

The role of the physician in the voluntary termination of life

Colophon

The role of the physician in the voluntary termination of life is a publication setting out the Position of the Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (KNMG), adopted by the Board of the Federation and effective as from 23 June 2011.

The KNMG physicians' federation represents over 53,000 physicians and medical students. KNMG member organisations include the Koepel Artsen Maatschappij en Gezondheid (Umbrella organisation for physicians and health – KAMG), the Landelijke vereniging van Artsen in Dienstverband (National society of employee physicians – LAD), the Landelijke Huisartsen Vereniging (National society of general practitioners – LHV), the Netherlands Society of Occupational Medicine (NVAB), the Nederlandse Vereniging voor Verzekerings-geneeskunde (Netherlands society of insurance medicine – NVVG), the Orde van Medisch Specialisten (Order of medical specialists – OMS) and the Dutch Association of Elderly Care Physicians and Social Geriatricians (Verenso).

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Design buro-Lamp, Amsterdam

Contact details KNMG PO Box 20051 3502 LB Utrecht - (030) 282 38 00 - www.knmg.nl/english

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Table of contents

/ Preamble	6
1/ Introduction	10
1.1 History	10
1.2 Background	12
1.3 Purpose of the memorandum	13
1.4 Definition of terms and basic principles	14
1.5 Empirical data	15
1.6 Working method and accountability	16
1.7 Summary	17
2/ The Termination of Life on Request and Assisted Suicide (Review Procedures) Act	19
2.1 The Euthanasia Law	19
2.2 Unbearable and lasting suffering	20
2.3 Dimensions of suffering	21
2.4 The professional standard	24
2.5 Medical basis	25
3/ Insight into suffering and the assessment process: support and consultation	28
3.1 Attitude, experience and point of view	28
3.2 Support and consultation	29
3.3 Insight into suffering	30
4/ The role of the physician when euthanasia or assisted suicide is not an option	33
4.1 Physicians' scope for action	33
4.2 Conscious hastening of death	34
4.3 Drug method	36

5/	Conclusions, recommendations and follow-up steps	39
	Conclusions	39
	Recommendations	42
	Follow-up steps	43
/ Appendices		
I	Participants	45
II	Web consultation results	46
III	KNMG member panel results	49
IV	Euthanasia case histories: Uit Vrije Wil versus Regional Review Committees	56
V	Outline and practical implications of different dimensions of suffering over time	58
VI	References	60

Preamble

There is a common misconception in the Netherlands that patients have a basic right to euthanasia and assisted suicide. Performing euthanasia or assisted suicide is a punishable offence. These procedures can only be performed unpunished by physicians, and then only under exceptional circumstances and provided all the requirements of due care are fulfilled. Euthanasia and assisted suicide are not included in the standard care packages offered by physicians, (1) and physicians are not under any obligation to assist in euthanasia. Physicians who have fundamental objections to euthanasia and assisted suicide must be respected in their views.

The KNMG has always taken the position that any procedure to terminate the life of a patient at his request is a last resort, to be used in cases in which the patient and physician have exhausted all options and the suffering cannot be remedied or alleviated by any means other than by ending the life of the patient at his request. Justifying physicians' involvement in euthanasia and assisted suicide is an issue mired in conflicting obligations. On the one hand, physicians have a duty to protect the lives of their patients; on the other, they have to alleviate their patients' suffering. Medical ethics and the law recognise that physicians confronted with such conflicting obligations may decide that their duty to honour a patient's request to end suffering can outweigh the duty to preserve that patient's life.

The KNMG continues to regard euthanasia and assisted suicide as a last resort measure. Physicians are always under the obligation to make every effort to determine if any reasonable alternatives can be found, in consultation with the patient.

A request for euthanasia is one of the most intrusive and onerous demands that a patient can make of a physician. Most physicians find it difficult to perform euthanasia or assisted suicide. This is all the more true if that wish is not prompted by a terminal illness.

Current public debate about the termination of life has come to centre particularly on patients in different stages of dementia, those with psychiatric conditions and seniors who feel they have 'completed life'. Society has high expectations. This public pressure is perceived as both burdensome and risky by physicians, who cite society's stigmatisation of the aged and people with dementia. Dementia, for example, is portrayed as one of society's urgent problems, partly in view of the estimated numbers of people expected to be affected by this syndrome in decades to come, and based on the premise that dementia necessarily leads to a poor quality of life and an undignified death. The KNMG wishes to emphasise that euthanasia

is an exceptional medical procedure that inherently entails a dilemma for the physician requested to perform it and will never become 'standard'. There will continue to be plenty of physicians who are either unwilling or morally indisposed to be able and willing to make full use of the statutory freedom, to which society is laying an increasingly vocal claim as integral to its right to self-determination.

It is important to recognise that physicians are insufficiently aware of the fact that patients in early (or late) stages of dementia or chronic psychiatric illness have equal recourse to the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (*Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*). Yet we also know that any assessment of the considerations prompting such a request and of whether the suffering is indeed unbearable and lasting is generally much more complicated in this category of patients than among those who are suffering due to somatic problems and ailments. It is in part for this reason, and the threat of criminal proceedings, that physicians act with extreme caution and restraint in such situations. The KNMG feels such restraint is justified.

The KNMG's position paper also demonstrates that an accumulation of geriatric afflictions, including loss of function, that result in progressive deterioration may also qualify as unbearable and lasting suffering within the meaning of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. However, there must always be a medical basis in such cases, meaning that the patient must have a condition that is defined as a disease or combination of diseases/ailments. Of course, this is precisely the physician's domain of expertise. In the KNMG's view, physicians can benefit greatly from consulting colleagues and/or other professionals in order to take stock of all alternatives. A physician's first duty, after all, is that of care.

Equally, a physician has a duty of care when a patient with a strong wish to die has no recourse to the Termination of Life on Request and Assisted Suicide (Review Procedures) Act or is refused by his physician and chooses to deny food and drink on his own initiative. In that case, the physician not only should inform the patient as thoroughly as possible about the pros and cons, but also ultimately bears a duty of care to prepare and supervise the patient and to implement palliative care or, where medically indicated, palliative sedation.

Patients, too, often have difficulty telling a physician they have an authentic wish to die. Physicians, for their part, are under an obligation to take such requests seriously. This also means that if a physician cannot or does not wish to honour a patient's request for euthanasia or assisted suicide he must give the patient a timely and clear explanation of why, and furthermore must then refer or transfer the patient to another physician in good time. Vague promises, failure to transfer patients during absences, causing delays or indicating at a late stage or too late that the physician has reconsidered his decision to perform the euthanasia all demonstrate a lack of professionalism. The KNMG therefore calls on all physicians to act as they would wish themselves or their loved ones to be treated.

In publishing this position paper, the KNMG seeks to provide an overview of the role, responsibilities, possibilities and limitations of physicians today – ten years after the Termination of Life on Request and Assisted Suicide (Review Procedures) Act was passed – in matters surrounding the voluntary termination of life.

Prof. A.C. Nieuwenhuijzen Kruseman
Chairman KNMG

1 / Introduction

1.1 History

The Netherlands' Supreme Court decision in the Brongersma case gave rise to debate within both the medical professions and society in general on the question of whether physicians should play a role in administering assistance in the termination of life in cases where the desire to die does not stem from a clear medical disease or condition. Brongersma was an 86-year-old former Labour Party senator whose GP helped him to commit suicide. Apart from a few old-age afflictions, Brongersma had neither any serious somatic ailments nor any psychiatrically classifiable illness or condition. His suffering consisted in physical and social deterioration, the loneliness of his existence, his general condition of dependency and a perception of the pointlessness of his existence. Such cases are sometimes described as 'suffering from life'. His GP and two colleagues whom he consulted concluded that Brongersma's case was one of unbearable and lasting suffering.

The court of appeal in Amsterdam convicted the GP in 2001 for 'purposefully aiding another person to commit suicide and providing him with the means to do so, resulting in the suicide', with the GP unable to claim necessity (*force majeure*) in the sense of an intolerable situation or other statutory defence. The GP appealed this verdict before the Supreme Court. Citing previous case law and the history of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (Euthanasia Law) passed in 2001, the Supreme Court rejected the GP's appeal in 2002, (2) concurring that the GP in this case could not claim necessity in the sense of an intolerable situation. While emphasising that an appeal on the grounds of an intolerable situation is not automatically excluded merely because the unbearable and lasting suffering does not stem from a definite somatic or psychological cause or because the patient is not in an end-of-life phase, it went on to point out that the patient's suffering – whether due to old-age afflictions, symptoms of deterioration or a perceived pointlessness of existence – should have its principal basis in one or more medically classifiable somatic or psychological illnesses or conditions. This is precisely a physician's domain of expertise, according to the Supreme Court. The Supreme Court therefore upheld the court of appeal's verdict, extending to the decision not to impose a penalty.

In 2003, the KNMG instituted the Dijkhuis Committee to formulate a response to the questions called up by the case both in the lead-up to and following the Supreme Court ruling. (3) Its conclusions, reported a year later, were that there are a variety of possible approaches, and therefore answers, to the question of how a physician should deal with patients who request assistance in dying due to a sense of suffering from life. The committee set out four possible views:

- 1 a more rigid definition of the medical professional domain of the physician;
- 2 a more open, but not unbounded, definition of the medical professional domain of the physician;
- 3 a domain that is shared by a variety of professional care providers;
- 4 assisted suicide has no place in the professional environment.

The committee determined that none of these views could count on sufficient support from and consensus among the occupational group of physicians or the general public. The committee did voice its preference for the second option – proposing a more open, but not unbounded, definition of the medical professional domain of the physician – on the grounds that:

- ▶ the source of the suffering is not determinative for the degree to which the patient experiences the suffering;
- ▶ legal methods of demarcation do not actually solve these problems in practice and tend to underestimate the complexities physicians face when assessing suffering;
- ▶ physicians are in fact knowledgeable about suffering from life (and can expand on this knowledge);
- ▶ it is important to respect the full array of views that physicians have about and how they perform their tasks; and
- ▶ the fact that this type of request for assistance is more likely to increase than decrease.

The report issued by the Dijkhuis Committee prompted the KNMG to urge that further research be conducted among physicians and patients. In particular, the KNMG sought to compile a survey of case histories on the basis of which to determine the magnitude of the issue and, subsequently, set up a policy framework keyed to this occupational group. But for the government at that time, which did not wish to change euthanasia policy, this was a sensitive issue, and so the KNMG's proposed research never took shape.

1.2 Background

In 2010, public debate flared around the issue of whether people who feel they have completed life should be able to ask for assistance to end their lives in a dignified manner. Essentially, this was a continuation of previous debates about the Drion Pill (1991), the Brongersma case (2001), the Dijkhuis Committee report (2004) and Chabot's publications on covert means of ending life (2007).

The citizens' initiative *Uit Vrije Wil* ('By Free Choice') is lobbying to make it possible for people aged 70 and older who feel they have completed life and wish to die in a dignified manner to receive assistance in doing so if they expressly request it. (4, 5) At present, providing assistance aimed at terminating life is illegal and punishable. *Uit Vrije Wil* argues that assisting seniors to die at their request should no longer be a punishable offence, and that Dutch citizens who seek to die a dignified death should therefore be given the freedom to do so by amending the existing legislation. The implication is that this assistance be professional, administered with due care and verifiable. Specially trained care providers would be designated to respond to such requests, including psychologists and mental care practitioners; physicians would not be expressly excluded. In the proposal framed by *Uit Vrije Wil*, the care provider would conduct a series of interviews with the senior who feels he has completed life and wishes to die with dignity. If the care provider is convinced that all relevant criteria have been fulfilled (voluntary, well-considered, enduring, competent, authentic wish to die, Dutch citizen, 70 years or older), then a second, independent practitioner is called in to act as a consultant. This practitioner would meet with the senior and issue an independent opinion in the case. Only after all these steps are taken would the care provider decide whether to agree to the assisted death. Notification of the assisted suicide would subsequently be provided by the care provider, who would be evaluated in the manner already set out in the current Euthanasia Law.^a

The KNMG feels this bill is problematic in several respects. Most important is that the proposal opens up a second road to euthanasia and thereby undermines the existing Euthanasia Law. That law rests on two pillars: a voluntary, well-considered request and unbearable and lasting suffering. The bill proposed by *Uit Vrije Wil* abandons the criterion on suffering and only considers whether the request is well-considered and the person is

a On 16 February 2011 the Safety and Justice Committee of the Lower Chamber of Dutch parliament evaluated the Assisted Death for the Elderly (Review Procedures) Act (*Wet toetsing stervenshulp aan ouderen*).

aged 70 or over. As the bill allows seniors to choose which law to apply, it is unlikely that they or their physicians would continue to apply to the Euthanasia Law in future. After all, it is more likely that seniors, and their physicians with them, would opt for the easiest road to assisted death. (6) In this scenario the transparency and due care of the current Euthanasia Law are at risk of being lost, if only because over 60% of reported cases of euthanasia are performed for people who are 70 or older. Another risk is that assisted death will be administered to people who might have been better served by some other form of care; indeed, we know that many suicide attempts are motivated by psychological and social problems.

The *Uit Vrije Wil* citizens' initiative has succeeded in putting the issue of seniors with a wish to end their lives on the public and political agenda. In seeking a balanced debate, the KNMG feels it is essential to first lay a foundation of research to determine the nature and magnitude of the issue. The current Euthanasia Law is founded on research by Van der Maas and Van der Wal, whose authoritative studies were instrumental in shaping the due care framework for decisions relating to terminal care. (7, 8, 9)

1.3 Purpose of the memorandum

The purpose of this memorandum is to present the KNMG's current standpoint on the role, responsibilities, possibilities and limitations that physicians have with regard to the issue of the voluntary termination of life. Physicians' standards and practices for euthanasia and assisted suicide have developed apace since the Euthanasia Law entered into force. This is particularly clear if we trace the opinions issued by the Regional Review Committees on Euthanasia, especially where views on unbearable and lasting suffering are concerned. The purpose of this memorandum is to provide a coherent overview of these progressing insights and views.

The memorandum also discusses the tension between the citizen's emphatically claimed right of self-determination in the individual's right to end his life and the role that the physician fulfils by providing the requested assistance. However, the scope of this document goes beyond euthanasia and assisted suicide alone. Citizens and patients have various other means at their disposal when it comes to voluntarily ending life. It is hardly conceivable that physicians would not have a role when seniors

voice a serious wish to die, even where this wish stems from the sense of having completed life. Ultimately, physicians also have a duty to provide their patients with all the information they need to make a well-considered choice, while patients have a right to medical supervision and treatment.

1.4 Definition of terms and basic principles

Concepts such as ‘done with life’, ‘suffering from life’ and a ‘completed life’ are used interchangeably both in the public debate and among physicians and patients.^b As these concepts overlap to various degrees, making practical distinctions can be difficult.

In the parliamentary discussion of the Euthanasia Law, ‘finished with life’ (*klaar met leven*) was described as ‘the situation of people, usually of an advanced age but not suffering from any medical disease or condition that is untreatable or a cause of severe suffering, who have determined for themselves that their own quality of life has diminished to such an extent that they prefer death over life’. (3)

The Dijkhuis Committee prefers to use the term ‘suffering from life’ (*lijden aan het leven*), which it defines as: ‘suffering at the prospect of having to continue living in a manner in which there is no, or only a deficient, perceived quality of life, giving rise to a persisting desire to die, even though the absence or deficiency in quality of life cannot be explained in any or significant measure by an identifiable somatic or psychological condition’. (3)

According to Right to Die-NL (NVVE) the concept of a ‘completed life’ is used for ‘people who suffer from a complex constellation of factors connected with old age. These are non-life threatening conditions and physical deterioration (poor eyesight, deafness, difficulty walking, fatigue, apathy, incontinence), resulting in a loss of independence and personal dignity, dependence on care, loss of status and control, a shrinking social network, loss of a sense of purpose and meaning, disengagement from society, fear of the future and the absence of future prospects. A ‘completed life’ refers to people who go a step further: rather than wait for a natural death, they decide to end life by active means (with or without help)’. (10)

^b Other common references are to being ‘tired of life’ and ‘old and full of days’ and, in this connection, to the Drion Pill and the Last Will Pill – representing metaphorical pills that do not yet exist as such.

Most apposite in the KNMG's view is the term 'suffering from life' (*lijden aan het leven*) and its definition. The KNMG applies the concept of suffering from life because *suffering* is at the heart of the entire issue. More explicitly, the KNMG holds with the Chabot ruling, which reasons that the source of the suffering does not determine the extent of the experience of that suffering. (11) Suffering can both arise from myriad causes and have various dimensions, and is personal in nature.^c When a patient requests assisted death, it is up to the physician to ascertain if there is an unbearable burden of suffering and no prospects for improvement, as required by the Euthanasia Law. The physician is always responsible for determining the burden of suffering on the patient and what the components of that suffering are, regardless of its source or the way in which the patient characterises the suffering (see also section 2.3). This applies equally if the patient's wish to die stems from a sense of having led a 'completed' life.^d But the judgement that life is completed – assuming that completion as such exists – is one that a person can only make for himself. The KNMG does not see any role for physicians in judging if a life is indeed completed.

In framing this position, the KNMG again applies the Euthanasia Law. Under the current Dutch laws, life-terminating procedures or assisted suicide are only exempted from punishment if the procedure is performed by a physician in accordance with the requirements of due care and the physician makes notification of the euthanasia or assisted suicide. The KNMG's position paper on Euthanasia (2003) is based on the current law. (1)

1.5 Empirical data

In 2005, approximately 8,400 explicit requests for euthanasia within the 'foreseeable future' were registered in the Netherlands. (12) The nature of the suffering motivating these requests for euthanasia (honoured or not) were a physical condition in 93% of cases, a psychiatric condition in 1% of cases and feeling 'finished with life' or 'suffering from life' in 6% of cases. Geriatricians dealt with 17% of these explicit requests based on feeling 'finished with life' or 'suffering from life' in 2005, GPs with 5% and medical specialists with another 5%. In 2001, a year before the implementation of the Euthanasia Law, those figures were 12%, 5% and 2%, respectively. In

^c Which is not to say that all suffering falls within the province of medicine. See also chapter 2.

^d Alternative phrasings include 'finished with life', 'life fatigue', 'old and full of days', 'death has forgotten me' and 'the party's over and I want to go home'.

that year, medical specialists indicated that 1% of assisted deaths were based on 'finished with life' or 'suffering from life', while GPs and geriatricians did not perform any assisted deaths based either wholly or partly on 'finished with life' or 'suffering from life'. (9, 13)

A mortality survey carried out in 2005 showed that, of all deaths in the Netherlands, 1.7% and 0.1% were cases of euthanasia and assisted suicide, respectively, or an estimated 2,325 and 100 deaths in real numbers. (12) Of this combined total, 39% of the patients were between the ages of 65 and 79, and 23% were 80 or older. Eighty-four percent of these cases involved a primary diagnosis of cancer, 6% of pulmonary diseases and 10% other or unknown disorders. In exceptional cases, physicians feel assisted suicide is acceptable for very elderly patients who have a sense of being 'finished with life' or 'suffering from life' but are not experiencing serious physical suffering, 34% of medical specialists, 25% of GPs and 25% of geriatricians agreed fully or partly, while 52% of geriatricians, 41% of medical specialists and 50% of GPs disagreed fully or partly.

1.6 Working method and accountability

This position paper is based in part on discussions held by two expert groups (see Appendix I). The draft text was drawn up and submitted to the Administrative Council and the General Meeting of the KNMG for review. Members of the expert groups were also asked to provide written commentary on the draft text. The text was placed on www.knmg.nl for the purpose of online consultations (see Appendix II). The KNMG member panel was asked for its advice (see Appendix III) and discussion meetings were organised in the KNMG districts of Groningen, Arnhem, Midden-Brabant, Spaarne & Amstel, Amsterdam and during the KNMG district chairman's meetings. [Note: The Federation Board of the KNMG adopted this position paper on 23 June 2011.]

Additional resources used in drawing up this position paper include literature, case law and the opinions and annual reports of the Regional Review Committees on Euthanasia. This position paper represents a codification of the standards formulated in the manner described and of the general practices and views held by physicians.

1.7 Summary

Chapter 2 outlines the statutory framework, providing a detailed explanation of the key concepts of unbearable and lasting suffering in relation to the professional standard. Chapter 3 focuses on clarifying the notion of suffering and the assessment process. Chapter 4 sets out the role of the physician when euthanasia and assisted suicide are not an option. The paper closes with a point by point summary of the conclusions, together with a number of recommendations for follow-up steps.

2 / The Termination of Life on Request and Assisted Suicide (Review Procedures) Act

The KNMG applies the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act (the Euthanasia Law) as its reference framework as standard, and therefore also for this memorandum. This chapter provides a detailed explanation of the key concepts of unbearable and lasting suffering.

2.1 The Euthanasia Law

Under the law, the definition of euthanasia applies when a physician ends the life of a patient at his express request due to unbearable and lasting suffering. Euthanasia means that the physician administers a lethal substance to the patient. In the case of assisted suicide, the physician supplies a lethal substance that the patient takes in the physician's presence. Euthanasia and assisted suicide are punishable offences in the Netherlands, except when performed by a physician who fulfils the due care requirements of the Euthanasia Law and provides notification of the procedure. The requirements of due care referred to in Section 293, paragraph 2 of the Penal Code stipulate that the physician:^e

- a holds the conviction that the request by the patient was voluntary and well-considered,
- b holds the conviction that the patient's suffering was lasting and unbearable,
- c has informed the patient about the situation he was in and about his prospects,
- d and the patient hold the conviction that there was no other reasonable solution for the situation he was in,
- e has consulted at least one other, independent physician who has seen the patient and has given his written opinion on the requirements of due care, referred to in parts a-d, and
- f has terminated a life or assisted in a suicide with due care.

^e These due care requirements also apply to assisted suicide (Section 294 of the Penal Code).

Physicians who perform euthanasia or assisted suicide do not issue a certificate of death by natural causes but instead report the death to the municipal autopsist.^f This is the statutory guideline by which all physicians in the Netherlands must abide when they perform euthanasia. Though the Euthanasia Law says nothing about where the limitations on a physician's freedom lie, these limitations are discussed in the Supreme Court's ruling in the Brongersma case. (2, 14)

2.2 Unbearable and lasting suffering

The most hotly debated due care criterion in the Euthanasia Law is: 'the physician holds the conviction that the patient's suffering was lasting and unbearable'. Lasting suffering and unbearable suffering are inextricable concepts. It is the physician's duty to assess and weigh both aspects individually and together. When appraising whether the suffering is lasting, the physician's professional opinion about the treatment and care options still available to the patient plays a vital role. Is it likely that the patient's condition will improve to a satisfactory degree? Or is it more likely that it will only deteriorate? What remedy can the physician offer and how reasonable is that alternative for the patient? How does the stress of the treatment weigh up against the patient's capacity to bear it? How severe is the loss of function? What can be done about it? Can the patient still lead a meaningful life?

The question of whether suffering is unbearable is one that only the patient can answer. Suffering can be defined as the experience of pain or distress. (11) In essence, it involves a grave situation that the patient consciously feels and experiences as being so. It is up to that patient to make clear what the nature of the unbearableness of *his own* suffering is. This suffering might take on such serious and/or unbearable forms that it affects that person's very being and makes the desire for death greater than the desire to remain alive. The person in question is not able or inclined to derive meaning from his suffering except by ending life in order to end the suffering. Suffering is an expression of the whole being and is influenced by personal experiences and conceptions and by cultural values and standards. (15, 16) It is therefore the patient who determines if his suffering is unbearable. When it comes to deciding whether or not to perform euthanasia or assisted suicide, however, this consideration is

^f For ease of reading, the term 'euthanasia' is used as much as possible instead of 'euthanasia and assisted suicide'.

not determinative. The physician must be convinced of the nature of the suffering, based on his professional assessment of its duration in relation to the unbearableness of the patient's suffering.

Actual figures over the period from the establishment of the Regional Review Committees on Euthanasia in 1998 up through 2010 reveal that more than 23,268 notifications were assessed. Of those notifications, 21,055 concerned euthanasia and 1,852 assisted suicide. In 50 cases the committees found that the physician had not acted with due care, with four of those cases relating to doubt about the unbearable and lasting suffering. These cases mainly involved patients with reduced consciousness, making it impossible to establish the unbearableness of the suffering. The KNMG has responded by laying down a euthanasia guideline for people with reduced consciousness. (17) It can therefore now be assumed that where a practising physician and consulted physician are convinced that a patient's suffering is unbearable and lasting, the subsequent evaluation by the Regional Review Committees on Euthanasia will probably not find differently. (14, 18)

2.3 Dimensions of suffering

Research and practice (including on notification) has demonstrated that euthanasia is most commonly performed in cases involving unbearable suffering caused by somatic problems and ailments, with 80-90% of notified cases concerning malignancies. Often, the resulting – untreatable – ailments are visible and very convincingly present. It is therefore not surprising that physicians use somatic suffering as the foremost measure by which to judge if suffering is in fact unbearable. Patients in these cases may be in severe pain, but may also have other serious symptoms for which further treatment is too stressful and/or not effective. (9, 12, 18, 19)

Aside from the somatic dimension, other dimensions of suffering stemming from mental and psychosocial ailments and ailments^g of a spiritual nature may also require alleviation or remediation through palliative care. (20)

^g Psychosocial problems can also be described as existential suffering, existential distress, Meaning in Life problems, emptiness, meaninglessness or preventing humiliation. (21)

Psychosocial or existential suffering therefore also fall within the medical domain.^h However, in cases where this dimension tips the balance in the determination of whether the suffering is unbearable, specialists in the field of psychosocial and Meaning of Life problems, such as social workers, psychologists and spiritual counsellors, are designated to perform or take part in that assessment. (19, 27) The mechanisms of the law make physicians personally responsible for ascertaining that a patient is in fact experiencing unbearable and lasting suffering. This does not exclude physicians from forming their opinions by drawing on the expertise of other physicians, care providers and/or those near to the patient. Indeed, this is often the obvious course in such cases.

In the future, physicians will be confronted more than ever before with seniors in vulnerable positions, ever-more advanced in age and, moreover, keen to live independently for as long as possible. At the time of writing, there are more than one million elderly people with multimorbidity. This number is expected to rise over the next decade to 1.5 million, or almost ten percent of the total population of the Netherlands.

Many older people have various afflictions that are not actually life-threatening but do make them vulnerable. The term vulnerability – also fragility, or frailty – is used to refer to a concurrent decline in several areas of a person’s capacity to endure physical stress and threats from factors in their surrounding environment. They experience a loss of both physical and mental vitality. Multimorbidity furthermore significantly increases the likelihood of depression – and therefore vulnerability. Vulnerability stems not only from health problems and the ensuing limitations, but also the measure in which people have social skills, financial resources and a social network. Vulnerability has an impact on quality of life and on prospects for recovery, and can lead to unbearable and lasting suffering. (22, 23, 24, 25, 26)

When viewed against the backdrop of these developments, and of the response to these developments within the medical profession, it is wholly justifiable that vulnerability – extending to such dimensions as loss of function, loneliness and loss of autonomy – should be part of the equation physicians use to assess requests for euthanasia.ⁱ Before taking any

^h Even in terminal cancer patients it is the physician who makes the actual judgement regarding the patient’s existential state. This is because some patients submit to the suffering while others with the same ailments ask for euthanasia.

ⁱ Dignity and humiliation are not specifically cited here as these aspects have been accepted since the Supreme Court ruling of 1984.

such steps, however, a physician's first duty is always to determine if any suitable interventions or reasonable alternatives can be found (consulting geriatricians or other experts, where needed).

The sum of this non-linear equation and the complexity of what are usually non-fatal afflictions is increasing deterioration leading to an unacceptable existence and thus to unbearable suffering for the patient. (6) Many such patients have already been through a period of marked physical decline that has exceeded their abilities to cope. As various other ailments and complications such as disorders affecting vision, hearing and mobility, falls, confinement to bed, fatigue, exhaustion and loss of fitness take hold, so too does their degree of dependence.^j The patient perceives the suffering as interminable, his existence as meaningless and – though not directly in danger of dying from these complaints – neither wishes to experience them nor, insofar as his history and own values permit, to derive meaning from them.

In the KNMG's view, such cases are sufficiently linked to the medical domain to permit a physician to act within the confines of the Euthanasia Law. This view further reflects the second option cited by the Dijkhuis Committee.

The Regional Review Committees on Euthanasia have on multiple occasions found that 'due care' was taken in cases where the unbearable suffering was caused by an accumulation of various old-age afflictions or a combination of factors, and in which the individual ailments were neither life-threatening nor fatal.^k Physicians have been able to make a sufficiently credible case to these review committees, which are charged with testing physicians' actions against the Euthanasia Law, case law and in light of scientifically-supported medical insights and medical ethics standards, that these cases equally involved unbearable and lasting suffering.

The KNMG therefore concludes that the current statutory framework and the concept of suffering are broader than their interpretation and application by many physicians today.^l

^j See also cases 7, 8 and 9 in the 2009 Annual Report of the Regional Review Committee on Euthanasia. The Hague 2010. See no. 18 in the References.

^k See also the Annual Reports of the Regional Review Committees on Euthanasia: 1998/1999 p. 11, 2002 p. 24, 2003 p. 19 and 2009 p. 20. See no. 18 in the References.

^l The same applies to Uit Vrije Wil. See Appendix VI, in which a case example from Uit Vrije Wil is compared with two cases taken from the 2009 Annual Report of the Regional Review Committees on Euthanasia.

2.4 The professional standard

During the parliamentary sessions on the Euthanasia Law, discussion repeatedly returned to the question in how far the nature of the patient's suffering needs to coincide with the physician's area of expertise. This question was prompted by the Brongersma case, which was generating interest in the late nineties, before the Euthanasia Law was adopted in 2001. In the words of the legislators, the suffering must 'incorporate a medical dimension that *may* be regarded as an illness' (KNMG's italics). The government further remarked that it saw little sense in conducting a parliamentary debate about the Drion Pill as this debate had not evolved to the same stage. Nor does the government see itself as leading this debate, although it does not exclude the possibility of new insights. (22, 26)

The rule for physicians is that they perform their tasks 'with due regard for the care provided by a good care provider and acting in accordance with the responsibility they bear pursuant to the professional standard to which care providers are subject' (Section 7:453 of the Dutch Civil Code). The professional standard for physicians encompasses attention to the patient's overall wellbeing, providing guidance to patients who have existential questions arising from their illness, demonstrating empathy and offering palliative care, terminal guidance and emotional comfort. Or, in the words of the World Health Organization's definition of palliative care: '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'. (20)

There is consensus among physicians that the foregoing properly falls within the domain of medicine. Nevertheless, it will not always be possible to cite scientifically-founded medical insight for such procedures. Though a growing body of scientific research is being amassed in the field of palliative care, there have been no thorough studies to provide good (quantitative and qualitative) data about seniors who wish to end their lives. No one knows how many people are affected, which problems they have and which solutions might be acceptable to them. (27) Given their vital significance and complexity from a social standpoint, the KNMG feels the government should commission research into these questions.

2.5 Medical basis

Since the Supreme Court made its ruling, which fits in with the history and text of the law, there has been much discussion surrounding the explanation of the requirement that the patient's suffering must have 'its principal source' in 'medically classifiable somatic or psychological illnesses or conditions'. At the time, physicians interpreted the Supreme Court's ruling as imposing a restrictive approach to euthanasia requests. The KNMG agrees with the Supreme Court's position that physicians may only perform euthanasia or assisted suicide without punishment if the request to end life is motivated in part by a medical ground. A euthanasia request can only be considered if the patient has a condition that fits the medical definition of a disease or combination of diseases/ailments. Medical classification can therefore aid in assessing the nature of the suffering within the meaning of the Euthanasia Law.

However, the medical classification of a condition can never be assumed to be a measure of the severity of suffering.^m A patient is always more than a person with an illness.ⁿ Patients may develop symptoms that cannot be traced to a specific (classifiable) disease, and it goes without saying that there can be suffering without illness – or illness without suffering. (3, 19) Moreover, distinguishing between the various dimensions of suffering that patients experience is difficult in practice, and these dimensions together can furthermore have a mutually reinforcing effect. However, not all suffering belongs to the domain of medicine.^o The KNMG holds the view that when suffering is assessed within the framework of ending life, there must always also be a medical basis, meaning a condition that can be defined as a disease or combination of diseases/ailments. Suffering that has no medical basis falls outside the domain of medicine and therefore outside the Euthanasia Law.

Since 2002, when the Euthanasia Law entered into force, the Regional Review Committees on Euthanasia have been confronted with physicians' notifications that involved complex combinations of different dimensions of suffering, often paired with non-fatal old-age afflictions causing progressive

m Too great an emphasis on medical classifications can have undesirable side effects; physicians may be led to apply the criterion strategically (some type of diagnosis is always possible) or, conversely, to apply extreme restraint with regard to euthanasia (criterion of diagnostic certainty).

n Physicians also attend pregnant women, even though pregnancy is not considered an illness.

o If a person is 99 years old and does not wish to reach 100, for example, this falls outside the bounds of medicine, and therefore of the Euthanasia Law.

deterioration and unbearable suffering for the patient. It would seem that physicians' interpretations of what constitutes unbearable suffering in the context of euthanasia requests have become less restrictive than in the period immediately after the Supreme Court ruling.

The opinions issued by the Regional Review Committees on Euthanasia, which test physicians' actions against the Euthanasia Law, case law and in light of scientifically-supported medical insights and medical ethics standards, show they consider physicians to be acting within the bounds of the Euthanasia Law. The KNMG feels it should be emphasised that the presence of a medical basis is and must always be an absolute criterion when assessing suffering within the context of a request to end life.

The KNMG has noted that the current statutory framework and the concept of suffering have already become broader than their interpretation and application by many physicians to date (see section 2.3). This makes patently clear not only that physicians' practice and the professional standard are not set in stone, but also that the legal assessment framework is attuned to such advancing insights.

3

Insight into suffering and the assessment process: support and consultation

This chapter focuses on clarifying the notion of suffering and its significance in the assessment process. Here, every physician is guided by his own knowledge, attitude, experience and point of view.

3.1 Attitude, experience and point of view

An average of 8,400 express requests for euthanasia or assisted suicide are made each year. (12) Approximately 2,400 of these requests are actually carried out. These figures indicate that individual physicians have little direct experience with euthanasia and assisted suicide. One third of all physicians has never performed euthanasia or assisted in a suicide, but would consider doing so. Just over half of all physicians have performed euthanasia or assisted in suicide.

A patient's request to end his life may well make a physician feel uncomfortable. For a physician, a request for euthanasia or assisted suicide is one of the single most drastic demands a patient can make. Physicians may have difficulty determining the best attitude to take and formulating their own point of view. In nearly 6,000 of the aforementioned 8,400 cases, these requests were not granted, sometimes for a combination of reasons. (12) In around 7% of these cases the request was rejected due to reasons of principle or institutional policy. In 39% the patient died before the request could be granted. Problems relating to whether the request was indeed voluntary and well-considered were cited in 6% and 18% of the cases, respectively. In another 16% the suffering was not judged to be unbearable and in 8% it was not lasting. Almost 10% of the patients retracted their request.

The KNMG advises all physicians who receive a request for euthanasia or assisted suicide from a patient to contact a SCEN physician^p in good time for *support*, all the more in the event of dilemmas or uncertainty in terms of experience, attitude and point of view. A logical preliminary step for physicians is to first talk with colleagues (in their GP/physicians' practice) and, if necessary, seek advice from other professionals (specialised in the relevant area), such as palliative care consultation teams.^q

3.2 Support and consultation

The Euthanasia Law stipulates that physicians consult at least one other, independent physician who has seen the patient and has given his written opinion regarding the requirements of due care (see also section 2.1). The KNMG is of the opinion that the independent consultation required by law must always be carried out by a SCEN physician.^r Consultation means seeking the advice of another independent physician from an exploratory standpoint and by means of targeted questions. The central question in a consultation is whether all due care requirements (a through d, see section 2.1) have been fulfilled. The SCEN physician draws up a written report of his findings (of whether or not the due care requirements have been fulfilled), which then forms the SCEN physician's recommendation to the attending physician. Though the attending physician need not take the SCEN physician's advice, he is required to substantiate his decision if he does not do so.

The SCEN physician also has the task of providing the attending physician with *support*, either during or before the due care assessment procedure. If a physician is uncertain or there is reasonable doubt as to the unbearable and lasting nature of the suffering, a SCEN physician can offer support – in the form of a programmatic and substantiated analysis – to enable him to form his own professional opinion about the suffering. The basic aim is gain insight into the patient's state and thereby enable the physician requesting the support to form his own opinion. This form of support is

p Steun en Consultatie bij Euthanasie in Nederland (Support and Consultation for Euthanasia in the Netherlands) is a programme organised by the KNMG. SCEN physicians are specially trained and certified by the KNMG. See www.scen.nl for telephone numbers of regional SCEN groups and additional information. SCEN physicians can only be called in by other physicians and not by patients, their family members or friends.

q For regional contact details, see www.ikcnet.nl.

r To clarify: consulting a SCEN physician is not a statutory requirement. See also footnote 16.

distinguished from a consultation by the fact that it explores ‘only’ partial aspects of the due care requirements. It needs to be clear to the physician, the patient and the SCEN physician from the outset which is being requested: support or consultation.

Physicians all have their own personal ideas and views about when suffering can be defined as unbearable, and SCEN physicians are no exception. When seeking to gain insight into the suffering, the SCEN physician should strive to set all personal views about the due care requirements aside. His task is to assess the case within the framework of the Euthanasia Law, to which end the SCEN physician must test the requirements of due care against the Euthanasia Law in as professional and objective a manner as possible. Acting in this capacity, the SCEN physician must step outside the normative framework for judging unbearable suffering that he would apply were he asked to perform euthanasia himself. That personal framework may be more restrictive than the law, or possibly even broader. Some physicians (thus also SCEN physicians) feel that suffering can only be deemed unbearable in the terminal phase of a physical illness. However, the Euthanasia Law expressly also applies to patients with dementia and psychological illnesses. The fact that few physicians are prepared to perform euthanasia in such cases is a different matter. (28) The task of the SCEN physician consists in shedding light on the unbearableness of the suffering by making a systematic and substantiated survey of the suffering (see section 3.3). Ultimately, it is not the SCEN physician but the physician requesting the support or consultation who must be convinced that the patient’s suffering is or may be deemed unbearable.

3.3 Insight into suffering

Suffering is linked to the individual. In some cases, the burden of suffering is experienced as being so severe that a patient wishes to end it by ending his life. But when can suffering actually be defined as unbearable? How can any physician assess a patient’s suffering when that suffering is a personal experience? In order to answer this question, physicians must gain insight into the different dimensions of suffering, based on a systematic inventory and substantiation of those dimensions. Such insight into patients’ suffering supports a more objective view of that suffering. A good aid in this context is the chart developed by Gerrit Kimsma (see Appendix V). (15)

This chart outlines and presents the practical implications of different dimensions of suffering over time. Among other things, it requires that the components of the suffering be described. What are the current ailments and symptoms? What is the nature of the loss of function? Also, which ailments and losses of function have gotten worse and will get worse? How does the patient experience these declines?

Equally, the patient's future suffering must be considered. On what is the prediction of that future suffering based, and how realistic is it? Is the suffering treatable and is it realistic to propose this to the patient? As suffering is personal, personal facets must also be considered. How does the person describe his own character? Which ailments does the patient mind most, and why? What is the patient's personal history? What significance does the patient attach to his experiences with illness? What is his living situation, arrangements for informal care and what is the capacity of versus burden on the patient and his environment?

These insights must be sought from the patient's perspective and with reference to each dimension of suffering, both individually and in conjunction with each other. For most patients, suffering is not the simple sum of its parts but a complex constellation of different dimensions that serve to make it unbearable. The process of gaining insight into patients' suffering is integral to the professional standard.

Having pieced together a substantiated picture of the patient's suffering, the physician must next assess it and use it to support and anchor the conviction required of him by law that the patient's suffering is indeed unbearable. In short, the physician must establish and be convinced of the burden of suffering on the patient and find that this suffering is unbearable.

4 / The role of the physician when euthanasia or assisted suicide is not an option

It is up to the physician to issue a professional opinion about the suffering, based on his knowledge and practical experience. This assumes not only that he can cite a medical basis but also that he has performed a thorough analysis of the different dimensions of suffering. He may also conclude that the suffering is not unbearable and lasting within the meaning of the Euthanasia Law. What is the proper role of a physician when he concludes that euthanasia or assisted suicide is *not* an option? Section 4.1 takes a closer look at the physician's scope for action. Section 4.2 discusses conscious hastening of death by denial of food and drink, and section 4.3 details what possibilities are and are not open to a physician when patients stockpile medicines with the express intention to commit suicide.

4.1 Physicians' scope for action

Patients have the right to request euthanasia, but physicians are not obligated to grant their request: fundamental objections to euthanasia and assisted suicide must be respected. After all, euthanasia and assisted suicide are anything but ordinary medical procedures.

However, professional standards do dictate that physicians give their patients clear and timely information about their personal views. It is therefore important that physicians first clarify for themselves if they would in principle be willing to perform euthanasia or assisted suicide. The KNMG holds the opinion that if a physician is not prepared to consider a euthanasia request from his patient then he also should not initiate the procedure (see section 3.1 and 3.2). In that case, it is his duty to put his patient in touch with a colleague who does not have fundamental objections to euthanasia and assisted suicide. Though there is no legal obligation to refer patients, there is a moral and professional duty to provide patients with timely assistance in finding a physician (for example, within the clinic) who does not have fundamental objections to euthanasia and assisted suicide.

A physician may also feel or become unable to carry out a request to end life or an assisted suicide due to personal views, even though he does not object to euthanasia and assisted suicide in principle and all the due care criteria of the Euthanasia Law appear to be fulfilled. In such situations, the physician must explain to the patient why he cannot grant the request

and, preferably, transfer the patient to a colleague in good time. But the situation is not always so simple in practice. For example, is a physician justified in pointing out to a patient that he could simply deny food and drink? Is the physician neglecting his duty to his patient?

If a physician is in doubt about his willingness to grant a request then his scope for action ends at conducting a formal consultation. By initiating a formal consultation, the physician leads the patient to believe he is willing to perform euthanasia, given that such a consultation is a purposive question on the physician's part to ascertain whether the due care requirements have been fulfilled. If the consulted physician then determines that these requirements are indeed satisfied, the physician is left with very little room to reject the request after all. A second consultation might then serve to remove all doubt. As long as no formal consultation has taken place, the physician is entirely free to refuse to grant the request on personal grounds. In such cases, and where the patient cannot be transferred and persists in his wish to end his life, the physician may point out the option of denial of food and drink.

4.2 Conscious hastening of death

Where the physician concludes that the suffering is not unbearable and lasting within the meaning of the Euthanasia Law, he cannot perform euthanasia or assisted suicide. Refused this assistance by his physician, a patient with a strong wish to die may decide for himself to deny food and drink. In that case, the patient is making a conscious choice to hasten death. Studies indicate that there are some 2,500 such cases each year. (29) These studies further show that the conscious denial of food and drink, when combined with effective palliative care, can offer a dignified death.⁵ The KNMG endorses this view.

If a patient brings up the possibility of denying food and drink, the physician has an obligation to discuss this option with him. It is the physician's duty to inform the patient as fully as possible about all the pros and cons of such a decision. In this role, the physician must act as a good care provider, even when the patient makes choices that will lead to health problems or if the physician does not agree with the patient's decision.

⁵ Debate evenings held in the KNMG districts of Groningen, Arnhem, Tilburg, Haarlem and Amsterdam yielded many personal stories indicating that this is a viable option for seniors, provided they are well prepared and receive proper guidance.

The offer of information can consist in drawing on experiences with other patients, consulting hands-on experts and referring the patient to information that is readily available. (30) The patient should furthermore be pointed to the fact that although there is a wealth of information on the Internet about hastening death, it should not always be assumed to be reliable. (31)

A physician can also point out the possibility of denying food and drink without need for the patient to bring it up himself. There is no obligation on the physician to do so, however, as he was not convinced that the suffering was unbearable and lasting in the first place. Depending on his professional opinion, a physician thus still has some reasonable alternatives to alleviate a patient's suffering. And in those situations in which the patient persists in his desire to end his life, the physician may ultimately decide to point out the option of denying food and drink.

Where a patient tells his physician he wishes to deny food and drink, doubts about competence may well arise. (32) However, if the patient has thoroughly considered his decision, is mentally able to assess the pros and cons of treatments and understands the consequences, the physician must respect that patient's decision. A patient should always be deemed competent unless there is evidence to the contrary. The wish to die does not, in itself, indicate a patient is suffering from depression. A physician cannot claim that a patient is a 'danger to himself' based only on a decision to deny food and drink, and then use this to justify admission (compulsory or not) into psychiatric care.

In many such cases the patient will already have arranged for a refusal of treatment.[†] The physician is obligated to respect this. However, this does not relieve physicians from their duty to supervise their patient and

[†] Patients are advised to lay down in writing which treatments they do not wish to have performed (any longer). The physician is obligated to respect this 'negative' statement of the patient's wishes, unless he believes there are 'justified reasons for deviating from them' (Section 7:450 of the Dutch Civil Code, part of the Medical Treatment Contracts Act (Wet op de geneeskundige behandelingsovereenkomst, or Wgbo)), since he does not actually have permission for certain treatments. Such a statement of a patient's wishes does not prevent the physician from taking measures to alleviate the suffering as much as possible, in consultation with the patient. In many cases patients appoint a medical proxy. The patient's rights are then transferred to this representative or medical proxy insofar as needed. The Wgbo prescribes that the following persons qualify for this role: the patient's legal representative (guardian or mentor), or failing this a medical proxy, or failing this a spouse, partner or life companion, or failing this a parent, child or sibling (Section 7:465 of the Dutch Civil Code). The representative appointed by the patient is charged with taking decisions on the patient's care and treatment at such time as he is not longer able to do so himself. Euthanasia and assisted suicide are excluded as requests for these procedures are reserved exclusively to the patient, because the decisions are irreversible and because euthanasia and assisted suicide are not ordinary medical procedures.

offer support in steps to deny food and drink. Among other things, they must provide the patient with reliable information, preparing him for the process, supervise him and alleviate suffering, including if complications arise. If a patient decides to hasten death in this way, the physician must arrange for effective palliative care, such as in the form of an antidecubitus mattress, oral care and control measures against pain, confusion and other complaints. Patients with a medical indication for palliative sedation can also be put on intermittent or continuous sedation.^u The objective here, as elsewhere, is that the physician alleviates the suffering as much as possible and is accessible and available to the patient. Physicians are advised to seek advice from relevant experts, such as geriatricians or palliative care consultation teams. If a physician doubts his own competence, then the professional standard dictates that he consult the proper expert in good time. (27) When a patient dies due to not eating and drinking this constitutes a natural death, even if the patient was under continuous sedation according to accepted treatment.

4.3 Drug method

In some cases patients will choose to end life by taking a quantity of medications (one type or a combination). This drug method requires thorough preparation on the patient's part. (29, 30) Patients may or may not inform their physician of their intention, ask for advice or request assistance. Under the Dutch Penal Code, assisted suicide is a punishable offence. Physicians are exempted from punishment if they comply with the due care requirements of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act and report the death to the autopsyist in the manner stipulated in the Burial and Cremation Act (*Wet op de lijkbezorging*).

There is no punishment for physicians and other persons if they provide information about suicide. Physicians are also legally permitted to refer patients to information that is available on the Internet or to publications sold by book vendors, or provide these on loan, and to discuss this information with patients. (30, 31) In fact, it is the physician's professional responsibility to engage the patient in discussion if the latter voices an intention to stockpile drugs with a view to using them to end his life. The physician can, but is not obligated to, refer the patient to available resources and experts, including spiritual care providers such as a pastor,

^u See the KNMG guideline on palliative sedation.

minister or humanistic counsellor. The physician is permitted to inform, but with an express emphasis on what patients should not do. When a patient has a wish to die, his physician can also point out the option to stop taking medications that have or may have a life-prolonging effect or to draw up a refusal of treatment certificate, including a treatment plan for managing symptoms.

It is a punishable offence not only to encourage suicide but also to give advice that has the character of an instruction, to issue instructions or tasks, perform acts or direct steps towards assisted suicide. (30) A substantial body of case law has been developed around the question of where to draw the line between ‘informing’ and ‘encouraging’,^v from which we can conclude that ‘encouraging’ goes beyond the professional provision of information about options for committing suicide and the associated risks.

It is a criminal offence for physicians to prescribe medications over a long period of time with the intent that a patient take these at a moment of his choosing in order to end his life, the rationale being that physicians are not to breach the boundaries of their profession. Yet offering moral support by being present at a suicide is not punishable. The KNMG feels this last to be unwise, however, since unforeseen circumstances, such as a failed suicide attempt, may ultimately cause a physician to feel obligated to go beyond offering moral support after all.

^v For example, see the Supreme Court ruling of 5 December 1995, NJ 1996, 322 (with commentary from A.C. 't Hart), Supreme Court ruling of 22 March 2005, GJ 2005, 61 (with commentary from W.L.J.M. Duijst-Heesters), District Court of Amsterdam 31 August 2006, GJ 2006, 146 (with commentary from A.C. de Die), TVGR 2007, 42 (with commentary from J. Legemaate under no. 2007, 43) and Supreme Court ruling of 18 March 2008, RvdW 2008, 344.

5 / Conclusions, recommendations and follow-up steps

This chapter presents a point by point summary of the KNMG's conclusions about the role, responsibilities, possibilities and limitations that physicians have with regard to the issue of the voluntary termination of life. These conclusions are substantiated in the previous chapters. The chapter closes by proposing a number of recommendations and follow-up steps.

Conclusions

- ▶ The professional standard for physicians encompasses attention to patients' overall wellbeing, providing guidance to patients who have existential questions arising from their illness, demonstrating empathy and offering palliative care, terminal guidance and emotional comfort.
- ▶ The physician is always responsible for determining the burden of suffering on the patient and what the components of that suffering are, regardless of its source or the way in which the patient characterises the suffering, and even if the patient's desire to die stems from a sense that his life is 'completed'.
- ▶ The judgement that life is completed – assuming that completion as such exists – is one that a person can only make for himself. Physicians have no role or task to fulfil when it comes to judging if a life is completed.
- ▶ When physicians assess suffering within the framework of ending life, there must always also be a medical basis, meaning a condition that can be defined as a disease or combination of diseases/ailments. A medical classification can aid in assessing the nature of suffering.
- ▶ Distinguishing between the various dimensions of suffering that patients experience is difficult in practice, and these dimensions together can furthermore have a mutually reinforcing effect.

- ▶ A request for euthanasia is one of the most intrusive and onerous demands that a patient can make of a physician. Most physicians find it difficult to perform euthanasia or assisted suicide. This is all the more true if that wish is not prompted by a terminal illness.
- ▶ Before deciding to grant a request for euthanasia or assisted suicide, the physician must gain or facilitate insight into the suffering and be convinced that the suffering is unbearable and has at least in part a medical basis. Gaining insight into the different dimensions of suffering requires compiling a systematic inventory and substantiation of those dimensions. Relevant experts must be called in based on the main causes (medical or non-medical) contributing to the burden of suffering.
- ▶ The current statutory framework and the concept of suffering are broader than their interpretation and application by many physicians to date. Vulnerability – extending to such dimensions as loss of function, loneliness and loss of autonomy – should be part of the equation physicians use to assess requests for euthanasia. The result of this non-linear sum of medical and non-medical problems, which are usually not in themselves life-threatening or fatal, can lead to lasting and unbearable suffering within the meaning of the Euthanasia Law.
- ▶ Contrary to what is generally assumed, the Euthanasia Law includes provisions permitting assisted suicide for patients with psychiatric conditions and dementia. The assessment of these groups of patients must pay particular attention to the patients' competence and the considerations prompting the request. It is generally advisable to carry out more than one consultation (multidisciplinary, where necessary).
- ▶ If a physician is not prepared to consider a euthanasia request from patients then he also should not initiate the procedure. The physician must then put the patient in touch with a colleague who does not have fundamental objections to euthanasia and assisted suicide. Though there is no legal obligation to refer patients, there is a moral and professional duty to provide patients with timely assistance in finding a physician (for example, within the practice) who does not have fundamental objections to euthanasia and assisted suicide.

- ▶ In situations where a physician does not object to euthanasia and assisted suicide in principle, but feels or becomes unable to carry out a request to terminate a life due to personal views, then he must explain to the patient why he cannot grant the request even though all the requirements of due care are likely to be fulfilled. The preferable course of action is then to transfer the patient to a colleague in good time.
- ▶ Suffering that has no medical basis falls outside the domain of medicine and therefore outside the domain of the physician's professional expertise and outside the Euthanasia Law.
- ▶ If a patient with a strong wish to die is refused euthanasia by his physician or does not meet the requirements of due care, the patient may decide for himself to deny food and drink. The physician must have due regard for the care provided by a good care provider, even if he does not agree with the patient's decision to deny food and drink. This means that the physician is obligated, in such cases, to supervise the patient and to alleviate the suffering by arranging effective palliative care.
- ▶ Physicians have a professional duty to engage a patient in discussion if the latter reveals a desire to end his life by taking (a combination of) drugs stockpiled for that purpose. Physicians may provide information and talk with patients about this issue without being liable to punishment.

Recommendations

- ▶ The KNMG recommends that all physicians discuss patients' wishes and expectations as regards terminal care with them in a timely manner.
- ▶ The KNMG advises all physicians who receive a request for euthanasia or assisted suicide from a patient to contact a SCEN physician in good time for *support*, all the more in the event of dilemmas or uncertainty in terms of experience, attitude and point of view. A logical preliminary step for physicians is to first talk with colleagues (in their GP/physicians' practice) and, if necessary, seek advice from other professionals (specialised in the relevant area), such as palliative care consultation teams.
- ▶ The KNMG urges all physicians to consult an SCEN physician in cases where there is a reasonable doubt as to whether the suffering is unbearable but the physician feels the patient's right to have his request assessed should not be dismissed out of hand. SCEN physicians are capable of making a systematic survey of a patient's suffering. The SCEN physician does not issue an opinion in such cases, but offers support by providing insight into the suffering. This form of support is distinguished from a consultation by the fact that it explores 'only' partial aspects of the due care requirements. It needs to be clear to the physician, the patient and the SCEN physician from the outset which is being requested: support or consultation.
- ▶ The KNMG recommends that the government commission further scientific studies among physicians and patients. Such studies should focus on collecting and analysing case histories in order to chart the nature and scale of this issue, extending to situations in which the basis of the suffering is not solely medical.

Follow-up steps

- ▶ Working in coordination with organisations representing practitioners in other relevant fields of expertise, the KNMG will develop a consultation protocol for situations in which the main criterion is a patient's existential or psychosocial suffering.
- ▶ The KNMG will develop a continuing education programme for SCEN physicians to provide further training in systematically surveying and substantiating the various dimensions of suffering.
- ▶ The KNMG has observed that physicians are insufficiently trained in supervising patients who wish to deny food and drink. The KNMG will therefore develop a guideline in coordination with the relevant occupational associations.

I / Participants

PARTICIPANTS MEETING OF 3 JUNE 2010

Prof. A.C. Nieuwenhuijzen Kruseman, *chairman of the KNMG (chairman)*
 M. Dees, *GP, SCEN physician*
 Dr A. de Graeff, *internist-oncologist**
 C. Goedhart, *geriatrician, member of the Christian Medical Fellowship**
 P. Sutorius, *GP, SCEN physician*
 Dr J. Lavrijsen, *geriatrician**
 Dr B. Chabot, *non-practising psychiatrist**
 Dr L. Wigersma, *director of Policy & Advice at the KNMG*
 B. Keizer, *geriatrician, SCEN physician**
 C. de Graaf, *geriatrician, SCEN physician**
 P. Lieverse, *anaesthesiologist, member of the Christian Medical Fellowship**
 W.P. Rijksen, *general director of the KNMG*
 G. van Dijk, *ethicist at the KNMG*
 G. Kimsma, *GP, SCEN physician, philosopher**
 E.H.J. van Wijlick, *policy advisor at the KNMG (official secretary)*

PARTICIPANTS MEETING OF 29 JUNE 2010

Prof. A.C. Nieuwenhuijzen Kruseman, *chairman of KNMG (chairman)*
 Dr E. Borst-Eilers, *physician, minister of Health, Welfare and Sport during the parliamentary discussion of the Euthanasia Law in the Upper and Lower Chambers**
 H. Groenenboom, *GP, member of the Christian Medical Fellowship**
 G. van Ravenswaay, *GP, SCEN physician*
 R. van Coevorden, *GP, palliative care consultant*
 Prof. A. Hendriks, *professor of Health Law at Leiden University, chairman of the SCEN Complaints Committee*
 Y. van Ingen, *geriatrician, palliative care consultant, SCEN physician**
 Prof. M. Trappenburg, *professor by special appointment of Socio-Political Aspects of the Welfare State and Social Dialogue at the University of Amsterdam*
 W.P. Rijksen, *general director of the KNMG*
 G. van Dijk, *ethicist at the KNMG*
 W. te Water, *clinical geriatrician, SCEN physician**
 Prof. C. Spreeuwenberg, *professor emeritus of the Integration of Care for the Chronically Ill at Maastricht University*
 R. Dijkman, *geriatrician*
 R. Jonquière, *physician, former director of the NVVE, member of the SCEN Advisory Board**
 Prof. J. Legemaate, *health law coordinator at the KNMG**
 Prof. G. Widdershoven, *professor of Medical Philosophy and Ethics at the VU University Medical Center**
 R. van der Meer, *psychiatrist, SCEN physician*
 E.H.J. van Wijlick, *policy advisor at the KNMG (official secretary)*

* These members submitted a written response to the draft position paper of 12 November 2010. Responses were also received from J. Boskamp, H. Mencke, E. Kenter, Dr S. van de Vathorst, Dr E. Dekker, the coordinating chairman of the Regional Review Committees, the Humanistisch Verbond (Humanist Union) and the Medical Advisory Board of the NVVE.

II / Web consultation results

Statistics			
Form name	voluntary termination of life		
Form title	WEB CONSULTATION Role of the physician in the voluntary termination of life. Test your knowledge and give your opinion here.		
Number of questions	15		
Total number completed	324		

1. The Euthanasia Law provides no scope for assisting patients with dementia end their lives at their request.

(Question type: Multiple choice, one answer)

Answer	Number	Percentage
This is the current standard	168	51.85 %
This is not the current standard	156	48.15 %
Number of respondents	324	

2. To what extent do you agree or disagree with statement 1:

(Question type: Multiple choice, one answer)

Answer	Number	Percentage
disagree entirely	57	17.59 %
disagree	89	27.47 %
neither agree nor disagree	56	17.28 %
agree	60	18.52 %
agree entirely	62	19.14 %
Number of respondents	324	

3. 2. A combination of medical and non-medical problems can lead to unbearable suffering within the meaning of the Euthanasia Law.

(Question type: Multiple choice, one answer)

Answer	Number	Percentage
This is the current standard	227	70.06 %
This is not the current standard	97	29.94 %
Number of respondents	324	

4. To what extent do you agree or disagree with statement 2:

(Question type: Multiple choice, one answer)

Answer	Number	Percentage
This is the current standard	43	13.27 %
This is not the current standard	40	12.35 %
neither agree nor disagree	28	8.02 %
agree	120	37.04 %
agree entirely	95	29.32 %
Number of respondents	324	

5. 3. A medically classifiable condition is a prerequisite for performing euthanasia or assisted suicide.

(Question type: Multiple choice, one answer)

Answer	Number	Percentage
This is the current standard	226	69.75 %
This is not the current standard	98	30.25 %
Number of respondents	324	

6. To what extent do you agree or disagree with statement 3:

(Question type: Multiple choice, one answer)

Answer	Number	Percentage
disagree entirely	55	16.98 %
disagree	77	23.77 %
neither agree nor disagree	45	13.89 %
agree	86	26.54 %
agree entirely	61	18.83 %
Number of respondents	324	

7. 4. The Euthanasia Law provides scope for assisting patients with psychiatric conditions end their lives at their request.

(Question type: Multiple choice, one answer)

Answer	Number	Percentage
This is the current standard	170	52.47 %
This is not the current standard	154	47.53 %
Number of respondents	324	

8. To what extent do you agree or disagree with statement 4:

(Question type: Multiple choice, one answer)

Answer	Number	Percentage
disagree entirely	73	22.53 %
disagree	67	20.68 %
neither agree nor disagree	42	12.96 %
agree	99	30.56 %
agree entirely	43	13.27 %
Number of respondents	324	

9. 5. If a patient's wish to die stems from a sense of having 'completed' life, the physician is not obligated to investigate whether the patient is suffering and what the components of that suffering are.

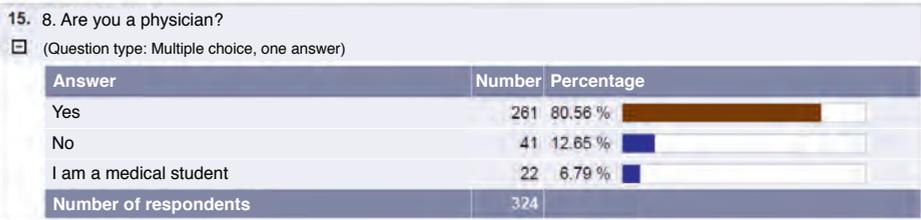
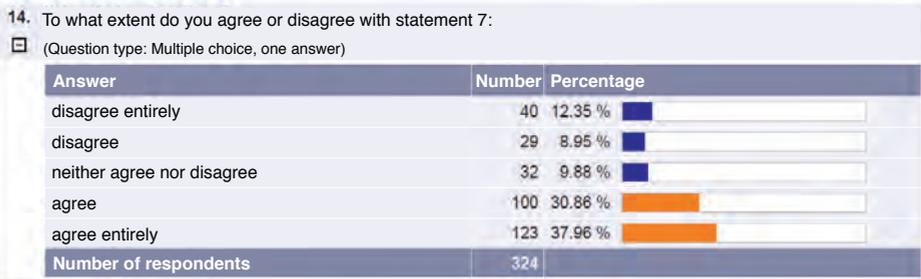
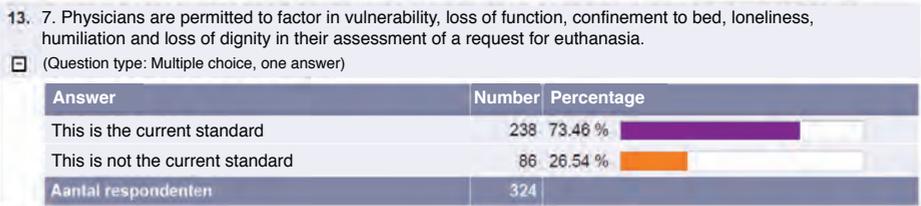
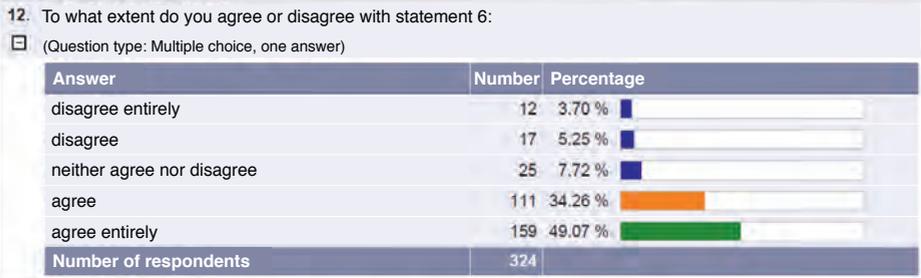
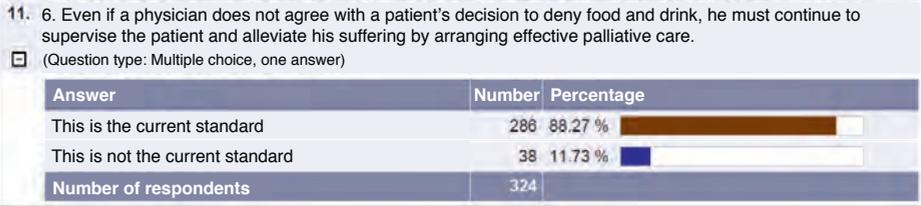
(Question type: Multiple choice, one answer)

Answer	Number	Percentage
This is the current standard	43	13.27 %
This is not the current standard	281	86.73 %
Number of respondents	324	

10. To what extent do you agree or disagree with statement 5:

(Question type: Multiple choice, one answer)

Answer	Number	Percentage
disagree entirely	165	50.93 %
disagree	85	26.23 %
neither agree nor disagree	23	7.10 %
agree	34	10.49 %
agree entirely	17	5.25 %
Number of respondents	324	



III / KNMG member panel results

BACKGROUND AND OBJECTIVES

Standards and practices relating to euthanasia and assisted suicide have seen ongoing development since the Euthanasia Law was adopted in 2001. The KNMG describes these developments in its draft position paper on 'The role of the physician in the voluntary termination of life'. Among other things, the KNMG seeks to clarify the possibilities for and limitations on the performance of euthanasia. However, even where all standards and statutory requirements are fulfilled, it is always, without exception, up to the individual physician to decide whether or not he wishes to proceed. After all, a request for euthanasia is one of the most intrusive and onerous demands that a patient can make of a physician.

Wishing to consult the medical professions about this draft position paper, the KNMG conducted an online survey among participants in the KNMG member panel, the results of which will be:

- ▶ integrated in the definitive position paper in 2011 and
- ▶ linked up with the social and political debate.

ONLINE QUANTITATIVE SURVEY

The survey was conducted online using the CAWI method (Computer-Assisted Web Interviewing). An email was sent to all KNMG members inviting them to take part in the survey. The physicians could access the survey by clicking on a link in this invitation. The physicians who were invited had previously indicated their willingness to take part in surveys conducted by the KNMG (participants in the KNMG member panel).

SURVEY SETUP

The survey contained 23 statements, comprising 16 possible viewpoints on euthanasia and/or assisted suicide and 7 on the interpretation and application of the Euthanasia Law (asking to what extent the statement reflected the current standard).

RESPONSE

A total of 945 physicians were invited to take part in the survey. Of these, 430 completed the online questionnaire, corresponding to a response rate of 45.5%. One respondent indicated that he was not (and never had been) a physician, and was therefore not included in the analysis.

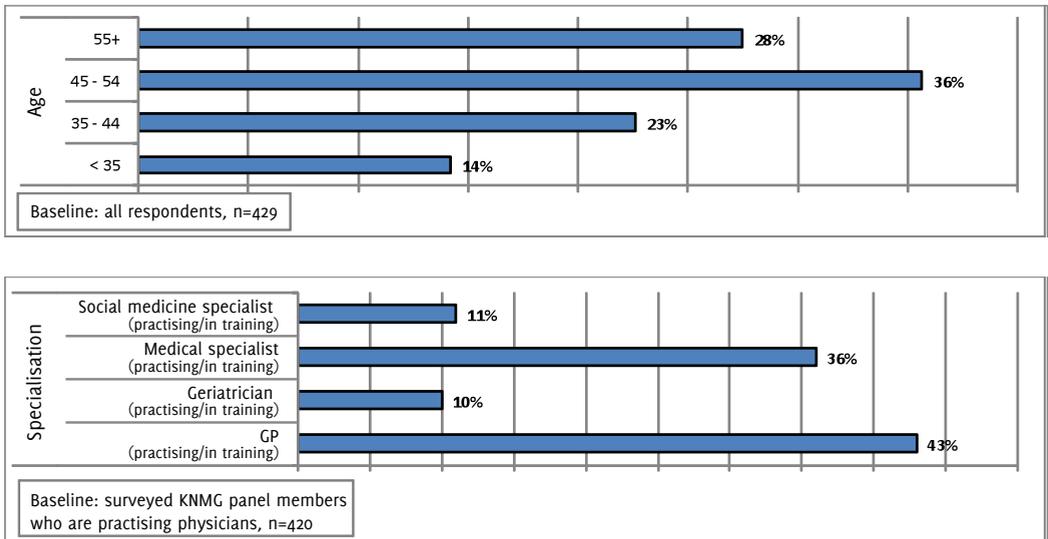
ANALYSIS AND REPORT

This management summary provides an overview of the most important and most notable results. Of particular interest to the KNMG is whether any differences can be distinguished between physicians based on their specialisation or age group. Specialisations have been grouped together (see respondent profile) into logical categories, each with a minimum number of respondents. Where the text refers to ‘GPs’, this means all surveyed practising GPs and GPs in training, where it refers to ‘medical specialists’ it means all surveyed practising medical specialists and medical specialists in training, and so on.

RESPONDENT PROFILE

A total of 430 physicians took part in the online survey. One respondent indicated that he was not (and never had been) a practising physician, and was therefore not included in the analysis and report. Figure 1 below presents the profile of the 429 physicians on the KNMG member panel who took part in the survey. As indicated, a number of answer categories (specialisations) have been grouped together into logical categories with a minimum number of respondents.

Figure 1 Respondents grouped by age and specialisation.



Views on euthanasia and assisted suicide

Physicians on the dangers of committing suicide using medications, consulting on the burden of suffering and assessing the burden of suffering as related to the notion of a 'completed life'

Of the physicians surveyed, most agreed with the statements that they 'would always point out the dangers to a patient who stockpiles medications with the intention to commit suicide' (88%), that it 'is logical to consult other experts when assessing the unbearableness of suffering in the case of non-medical causes' (86%) and that 'they would investigate the burden of suffering if the wish to die stems from a sense of having completed life' (85%).

Physicians do not stop supervision on disagreeing with patient's decision to deny food and drink

The physicians surveyed were least in agreement with the statement that 'if they did not agree with a patient's decision to deny food and drink they would not supervise them in doing so', with 80% of respondents stating they disagreed or disagreed entirely. Additionally, 70% of the physicians disagreed or disagreed entirely with the statement that 'assisted suicide should be removed from the Penal Code to permit individuals other than physicians to perform assisted suicide'.

Respondents least opinionated on informing about denying food and drink, euthanasia for psychiatric patients and medical condition as prerequisite

Respondents were least opinionated (i.e. most neutral) as regards the statements about 'informing a patient who stockpiles medications with the intention to commit suicide about the option to deny food' (33%), 'euthanasia is an acceptable option for psychiatric patients' (29%), and 'a medically classifiable condition should be a prerequisite for performing euthanasia' (28%).

Greatest difference in views between GPs and other specialists

In terms of their views, GPs differed most from the other specialists surveyed, and particularly medical specialists. GPs find it less acceptable than medical specialists to perform assisted suicide for psychiatric patients (39% vs. 24% disagreed or disagreed entirely). Compared to medical specialists (14%) and social medicine specialists (7%), more GPs (26%) feel that assisted suicide is not acceptable for patients who experience unbearable suffering due to a large number of geriatric ailments. By contrast, more GPs (59%) than medical specialists (34%) and social medicine specialists

(37%) would inform patients who stockpile medication with the intention to commit suicide about the option to deny food and drink.

At the same time, GPs feel more strongly (71%) than medical specialists (55%) that their scope for refusing a request for euthanasia is very small after a consultant concludes that the due care requirements are fulfilled. Moreover, a larger number of GPs (86%) than medical specialists (72%) would not stop supervising a patient who decides to deny food and drink, despite disagreeing with the patient’s decision.

A notable finding is that, of the physicians surveyed, those who are older (55+) are more likely than those who are younger than 35 to inform patients who stockpile medications with the intention to commit suicide about the option to deny food and drink (58% vs. 31%).

Figure 2 Overview of the degree to which surveyed physicians agreed or disagreed with various statements.

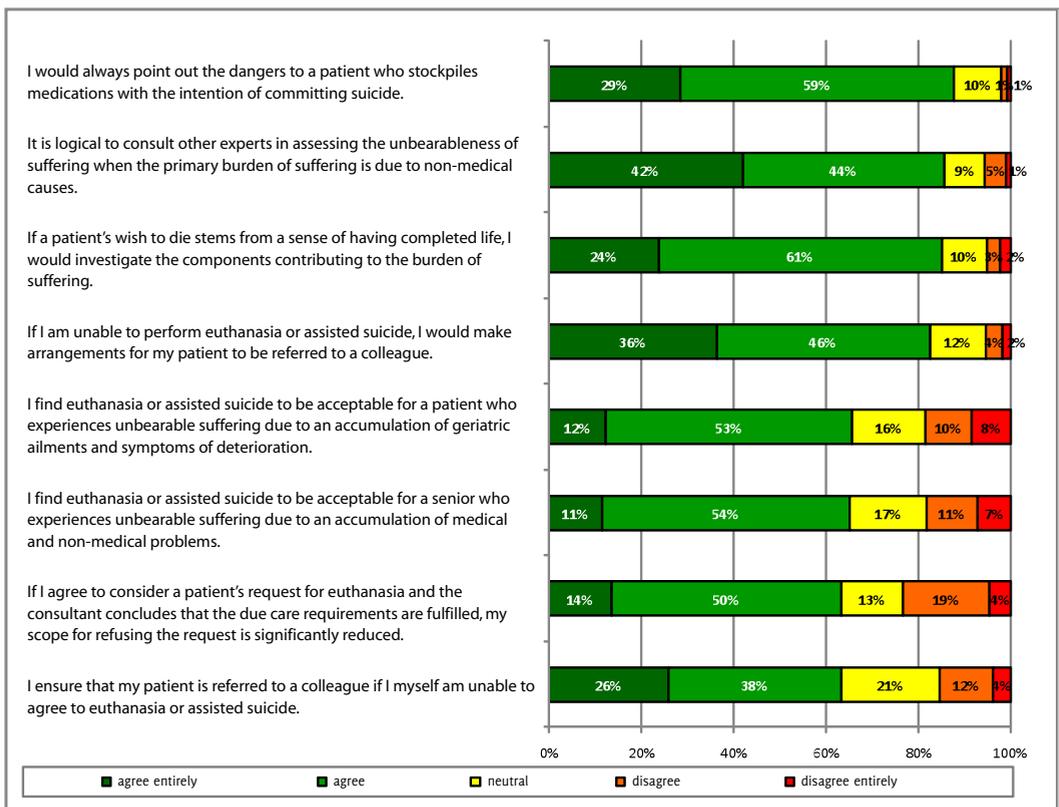
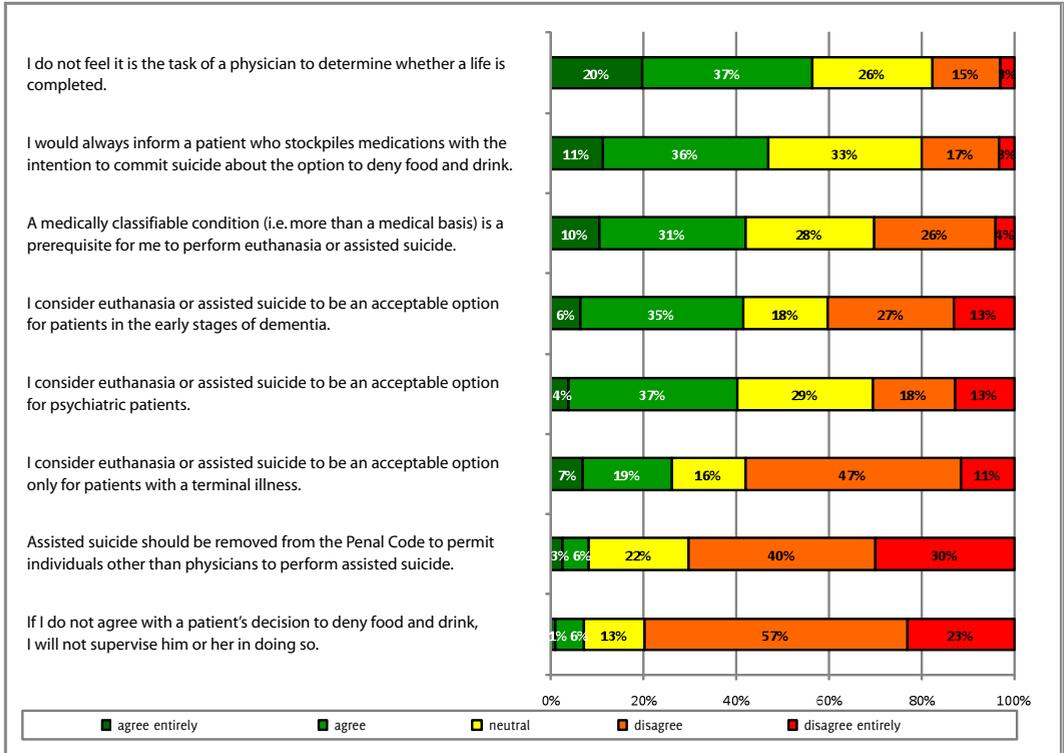


Figure 3 Overview of the degree to which surveyed physicians agreed or disagreed with various statements.



Current standard: interpretation and application of the Euthanasia Law

Current standard: continue patient supervision despite disagreement with decision to deny food and drink

The physicians surveyed felt that the standard prescribing that a physician should continue to supervise a patient despite disagreeing with his decision to deny food and drink to be the most current, with 84% stating they felt this to be the current standard. According to three quarters of the physicians (75%), it is now standard practice for physicians to factor in aspects such as loneliness and loss of function when assessing a request for euthanasia. Additionally, seven out of ten physicians (70%) feel that a medically classifiable condition is currently a prerequisite for performing euthanasia.

Not the current standard: no investigation of the burden of suffering when the wish to die is based on the notion of a 'completed life'

A large majority of the physicians surveyed do not feel it is currently standard for a physician not to be required to investigate the burden of suffering if a patient's wish to die stems from a sense of having completed life; 89% of the physicians feel this is not the current standard. A smaller but still substantial group of around half of the physicians surveyed (52%) feel that the Euthanasia Law currently does not provide any scope to grant requests for assisted suicide from psychiatric patients.

More GPs agree that aspects such as loneliness should also factor in and that physicians should continue supervision despite disagreement with decision to deny food and drink

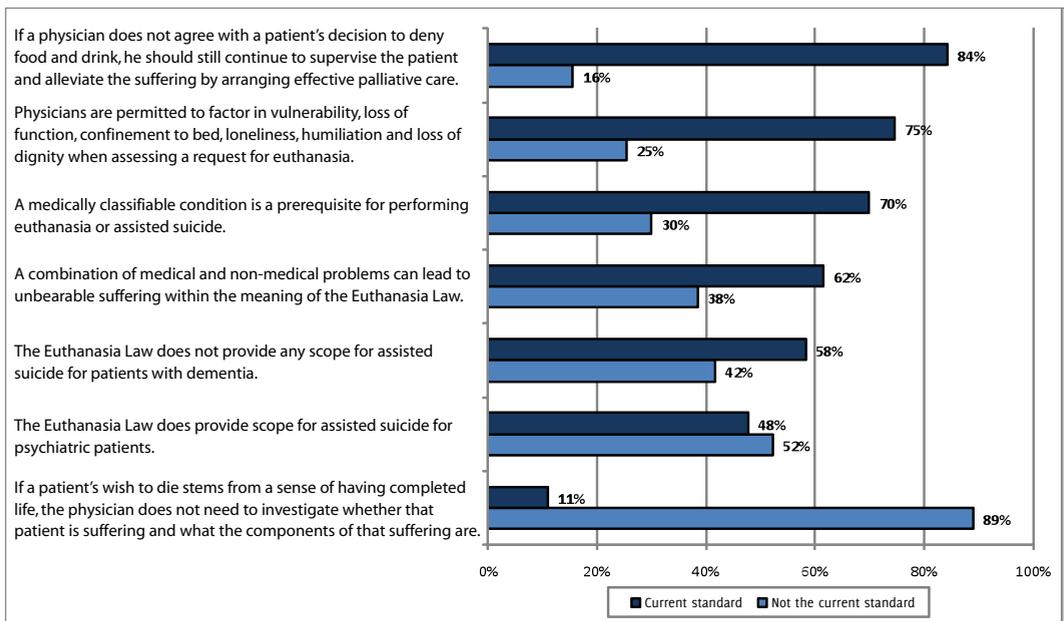
Opinions on the statements about current standards similarly saw the greatest divergence between the views held by GPs and those of the other specialists surveyed. More GPs (89%) hold the opinion that, at present, aspects such as loneliness and loss of function may be factored in to the assessment of a euthanasia request. To compare: 74% of geriatricians and 65% of medical and social medicine specialists feel that this is currently the standard. Furthermore, according to GPs (90%), the current standard prescribes that a physician should continue to supervise a patient who denies food and drink, even if he does not agree with this decision.

Geriatricians: current law provides scope for assisted suicide for patients with dementia

A notable finding is that a majority of geriatricians (67%) feel the statement that the Euthanasia Law provides no scope for assisted suicide for patients with dementia does not reflect the current standard. Medical specialists, for their part, differ from GPs and geriatricians in their opinion on the statement that the Euthanasia Law allows that a combination of medical and non-medical problems can lead to unbearable suffering. Half of the medical specialists (50%) feel this is not the current standard, whereas 69% of GPs and 74% of geriatricians feel that it is.

Age-based differences were found in respect of the statement that a medically classifiable condition is a prerequisite for euthanasia, with 44% of physicians aged 35 or younger indicating this is not currently the standard, while 77% of physicians in the 35 to 45-year age group feel that it is.

Figure 4 Overview of the degree to which surveyed physicians feel that various statements reflect the current standard.



IV / Euthanasia case histories: Uit Vrije Wil versus Regional Review Committees

According to the Uit Vrije Wil initiative group, providing assisted suicide to seniors who feel their lives to be completed is a punishable offence under the present law. The initiative group uses the following case example to illustrate their point:

A 92-year-old woman had spent many years caring for her husband, who had dementia. Eventually he was admitted into a nursing home, where she visited him every day. Two years ago, he died. The woman's health is now quite poor: she is nearly blind, has a very painful back and can hardly walk anymore. (6)

The extent to which the supposed split between the proposals advanced by Uit Vrije Wil and the opinions issued by the Regional Review Committees on Euthanasia really exists is debatable. The 2009 Annual Report of the Regional Review Committees on Euthanasia includes several cases that closely resemble the case example cited by Uit Vrije Wil:

CASE 7

A woman in the 80 to 90-year age category had been suffering from severe spinal arthritis, with repeat compression fractures and other complications since 2004. She underwent various treatments. Recovery was no longer possible. Opiate-based painkillers and the occurrence of side effects caused rapid deterioration in the patient's overall condition during the final weeks. She was completely confined to her bed and remained in pain despite an increased dosage of painkillers and morphine. Further side effects occurred, including grogginess, reduced appetite and difficulty finding words. The unbearable nature of the patient's suffering was comprised in her complete confinement to bed and her dependence on others for daily care, inability to stand on her own, bad back pain, constipation, difficulty sleeping, dry mouth, reduced appetite and difficulty finding words. The patient further experienced unbearable suffering due to the interminability of her situation, complete dependence, immobility and fear of humiliation and loss of dignity.

CASE 9

The patient – a man in the 80 to 90-year age category – had had glaucoma in both eyes since 1993. By 2009 he was nearly blind. He had also lost almost all hearing. He had severe back complaints due to degenerative disc disease. No recovery was possible and the suffering was lasting. The patient suffered due to the fact that he was incapable of doing anything owing to his poor eyesight and that he had no choice but to sit in his chair all day with nothing to look forward to. He could only move around a little with the aid of a walker and supervised by the care staff of the nursing home where he lived. He had already had several falls. Having always been independent, the patient suffered due to his dependence and the knowledge that there would be no change in his situation. The patient felt this lasting suffering to be unbearable.

In both cases the physician administered euthanasia, and both cases were judged by the Regional Review Committees on Euthanasia to have fulfilled the requirements of due care. The comparison between the case example cited by Uit Vrije Wil and the cases assessed by the Regional Review Committees on Euthanasia as fulfilling the requirements of due care show that the split between the views held within the profession and those held by society may be much smaller than has been claimed. Research into this issue is imperative. The KNMG does not feel a change in the law would be expedient at this time.

V / Outline and practical implications of different dimensions of suffering over time

This chart outlines and presents the practical implications of different dimensions of suffering over time. These insights must be sought from the patient's perspective and with reference to each dimension of suffering, both individually and in conjunction with each other. For most patients, suffering is not the simple sum of its parts but a complex constellation of different dimensions that serve to make it unbearable.

1 SUFFERING AND TIME

1.1 Actual suffering

1.1.1. Synchronous aspects

1.1.1.1 *Current ailments and symptoms*

Synchronous aspects checklist: anxiety, ascites, bladder retention, cachexia, confusion, constipation, coughing, dehydration, depression, diarrhoea, dry mouth, dysphagia, fever, hiccups, intestinal obstruction, nausea, pain (localised/forms), pressure sores, pruritus, shortness of breath, sleeping disorders, urinary/faecal incontinence, other symptoms.

1.1.1.2 *Loss of function*

ADLs/communicative functions checklist: standing, walking, dressing unassisted, washing, eating, drinking, toilet use, speech, hearing, vision, writing, consciousness, concentration.

What does the loss of function mean for this patient?

1.1.2 Diachronous aspects

1.1.2.1 *Diachronous ailments and symptoms*

Which ailments have gotten worse and will get worse? How does the patient experience these declines?

1.1.2.2 *Loss of function*

Which losses of function will stabilise and which will only decline further?

How does the patient experience this?

1.2 Future suffering

Which future suffering is anticipated? On what is this based? Is this realistic? Is this suffering treatable? If so, is it realistic to propose this treatment to the patient? If not, why? Does the patient wish to refuse treatment and is that refusal realistic in view of the anticipated consequences?

2 SUFFERING AND PERSONALITY

How does the patient describe his own character? Which ailments does the patient mind most, and why?

3 SUFFERING AND PERSONALITY-OVER-TIME (PERSONAL HISTORY)

Is the patient religious? What was the patient's occupation? What are the patient's experiences with illness? What significance does his past have for the patient (loss of partners, experiences with violence)?

4 ENVIRONMENT

Living situation, informal care, need of care versus willingness to provide care, capacity of versus burden on the patient and his environment, also in view of the duration of the illness.

Source: Kimsma GK. *Het lijden beoordeeld. Een voorstel voor een conceptueel kader.*
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The KNMG physicians' federation represents over 53,000 physicians and medical students. KNMG member organisations include the Koepel Artsen Maatschappij en Gezondheid (Umbrella organisation for physicians and health – KAMG), the Landelijke vereniging van Artsen in Dienstverband (National society of employee physicians – LAD), the Landelijke Huisartsen Vereniging (National society of general practitioners – LHV), the Netherlands Society of Occupational Medicine (NVAB), the Nederlandse Vereniging voor Verzekeringsgeneeskunde (Netherlands society of insurance medicine – NVVG), the Orde van Medisch Specialisten (Order of medical specialists – OMS) and the Dutch Association of Elderly Care Physicians and Social Geriatricians (Verenso).