be considered for severe non-physical problems such as refractory depression, anxiety, demoralization or existential distress, although there is less consensus on the appropriateness of sedation for these indications.

In contrast to this, in France, a bill has been passed by the National Assembly on palliative sedation, which includes a right for patients with a life-limiting disease to receive palliative sedation until the time of death. Physicians would be compelled to provide palliative sedation if the patient requests it. The bill has been turned down by the senate in June 2015, but the bill is still in the legislative system.

There was low agreement in the Delphi process on this statement and it did not reach consensus among the board members of national palliative care associations in Europe. Some comments expressed concern that palliative sedation might be regarded as an alternative to euthanasia, which is not in line with the intention of this white paper.

12. Palliative sedation in those imminently dying must be distinguished from euthanasia. In palliative sedation, the intention is to relieve intolerable suffering, the procedure is to use a sedating drug for symptom control and the successful outcome is the alleviation of distress. In euthanasia, the intention is to end the life of the patient, the procedure is to administer a lethal drug and the successful outcome is immediate death.

Palliative sedation should never have the intention to shorten life.<sup>2,48</sup> In a survey on the practice of palliative sedation, 17% of the responding physicians stated that hastening death was the explicit intention,<sup>49</sup> but this indicates a misuse of the procedure. In very fragile patients, a non-intended life-shortening side effect may not be excluded, although two systematic reviews clarified that palliative sedation does not shorten survival in terminally ill cancer patients.<sup>50,51</sup>

It is important that the responsible physician reviews and documents his or her own intention in initiating palliative sedation in order to avoid misuse or malpractice. It is recommended that the decision to use palliative sedation

should be a team decision or at least should be scrutinized with inter- or supervision.

13. Palliative care is provided up until the end of life and is by definition never futile.

Palliative care is never discontinued as it is provided up until the very moment of death (and even beyond with bereavement support for the family). So, whereas life-prolonging measures may be found to be futile, palliative care never is.<sup>39</sup> The patient may reject palliative care interventions, but this does not mean that the palliative care approach is futile. Quite the contrary, palliative care is effective in relieving distressing pain and symptoms, and the care for patients – physical, psychosocial and spiritual – continues until death.

Some have argued that the concept of palliative futility supports the need for euthanasia.<sup>52</sup> This term, however, is a misnomer and a contradiction in terms, based on a false understanding of what palliative care is.

14. The provision of euthanasia and PAS should not be included into the practice of palliative care.

We hold that there are philosophical as well as medical reasons against the use of euthanasia. From the philosophical point of view, euthanasia makes the human life a means for ending suffering, as human life has to be forfeited in the act of euthanasia to end suffering. From the medical point of view, euthanasia is a medical act (injection of lethal drugs), but not a medical treatment or therapy in any sense of these words, as the primary task of the physician is to alleviate and cure, but not to end life.<sup>39</sup>

However, Bernheim et al. discussed the interaction of palliative care and legalization of euthanasia, claiming that the case of Belgium suggests that there is a synergistic effect between the two. They described a model called integral palliative care, in which euthanasia is considered as another option at the end of a palliative care pathway.<sup>52</sup>

In another more recent article, protagonists of the Federation of Palliative Care Flanders explained how after being confronted with the introduction of the legal possibility of euthanasia different kinds of experiences led to the growing involvement of palliative care professionals and teams in what they call ‘the accompaniment of euthanasia’. Referring to continuity of care, they chose not to abandon patients asking for euthanasia by referring them to external practitioners, outside the familiar care environment, but to continue to provide them with all the necessary support. In this way, they wanted to express that euthanasia and palliative care remain two distinct matters, but that they can ‘occasionally be considered together when caring for one and the same patient’.<sup>53</sup>

Palliative care clinicians in other countries are concerned about these proposals, as their clinical experience



in palliative care has taught them to be sensitive in the acknowledgement but also very careful with the interpretation of the request for euthanasia from palliative care patients.

The definition of palliative care does not seem to be compatible with euthanasia. The WHO clearly stated in 2002 that palliative care neither hastens nor postpones death,<sup>26</sup> and this has been taken up in other definitions of palliative care.<sup>41</sup>

However, even if palliative care is delivered with the utmost quality, this will not prevent individual patients from asking for hastened death, including requests for euthanasia or PAS.<sup>54-56</sup> It is the responsibility of palliative care professionals to hear and explore the implicit or explicit requests for euthanasia and address the suffering underlying these requests.

There was moderate agreement on this statement in the Delphi process, and it did not reach consensus among the board members of national palliative care associations in Europe. A number of respondents (mostly from Benelux countries) disagreed strongly. The dissent thus reflects the actual situation in Europe. However, this statement was maintained as a normative statement, although it is understood that the moral understanding of hastening death may be different in different cultures or subcultures.

### Key issues on the organizational level

15. It is recognized that within Europe several approaches to euthanasia and PAS are emerging, and open and respectful debate surrounding this is to be encouraged.

This debate should contribute to an understanding of the areas of consensus and dissent on euthanasia and PAS in Europe and inform the social, existential, spiritual, ethical and legal implications of the different approaches, both for patients and for caregivers, for healthcare professionals and for society.

While this statement received high agreement in the Delphi process, it did not reach consensus among the board members of national palliative care associations in Europe according to the strict definition used in this study.

16. Studies of attitudes to euthanasia and PAS among professionals, patients and the wider public as well as studies of their experiences of these issues may inform the wider debate.

Many published studies, however, suffer from methodological weaknesses, starting with deficient definition of the concepts used, raising doubts about the evidence base.<sup>57</sup> A more coordinated approach to these studies is needed.

Palliative care might undertake research on issues related to euthanasia and PAS, although this should be

embedded in the context of the palliative care field, for example, on knowledge or attitudes related to euthanasia or PAS. Care has to be taken that studies are of good quality and high generalizability.

While this statement received high agreement in the Delphi process, it did not reach consensus among the board members of national palliative care associations in Europe according to the strict definition used in this study.

17. Fear of loss of autonomy at the end of life can be addressed using advance directives and ACP, contributing to improved communication and thereby enhancing the autonomy of the patient.

Within the modern medical system, patients may fear that life will be prolonged unnecessarily or end in unbearable distress. As a result, euthanasia or PAS may appear as an option. However, patient consent is an ethical prerequisite of medical treatment, and the patient's right to refuse any treatment is increasingly acknowledged in most European countries.

Advance directives ('living wills'), power of attorney for a surrogate decision-maker and other instruments of ACP may strengthen the autonomy of the patient and may alleviate anxiety. However, a legal framework for ACP is not yet provided in all European countries.

18. If euthanasia or PAS is legalized in any society, there should be special attention to avoid (1) the underdevelopment or devaluation of palliative care and (2) conflict between legal requirements and the personal and professional values of physicians and other healthcare professionals.

Empirical data on the effect of euthanasia and PAS on a societal level may be hard to obtain for a number of reasons: (1) only very few countries have legalized euthanasia and PAS; (2) it takes a long time before legal changes have effect on a societal level and legalizations are relatively recent; (3) it is hard to gain evidence for the correlation between legal changes and changes on a societal level, legal changes being embedded in a broad socio-cultural spectrum of causes; and (4) research may be consciously or unconsciously biased by ethical presuppositions. Nevertheless, from a palliative care perspective, a number of worries can be formulated with regard to the legalization of euthanasia and PAS, which may contribute to special attention to avoiding undesired developments.

Only little information is available on how often palliative care is offered or provided for patients requesting euthanasia or PAS. In Belgium as in the Netherlands, involvement of palliative care experts is no prerequisite of euthanasia or PAS, although the Belgian legislation states that the patient must be informed about the possibilities of palliative care. In Belgium, there is no clear information in

the reports of the Federal Committee,<sup>58</sup> although all reports conclude that physicians and palliative teams were often voluntarily consulted outside the legally obligatory consultations. The numbers of consultations with palliative care teams are registered in most of the reports (710 cases in 2013).<sup>14</sup> In a recent nationwide survey, participating physicians reported a much higher percentage, with involvement of palliative care services in 73.7% of cases in 2013.<sup>15</sup> Reports of the Federal Committee regularly express concerns of some committee members that palliative care consultations should not become a constraint on patient autonomy.<sup>14</sup>

Throughout history it has been imperative that medicine is concerned with healing and caring and not with purposeful ending of life.<sup>36</sup> Most physicians include this in their personal and professional values, even in jurisdictions where the public favours or the legislation allows euthanasia or PAS. Establishing physicians as collaborators in euthanasia and PAS thus may lead to role conflicts.<sup>53,59</sup> However, the impact of characterizing euthanasia as medical treatment on physicians' professional identity and on the institutions of medicine and law has not been evaluated yet.

19. In the case of legalization of euthanasia or PAS, special attention should also be paid to avoid (1) the widening of the clinical criteria to include other groups in society, (2) pressure on vulnerable persons and (3) killing to become accepted within society.

An evaluation of the rates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for vulnerable groups such as racial or ethnic minorities, compared with background populations.<sup>60</sup> However, the first population-based study in Switzerland described that assisted suicide was associated with female gender and situations that may indicate greater vulnerability such as living alone or being divorced, although it was also associated with higher education and higher socio-economic position.<sup>61</sup>

In the context of euthanasia, the danger of sliding down a 'slippery slope' has been discussed. This means that even if legislation for euthanasia is formulated with clear indications, the regulations will be extended and finally be overruled by ongoing practice.<sup>38,53</sup> Bernheim and colleagues as well as other authors have stated that data from the Netherlands and Belgium do not provide any evidence of a slippery slope.<sup>52,62</sup> However, drug-induced ending of life without patient's request – by definition not euthanasia – and abuse of palliative sedation are two indicators for such a 'slippery slope'.

In the Netherlands, despite the new law of 2002, 0.4% of all deaths are instances of medicalized killing without an explicit request from the patient.<sup>63</sup> Recent reports have

suggested that there is also an increased abuse of 'terminal sedation' in that country. Physicians report having initiated continuous deep sedation with the intention to overdose patients to hasten death.<sup>49</sup> 'Slippery slope' is also the provision of euthanasia and of PAS for depressed persons and those in the early stages of dementia, when the patient is still able to formulate an explicit request as proposed by the organization Nederlandse Vereniging voor een Vrijwillig Levenseinde (NVVE) in the Netherlands. The latest report from the RERCs stated that in 2013 euthanasia had been performed for 97 patients with dementia and 42 patients with psychiatric diseases.<sup>12</sup> Dutch legislation also permits physicians to terminate the lives of newborn infants if they are born with such serious disorders that termination of life is regarded as the best option.<sup>64</sup>

In addition, specific cases in Belgium and the Netherlands have shown an extension of indications. In the Netherlands, dementia or depression is accepted as an indication for euthanasia.<sup>65</sup> In Belgium, since the introduction of the euthanasia law in 2002, 25 projects for enlargement of the law have been proposed.<sup>3</sup> Just recently, the Belgium parliament voted that children and adolescents also are allowed to receive euthanasia or PAS.<sup>20</sup>

In Belgium, a tendency of family members to consider the dying process as undignified, useless and meaningless, even if it happens peacefully, comfortably and with professional support has been described.<sup>53</sup>

20. The EAPC encourages its members to engage in direct and open dialogue with those who promote the legalization of euthanasia and PAS.

Understanding and respect for alternative viewpoints are not the same as the ethical acceptance of either euthanasia or PAS. An open dialogue is required to clarify the underlying values and priorities and map out the meta-ethical incompatibilities and cultural differences that cause misunderstanding and condemnation. The discussion should focus on optimal holistic care for the patient and his caregivers, from a palliative care perspective. Healthcare ethics and the personal and professional values of healthcare professionals may also play an important role and must be included in the discussion.

Even with critical reflection on the experiences in Belgium, the Netherlands and Oregon, it has to be acknowledged that there may be more transparency and open discussion around end-of-life than in most other countries, where similar procedures may happen in a more covert way.<sup>66</sup>

21. EAPC does respect individual choices for euthanasia and PAS but stresses the importance of refocusing attention onto the responsibility of all societies to provide care for their older, dying and vulnerable citizens. A major component in achieving this

is the establishment of palliative care within the mainstream healthcare systems of all European countries supported by appropriate finance, education and research.

Realizing this goal is one of the most powerful alternatives to calls for the legalization of euthanasia and PAS, the EAPC advocates for access to adequate palliative care for all who need it as a human right.<sup>67</sup> Good provision of palliative care is paramount in order to ensure that people don't ask for euthanasia through lack of optimal symptom control or private or societal marginalization.

## Conclusion

The EAPC position paper states that euthanasia is not a part of palliative care. Certainly, even the best palliative care model or service cannot prevent patients sometimes asking for hastened death. However, there is a fundamental difference in the approach to these patients between euthanasia and palliative care. Proponents of the legalization of euthanasia take the request of the patient as the point of reference of the patient's autonomy and try to comply with this personal preference. Palliative care experts should also acknowledge the requests for euthanasia in those patients who express them, but make this the starting point of holistic care, beginning with comprehensive assessment and communication and trying to understand the motivation and attitude behind the patient's wish.

In conclusion, patients requesting a lethal injection to end their suffering by the induction of death are a great challenge in palliative care. Those patients deserve not only the best form of medical therapy for symptom control but also special psychosocial and spiritual counselling, based on individual respect and understanding in situations of misery and despair.<sup>2</sup>

Palliative care is based on the view that even in a patient's most miserable moments, sensitive communication, based on trust and partnership, can improve the situation and change views that his or her life is worth living.

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