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# Reflections by the Royal Dutch Medical Association (KNMG) on the 'Government Response and Vision on Completed Life'

29 March 2017

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## Foreword

How do we find a respectful and appropriate approach to the issue of elderly people who suffer from a sense of meaninglessness in their lives? Will a 'completed life' assisted-suicide act help? This is a question that concerns both society in general and the medical profession in particular, as it is in consultation rooms, in homes and at bedsides that the elderly often express their deepest wishes, or where the question hangs in the air unspoken. The Royal Dutch Medical Association (KNMG) has therefore taken the time to formulate a well-considered and substantiated response to the government's proposal on the subject. This process entailed an extensive survey among doctors (via the KNMG physicians' questionnaire and in district meetings) regarding the practical dilemmas involved, the results of which were the subject of intensive discussion with the federation partners who together constitute the KNMG. The final results are presented here. Our conclusion is that, however understandable it is (even to doctors) to want to end one's own life during its final stages, any such legislation would be fraught with too many risks and adverse effects and is therefore inadvisable.

As doctors, we object to the distinction drawn by the government between 'healthy' and 'sick' people wishing to end their lives – this is not an accurate reflection of the reality observed by doctors and citizens. The current Euthanasia Act is effective and has a broad application: current euthanasia practice is detailed, transparent, verifiable, safe for patients and doctors, and has widespread support. Separate legislation in addition to the Euthanasia Act could serve to undermine current euthanasia practice, which we find unacceptable.

Another concern among our members relates to the potential adverse effects on society as the result of the proposed legislation, such as the elderly feeling unsafe, or the stigmatisation of later life. Instead of opening up a new path to assisted suicide, KNMG therefore wishes to argue for investments in solutions that directly address the feelings of meaninglessness experienced by the elderly.

The concept of a 'completed life' has a positive connotation in the social debate. However, the issue is a complex and tragic one, for which no simple solutions exist. Additional research will increase understanding of those affected by such suffering, and aid the search for alternative solutions to those currently proposed by the government.

On behalf of the KNMG Federation Board,



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President

## Summary

The question of how to help elderly people who are suffering is one that concerns all of society, and one which confronts doctors in their consultation rooms. The Royal Dutch Medical Association (KNMG) understands the certainty and reassurance sought by many people regarding the termination of their own lives, even if they do not currently have a desire to do so. KNMG therefore believes it has a responsibility to contribute to the social debate on this issue.

The government has proposed legislation that would grant senior citizens who feel their life is 'complete' access to assisted suicide. Such legislation would cater to 'healthy' elderly people with a current and well-considered wish to end their lives, who feel they need to do so actively. Any such legislation would be in addition to the current Euthanasia Act, which is aimed at people whose suffering is unbearable and incurable, and which has its origins (fully or partially) in a medical condition.

There are many objections – both on principle and in practice – to a law with such far-reaching consequences. Based on these objections and following extensive consultation with its members, KNMG has concluded that the government's proposal to institute a 'completed life' assisted-suicide act is undesirable.

Our reasons are summarised below:

- The government draws a distinction between 'healthy' people wishing to end their lives based on the 'completed life' principle, and 'sick' people wishing to end their lives. KNMG believes that the distinction between 'healthy' and 'sick' is a theoretical one that does not accurately reflect the reality observed by citizens and doctors.
- The Euthanasia Act is effective, and is implemented professionally by doctors. Current euthanasia practice is detailed, transparent, verifiable, safe for patients and doctors, and has widespread support. Separate legislation in addition to the Euthanasia Act could therefore serve to undermine current euthanasia practice.
- The Euthanasia Act permits broad application, and vulnerability in later life as the result of compounded medical and non-medical problems can also be seen as unbearable and incurable suffering as defined under the Euthanasia Act. At the same time, however, not all doctors are willing to perform euthanasia in such situations, as they are aware of other suitable interventions and fear a 'slippery slope'. KNMG will continue to invest in both informative and professional development activities.
- The proposed legislation may also lead to potential adverse effects on society, such as the elderly feeling at risk, or the stigmatisation of later life.
- The concept of a 'completed life' has a positive connotation in the social debate. In practice, however, most of the people involved will be those experiencing feelings of loneliness and a lack of meaning in their lives, and who are dependent on others for help. Instead of investing in a new path to assisted suicide, KNMG therefore wishes to argue for investments in other solutions that directly address the feelings of meaninglessness experienced by the elderly. Instead of a tunnel with only one possible outcome (i.e. death), the assistance provided to these citizens should be a broad spectrum of options that examines the actual needs of the elderly.
- KNMG is struck by the government's intention to institute new legislation specifically for the 'completed life' scenario, as it represents a deviation from disciplinary and other judiciary proceedings, as well as the standpoint held by the Regional Euthanasia Review Committees and current professional standards. After all, doctors are advised to take a reserved approach

and act with extreme caution. KNMG also finds it remarkable that the complexity of the 'completed life' scenario is to be subject to a simpler assessment and evaluation framework than for people suffering due to a medical cause, producing the curious – and undesirable – situation in which a 'severe' assessment is applied to cases with a predominantly medical basis, and a 'lenient' assessment to the more complex 'completed life' scenario.

- The group defined by the government (with a current, lasting and well-considered desire to end their lives and an active need to do so, but whose suffering does not have a medical basis) is probably very small. KNMG believes it is inadvisable to create a separate legal framework for this group – first more clarity is required on the size of the group, the nature of the problems they are grappling with, and the alternatives that can be offered to them.
- The government has stated that doctors need not be involved in assessing the desire to die. However, KNMG has serious doubts about whether this may pose a potential threat to thoroughness, verifiability and safety. Moreover, the proposed assessment framework will most likely involve medical elements, requiring the (unintentional) involvement of doctors in the procedures surrounding 'completed life'.

## Introduction

Since 1991, society has been discussing whether elderly people who feel their life is 'complete' should be granted access to assistance that would enable them to end their own lives. A desire for the means to end one's own life is therefore nothing new.

However, in early 2016 the Expert Committee on assisted suicide for people who deem their lives complete (the Schnabel Committee) stated that the current Euthanasia Act functions effectively, is far more broadly applicable than many people think, and that expanding the legal options for assisted suicide would be undesirable.(1)

In response, in October 2016 the government published a letter to parliament titled 'Government Response and Vision on Completed Life'[Kabinetsreactie en Visie Voltooid Leven](2), in which it rejects the recommendations of the Schnabel Committee. The government proposes additional legislation supplementary to the current Euthanasia Act that would grant access to assisted suicide under the 'completed life' principle, and is aimed at people whose suffering has no medical basis. The current Euthanasia Act would continue to exist, aimed at those with unbearable and incurable suffering due (wholly or in part) to a medical cause.

### Purpose and justification

In their practices, doctors are also confronted with elderly people experiencing feelings of meaninglessness, making the issue of elderly people who are 'suffering from life' one that is relevant to doctors. [see box]

This document aims to provide a response to the letter to parliament titled 'Government Response and Vision on Completed Life', dated 12 October 2016.(2) In its response to the government's proposal to institute an Act granting access to assisted suicide for people based on the 'completed life' principle in addition to the current Termination of Life on Request and Assisted Suicide (Review Procedures) Act, KNMG's arguments are based on:

- an analysis of KNMG standpoints, policy documents, prior consultation of the medical panel on this topic, the report by the Schnabel Committee and the government's letter to parliament, as well as general responses from society;
- consultations with the KNMG medical panel held between 28 November 2016 and 11 December 2016; and
- KNMG district meetings in Limburg, Gooi-Eemland-Northwest Veluwe, Holland North, Twente, Southern South Holland, Flevoland/Zwolle and Northern Spaarne Amstel. Some meetings were held following the announcement of the government's letter.

#### Suffering from life

In this document, KNMG uses the term 'suffering from life' (lijden aan het leven), which it defines as follows: '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 persistent 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) KNMG chooses to use this term, as it constitutes the core element of the issue at hand. Suffering of this type can result from the feeling that life is 'complete', but it may also have other causes. We consider the term 'completed life' to be unsuitable as it contains an innate value judgement, and only the individual themselves can decide whether their life is 'complete' or not.

### Guide to this document

Section 1 outlines the background to the debate, from 'Drion's Pill' to the Government Vision. Section 2 continues with an overview of responses from other parties in society shortly following publication of the Government Vision. The results from the KNMG questionnaire, literature study,

and other documents are presented in Section 3, which also contains provisional conclusions and recommendations.

# 1 Background to the debate

In recent decades, there has been a discussion in society regarding autonomy in ending one's own life. It started with the essay titled 'Elderly wishing to end their own lives' [*Het zelfgewilde einde van oude mensen*] by Huib Drion in 1991, in which he argues for the provision of lethal means to the elderly that would allow them to end their own lives in a dignified manner and when they so choose. The essay received much acclaim, but did not develop into the 'Free Will Citizens' Initiative [*Burgerinitiatief uit Vrije Wil*] until two decades later.

## 1.1 The 'Uit Vrije Wil' ('By Free Choice') citizens' initiative

In 2010, Uit Vrije Wil brought new momentum to the debate on assisted suicide. The purpose of the initiative was to 'legalise suicide assistance for elderly people who deem their lives complete' (4), at their express request and subject to due-diligence and verification criteria. To a large extent the proposal resembled the current Euthanasia Act, including initial assessment by an independent consultant and subsequent review by a committee. The key difference between the two acts was the line drawn by the due care criteria between 'unbearable and incurable suffering' and 'reasonable alternatives'. Additionally, assistance would only be granted to people aged 70 and over, as the initiators believed they should have earned their 'certificate of life'. The Uit Vrije Wil proposal would co-exist alongside the current euthanasia laws. KNMG found the proposal problematic, partly because it would serve to undermine the level of due care already established in current euthanasia practice. Ultimately, there proved to be insufficient support for the proposal in the House of Representatives.

## 1.2 KNMG position paper: The role of the physician in the voluntary termination of life

In 2011, KNMG published its position paper titled 'The role of the physician in the voluntary termination of life' [*De rol van de arts bij het zelfgekozen levenseinde*](5), which was prompted by Uit Vrije Wil and was partly related to the standardisation and professional development of physicians regarding euthanasia and assisted suicide following the introduction of the Euthanasia Act in 2002.

The position paper clarified some of the terminology being used for people with a long-term wish to die. Concepts such as 'done with life', 'finished with life', 'completed life' and 'suffering from life' are used interchangeably both in the public debate and between doctors and patients. KNMG uses 'suffering from life' for this purpose, as it believes that suffering lies at the core of the debate. By 'suffering from life', KNMG means: '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 persistent desire to die, even though the absence or deficiency in quality of life cannot be explained in any or significant measure by an identifiable medical or psychological condition'.(3)

The KNMG position paper explains that 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. This applies equally if the patient's wish to die stems from a sense of having led a 'completed' life. However, the judgement that life is completed – assuming that such completion can exist – is one that only individuals can make for themselves. Due to the personal nature of such a judgement, KNMG can identify no role or responsibility for physicians in determining whether a life is 'completed'. It does, however, argue that the government should carry out research into the nature and scope of the issue.(5)

The position paper also explains that the Euthanasia Act provides for vulnerable elderly citizens who wish to die and are suffering from compounded conditions of later life. KNMG believes that vulnerability – which extends to loss of function, loneliness and loss of autonomy – should be part of the equation physicians use to assess requests for euthanasia. Still, the suffering should always have a medical cause when talking about termination of life, and before taking any such steps, a physician's first duty is always to determine whether any other suitable interventions can be

found (consulting other experts where necessary). Such complex situations demand a particularly reserved and cautious approach.

In its 2011 position paper, KNMG expressly points out that there are other methods available for citizens and patients to end their own lives, such as deliberately refusing to eat or drink. It also points out the dangers of stigmatising old age, and the fact that there are often better ways to help people than euthanasia.

### 1.3 Perspective study: Clear patient communication regarding euthanasia

The perspective study titled 'Clear patient communication regarding euthanasia' [*Helder communiceren rond euthanasie met de patiënt*] published by KNMG, the Dutch Association of Medical Specialists, the National Association of General Practitioners (LHV), Verenso and the Dutch College of General Practitioners (NHG) revealed that, while physicians see euthanasia as a worthwhile aspect of their work, it is also a burden.<sup>(6)</sup> Although euthanasia is an emotionally charged issue requiring much time and energy (an 'emotional roller-coaster'), euthanasia that is performed with care and attention can be very fulfilling: *'It is an intense but satisfying experience.'* *'A careful and proper euthanasia gives you the feeling that you were there for the patient in the right way.'*

The less physical suffering involved, the more emotional difficulties physicians have performing euthanasia. As such, doctors are hesitant to offer euthanasia in cases of compounded complaints related to old age.

According to the study, doctors nowadays see more patients than before who believe they are entitled to euthanasia, which sometimes stands in the way of effective communication. Patients sometimes have misconceptions regarding the limits of euthanasia. Doctors are pressured by patients or their loved ones to perform euthanasia, and this pressure has increased in recent years. Many doctors believe that correctly evaluating and carrying out a euthanasia request falls under their professional responsibilities. However they also want more acknowledgement of the fact that euthanasia is very emotionally taxing for doctors, and that patients and the community should realise that it is a doctor's duty to ensure that due care is carried out.<sup>(6)</sup>

### 1.4 Expert Committee

In July 2014, the Ministers of Health, Welfare & Sport and Security & Justice instituted the Expert Committee on assisted suicide for people who deem their lives complete (hereinafter: the Schnabel Committee).

On 4 February 2014, the Schnabel Committee published the report titled 'Completed Life: Assisted suicide for people who deem their lives complete' [*Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven voltooid achten*]. Some key conclusions from the report:

- The Euthanasia Act is effective, and is fulfilling its purpose. Current euthanasia practice is detailed, transparent, verifiable, and has widespread support.
- The committee sees no cause to amend the Euthanasia Act. Most people in the 'completed life' category also experience medical issues, meaning they also fall under the Euthanasia Act. The number of people who suffer from life and have a well-considered desire to die without any medical cause whatsoever is probably very small.
- For reasons of safety, professional competence and verifiability, the committee sees no need to extend the Euthanasia Act to include non-physicians. Matters concerning the termination of life demand the utmost care, which is why a doctor should always be involved.
- The committee also believes that complex cases such as 'completed life' call for even greater caution (e.g. in the form of an additional consultation), not for a 'simplified' procedure.
- The committee believes that society's view of a 'completed life' is too positive. In reality, the people involved are very vulnerable, and often dependent on others for help.
- Because it is literally a matter of life and death, the delicacy required by the procedure means it is important for a doctor to be involved in assessing whether the due care criteria

under the Act have been met. This is what makes euthanasia practice transparent and verifiable.

- The committee also points out the danger of stigmatising later life: the elderly are a vulnerable social group who could potentially feel pressured to actually make use of any such extension to the Euthanasia Act. Pre-existing negative perceptions of the elderly, which could be reinforced by an additional legal framework, may influence citizens to consider how desirable the option is, i.e. whether they want assisted suicide or not. This means that citizens could also be 'encouraged' – consciously or not – by their communities to seriously consider such an option.
- Lastly, the Committee concluded that awareness of the scope of the Euthanasia Act can also be improved among physicians and the general public.

The recommendations by the Schnabel Committee were not in agreement with the initial Free Will citizens' initiative, which had proposed the opposite, i.e. a second Act in addition to the Euthanasia Act for assisted suicide in cases of a 'completed life'.

In a news item, KNMG announced that the Schnabel Committee's opinion was in line with the previously published position paper by KNMG, 'The role of the physician in the voluntary termination of life'.(7)

### **1.5 Government Response and Vision on Completed Life**

On 12 October 2016, the government published a letter to parliament titled 'Government Response and Vision on Completed Life'(2), in which it rejects the recommendations of the Schnabel Committee. The government proposed a second Act supplementary to the current Euthanasia Act that would decriminalise assisted suicide under the 'completed life' principle. To ensure that such assistance is offered legally, the government proposed the training of specialised 'assisted suicide professionals'. These people need not be doctors, however they must have completed a 'top-up course in addition to medical studies'. Before proceeding to assisted suicide, the professional must have the case evaluated by an independent expert, and review committees must be instituted to review the assistance provided afterwards. Furthermore, any request made must be: from a person who is decisionally competent, consistent, voluntary, well-considered and not subject to influence by others. The unbearable and incurable nature of the suffering must be deciding factors in the patient's desire to die, and subject to objective criteria (yet to be developed). The government also wishes to set a lower age limit for assisted suicide (although there is no upper limit).

The government's proposal closely resembles the Euthanasia Act, except that assistance can be provided by non-physicians, the suffering need not have a medical basis, and only the elderly qualify for such assistance. The government's letter does not address the matter of how the two Acts will co-exist in a legal sense.

## 2 Community response

This section provides an overview of the initial responses that appeared shortly after the government's vision in October 2016.

### 2.1 Verenso

Among other channels, chairwoman Nieuwenhuizen gave responses in the *Nieuwsuur* news programme and in weekly publication *Medisch Contact*(8).

She stated that she failed to understand the government's decision to ignore the recommendations by the Schnabel Committee. She believed that the government's plans were too short-sighted, and that she had doubts about the 'completed life' criteria to be drawn up. She also questioned the message that society is sending the elderly via the proposal.

### 2.2 Dutch Association for Psychiatry

President Denys of the Dutch Association for Psychiatry (*Nederlandse Vereniging voor Psychiatrie*, NVvP) responded in the *Trouw* daily newspaper.(9) He calls it problematic that the Act is intended for elderly citizens without a medical condition, which would necessitate determination of the absence of a medical condition (e.g. a treatable case of depression). This is a psychiatrist's job. Indirectly, however, a verdict of 'no depression' by a psychiatrist is essentially a value judgement regarding the extent to which a person's life is 'completed'. Most psychiatrists will not cooperate with such a procedure.

### 2.3 Dutch Association of Psychologists

In response to the government's proposal, the Geriatric Psychology division of the Dutch Association of Psychologists (*Nederlands Instituut voor Psychologen*, NIP) formulated a number of key points relating to care for the elderly with a long-term desire to die.(10) They state that, while from a psychological perspective there is no fundamental difference between age groups when it comes to a desire to die, the government proposal nonetheless draws this distinction.

Greater insight and more research is necessary into the types of issues that affect assistance for the elderly with a long-term desire to die. Psychological factors contributing to a desire to die are not discussed in the government's proposal, despite the need for professional attention in this regard. Generating a more positive image of old age has a higher priority. The conversation surrounding the elderly and assisted suicide influences public perceptions of later life.

The government's proposal emphasises evaluation, while professional care is just as important. Psychologists are, of course, available to provide such care, but not if the focus is on evaluation and the outcome is pre-determined. The NIP reiterates the Schnabel Committee's claim that current euthanasia practice does offer sufficient scope, but that it can be better utilised, such as by increasing the involvement of professional groups other than doctors (e.g. psychologists) in the process. The NIP fears the stereotyping of old age.

### 2.4 Dutch Patients' Association

The Dutch Patients' Association (*Nederlandse Patiëntenvereniging*, NPV) is disappointed and disturbed by both the procedure followed and the content of the proposal.(11) Who was consulted as part of the process? Many civil-social organisations were surprised. And why did the government ignore the Schnabel Committee's recommendations, and simply issue an 'easy and populist' decision?

Although the NPV is not in favour of the current Euthanasia Act, it nonetheless understands the Schnabel Committee's lack of desire to extend or supplement it with new legislation. Aiding autonomous individuals in ending their lives must not infringe on the government's duty to protect life. The government's proposal is not in line with either the Christian or liberal perspectives in this regard. The NPV also wonders whether the elderly are having death forced upon them. A legal option from the government may help feed the notion that assisted suicide is a fitting solution to the 'completed life' issue. They state that: 'The problem of completed life calls for a renewed sense of purpose in life, not for its termination. Give them people who will help them to live, not

help them to die. Do not just tell them that all people matter until the end – let them experience it too.'

## 2.5 The Union of Catholic and Protestant Christian Senior Citizens' Associations

The Union between the Catholic Senior Citizens' Association (KBO) and the Protestant Christian Senior Citizens' Association (PCOB) believes that the proposal to regulate assisted suicide for senior citizens who deem their lives complete is both unnecessary and undesirable.(12) These organisations question whether the group envisaged by the government (i.e., self-assured, articulate senior citizens who know what they want and desire the legal right to end their lives) is representative of all senior citizens as a whole. KBO-PCOB director Vanderkaa believes that many senior citizens asking for this legislation do not yet have an active desire to die; they are seeking reassurance, a guarantee that assisted suicide will one day be an option for them. Other senior citizens are lonely and disassociated, and are looking to re-establish a connection with life. The organisation's members report that a desire to die is far from always accompanied by the wish for an organised death. An elderly person's desire to die can be temporary, context-dependent or due to a combination of feelings including loneliness, uselessness and powerlessness. KBO-PCOB doubts whether the government's proposal is the right way to address this problem. People also need to be aware of the image of later life that the proposal will project, both to the elderly themselves and to younger generations.

## 2.6 Right to Die (NVVE)

The Dutch Right to Die Society (*Nederlandse Vereniging voor een Vrijwillig Levenseinde*, NVVE) agrees with the government, saying that new legislation is necessary that provides for verifiability, transparency and due care. 'After 25 years of discussion, there is finally hope for people with a well-considered desire to die who are suffering from life without a medical cause.'(13) In 2016, the NVVE and the University of Humanistic Studies initiated a study programme to train people as 'assisted suicide professionals'. The NVVE attests to the vision of the elderly who are suffering from life and are not eligible for euthanasia, a position based on an analysis of reports by the NVVE advisory centre.(14)

## 2.7 D66 'Completed Life' bill

On 18 December 2016, Dutch political party D66 published the 'Dignified Death' (*Waardig Levenseinde*) draft bill,(15) whose aim was to grant elderly people who deemed their life 'complete' access to assistance from an 'end-of-life consultant' (*levenseindebegeleider*). This proposal had both similarities and differences with the Euthanasia Act and the government's vision. The government's 'assisted suicide professional' had become an 'end-of-life consultant' in the D66 bill. A key difference with the current Euthanasia Act was the absence of the 'unbearable and incurable suffering' criterion. While the government does not specify an age limit, the D66 proposal sets a limit of 75 years. On the subject of 'reasonable alternatives', the proposal states that the requesting party and the consultant must together conclude that any available alternatives are 'undesirable'. Unlike in the current Euthanasia Act, D66 states that the request must be 'persistent', and prescribes a waiting period of two months between the request and its actual implementation. The D66 proposal would allow assisted suicide to be performed by someone other than a physician, while the Euthanasia Act stipulates that only a physician may do so. Specifically, D66 suggests nurses, psychotherapists and healthcare psychologists. Similarities with the Euthanasia Act include the requirement that an independent second consultant evaluate the case in advance, as well as a subsequent review by review committees (as stipulated by the Euthanasia Act). The proposed bill also prescribes that the end-of-life consultant must be present when the assisted suicide is carried out. The patient is therefore not given access to the euthanasia drugs themselves.

KNMG sees the D66 proposed bill as a more detailed and crystallised version of the government's proposal. KNMG posed questions to the initiator of this proposal in a separate response.(16) The government's proposal is discussed in greater detail below.

## 3 Findings and arguments

The arguments employed by the KNMG in responding to the government's proposal are based on various sources, including literature and previous KNMG position papers (see introduction).

In their consultation rooms, physicians are confronted with feelings of meaninglessness among the elderly, making this social issue one that is also relevant to doctors. The government's letter to parliament was therefore the right time to issue a physician's questionnaire, in which doctors were asked to present their views on the various aspects of the government's letter. In total, 3,071 physicians were invited to participate, 1,375 of whom completed the digital questionnaire (45%). Of this number, 43% were GPs, 30% were medical specialists, 9% were geriatricians and 18% were other specialists. Of all respondents, 55% were male and 75% were aged 51 or over. The average age of the respondents was higher than that of all KNMG members, however this over-representation among the upper age groups has no significant consequences for interpreting the relevant results from the questionnaire. Appendix 1 gives an overview of the results of the questionnaire (Appendix 1).

Over the course of their career, nearly 70% of the respondents had had one or more requests for euthanasia/assisted suicide. One in three doctors had never received such a request, often because it was not relevant to their specialisation (22%). Of the doctors who had received such requests, over 70% had had actual experience with performing euthanasia or assisted suicide (8 times on average), 21% had not, and 8% objected on principle.

The questionnaire also revealed that six out of ten doctors did not approve of the government's proposal: 62% did not agree that people suffering under the 'completed life' principle but without a medical cause should receive professional assistance. The key reasons cited include the belief that the plan will send negative signals to society about later life (58%) and difficulties with interpreting the sliding scale (56%).

Twenty-four percent of the respondents have a different opinion, and support the government's proposal. Their main reasons for doing so are the belief that unbearable and incurable suffering can exist without a medical cause (70%) and that it would give people greater control over their lives (63%). Lastly, 14% of the doctors said they do not know what they think of the government's proposal.

In addition to their answers to the closed questions, the participants also left many comments in the open text fields that give evidence of both their level of engagement and the concerns:

- 'This gives me food for thought.'
- 'Absurd thoughts in this "completed life" debate!'
- 'The Euthanasia Act works fine! It offers plenty of scope already. Do we really need to spell everything out/social engineering?'
- 'Expand the current legislation? Yes. A second "avenue"? No.'
- 'It's good that there is social debate on this issue.'
- 'We should really look at our communal attitudes and approaches to ageing: how can people stay part of their communities as their vitality decreases?'

This section addresses the points raised in the letter to parliament titled 'Government Response and Vision on Completed Life' one-by-one.

### 3.1 Elderly with a current desire to die

The government believes there is a group of people who do not qualify for assistance under the Euthanasia Act: a group with a current and persistent desire to die and a wish to actively terminate their lives due to unbearable and incurable suffering without any medical cause.

However, the government does not empirically substantiate the existence or scope of this group in any way. In its letter, the government also refers to people who 'are suffering from the loss of independence and mobility' and 'people with general loss of vitality and degeneration'. These

descriptions suggest that there is indeed a medical basis for these people's suffering, which would in principle make them eligible for assistance under the Euthanasia Act. It is therefore unclear exactly which people the government is referring to in its letter, or how many there are.

Via a literature study, the meta-analysis conducted by the Netherlands Organisation for Health Research and Development (ZonMw) titled 'The Elderly and the Voluntary Termination of Life' (*Ouderen en het zelfgekozen levenseinde*) attempted to identify numbers of senior citizens with a desire to end their lives.<sup>(17)</sup> The study distinguished between various groups either with or without a current desire to die, varying from people with a serious, medically classifiable condition to people with no such condition. The analysis concluded that there is (as yet) no research available aimed specifically at determining how many elderly there are with a desire to die without a serious/other medically classifiable condition.<sup>(17)</sup> However, prior research by Rurup and colleagues has shown that around 3% of elderly people have either a current desire to die or a reduced desire to continue living,<sup>(18)</sup> although it is unknown how many of these cases involve a medical condition, potentially placing them under the Euthanasia Act. It is also unknown how many people with a current desire to die or a reduced desire to continue living actually actively wish to end their lives – these are two separate matters, which are often not treated as such in the debate. The group who 'wouldn't mind if they died' is not the same as those who have a current and active desire to end their lives.

The Schnabel Committee also attempted to evaluate the size of the group who deem their lives 'complete' and have a current desire to end their lives but who do not suffer from a medical condition, and concluded that the group is probably 'very small'. Most senior citizens, for example, have experienced compound losses at various levels (physical, mental, cognitive, psychosocial and/or existential), making virtually all of them eligible for assistance under the current Euthanasia Act.<sup>(1)</sup>

Four out of ten questionnaire respondents who had ever received a euthanasia request stated that in some cases, they were from 'completed life' patients without any underlying medical condition as the cause. The doctors at all KNMG district meetings, on the other hand, stated that they only rarely received such requests. This latter observation matches the Schnabel Committee's findings from the SCEN-physician focus groups.<sup>(19)</sup> The fact that doctors from the panel questionnaire did receive such requests calls for further exploration, as the questionnaire results do not clarify what kind of 'completed life' patients with a desire to die these doctors were confronted with. Were they patients who were also experiencing compound conditions of later life, making them eligible for assistance under the current Euthanasia Act? And was their desire to die an active one?

It is KNMG's opinion that, given these findings, the group of people concerned (with a current, well-considered desire to die, the active need to end their lives and suffering without a medical cause) is probably extremely small. KNMG therefore believes it is inadvisable to create a separate legal framework for this (probably very small) group that will have far-reaching consequences, without first clarifying the size of the group, the nature of the problems they are grappling with, and the alternatives that can be offered first. Further research is therefore urgently recommended.

### 3.2 Completed life

The government fails to clearly explicate the meaning of 'completed life'. The letter refers to 'people whose life no longer has any meaning, and who see continuing to live any longer as a (too severe) burden.' It also mentions people 'for whom life has become unbearable'.

The actual problem at hand is not clarified in the letter: is it about a lack of meaning, or the unbearable nature of their suffering?

KNMG believes that as a term, 'completed life' is not suitable for describing the problem, partly because it contains an innate value judgement. In KNMG's view, the sole concern should be the core element underlying the desire to die: suffering. The suggestion that suffering can only emerge when life is 'completed' does not accurately reflect the complex issue of elderly people

who are suffering from life. The KNMG therefore prefers the term 'suffering from life', to make it clear that suffering is the core aspect of the problem,(3) and also to allow for the possibility that the suffering may have a cause other than a 'completed' life. Doctors have a responsibility to explore the burden of suffering in patients who express a serious desire to die, even if the cause is purely existential in nature. As early as 2011, in its position paper titled 'The role of the physician in the voluntary termination of life' [*De rol van de arts bij het zelfgekozen levenseinde*], KNMG stated that it is hard to imagine physicians not being involved when it comes to people with a desire to die, even if the desire is based on the 'completed life' principle.(5)

Nonetheless, KNMG does not see any role for physicians in judging whether a life is indeed completed – this is a personal judgement that can only be made by the individual themselves. The personal and individual nature of the 'completed life' judgement therefore raises the question of whether it is possible to create a system as proposed by the government that provides for enough transparency, verifiability and due care.

### 3.3 Nature of suffering

In its letter, the government proposes creating an additional option for people who desire to die but who are not suffering from any medical condition. It is odd that the government intends to create legislation specifically for such complex situations in which physicians are usually advised to do the opposite and act with reservation and extreme caution (in accordance with disciplinary and other jurisdiction, as well as the findings of the Regional Euthanasia Review Committees and current professional standards).

It is also difficult to justify why a less rigorous assessment and evaluation framework should be applied to the more complex issue of 'completed life' than for less complex cases that primarily involve suffering based on a medical cause. This would essentially result in the undesirable situation of a 'severe' assessment framework being applied to cases with a predominantly medical basis, and a 'lenient' assessment to the more complex 'completed life' scenario.

The current Euthanasia Act requires doctors to be convinced that the patient's suffering is both unbearable and incurable. The suffering must be medical in nature, but need not involve a serious, incurable or terminal condition. In line with the KNMG position paper, compounded age-related conditions (such as loss of function) may also constitute a justification for euthanasia or assisted suicide,(5) and non-medical problems may also contribute to the decision-making process. As such, the Euthanasia Act and the associated framework of standards offers greater scope than many doctors and citizens realise.

Nine out of ten doctors claim to be aware of KNMG's position in this respect. The respondents are divided when it comes to their actual willingness to perform euthanasia on, or grant assisted suicide to, a patient with compounded age-related conditions. Around half of respondents indicate a willingness (or a probable willingness) to perform euthanasia or grant assisted suicide to a patient with a combination of medical and non-medical conditions, and 18% are unsure. Twenty percent said they would probably not do it, and 15% said they would definitely not be prepared to perform euthanasia.

The doctors who said they were probably/definitely willing to perform euthanasia or grant assisted suicide to patients with compounded medical and non-medical problems give the following reasons (among others, multiple answers possible): compounded conditions can result in unbearable suffering (83%), their suffering is understandable (63%) and out of respect for the patient's autonomy (48%). Doctors with euthanasia experience who are probably/definitely willing mostly cite suffering as their reasons ('compounded conditions can also result in unbearable suffering' and 'their suffering is understandable'). On the other hand, specialists who are not asked to perform euthanasia focus more on patient wishes ('respect for the patient's autonomy' and 'it gives people control over the end of their own lives').

The reasons given by doctors who say they are probably/definitely unwilling (multiple answers possible) include: difficulty with the sliding scale (69%), there are often other ways to relieve

suffering (52%), they would only do it in the case of a life-threatening or terminal illness (21%), the cases are often too complex (17%) and only medical problems should contribute to the decision (16%).

Compared to those who are not involved with euthanasia due to their specialisation, doctors with euthanasia experience are more often willing to provide euthanasia/assisted suicide in cases of compounded age-related conditions. The group expressing an unwillingness to perform euthanasia consists mostly (62%) of doctors who have no previous experience with euthanasia. This partly explains the 35% of doctors who are unwilling to provide euthanasia/assisted suicide in cases involving compounded medical and non-medical problems. KNMG will continue to invest in both informative and professional development activities.

It has already been shown that doctors are reluctant to perform euthanasia in cases where somatic (medical) suffering is not the main concern, such as compounded age-related conditions.<sup>(6)</sup> Such situations, after all, often involve a combination of medical and non-medical problems that can be influenced by loneliness, vulnerability, mourning, dependence on formal/informal care and a loss of meaning. Psychiatric conditions, recent losses and increasing pressure on informal care can also influence a person's desire to die. These aspects have also been cited multiple times by doctors during the KNMG district meetings, and described in the research conducted by the Schnabel Committee.

In such complex situations, it is extraordinarily difficult for doctors to establish whether suffering is unbearable/incurable, and whether reasonable alternatives exist. From a proper healthcare perspective, KNMG therefore believes it is important for doctors in these situations to focus on providing effective help and support, and to only consider euthanasia once all other options have been exhausted.

Under the government's proposed legislation, the complexity of the desire to die among those suffering from life will be no different than under the current Euthanasia Act. This raises the question of whether the 'assisted suicide professionals' in such situations may arrive at a different assessment of the interminable nature of the suffering, the well-considered nature of the request and the existence of reasonable alternatives than their physician counterparts.

### 3.4 Assisted suicide professionals

The government has proposed the involvement of specially-trained 'assisted suicide professionals' in the desire to die under the 'completed life' principle. For this purpose, the government wishes to create a new group of professionals who have experience with problems of an existential and psychosocial nature, and also caring for those in the final stages of their lives. The proposal suggests nurses, psychologists and doctors for this role, who would need to complete a follow-up or other training programme: a 'top-up course' in addition to previous medical study.

KNMG believes that special training for assisted suicide professionals carries risks. Proper healthcare guidelines dictate that citizens and patients should receive effective help for the problems they suffer, not that they be guided towards a foregone conclusion. Proper carers do more than simply check a patient's desires against the due care criteria. Caring for a person with a persistent desire to die may also require types of help other than assisted suicide. The risk of specially training assisted suicide professionals is that of cultivating tunnel vision, which may eclipse the alternatives or cause potential quality-of-life improvements to be missed or ignored.

The government also mentions a 'top-up course supplementary to medical studies' without any further specification. This phrasing leaves a lot of room for interpretation. The objectives, duties and associated responsibilities of a care professional in these situations should be set out in extremely precise detail, including the associated training programme. By first mentioning doctors, nurses and psychologists (among others) and then prescribing a top-up course supplementary to medical studies, it remains unclear which qualifications the government believes are necessary for the proposed professional to possess. It is also unclear why doctors

would need to take a 'top-up course' when they currently already assist those in the final stages of their lives and may legally perform euthanasia.

The majority of questionnaire respondents are not in favour of introducing the 'assisted suicide professional'. 52% disagree with the proposition that 'there should be professionals who are allowed to provide assisted suicide in addition to doctors'. On the other hand, 29% of respondents are in favour of the proposition.

The government's letter briefly discusses the role of such a professional in the initial evaluation stage, however there is no discussion of the professional's role in actually carrying out the assisted suicide. This makes it unclear whether the professional should have any (and if so, which) role in performing assisted suicide.

Doctors are given as one example of those who could be eligible for the role of assisted suicide professionals. In current practice, providing care during the final stages of life is indeed one of the duties that doctors carry out. Assisted suicide may be the final component in such care, however it should not be the objective from the outset.

### 3.5 Physicians' involvement

The government believes that the basis for the desire to die among people who deem their lives 'complete' is fundamentally different than among those whose desire is based on a medical condition. According to the government, no doctor or physician need be involved in assessing the desire to die among the former group.

The distinction between these two groups, however, can only be made following an exploration into the nature of the patient's complaints – an evaluation which KNMG believes can only be made by a doctor. After all, the possibility needs to be excluded that the desire may be the result of a reduction in decisional competence, the onset of dementia, a treatable psychiatric condition or other medical conditions, to name some examples. Evaluating the desire to die may therefore always require the involvement of a doctor.

The respondents agree: 70% believe that a doctor should always be involved in assessing a request for assisted suicide due to unbearable suffering under the 'completed life' principle.

At the same time, the role of the physician cannot be restricted only to evaluating the desire to die and determining the medical basis of the suffering. In such situations, doctors may potentially conclude that the requirements of the Euthanasia Act are not met due to the lack of a medical cause for the suffering. However in such cases, patients would still have access to the government's proposed legislation which does not require any medical basis for the suffering, raising the question of why such a medical basis would still need to be evaluated under the Euthanasia Act. The elimination of the medical-basis criterion in the government's proposed bill would essentially serve to undermine the current Euthanasia Act, which KNMG deems inadvisable.

The government's vision document states that, once it has been determined that the assisted-suicide request satisfies the set criteria, the necessary drugs would be provided via a pharmacy. Such a prescription could be issued by the assisted suicide professional, but also by a doctor, and the actual handing over of the drugs could be further limited until shortly before their intended use.

However, doctors cannot be asked to write prescriptions without having been involved in assessing the patient's desire to die. Doctors may only prescribe medicine when there is an indication to do so, or – in the case of voluntary termination of life – if the doctor has themselves determined that all due care criteria are met. Doctors cannot be expected to be involved in performing euthanasia on a patient without having been involved in assessing the patient's request.

The responses from the questionnaire support this view: 50% state that a doctor should always be involved in performing assisted suicide in cases of unbearable suffering under the 'completed life' principle.

One of the criteria in the current Euthanasia Act states that medical care must be taken in performing euthanasia or assisted suicide. Among other things, this means that doctors may not issue assisted-suicide drugs for patients to administer themselves, must be present when they are taken and must remain with the patient until their actual death. One reason for these requirements is because a doctor must be available to take action if the assisted suicide fails due to unforeseen circumstances.<sup>1</sup>

As stated above, doctors' responses support the need for the involvement of a doctor in both the assessment and actual performance of assisted suicide. These doctors also consider a doctor's involvement as not only necessary, but inevitable. Sixty percent agree with the proposition that it is inevitable that doctors will play a role in assisted suicide under the 'completed life' principle. Roles mentioned in this context include: supplying medications, excluding underlying psychiatric conditions, and monitoring due care.

Due care dictates that a doctor must always be involved in both the evaluation of a persistent desire to die and the act of performing euthanasia or assisted suicide. However, the role of the doctor cannot be limited to granting access to the legislation proposed by the government and actually carrying out the assisted suicide without the doctor first being involved in the prior evaluation. This falls outside the sector's professional standards.

### 3.6 Two parallel systems

The government's plans open up a second pathway to assisted suicide, which would co-exist alongside the current Euthanasia Act. However, it is still unclear (legally and otherwise) how these two pathways can function simultaneously, as it would require two different groups of carers (doctors and assisted suicide professionals) to apply different criteria when assessing the unbearable and incurable nature of the suffering and the related desire to die.

The existence of two parallel systems would in principle allow a patient who had been denied euthanasia by a doctor (for whatever reason) to turn to an assisted suicide professional to have their request assessed a second time. The government's letter does not specify whether the assisted suicide professional in such a case must refuse the request solely due to the existence of a medical cause (scenario 1), or whether they may grant the request without assessing the medical cause of the suffering (scenario 2).

In the first scenario (in which the request is denied), a patient with a medical cause for their suffering is treated differently than somebody without such a cause. After all, people whose suffering is medical in nature are subjected to a more stringent assessment framework (under the Euthanasia Act) than people whose suffering is not (under the proposed new legislation). Setting aside the innate discriminatory character of this procedure, this difference in treatment is difficult to justify.

In the second scenario (in which the professional may also provide assisted suicide to people whose suffering has a medical cause), the professional will also assess (just like the doctor) whether the patient's suffering is unbearable and incurable. In this case, however, the medical aspect plays no (or a greatly lessened) role, meaning that the euthanasia procedure sets an additional (qualified) requirement on suffering, i.e. that it must be related to a medical cause. This fact alone makes the assisted suicide professional's due care criteria less stringent. The next question is, of course, why a person with medical grounds for their suffering would even consider

<sup>1</sup> In 2015, 239 instances of assisted suicide took place under the Euthanasia Act, along with 5,277 cases of euthanasia (Regional Euthanasia Review Committees Annual Report 2015). Among these 239, in 31 cases doctors ultimately switched to the euthanasia procedure. Why they did so is unclear, however it does show that assisted suicide is not 100% guaranteed to work. This means that assisted suicide cannot be placed entirely in the hands of non-physicians, and that a doctor must always be on hand to end the patient's life in case the assisted suicide is unsuccessful.

taking a euthanasia request to a doctor at all, since they would have an 'easier time' with an assisted suicide professional by not having to prove that their suffering was fully or partly medical in nature.

Based on the above, the government's proposed second parallel system would therefore be expected to undermine current euthanasia practice. Citizens and patients will choose the path of least resistance, nor can it be ruled out that doctors, too, will recommend the second path to their patients.

But the purpose of the current Euthanasia Act is not only to give doctors and patients legal security when granting a euthanasia request; it also aims to protect them against factors such as external pressures or a poorly-considered decision. Due care, legal security and the right to protection are the cornerstones of current euthanasia legislation and practice.

Partly based on both evaluations of the Euthanasia Act, KNMG believes that it functions effectively and is implemented professionally by doctors. The open standard of 'unbearable and incurable suffering' under the Euthanasia Act allows practice to adapt to changing views in society and the profession regarding the grounds on which doctors may deem a patient's suffering 'unbearable and incurable'.

### 3.7 Healthy or sick?

The government draws a distinction between 'healthy' people wishing to end their lives based on the 'completed life' principle, and 'sick' people wishing to end their lives. The government's proposed legislation is aimed at the former group, while the current euthanasia act will remain in place for the latter group of 'sick' people.

However, KNMG believes that the distinction between 'healthy' and 'sick' is a theoretical one that does not accurately reflect the reality observed by doctors. The difference between a 'sick' person and a 'healthy' person is not always clear-cut; moreover, it is a doctor's duty to establish this status based on expertise.

Furthermore, this distinction arises from a traditional and by no means self-evident view of sickness and health. The government adheres to a narrow, purely medical definition of 'health', while more modern views define sickness and health in broader terms. A broader view of sickness than the mere presence of medical symptoms instantly nullifies the relevance and utility of the distinction drawn by the government.

Huber's recent view of positive health, for example, defines health as 'the ability to adapt and apply control in the face of life's physical, emotional and social challenges'.<sup>(20)</sup> This definition of health also encompasses areas such as purpose and quality of life. Viewed in this light, people with a persistent desire to die because they are suffering from life (without any medical conditions) may not be healthy at all, but can be considered 'sick' because they are unwilling or unable to adapt to their changing circumstances.

Here, 'choosing' a certain definition of health is not appropriate. KNMG does, however, wish to show that the distinction drawn by the government between 'healthy' and 'sick' is not a self-evident one, does not reflect the reality observed by patients and doctors, is not workable in practice and is based on extremely narrow definitions of sickness and health.

### 3.8 Age limit

The government proposes imposing an age restriction on the new legislation, however the letter does not state the actual limit. The government's reasoning behind imposing an age limit is that 'the increasing desire to terminate one's own life is most common among senior citizens'. The reason is therefore purely statistical: 'completed life' feelings are reported to be more common among the elderly, and no supporting empirical evidence is supplied.

However, as also noted by the NIP, introduction of an age limit presupposes that an elderly person's desire to die will be treated fundamentally differently than the same desire in a younger person. In general, a young person desiring to die is labelled 'suicidal', and treatment focuses on preventing suicide, improving quality of life and the individual's right to protection. The government's proposal focuses unilaterally on the right to autonomy for the elderly.

From a medical, psychological and moral viewpoint, however, there are no reasons why an elderly person's desire to die necessitates a fundamentally different approach to that taken in the case of a younger person. Senior citizens, after all, also experience suicidal thoughts, which can be treated, and it is often possible to improve their quality of life. And conversely, people under the relevant age limit may also experience a desire to die due to feelings that their life is 'complete'.

The government posits that the incurable nature of suffering under the 'completed life' principle can be established using objective criteria. If this is so, it should also be possible to use objective criteria to establish precisely the same suffering among young people. In such a case, there is no reason whatsoever why the elderly should be eligible for assisted suicide, and why young people should not. A greater prevalence among the elderly does not, after all, mean that people of a younger age cannot suffer from feelings of a 'completed life' just as seriously or without hope of relief, or are less deserving of the right to autonomy than the elderly.

If 'completed life' feelings were to constitute a legitimate basis for assisted suicide, there is no reason why it should be limited to the elderly. The fact that these feelings are statistically more common among the elderly (for which there is, as yet, still insufficient evidence) does not adequately justify drawing such a distinction. An age limit of this type will also be difficult to defend legally.

The introduction of an age limit also sends a message to people over a certain age, suggesting that their lives are less worthy of protection than for those below the limit. Such a message could potentially amplify feelings of uselessness, make the elderly feel unsafe, lead to the stigmatisation of later life and result in a tendency among the elderly – possibly under pressure from their social circle or overburdened informal carers – to take the suicide option because 'they can, so they might as well'.

This stigmatisation of later life was also revealed by the questionnaire as one of the key reasons why doctors disagree with the government's vision.

For these reasons, KNMG sees an age limit for euthanasia or assisted suicide as problematic. An age limit would be arbitrary, inadequately justified, stigmatising to the elderly and in all likelihood legally indefensible.

### 3.9 Valuing the elderly

The aim of the government's proposal is to resolve the problem of elderly people who deem their lives 'complete'.

However, providing assisted suicide to people who deem their lives 'complete' is only one of the possible solutions that can be used to address the issue. Any suitable solution will first and foremost require establishing the origins of the desire to die and the feeling of 'completed life'. Why are they suffering from life, and why do they consider their lives 'complete'? And how can we prevent situations in which people deem their lives 'complete'?

The respondents to the questionnaire are very outspoken on multiple fronts about the fact that the government's proposed solution is not the one to the problem described: seventy percent of doctors believe that the 'completed life' issue among elderly in the community cannot be addressed using assisted suicide. In addition, the majority (77%) states that the government should invest in more effective geriatric care instead of creating a new euthanasia act. The call to investigate other solutions is also expressed in the many comments left by respondents in the

questionnaire's open text fields, and has also been stressed during the debates in the KNMG district meetings.

Recent research by Van Wijngaarden shows that senior citizens experiencing feelings of 'completed life' are often suffering from various problems of a social and existential nature.(21) They experience existential loneliness: they fall progressively out of touch with others, and remaining social contact becomes more one-sided. They also feel as though they are no longer important to others. The loss of self-expression is another aspect: people are no longer able to express themselves in their characteristic way. People can also feel 'tired of life', in the sense that they can no longer muster the energy to combat loneliness and monotony. One final feeling is the fear of dependence, i.e. uncertainty about the future, and a sense of shame regarding their physical degeneration. This relates not only to the shame and fear of losing control of their own bodies, but also the fear of whether children, family or care providers will continue to take good care of them.

The same research has also revealed that in many cases, the desire to die is not a consistent, purely rational decision – on the contrary, in practice the desire to die proves to be an ongoing dilemma and an 'intense feeling of ambivalence'. People feel like they do not want to die on the one hand, but see their current lives as unlivable on the other. People wrestle with their desire to die and experience a dichotomy between it and the will to continue living. Death is viewed as the only possible way out, while the question is still open of whether it is really the only option. The desire to die is therefore not as consistent as is sometimes claimed.(21)

According to Van Wijngaarden, feelings of a 'completed life' are rooted in the sense of feeling like a burden. The desire to die is influenced by internalised negative views of old age in society.(21) The explicit availability of an assisted suicide option above a certain age could serve to reinforce these negative attitudes.

Much has changed in aged care over recent decades. People wish to remain at home for longer, which is encouraged by government policy. Austerity measures have affected aged care, and traditional nursing homes have disappeared. Traditional social bonds have also disappeared, or changed significantly. Senior citizens' social environments and available options have changed significantly compared to those that existed in the past, partly as a result of these changes. The social value of later life has also decreased. The above developments mean that more elderly will experience a sense of purposelessness than was previously the case.

The Schnabel Committee stated that although the concept of 'completed life' has a positive connotation in the social debate, most of the people involved will be vulnerable people who are suffering from a lack of meaning in their lives, and who are dependent on others for help.(1) KNMG agrees with this assessment.

KNMG shares the government's view that a feeling of purposelessness among the elderly is a social issue. However, KNMG believes that the problem is a complex and tragic one, and complex problems cannot generally be resolved with simple solutions.

But additional research into the origins of such feelings can further understanding of those wishing to die under such circumstances, and aid the search for alternative solutions to those currently proposed by the government. Potential solutions proposed by SCEN doctors in the qualitative study commissioned by the Schnabel Committee include:

- More focus on 'care', and less on 'cure';
- Improved education for the elderly and society on ageing and later life;
- Acceptance of the loss of faculties in later life;
- Improving knowledge on the problem of senior citizens;
- Doctors must make more time available to care for older patients;
- Improvements to old-age healthcare and living environments;
- Greater respect for the elderly in society;

- Combating loneliness among the elderly;
- Improving advance care planning and palliative care.

KNMG supports these proposed solutions, and instead of investing in a new path to assisted suicide, KNMG recommends investing in the above potential solutions in order to directly address the feelings of meaninglessness experienced by the elderly.

### 3.10 The right to autonomy

The government believes that autonomy warrants a greater focus in the debate on termination of life. The government defines 'autonomy' as 'being the architect of one's own life, whilst also having the freedom to have these choices affect oneself'.

In KNMG's view, however, citizens' right to autonomy can be restricted (by denying free access to euthanasia drugs, for example) in cases where exercising the right to autonomy would jeopardise the rights of others. After all, it is not the government's only task to respect (and, to a certain extent, facilitate) citizens' right to autonomy, but also to protect vulnerable groups. The government's proposed legislation may jeopardise this latter government responsibility.

The question also remains of whether the government's proposed legislation will actually achieve the desired effect, as it still prescribes a procedure that may result in citizens' requests being denied. In such cases the desired 'autonomy' will remain out of reach, as the government's proposal still requires assessment by a professional, which carries the risk of assisted suicide being denied.

This is the paradox of autonomy inherent in euthanasia legislation and practice. Autonomy is what allows people to be the architects of their own lives. However, as soon as another person is made responsible and the procedure involves an assessment, citizens are subject to the possibility of their assisted-suicide request being denied, and their autonomy effectively being restricted. Due to the considerations of citizen protection, due care, safety, transparency and preventing abuse, an evaluation will be a necessary component of any such government regulation, making refusal a potential outcome of any citizen's request for assisted suicide.

The questionnaire revealed that doctors also wrestle with this paradox: Fifty-nine percent of respondents agreed with the proposal that people who deem their lives 'complete' should not have to place responsibility for their own death in the hands of other professionals. At the same time, 76% disagree that people should be granted access to the means for terminating their own life without professional assessment.

From the viewpoint of the right to life and protection of that life, the government's response raises fundamental questions. The fact that doctors are permitted to grant termination-of-life requests in cases of unbearable and incurable suffering with a medical cause can justify an infringement of the right to life, provided all due care criteria are satisfied. Assisted suicide professionals (in charge of assessing the suffering in cases of 'completed life') base their decisions on different criteria that focus principally on the perspective of the person wishing to die. The government's proposal therefore puts the patient's right to autonomy first, which is at odds with the government's responsibility to protect life.

### 3.11 Citizens' control of their lives

The government poses the question: 'How can we accommodate the wishes of this group of people who suffer from life unbearably and without hope of relief or a medical cause, and give them more control over the end of their lives?' This question is then translated into an exploration 'of the social and legal options for assisted suicide for people who consider their lives complete'.

However, the fact that more people want control over how to end their lives does not automatically mean that they currently have a desire to do so, as the government proposes. In many cases, the individuals will not have an actual, current desire to end their lives, but rather a need for future security or reassurance.

This increasing demand for greater control and certainty regarding termination of life can, in KNMG's opinion, be met in other ways. It is within citizens' own power, too, to take responsibility for their own death and execute their right of autonomy, via methods such as stopping medication or refusing to eat or drink. In such cases, doctors have the responsibility to talk to their patients and provide effective medical care as necessary.

Furthermore, few Dutch people talk to their loved ones and care providers about their preferences for treatment (including the absence or cessation thereof) during the final stages of their lives. Nor is it customary to document any wishes regarding the end of one's life. End-of-life wishes are still discussed too little, resulting in care providers and patients deciding to go ahead with further treatment.<sup>(22)</sup> Society's expectations of medical care are also too high, leading to inappropriate care for people who are approaching the end of their lives. KNMG believes that the focus in medicine should not only be on the remaining possible interventions, but also on when it might make more sense to shift the focus to palliative care and discuss a non-intervention policy. For doctors this would mean focusing more on the patient, not just their disease. It is important for citizens and patients alike to devote thought in advance to their wishes when approaching the end of their lives, and to discuss them with their doctor and loved ones.<sup>(23)</sup>

KNMG therefore urges the government to educate citizens on the importance of discussing their end-of life wishes in advance.

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