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# Why (not) legalise euthanasia and physician-assisted suicide?

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In the last three decades, euthanasia has been a topic of continuous debate in the Netherlands and elsewhere. It is obvious that euthanasia has medical, moral and legal aspects, but it also has cultural, social and political dimensions, as the example of the Netherlands demonstrates. Euthanasia should be understood within a historical context as a protest against medical power and a way to bring about a good death.

The euthanasia debate often starts with so-called 'paradigmatic cases' that appear to call for euthanasia. These cases are exposed in popular and scientific literature to illustrate the relevancy and plausibility of euthanasia in particular circumstances. However, as the debate has developed over time, more and more cases have surfaced that differed significantly from these paradigmatic cases, suggesting that euthanasia might also be justified in other conditions and circumstances. Thus, we find that the euthanasia debate has gradually expanded from its clearly delineated early stage to a much broader practice.

Euthanasia is a sensitive topic in most Western countries. It is an issue that continues to be associated with strong moral convictions. In the Netherlands, after three decades of debate and practical experience, euthanasia is still not an established or normal practice. In November 2000, the Lower House of the Dutch Parliament accepted new legislation, which, in turn, was passed by the Upper House in April 2001. The new law, enforced in April 2002, makes euthanasia a legal medical intervention under particular conditions.

However, the legal regulation of euthanasia does not mean that the practice has lost its controversial and contentious character. Even in the Netherlands, the medical, legal and political debate has continued with vigour. While Parliament was debating the new bill, the Brongersma case added new dimensions and created confusion: How could simply being old, without any physical or mental illness but tired of life, be a condition of unbearable suffering? And then came the case of van Ooijen, the GP who had figured prominently in the well-known television documentary 'Death on request'. He was on trial because he had terminated the life of a nursing home patient at the request of the family rather than the patient. Van Ooijen was found guilty of murder, yet not punished because he acted 'with integrity'.

The situation with regard to euthanasia, therefore, remains complex and multifarious. Opponents of euthanasia point to the expansion of the practice. Advocates do not think that this expansion is necessarily problematic, yet cannot agree where to draw the line between acceptable and unacceptable cases. The only thing that most people

seem to agree about is that the current practice has certain drawbacks that need to be amended, including the notification of euthanasia cases and the provision of alternatives, such as better palliative care.

In this presentation, I will focus on four issues. First, the legalisation of euthanasia in the Netherlands. Second, the comparison of rules and regulations in other European countries. Third, the issue of legalisation and the various arguments for and against legalising euthanasia. Finally, the approaches to death and dying that seem to emerge from the euthanasia debate.

## Legalisation of euthanasia in the Netherlands

In essence, the Termination of Life on Request and Assisted Suicide Act does three things. First, it revises articles 293 and 294 of the Penal Code. Second, it stipulates the requirements of due care which the physician must abide by in order to be immune against punishment. Third, it delineates the process for reporting and evaluating euthanasia cases.

The old article 293, which prohibits murder at the victim's request, has become the first paragraph of the new article 293. A second paragraph has been added, legalising euthanasia performed by physicians.

In an attempt to counter criticism from abroad, the Dutch government has insisted that the new law does not legalise euthanasia. After all, article 293, §1 of the Penal Code still prohibits any and all forms of requested murder. Paragraph 2 merely provides a punishment exclusion ground for euthanasia, akin to the more generic exclusion ground included in article 40 (*force majeure*). Thus, a judge can always reject the appeal to paragraph 2 when the conditions specified therein are not met.

Under the new law, the physician who commits euthanasia in accordance with the requirements of due care will never be in contact with the legal authorities. He or she has to submit a report to the municipal coroner, which a special committee will review. If accepted by the committee, the case will not be advanced to the prosecutor and no legal proceedings will ensue.

The same is true for the physician who assists in a patient's suicide. The old article 294 prohibiting such assistance has remained in force, but physicians are excluded if they fulfil the requirements of due care.

## Requirements of due care

In addition to revising the criminal law, the new law also provides detailed guidelines for the practice of euthanasia. In fact, these guidelines are not new. The various court decisions in the 1980s had already resulted in all kinds of

guidelines. In 1987, a bill was proposed that reduced the punishment for requested murder to 4.5 years, specified that good palliative care should not be considered requested murder – even if death ensued – and provided a list of requirements of due care. The law was not passed. But in 1990, the Ministry of Justice went ahead and issued a similar list of requirements as part of a formal notification procedure.

Since euthanasia was a crime, one could not legally expect physicians to notify the authorities of their actions. No suspect is legally required to assist in his own conviction. But without notification, it would also be impossible to regulate the practice. In 1993, the Dutch Parliament decided in favour of a typically Dutch manoeuvre: to issue guidelines formally on how to commit a crime and how to report it to the authorities. The new law incorporates these guidelines and the notification procedure from 1990.

The law states that the ‘requirements of due care’, which the euthanising physician must fulfil in order to be immune from punishment, are that the physician:

- a. Holds the conviction that the request by the patient was voluntary, well considered and lasting
- b. Holds the conviction that the patient’s suffering was without prospect and unbearable
- c. Has informed the patient about his situation as well as about his prognosis
- d. Holds the conviction, together with the patient, that there was no reasonable alternative solution for his situation
- e. Has consulted at least one other independent physician who has seen the patient and has formed an opinion about the requirements of due care listed under a through d
- f. Has terminated the patient’s life with due medical care.

In short, the new law does not set any new, stricter or even more precise requirements of due care for the practice of euthanasia. It does, however, create two new expansions of the already widespread practice of euthanasia.

First, it specifically states that a person does not need to be competent when euthanised (article 2, §2). The patient can make a request for euthanasia in writing in advance of becoming incompetent, a kind of ‘living will for euthanasia’. The law thus inherits all the problems that living wills typically invoke. Consider, for example, a patient in the beginning stages of Alzheimer’s disease. He/she fears a downhill slope and writes a living will requesting euthanasia. Can this patient, who has never before been demented and does not know how his/her brain, mind and attitudes will be affected by the disease, accurately predict that his/her wish for euthanasia will be lasting and that euthanasia will be the only reasonable alternative, as stipulated by requirements (b) and (d)?

Even more troublesome is the fact that minors can request euthanasia as well. The law stipulates that a minor between the ages of 16 and 18 who appears mature can be euthanised at his or her request, provided the parents have been consulted (article 2, §3). Note that the parents cannot stop the euthanasia. In fact, they may not be able to stop the euthanasia of their 12-year-old daughter either. If the parents of a child between the ages of 12 and 16

oppose euthanasia, but the physician believes that ‘serious harm’ can be prevented by means of euthanasia, the physician can override the parents and euthanise the 12-year-old girl at her request (article 2, §4).

### **Notification and evaluation**

The third and largest part of the new law delineates the procedure for notification and, foremost, evaluation of euthanasia. Since the Law on Burial and Cremation already contains guidelines specifying how a physician should notify the authorities when he/she has committed euthanasia, the new law only had to formalise the evaluative process.

The evaluation of euthanasia is completely retrospective. In fact, article 16 specifically prohibits any member of these committees from providing prospective advice to physicians who are planning to euthanise one of their patients. This is somewhat remarkable since euthanasia is now legal. While it was illegal, the authorities evidently could not evaluate and approve euthanasia prospectively. The courts could only find, in hindsight, that the physician had been compelled to euthanise the patient because of *force majeure*. But now that euthanasia has become legal, it is not clear why the tradition of retrospective evaluation has been continued.

As before, the physician is legally required to inform the coroner that the patient did not die of natural causes, but as a result of either euthanasia or assisted suicide. When the coroner receives such notice and the accompanying report, these documents will be forwarded to one of the regional committees that have been formed to evaluate all reported euthanasia cases. Each of these committees consists of at least three members – a lawyer who serves as president, a physician and an ethicist or moral theologian. These committees evaluate whether the physician committed euthanasia in accordance with the requirements of due care. A simple majority of votes is decisive. If approved by the committee, the physician will be informed in writing, but no report will be sent to the legal authorities. Only if the committee finds that the physician has not acted properly will the regional prosecutor be informed.

It should be pointed out that at present there are only five regional committees. At the current reporting rate of approximately 2,000 cases per year, that means each committee must review 400 cases per year, or about eight cases each working week. Since these committees operate only one day a week, there is about one hour to review each case. These figures clearly show that it would be impossible for the committee to carefully examine each case in-depth and determine that the patient was truly competent, informed and not pressured by family members or healthcare providers; that their request for euthanasia was sincere, authentic and not, in fact, a desperate call for compassion and help; that the patient’s condition was beyond prospect and all alternatives of good end-of-life care and symptom relief were exhausted; and that the patient’s suffering was truly unbearable and lasting. All of this needs to be assessed and evaluated, as well as the manner in which the physician went about euthanising the patient – all in about one hour or less.

## A European survey

In January 2003, the Council of Europe published the results of a survey on laws and/or practices concerning euthanasia and assisted suicide in 34 of its member countries (and in the United States) (<http://www.coe.int/euthanasia-report>). The conclusion is that euthanasia is only legally possible in one country: Belgium. Assisted suicide is legally possible in two countries: Estonia and Switzerland. The survey shows that considerable confusion exists regarding the definitions. The term 'euthanasia' is not used in the official literature and regulations of three countries, whereas 'assisted suicide' is not used in five countries. In 16 countries, the distinction between 'active' and 'passive' euthanasia is in use. Professional codes of practice relating to euthanasia do exist in ten countries and to assisted suicide in seven countries. Laws relating to euthanasia exist in ten countries. However, in 25 countries, legislation, regulations or other provisions do not make euthanasia possible, often explicitly prohibiting healthcare professionals to participate in it. At the same time, while only Italy, the UK and the Netherlands have had a National Commission on Euthanasia in the past, in many countries public debate has been and is intensive, initiating and engaging public bodies, such as national bioethics commissions or parliamentary committees, to issue regulations and recommendations. It is also indicated that members of the medical profession have been prosecuted after performing euthanasia in eight countries. Finally, laws regulating living wills or advance directives only exist in six European countries.

It is interesting to compare the situation in Belgium and the Netherlands. The Belgium Parliament passed the Law on Euthanasia in May 2002, shortly after the Dutch law was enforced. The structure of the laws is similar: euthanasia was legalised under strict conditions and after confirmation with a notification procedure. It is remarkable, however, that in replying to the Council of Europe questionnaire, the official response from Belgium was that it had indeed 'legalised' euthanasia, whereas the Dutch response was negative. There are also differences between the two laws. The Dutch law is concerned with euthanasia as well as physician-assisted suicide; the same regulations apply since no distinction in principle is made. The Belgian law only refers to euthanasia, using the same definition of euthanasia as the Dutch law. A significant difference is that Belgian law is more extensive on the requirements of prudent practice. In the Netherlands, over the last few decades, the rules and norms regulating the practice of euthanasia have evolved through a process of jurisprudence. Another difference is in their implementation. In the Netherlands, a notification procedure has developed with regional committees providing feedback to the physicians, thereby allowing professional education and quality assessment. In Belgium, the notification is anonymous through a central committee. The expectation, therefore, is that the implementation will be more difficult in Belgium than in the Netherlands. A contributing factor here is that the medical profession in the Netherlands has been deeply involved in the development and guidance of the euthanasia practice, while in Belgium professional support for the new law is uncertain. Data also show significant differences in euthanasia practices between the Netherlands (1995) and

Flanders (1998). The prevalence of end-of-life decisions is in the same range in both countries (42.6% in the Netherlands and 39.3% in Belgium). However, termination of life on request (euthanasia) is more common in the Netherlands (2.4%) than in Belgium (1.1%), while termination of life without request is more common in Belgium (3.2% and in the Netherlands 0.7%).

## The issue of legalisation

The question of whether a morally controversial practice such as euthanasia should be legalised first of all raises the issue of what 'legalisation' means. In a strict view, it means that human acts that were considered as illegal ('crime') are no longer regarded as such; they are no longer included in the Penal Code and have, therefore, been transformed into legitimate activities. In this strict sense, the Belgian and Dutch laws have not 'legalised' euthanasia. In both countries, the Penal Code has not changed in this respect; termination of life of another person is prohibited. But *de facto* they are 'legalised' because, when performed under strict conditions, they are no longer regarded as punishable. 'Legalisation' here means 'depenalisation' or 'decriminalisation'. The main argument in favour of this approach is that societies should guarantee the right to life; the basic good of human life should be protected and no exceptions to the fundamental prohibition of killing should be included in the Penal Code itself. Even societies that allow euthanasia under strict conditions can argue that they uphold this fundamental prohibition. It also implies that euthanasia can never be regarded as 'normal' medical practice.

A subsequent question, of course, is what the difference is with 'tolerance' – the situation that has existed over the last few decades in the Netherlands. In practice, without any legal regulations, physicians have been immune to punishment if they comply with strict norms.

The considerations of developing legal rules have been similar in Belgium and the Netherlands. Initially, providing some legal status to euthanasia was endorsed by the majority of the population. From many surveys, it is clear that most people want to have the opportunity of euthanasia in certain circumstances. Over the years, political majorities have emerged that could finally realise the agenda of 'legalisation'. Second, it was obvious that euthanasia was an existing practice. Patients and physicians have been involved in termination of human life. However, as long as this practice was legally unregulated, it was to a certain extent 'underground', invisible and, therefore, not open to public debate and control. The lawgiver primarily argued that legal clarity was important. One reason was that this could provide legal protection to physicians and patients who engage in this practice. During the development of jurisprudence, there was always a risk of prosecution depending on the political climate; there was no consensus about new cases and inconsistency among the verdicts. A second reason was that 'legalisation' offered opportunities for evaluation and quality control. Physicians have not reported cases of euthanasia because of legal uncertainty or because they feel regarded as 'criminals'; this obstacle can be removed by legal regulation. It is also an argument for why 'legalisation' in the strict sense is not preferable since there is less incentive to make people report

activities that are fully legal. Creating a notification procedure that is not within the legal domain will facilitate reporting of cases; it will open up a relatively hidden practice and allow some measures of professional audit and assessment. Although euthanasia is an individual decision, taking place in the private environment of the doctor–patient relationship, ‘legalisation’ as ‘depenalisation’ still insists that these decisions have a social dimension because a fundamental good is at stake.

An interesting argument relates to the question of ‘humanisation’. Especially in western societies, technologies have developed into impersonal arrangements. In healthcare, the focus on disease, intervention and technology sometimes overrides the attention for the personal, individual needs of the patient. Safeguarding a humane society also implies that politics guarantees the possibilities of a humane death. This argument is used to advocate legalisation of euthanasia. However, it can also be used to argue against legalisation, not only because euthanasia as a medical act expands the power of medicine, but also because legalisation would imply that a humane death requires killing another human being. Creating the legal possibility of euthanasia could easily bypass other efforts to ‘humanise’ death, such as palliative care.

It will be interesting to observe the effects of the current legislation. One hypothesis is that, once the possibility of euthanasia legally exists, ideological strife will diminish and more energy can be devoted to exploring other ways to bring about a ‘good’ death. Now that public anxiety about a horrifying deathbed has been allayed, professional efforts can focus on palliating death and suffering.

### **Approaches to death and dying**

The paradigm case that is typically presented in debates of euthanasia depicts a competent patient in the final stages of life with an incurable disease and in a state of unbearable suffering. Once becoming terminal, the patient himself or herself issues a voluntary and persistent request for euthanasia. The various elements of this paradigm case have been incorporated in the ‘official’ Dutch definition of euthanasia. This definition emphasises the intentional ending of the life of a patient, by a physician, at the specific request of that patient. Indeed, the label ‘passive’ euthanasia is no longer used, because the types of decisions this label refers to do not involve the physician’s intent to end the patient’s life and are, therefore, not considered euthanasia proper. Likewise, cases where there is no patient request are not considered cases of euthanasia.

#### ***Controlled death***

Both the structure of the paradigm case and the official Dutch definition of euthanasia exemplify the significance of one specific moral justification of euthanasia, that is, the moral principle of respect for individual autonomy. This principle is thought to provide the proper counterbalance against medical power. And, although individual freedom is not as decisive a political principle as it is in the USA, Dutch people harbour strong libertarian sentiments that favour an almost absolute patient’s right to autonomy.

The significance of autonomy has given rise to a specific approach to death and dying. Death is considered a personal decision, rather than an event that befalls human

beings and needs to be accepted as part of life.

The autonomous individual determines when and how death will occur. It is the rational outcome of an assessment of your life, the secularised last judgment made by the person himself or herself. According to this image of ‘controlled death’, the duty of physicians is to ascertain whether the patient has made a voluntary and carefully considered decision.

Yet on closer inspection, it is all but clear that the concept of patient autonomy is significant in the practice of euthanasia. Advocates of euthanasia have proposed that autonomy implies the possibility and justifiability to take decisions about one’s own life, including ending it. However, this proposition appears at odds with the philosophical and political tradition out of which the notion of respect for individual autonomy grew. In this libertarian tradition, autonomy has been deemed a basic characteristic of being human precisely because it guarantees that each person is free and able to make decisions according to his own free will. But it is also questionable whether an appeal to individual autonomy can justify the decision to end one’s life. If autonomy is a basic value, can the person eliminate the very basis of this important characteristic? If this is so, the implication is that there are certain limits to autonomy even when arguing within the confines of a philosophy of autonomy itself.

Now even if we assume that people have the right to end their lives, a second question immediately emerges: is it morally justifiable for other people to assist in this? In short, even if suicide is morally justifiable, that does not mean assisting in suicide is. In the Netherlands, it is generally assumed that assisting in suicide is justifiable, particularly if it is done by a physician. Why a physician? This again is not self-evident because, in other domains of life, we actually prohibit physicians to end the lives of other people. Although the Netherlands does not have the death penalty, almost everybody seems to agree that, of all people, physicians should not be engaged in capital punishment. There is no logical connection between the morality of suicide and that of physicians ending the lives of their patients. If it is the moral principle of autonomy that justifies suicide, one can consistently argue only that the doctor may prescribe the drugs necessary for the patient to end his/her own life, so that, in the end, the moral responsibility remains in the hands of the patient. Yet euthanasia is much more popular in the Netherlands than physician-assisted suicide.

#### ***Preventive death***

The image of ‘controlled death’ with the primacy of the principle of autonomy, although important in the early stages of the euthanasia debate, has become less influential because of the emergence of the image of ‘preventive death’. Nowadays in the public debate, the prominent image is that of a fast and painless departure from life. The Protestant ethicist Kuitert has made a comparison between living and being in a room; one enters through one door and can leave through another. This image of a sudden departure coincides with the expectation that suffering will be superfluous and preventable; a good death is one where the person is still active and feels well, just before any deterioration and decline due to disease or aging. If

unbearable suffering is a major justification for euthanasia, why wait until suffering has become unbearable?

Research data from 1995 show that, in comparison with an earlier study from 1990, the number of requests for euthanasia has grown. A distinction is made between two types of patient request. The first is a request to have euthanasia 'in due course'. For example, when patients are first diagnosed with cancer, many want to find out about their physician's stance towards euthanasia and they do so by asking for euthanasia. In 1995, more than 34,000 patients made this type of request (compared with 25,100 in 1990). It is important to pay attention to the meaning of these requests to have euthanasia in the longer term – such requests do not necessarily mean that these patients want to die. These patients are not dying but in the initial stages of a potential lethal disease. They are anxious and concerned that the doctor, in a later stage when they will be suffering, will do his or her utmost to relieve that suffering. A request for euthanasia is quite an effective way to ensure the complete attention of healthcare professionals.

The second type is a request for euthanasia 'in the foreseeable future'. This is a specific request when the patient is at a stage where death is imminent. In 1995, there were 9,700 of these requests for euthanasia (compared with 8,900 in 1990). These requests involve more deliberation than the 'in due course' requests because a practical decision whether to grant or refuse the patient's request must be made. In 1995, of those 9,700 requests, 3,200 were granted (compared with 2,300 out of 8,900 in 1990).

From the research data, a striking conclusion can be drawn. Only a minority of euthanasia requests are actually carried out; two-thirds of the requests for euthanasia are not granted. Apparently the patient's own explicit and persistent request is not decisive.

This conclusion is supported by another set of data, collected by the same research team. The data show that there were 4,500 cases of active termination of life in 1995. Of these 4,500 cases, 900 (or 20%) were without the patient's request. These 900 cases do not qualify as euthanasia proper (as delineated in the standard definition). This proves that there is considerable practice of termination of life without the explicit request of the patient.

These findings raise serious doubts about the value of the respect for autonomy argument within the practice of medicine. For medical doctors, it can be argued, respect for autonomy is not the decisive motive for action. In daily practice, the most important consideration and the main moral justification for euthanasia is relief of suffering. It is not really relevant whether the patient requests euthanasia or not. If, in their physician's opinion, patients are not suffering unbearably or their suffering can be treated, their request for euthanasia will not be granted. If, however, the doctor estimates that the situation of unbearable suffering is worse than being dead, he/she will consider the option of active termination of life. In such dire circumstances, the patient's request is not even a necessary condition. The empirical data reveal that many physicians simply assume that patients would have wanted euthanasia, even if patients have not been very articulate in requesting euthanasia or have merely hinted at the possibility of euthanasia. This is also the case if the patients are

incompetent, psychiatric patients, demented elderly or handicapped newborns.

These empirical data raise the question of what really is the basic justification for euthanasia. It is evident that, from a historical perspective, euthanasia has never been primarily linked to the issue of autonomy. It was foremost considered a form of 'mercy killing', an act of compassion where killing the person is better than letting them suffer. It is a situation where people are suffering, and the suffering is so severe, so unbearable, that it is better to die. But in the present Dutch debate, two different sets of moral justifications appear to be operating which are, moreover, often at odds with each other: (i) a non-medical justification, emphasising respect for patient autonomy (and the importance of a voluntary request), and (ii) a medical justification, emphasising relief of suffering (and the importance of a situation of unbearable suffering). The first paradox of the Dutch euthanasia debate is that it started out as a protest against medical power, emphasising patient autonomy as a counterbalance; but 30 years later, the power of physicians has only increased because it is physicians who decide whether the patient's suffering is so unbearable that the request for euthanasia can be granted.

This paradox is fuelled by the highly problematic consequences that either alternative would bring forth. For example, if autonomy would be truly decisive, ending human life without an explicit request would have to be ruled out. Yet, all patient requests for euthanasia would have to be taken seriously. The number of euthanasia cases would be at least three times the present number. Very stringent rules and guidelines would have to be put into place to ensure that the patients' requests were reliable (for example, repeated requests, second opinion, documentation). But the grounds for the request can no longer be evaluated; they are the proper domains of the individual patient's valuation. All of this appears quite consistent but, as the recent case of Mr Brongersma shows, the consequences of this logic are very troublesome. Mr Brongersma was 86 years old, had no physical or mental ailments, but was tired of living. In his view, life had become unbearable and an unacceptable source of suffering. The Supreme Court of the Netherlands recently (December 2002) rejected this line of reasoning as a justification for euthanasia; there should be some kind of medical condition explaining the suffering of the patient.

If, however, the decisive factor is relief of suffering, the discretionary power shifts to the physician who has to decide whether the patient's suffering is unbearable and whether euthanasia is, therefore, justified, even if the patient does not (or cannot) request it. Now the question arises as to what the objective criteria are that allow a physician to judge whether the patient's suffering is unbearable. Without such criteria, decision-making will depend on the subjective and arbitrary values of individual physicians.

As long as euthanasia is considered a medical act and the prerogative of physicians, the moral justifications lie primarily within the expertise of physicians. Indeed, the Dutch courts typically refer to 'medical opinion and the prevailing norms of medical ethics' to justify their lenient decisions. But the actual criteria underlying the physicians' assessments are often unknown, if only because an estimated 50% of all euthanasia cases are not reported.

Thus, we find that the paradoxical end result of the euthanasia debate is that medical doctors are more powerful than they have ever been.

The emerging image of 'preventive death' is useful to pacify the tensions between medical power and patient autonomy. The patient still has some control over the moment of death, if at least there is some underlying medical condition. In deliberation with his physician, he can conclude that death is desirable as a pre-emptive strike against the terrors of dying. Reminiscent of the famous aphorism of Epicurus: death is not the enemy but rather suffering is. Rational human beings anticipate future suffering and possible deterioration. Medical professionals act like 'drones'; they should support advance care planning and assist in determining the appropriate moment of a preventive strike.

The 1990 and 1995 empirical studies present data on the reasons for euthanasia requests. They illustrate the emergence of this new image of death and dying. Expectedly, 'unbearable suffering' is frequently mentioned, as are 'de-humanising condition', 'loss of dignity' and 'pain'. Considerably more surprising is a cluster of reasons that concern the individual patient's ability to cope with the situation: 'meaningless suffering', 'dependency' and 'tired of life'. These reflect the expansion of suffering as a justification for euthanasia from the somatic suffering of the paradigmatic cancer patient to mental and even spiritual suffering. Most remarkable is a third category of reasons such as 'escape from deterioration of suffering', 'prevention of suffocation' and 'prevention of pain'. These reasons show that euthanasia is no longer considered only a way out of a state of unbearable suffering, but also as a sensible strategy to prevent such a state from occurring in the first place. Why wait until the suffering becomes unbearable? The popularity of this new approach to euthanasia is evidenced by the fact that the Dutch Health Minister herself suggested during the parliamentary debates on euthanasia that it would be wise for people in the early stages of dementia to draft an advance directive requesting euthanasia. She also advocated the distribution of suicide pills among the elderly.

### ***Palliated death***

Reflecting upon these data, the question arises as to whether the Dutch focus on euthanasia, emerging as an option in the search for a good death, has not at the same time reduced the range of care options available at the end of life. If euthanasia is no longer the option of last resort when all alternatives to relieve suffering have failed; if instead euthanasia has become a means of preventing such suffering altogether, there is no need for alternative means of pain relief anymore. Why develop therapies to ameliorate patients' pain and suffering when euthanasia can prevent the emergence of severe suffering altogether? Why should society create social structures and networks to involve the elderly in human interaction and social life when euthanasia is an adequate remedy for older persons who experience loss of meaning in life such as Mr Brongersma? We thus find that the emphasis on euthanasia tends to deflect attention from other approaches to good death and dying. For example, many hospitals in the Netherlands only

recently developed policies for withholding and withdrawing treatment. Expert centres in pain control and management have only been established in the last decade. In contrast to other countries, palliative care only became a target of Dutch health policy a few years ago. Only now, after euthanasia has become a prevalent and legalised practice in the Netherlands, is a move towards the development of a wider range of available options at the end of life materialising, so that perhaps many requests for euthanasia could be prevented. The question is whether this is not too little too late. Paradoxically, the commitment to a good death created the euthanasia movement and, in turn, the commitment to euthanasia reduced the number of options available to patients to bring about a good death. Only recently interest in palliative care has been rising. Particularly, euthanasia consultants are increasingly aware of the wide range of possibilities to ameliorate suffering, developed in the new discipline of palliative care. This new awareness is creating another, new image of death and dying: 'palliated death'. Death can be good death, not because it is fully controlled by the patient or is a timely escape from the growing burden of suffering, but because it is the appropriate last chapter of the personal biography, always difficult and burdensome, but tolerable and worthwhile. However, medical professionals should be able to provide the best expertise available to make this last part of life as comfortable as possible. The recent debate on terminal sedation demonstrates the emergence of this new image of palliated death. Putting terminal patients to sleep has always been rejected because of the implied loss of control and autonomy. Nowadays, the option of sedation is discussed more and more and explored by many healthcare professionals.

### **Conclusions**

The evolution of the euthanasia debate in the Netherlands provides some lessons that can be significant for other countries confronted with debates concerning euthanasia and those considering legalisation of euthanasia and physician-assisted suicide.

- Notwithstanding the fact that the Dutch euthanasia movement originated out of a concern for the medicalisation of death and dying, euthanasia and assisted suicide have become medical practice and are the prerogative of physicians.
- Even though human dying and death will always defy human control, there appears to be an incessant attempt on the part of contemporary societies and modern medicine in particular to control death. This explains the attraction of euthanasia and physician-assisted suicide, as opposed to palliative medicine and hospice care.
- The increasing focus on the patient's quality of life is an opportunity for the emerging approach of palliated death, going beyond the images of 'controlled death' and 'preventive death'.
- The ethics of end-of-life care are complex. Careful distinctions are necessary to identify care approaches that make the last phase of human life worthwhile, while at the same time mitigating the harmful effects of medical interventions, without having to take recourse to euthanasia in order to effectuate the desire for a good death.

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- The Dutch experiment shows that prevention of the practice of euthanasia is both an important and feasible alternative. If euthanasia is truly to be a means of last resort, other strategies towards good end-of-life care have to be realised first, including improved palliative care

units and consultation services, expanded home care services and respite care options, and revisions of medical education programmes, as well as patient education programmes.

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## Response

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**D**r ten Have has skilfully demonstrated the complexity of this issue, illustrating the difficulties of legislating and the question of whether we should do so. He has reminded us that the Netherlands has not legalised euthanasia but merely provided a punishment exclusion clause. Some might argue that legalisation and decriminalisation are, in effect, the same thing.

He reminds us that euthanasia is usually proposed out of respect for patient autonomy, freeing the patient from medical domination. But any request for euthanasia has to be considered by a doctor, the act itself performed by a doctor and the report on it (to confirm whether criteria were met), studied by a panel one of whom is a doctor. As if that is not sufficient evidence that it is not guaranteeing patient autonomy, he reminds us that many requests are turned down while other patients have been euthanised without having requested it. One is reminded of the wholesale abuse of another well-intentioned law – the Abortion Act of the UK.

As a clinician I have problems with several of the so-called ‘requirements of due care’. The request must be ‘voluntary, well considered and lasting’. I do not know how to be sure there has not been any coercion by relatives (so gentle and unobtrusive as to be almost subliminal) or how to recognise when a patient requests something as much for the exhausted relatives as for his own sake. All palliative medicine physicians are familiar with patients unexpectedly asking to be transferred from home to an inpatient unit and later explaining they did not want it for themselves but for the sake of relatives.

I wonder if my experience over the past 25–30 years in palliative medicine has been unusual. I have never had a single request from a patient for euthanasia, though many have said they considered it before receiving palliative care. I have had many, many relatives ask for euthanasia, illegal as it is in my country, offering me substantial financial inducements.

The suffering must be perceived by the attending doctor as ‘without prospect and unbearable and there must be no reasonable alternative solution for the patient’s situation’. As Dr ten Have has said, the response to such suffering is palliative care – widely available, easily accessible and universally taught in medical and nursing schools. I applaud that statement. It seems to me that none of us has the right to condemn those who call for legalised euthanasia if we have not done all in our power to make it available. I have recently found that of 700 medical schools around the world, only 170 teach palliative care.

Not only do we have a responsibility to provide and to teach ever-improving palliative care, we have a moral responsibility to ensure that the general public are aware of its availability and, equally, a moral responsibility to research every aspect of what we do. I agree with Dr ten Have that if euthanasia becomes the means of preventing – as well as of relieving suffering – in this ‘quick-fix’ society of ours then there is no incentive to research better care. In my view, this would be a disaster.

Another thing which troubles me is that, provided the patient was mentally competent when the request for euthanasia was originally made, he/she need not be competent when euthanised. This presupposes that patients do not change their minds the nearer they get to death – something we all know not to be true. The fact that they are no longer competent does not alter the fact that their wishes may have changed – though we cannot confirm that. We have all encountered competent people previously eager for euthanasia who have changed their minds and happily told us of their gratitude to palliative care. How many of our incompetent, confused patients may be the same? Have we forgotten that the prevalence of delirium or confusion in the final week of life nears 40%?

May I add some personal comments to Dr ten Have’s paper. The older I get the more difficult I find it to quantify the suffering of a patient or the quality of their life. I have seen what I regard as appalling suffering and anguish, yet the patient has still claimed that he or she has some residual quality of life. Do I have the moral right, do I have the clinical ability to disagree with him? Is it not crass arrogance for me ever to say I know how much someone is suffering or that I know what is best for him?

I agree with Dr ten Have that this debate has cultural and economic dimensions. In no third world country I have visited has euthanasia ever been raised as an issue. The more Westernised, the more secularised a country, the more often is euthanasia mentioned and seen as an issue.

Am I alone in having had many elderly, competent patients who have told me they do not want euthanasia and, in fact, find the idea repugnant, but would be willing to have it if they thought their early death would reduce the country’s burden of caring for increasing numbers of old people no longer economically useful to society?

Dr ten Have’s paper expresses many of my own feelings better than I could ever have done and I am indebted to him. I have long felt unhappy with the possibility of legalised euthanasia and have seen palliative care as an alternative. At the same time, I can well understand why

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some are eager to legalise it. We have been slow to disseminate the principles of palliative care; slow to get it introduced as a core subject in our undergraduate and postgraduate training; less committed than we might be to researching palliative care; and less interested than we should be in learning of, and trying to understand, the profound spiritual and existential experiences of our dying patients. Every day we see patients whose physical suffering we have successfully relieved yet they remain sad or disappointed, feel undervalued or unwanted. Because it is easier to prescribe for the physical and the psychological suffering, because it is easier to research, we

are in grave danger of overlooking the equally agonising, destructive suffering of the spirit. I believe we, in palliative care, will have failed and left the way open for legalised euthanasia with all its pitfalls, if we do not seek to know and to understand more of the experiential suffering of the dying.

We, in palliative care, have no right to condemn those who promote euthanasia as a genuine, sincere attempt to ease suffering unless we ourselves have done everything possible to promote palliative care as an appropriate, universally accessible alternative.

Dr ten Have, thank you for your stimulating paper.