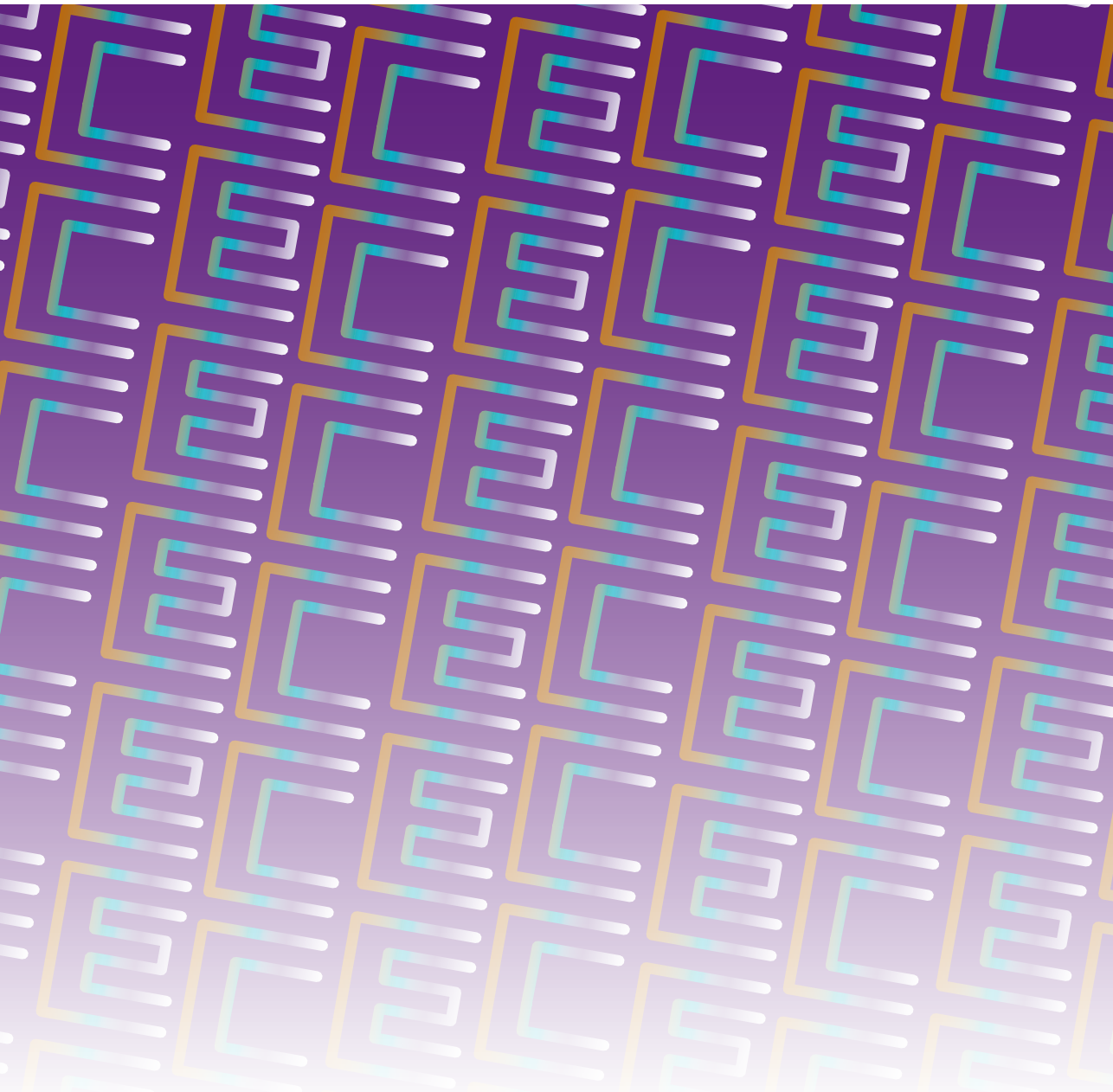


Euthanasia Code 2018

REVIEW PROCEDURES IN PRACTICE



REGIONAL
EUTHANASIA
REVIEW COMMITTEES

RTE

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INTRODUCTION

When the first Code of Practice was published in April 2015, the Regional Euthanasia Review Committees (RTEs) undertook to update it regularly. The present document is the first updated version, with a new, more fitting title: Euthanasia Code 2018. Review Procedures in Practice.

As its title indicates, the Euthanasia Code 2018 explains how the review procedures work in practice. Or, as stated in the third evaluation of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act ('the Act') of 2017, the Code gives 'a practical overview of how the RTEs interpret the due care criteria'. Compared with the 2015 Code of Practice, the Euthanasia Code 2018 contains both editorial changes and a number of substantive changes providing clarification on specific details. These are based on findings published by the RTEs and on feedback received from various parties.

The issues clarified by the new Code include the degree of independence of the independent physician in relation to the physician who performs euthanasia, as well as the sections concerning patients with psychiatric disorders and those with dementia. In addition, clarification was provided – in line with the recommendations of the Schnabel committee – on the scope provided by the Act for patients who request euthanasia in connection with multiple geriatric syndromes.¹ As noted in the third evaluation of the Act, since the publication of the Code in April 2015 'no new developments [...] occurred with regard to the interpretation of the statutory due care criteria'. The Euthanasia Code 2018 is also indexed, to make it easier to find information.

The primary target audience of the Euthanasia Code 2018 is physicians who perform euthanasia and independent physicians. To find out whether physicians were familiar with the 2015 Code and what they thought of it, Professor A.R. Mackor and Dr H.A.M. Weyers carried out a survey in 2016 among physicians and independent physicians

1 See the report entitled 'Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven voltooid achten' [Completed life. On assisted suicide for people who regard their life as completed] The Hague, January 2016, pp. 210-212.

who had actually been involved in a termination of life or assisted-suicide procedure. The survey had a high response rate and showed that – despite some points of criticism – physicians generally consider the Code to be a valuable source of information. Nearly 90% of the independent physicians were familiar with the Code. But of the group of physicians who had actually performed euthanasia, nearly 80% were unaware of its existence.

Robust measures must be taken to improve physicians' knowledge of the legislation on euthanasia, in line with the coalition agreement.² Together with the Ministry of Health, Welfare and Sport, the Royal Dutch Medical Association (KNMG) and, in particular, the National General Medical Practitioners' Association (LHV), we will endeavour to increase familiarity with the Euthanasia Code 2018 among physicians performing euthanasia.

The Code also plays a useful role in harmonising the findings of the RTEs. If a committee is of the opinion that it must deviate from the Code, on account of very specific circumstances, this is always substantiated and explained in the committee's findings. The same persons who were involved in drawing up the Code in 2015 were also responsible for the present, updated Euthanasia Code 2018: Professor J.K.M. Gevers, Dr E.F.M. Veldhuis, Professor A.R. Mackor, and the general secretary, N.E.C. Visée LL.M, assisted this time by the secretary, C.A.M. Wildemast LL.M.

The RTEs would appreciate your feedback on the Euthanasia Code 2018. Please use the contact form on the website (www.euthanasiacommissie.nl) to send us your comments.

J. Kohnstamm LL.M, coordinating chair of the regional euthanasia review committees

The Hague, April 2018

1 PURPOSE AND STRUCTURE OF THE EUTHANASIA CODE 2018

Since the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (hereafter: the Act) entered into force in 2002, five regional review committees have had the statutory task to review reported cases of termination of life on request and assisted suicide. In the intervening years, the committees have reviewed many thousands of cases on the basis of the due care criteria, in accordance with that task.³ Each year, the committees give an account of these activities in a joint annual report. Many of their findings are also published on www.euthanasiecommissie.nl. The annual reports and the published findings of the committees give an impression of how they apply and interpret the statutory due care criteria for euthanasia. The committees have drawn up the present Euthanasia Code 2018 to make this information more accessible, in accordance with a recommendation in the report on the second evaluation of the Act (2012).

The Act distinguishes between termination of life on request and assisted suicide. The Code uses the term ‘euthanasia’ to refer to both forms of termination of life. The distinction between termination of life on request and assisted suicide is made only where necessary.⁴

The Euthanasia Code 2018 outlines the issues and considerations that the committees regard as relevant in connection with the statutory due care criteria for euthanasia. The aim is not to describe every conceivable situation. Rather, the Code is intended as a summary of the considerations that the committees have published in their annual reports and findings. The Code focuses on these considerations; it does not examine specific cases.

³ A translation of the Act is included in the annexe containing relevant statutory provisions.

⁴ This distinction is discussed in section 3.7, concerning due medical care in performing euthanasia and in section 4.1, on advance directives.

The Code is important above all for physicians performing euthanasia and independent physicians, but it also contains useful information for patients intending to request euthanasia and for other interested parties. It gives them an idea of the criteria that must be complied with. It is important that it is clear to everyone how the committees apply the Act.

The Euthanasia Code 2018 is structured as follows. Section 2 briefly outlines the legislation on euthanasia and the review committees' procedures. It also considers the relevance of medical professional guidelines.

Section 3 explains the statutory due care criteria in general terms. Section 4 then discusses some specific issues and situations, and section 5 lists a number of useful references.

2 OUTLINE OF THE ACT, COMMITTEE PROCEDURES AND RELEVANCE OF GUIDELINES

2.1. OUTLINE OF THE ACT: DUE CARE CRITERIA⁵

In the decades before the Termination of Life on Request and Assisted Suicide (Review Procedures) Act entered into force, a (legal) practice developed in the Netherlands in which a physician could under certain circumstances comply with a patient's request for euthanasia. The key considerations were the patient's request and the unbearable nature of his suffering, but there were other requirements too. These requirements were subsequently laid down in the Act, which has been in force since 2002.

Under articles 293 and 294 of the Criminal Code, euthanasia is prohibited in the Netherlands. The entry into force of the Act did not change that. The Criminal Code makes an exception for physicians only. Euthanasia performed by a physician who has complied with all the due care criteria set out in the Act and has notified the municipal pathologist is not a criminal offence (see section 2.2).⁶

Under section 2 (1) of the Act, the physician must:

- a. be satisfied that the patient's request is voluntary and well considered;
- b. be satisfied that the patient's suffering is unbearable, with no prospect of improvement;
- c. have informed the patient about his situation and his prognosis;
- d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation;
- e. have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled;
- f. have exercised due medical care and attention in terminating the patient's life or assisting in his suicide.

⁵ For more detailed information please go to www.euthanasiecommissie.nl.

⁶ Articles 293 and 294 of the Criminal Code are included in the annexe containing relevant statutory provisions.

The Act says nothing about the patient's life expectancy. There is no provision in the Act that euthanasia may only be performed in the 'terminal stage'. There is also no requirement that the patient must have a somatic condition, or that their medical condition should be life-threatening. In cases where the statutory due care criteria have been fulfilled, the patient's life expectancy plays no role. In practice, it will often be limited, but the Act does not rule out granting a request for euthanasia from a patient who might have many years to live. The key elements are the voluntary, well-considered nature of the patient's request, the unbearable nature of his suffering and the absence of any prospect of improvement.

The Act applies to euthanasia for patients aged 12 and over. However, it sets certain requirements regarding parents' involvement when a minor requests euthanasia.

> See also section 4.2

A number of Supreme Court judgments are of importance to the interpretation of the Act. They set requirements, supplementary to the Act, which remain relevant. These judgments are discussed below where appropriate.

> *The Brongersma judgment (2002): section 3.3*

> *The Schoonheim judgment (1984): section 3.3*

> *The Chabot judgment (1994): section 4.3*

The fact that the above due care criteria have been met does not mean that the physician is obliged to comply with a patient's request for euthanasia. Patients have no right to euthanasia, and physicians no duty to perform it. Physicians must however inform the patient at an early stage if they do not want to perform euthanasia, so that the patient can, if desired, approach another physician.⁷ In some cases, physicians will then refer their patients to another physician, in others to the End-of-Life Clinic.⁸

⁷ See The Hague Regional Disciplinary Board, 19 June 2012.

⁸ www.levenseindekliniek.nl.

2.2. OUTLINE OF THE ACT: NOTIFICATION AND REVIEW

A physician who has performed euthanasia must notify this to the municipal pathologist,⁹ completing the relevant form and handing it over at the post-mortem examination. He also provides the pathologist with his detailed report¹⁰ and the independent physician's report.¹¹ In general, the physician also submits other information, such as all or parts of the patient's medical records, letters from specialists and, if there is one, the advance directive. The municipal pathologist must send the notification to the appropriate regional review committee, including the various documents, which then reviews the reports and the euthanasia procedure.¹² If the committee finds that the physician has satisfied all the requirements, and thus acted with due care, it informs the physician in writing, and the review procedure ends.

If the committee finds that the physician did not fulfil one or more due care criteria, it will also inform the physician in writing. It is then also legally required to report its findings to the Public Prosecution Service (OM) and the new Health and Youth Care Inspectorate (IGJ).¹³ These bodies then consider what steps they think are appropriate.

The committees examine whether the notifying physician has acted with due care in the context of the Act, the legislative history and relevant case law. They also take previous committee findings and medical professional guidelines into account, as well as previous decisions of the OM and the IGJ in cases where a committee found that the physician had not acted in accordance with the due care criteria.

The committees establish whether all the aforementioned due care criteria have been fulfilled. For due care criteria (c), (e) and (f), this involves what Dutch lawyers refer to as a 'full review'. The committees establish whether the physician has informed the patient, whether he consulted at least one independent physician and whether he exercised due medical care and attention in carrying out the procedure. When considering due care criteria (a), (b) and (d), the committees establish whether the physician was reasonably able to

9 Where the Euthanasia Code 2018 refers to 'he', please read 'he/she'.

10 The model reporting form can be downloaded from the following websites: www.euthanasiacommissie.nl and www.knmg.nl.

11 See section 7 (2) of the Burial and Cremation Act, included in the annex containing relevant statutory provisions.

12 If necessary the committee can ask the municipal pathologist for further information.

13 Cases in which the committees find that the physician acted with due care are not forwarded to the OM and IGJ. It is however possible for these bodies to become aware of the case via another source (e.g. a third party). In that case, they have the authority to investigate the case.

conclude that the patient's request was voluntary and well considered, whether the patient's suffering was unbearable, with no prospect of improvement, and whether there was indeed no reasonable alternative. Dutch lawyers refer to this as 'limited review' or a test of reasonableness.

2.3. COMMITTEE PROCEDURES¹⁴

There are five regional review committees: one for Groningen, Friesland, Drenthe and the islands of Bonaire, St Eustatius and Saba, one for Overijssel, Gelderland, Utrecht and Flevoland, one for North Holland, one for South Holland and Zeeland, and one for North Brabant and Limburg.¹⁵

The committees assess the notifications they receive on the basis of the detailed report¹⁶ produced by the physician performing euthanasia,¹⁷ the independent physician's report and other relevant documentation (such as medical records, letters from specialists and/or an advance directive).

The committees distinguish between two categories of notification: straightforward notifications (which account for some 80% of cases) and notifications that raise questions (around 20% of cases).

Committee members review straightforward notifications digitally, and can consult with one another via a secure digital system. Straightforward notifications are not reviewed at the monthly committee meetings. Nevertheless, if any questions arise during the digital review process, the notification will be deemed to be non-straightforward. Notifications that raise questions from the start (because, for instance, the case is particularly complex or the information in the report leaves questions unanswered) are always reviewed at the monthly meetings.

The physician must answer the questions on the model reporting form. If the information provided is incomplete or raises questions, the committee can phone the physician who performed euthanasia or the independent physician to ask for additional information.

14 For more detailed information, see www.euthanasiecommissie.nl, where the Dutch version of the guidelines on regional euthanasia review committee procedures can be downloaded.

15 For the members and locations of the committees, see www.euthanasiecommissie.nl.

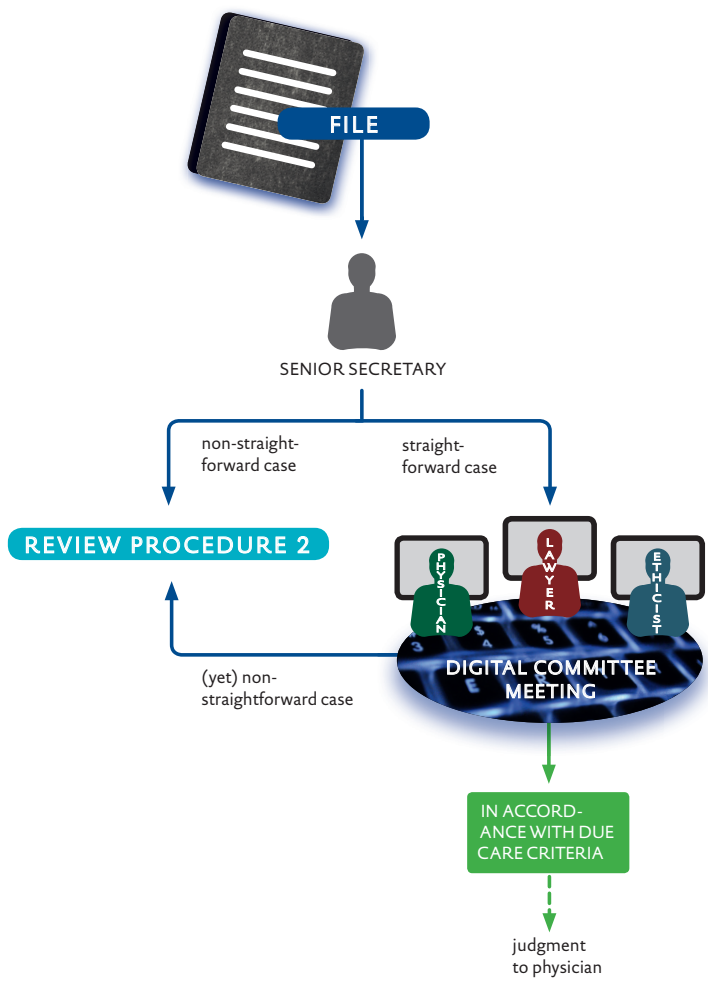
16 A 'detailed report' is obligatory under section 7 (2) of the Burial and Cremation Act. Failure to meet this requirement is an offence (section 81 of the Burial and Cremation Act).

17 Model reporting forms (in Dutch) can be downloaded from www.euthanasiecommissie.nl.

The committee may also ask either physician to provide further information in writing. Additionally, the committee may invite either physician to provide further information in person. A report is made of this meeting, which is sent to the physician concerned for comments. The physician may be accompanied by another person at the meeting. The committees are aware that such an interview with a committee is burdensome for the physician. However, an oral account may be needed to clarify any uncertainties. In some cases, such an account can be vital for a proper assessment.

REVIEW PROCEDURE 1

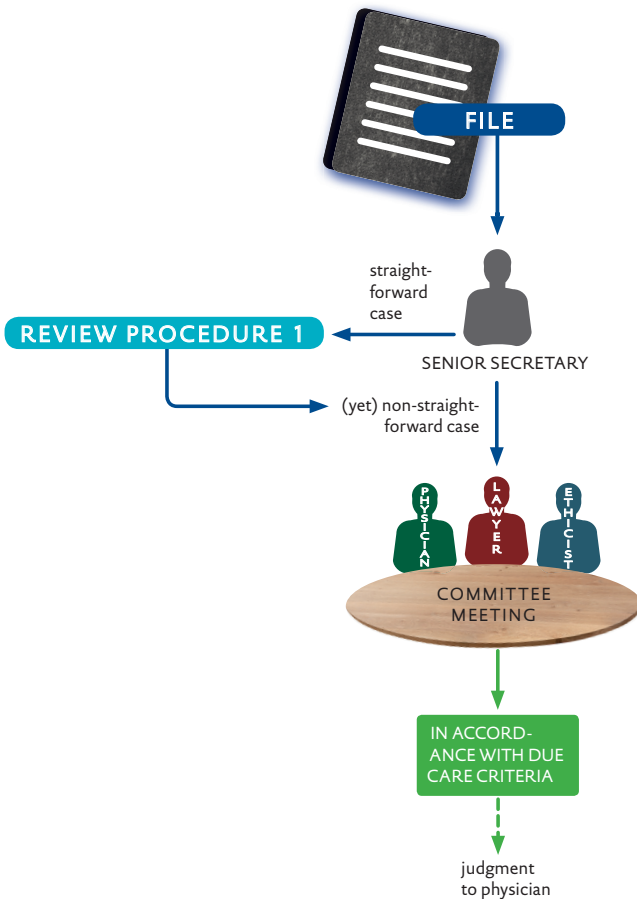
± 80% OF THE NOTIFICATIONS
(STRAIGHTFORWARD CASES)



If the committee is considering finding that the physician did not act in accordance with the due care criteria, he will always be invited for an interview before the decision is made, giving him the opportunity to explain his actions. Once again, a report is made of this meeting, which is sent to the physician concerned for comments. If the committee remains of the same opinion after the interview, the provisional findings will be submitted to the members of all committees for their recommendations. The committee will then reach a final decision.

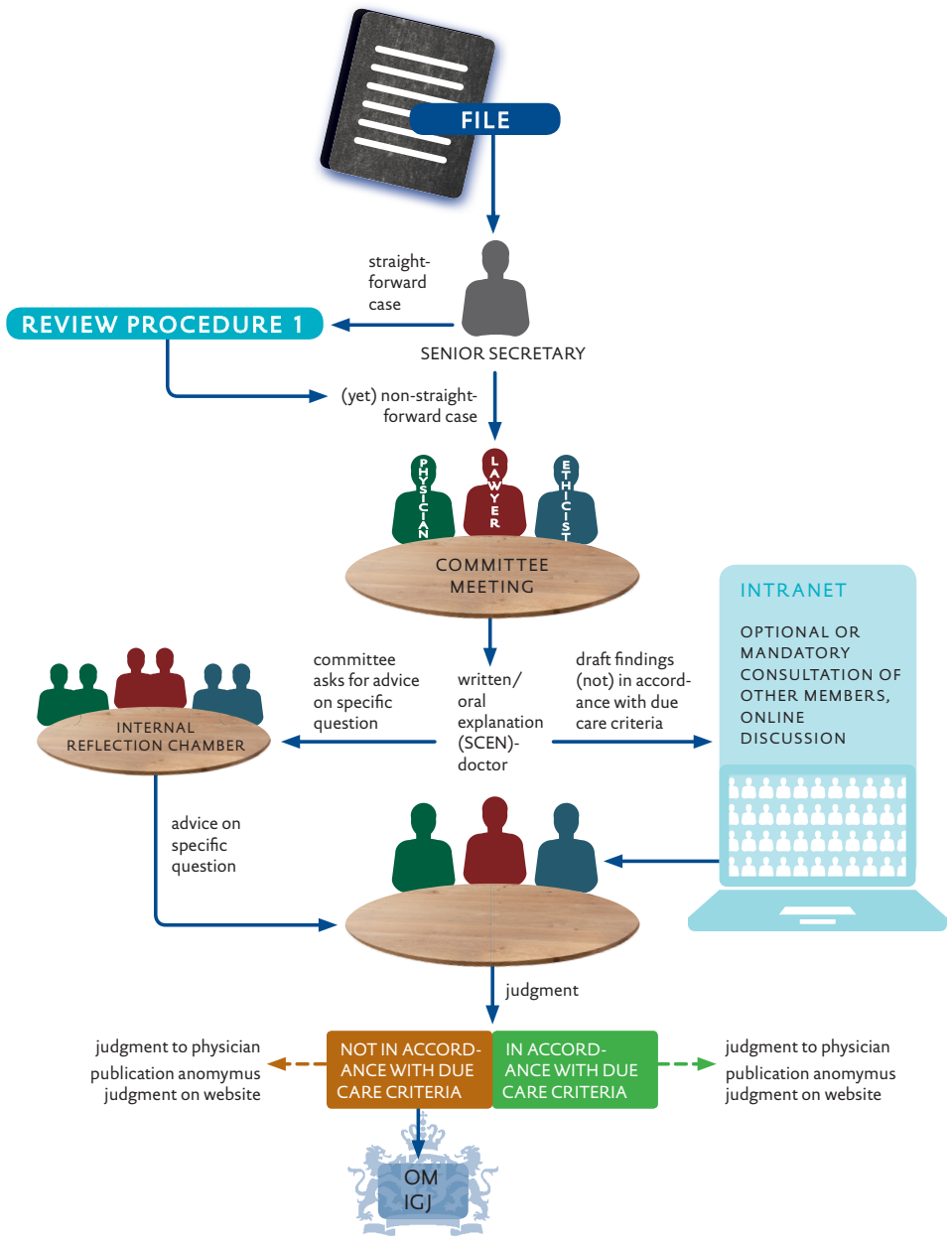
REVIEW PROCEDURE 2

± 19% OF THE NOTIFICATIONS
(NON-STRAIGHTFORWARD CASES)



REVIEW PROCEDURE 3

± 1% OF THE NOTIFICATIONS (NON-STRAIGHTFORWARD CASES)



Provisional findings may also be sent to the members of all committees in cases that are complex or that raise new legal or other issues, for instance. In this way, the committees try to harmonise their findings in the interests of legal certainty and legal uniformity. In 2017 the RTEs established an internal reflection chamber, which advises on points of law to further a number of aims including enhanced coordination and greater consistency in the committees' findings. The reflection chamber responds if one of the committees asks for advice on a particular issue. It is then up to the committee to decide what to do with the chamber's advice. In principle, the committee notifies the physician of its findings within six weeks of receiving the notification. That period can be extended by another six weeks if circumstances require it. The committee informs the physician of any such delay.

In 2015 the RTEs established complaints regulations. An independent committee was set up under these regulations to deal with any complaints the RTEs receive. Notifying physicians, independent physicians, pathologists and other health professionals, insofar as they are involved in or have an interest in the notification of euthanasia or assisted suicide, may lodge a complaint. These complaints must concern treatment by members or employees of the RTEs. The complaints committee does not deal with complaints concerning the content of a committee's finding or the grounds on which they are based. The complaints regulations are published on the RTEs' website.

2.4. RELEVANCE OF MEDICAL PROFESSIONAL GUIDELINES

Various guidelines have been developed by the medical profession that can be important to a physician in determining his views on a patient's request for euthanasia. These guidelines can provide help in interpreting the generally worded statutory due care criteria (more on which in section 3). In particular, the committees always refer explicitly to the 'Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide' produced in 2012 by the Royal Dutch Medical Association (KNMG) and the Royal Dutch Association for the Advancement of Pharmacy (KNMP) in order to assess compliance with the due care criterion on due medical care in performing euthanasia. This concerns, among other things, the choice of substance and the dose, and checks to establish the depth of the patient's coma. Given the reference in this due care criterion to due *medical* care, it is logical for the committee to focus on the standard that the medical professions themselves (physicians and pharmacists) have drawn up.

When reviewing notifications of euthanasia, the committees have their own responsibility which is based on statute. That means that medical professional guidelines apply in so far as they fall within the statutory framework. Conflicts may occur between a guideline and the law, particularly if the guideline sets stricter requirements than the law. In such cases, the law takes precedence in the committee's deliberations.¹⁸ Medical guidelines may also cover issues which the physician has a professional responsibility to consider, but which do not have a bearing on the committee's review of a notification.¹⁹ The committee may then find that a physician has complied with the due care criteria, even though he did not act entirely in accordance with the professional standards of his occupational group.

- ¹⁸ See also the letter of 4 July 2014 from the Minister of Health, Welfare and Sport to the House of Representatives (Parliamentary Papers, House of Representatives, 2013-2014, 32 647, no. 30).
- ¹⁹ Examples include the due care which, under disciplinary rules, the physician must exercise towards the patient's family. See for example Zwolle Regional Disciplinary Board 18 May 2006, GJ 2006/135 and The Hague Regional Disciplinary Board 23 October 2012, GJ 2013/8.

3 STATUTORY DUE CARE CRITERIA

3.1. THE PHYSICIAN PERFORMING EUTHANASIA

Under the Termination of Life on Request and Assisted Suicide (Review Procedures) Act only a physician is authorised to perform euthanasia at a patient's request. The law focuses on the physician who actually performs euthanasia. This is generally the attending physician (usually the patient's general practitioner), though this is not a requirement in the Act. In all cases, before terminating a patient's life on request or providing assistance with suicide, the physician must have informed himself thoroughly of the patient's situation and must have personally determined that all the due care criteria have been met. An attending physician who has known the patient for some time will be able to base this conclusion on his knowledge of his patient.

A physician other than the attending physician in non-acute situations

A physician other than the attending physician may also perform euthanasia at a patient's request. However, such a physician will generally have to make a convincing case that he took sufficient time to apprise himself of the patient's situation, in compliance with the statutory requirements. In cases where the physician performing euthanasia is not the attending physician, it is important that he indicate in his report to the committee how often and in how much detail the physician discussed the situation with the patient.

A physician other than the attending physician in acute situations

There may be circumstances (e.g. the attending physician is not available and the patient's condition has unexpectedly deteriorated) that lead to euthanasia being performed by a physician other than the attending physician (e.g. a locum or a physician in the same practice). By law, the physician who actually performs the euthanasia must submit the notification. He may base his decision on the information supplied by colleagues also involved in the case, but he will also have to ascertain for himself, insofar as is reasonably possible in the specific situation, that the statutory due care criteria have been met.

Below, 'physician' refers to the physician performing euthanasia.

3.2. VOLUNTARY AND WELL-CONSIDERED REQUEST

The Act states that the physician must be satisfied that the patient's request is voluntary and well considered. A written request is not required by law; an oral request is sufficient.

It follows from the Act that the patient must make the request himself. A request for euthanasia made by another person on behalf of the patient cannot be granted.²⁰ It must always be clear that the request has been made by the patient himself. The patient may make his request known well before euthanasia is performed, but if the patient's condition is deteriorating rapidly, there may be only a (very) short period of time between the request and the performing of euthanasia. In other words, a request need not necessarily have persisted for a long period of time in order to be granted. It is not unusual for patients to be hesitant about euthanasia, but ultimately the physician must be satisfied that the request is unequivocal and consistent.

Most patients are capable of normal (i.e. oral) communication until the moment that euthanasia is performed. In some cases the patient's ability to communicate is severely impaired or hampered by their illness. This can give rise to a range of situations:

- the patient is unable to express his request in words, but can still communicate in other ways (e.g. hand gestures, by nodding or by squeezing the physician's hand in response to 'yes or no' questions, or using a speech-generating device);
- the patient can still express his request orally, but is unable to present supporting arguments. In such cases, it must be plausible, on the basis of his behaviour and what the patient is still able to communicate, that he is making a consistent request. The utterances the patient is still able to make at that point can be assessed in conjunction with earlier oral or written directives, and the patient's behaviour or signals.

In situations where the patient has severe difficulty communicating or is completely incapable of communication, an advance directive may take the place of an oral request.

> *For advance directives, see section 4.1*

²⁰ A patient may not therefore authorise another person to make a request for euthanasia on his behalf. The basic principle is that the patient himself must make the request for euthanasia. See Parliamentary Papers, House of Representatives, 1998-1999, 26691, no. 3, p. 9. Others may however alert the physician to the fact that the patient has a wish for euthanasia, so that the physician can initiate discussion of the matter with the patient or, if the patient is no longer able to communicate, can assess any advance directive the patient might have made.

Voluntary request

The patient's request must be voluntary. There are two sides to this.

First, the request must have been made without any undue influence from others (external voluntariness). The physician must be satisfied that there has been no such influence. He should exercise particular caution when, for instance, a close relative of the patient becomes too overtly involved in the conversation between physician and patient, or repeatedly gives answers that the physician wishes to hear from the patient himself. It may then be necessary for the physician to speak with the patient privately. If a patient requests euthanasia partly because he feels he is a burden to others, the request may not necessarily be involuntary.²¹

Second, the patient must be decisionally competent (internal voluntariness).²² Decisional competence means that the patient is able to communicate intelligibly about his request for euthanasia and understand the relevant medical and other information. He must have insight into his condition: in other words he can assess his situation and the implications of euthanasia or alternative treatment. Finally, he must be able to make it clear why he wants euthanasia to be performed.

Decisional competence may fluctuate over time. A patient may also be decisionally competent in one matter (e.g. a request for euthanasia) but not in another (e.g. financial matters). This is also stated in the Medical Treatment Contracts Act (article 7:465 of the Civil Code), which takes as the basic principle for decisional competence that the patient must be deemed capable of making a reasonable assessment of his interests with regard to the decision in question. Decisional competence therefore means that the patient is able to understand relevant information about his situation and prognosis, consider any alternatives and assess the implications of his decision.²³

If a patient is decisionally incompetent, the Medical Treatment Contracts Act (WGBO) allows his representative to give informed consent on his behalf for a specific medical procedure. Such representation is not possible with regard to a request for euthanasia: the patient must be capable himself of assessing the scope of such a

- 21 The feeling that one is a burden to others can be a factor contributing to the unbearable nature of suffering.
- 22 The parliamentary documents concerning the Act repeatedly state that the patient must be decisionally competent in order to request euthanasia. See, for instance, Parliamentary Papers, House of Representatives, 1999-2000, 26691, no. 6, pp. 5-7.
- 23 See the guidelines on assessing decisional competence (2007 version, in Dutch) at www.rijksoverheid.nl (search for 'handreiking voor de beoordeling van wilbekwaamheid').

request, of understanding the information on his prognosis and the alternatives, and of coming to an independent decision on the matter. If a patient is no longer decisionally competent, an advance directive drawn up when he was still decisionally competent may take the place of an oral request.

In many cases, there will be no doubt as to the patient's decisional competence regarding his request for euthanasia. Sometimes, especially for specific groups of patients, the physician will have to consider the matter of the patient's decisional competence more explicitly and in greater depth. If there are any doubts as to the patient's decisional competence, it is wise for the physician to seek the advice of another physician with relevant expertise. This request for advice may be included in the specific questions put to the independent physician as referred to in section 2 (1) (e) of the Act, but the patient's decisional competence can also be determined by a specialised physician prior to consultation with the independent physician.

> For specific groups of patients, see sections 4.3, 4.4 and 4.5

Well-considered request

The request must also be well considered. This means that the patient has given the matter careful consideration on the basis of adequate information and a clear understanding of his illness. The request must not have been made on impulse. Caution is also required in cases where the patient expresses doubt by repeatedly making and withdrawing requests over a given period of time. That a patient hesitates or has doubts regarding such a profound step as euthanasia is understandable and not necessarily a contraindication. The important thing is that the request should be consistent, taking account of all the patient's circumstances and utterances. A repeated request can be a sign that the patient is consistent in his desire for euthanasia.

In cases involving, for instance, psychiatric patients, patients with dementia, patients with intellectual disabilities, patients with aphasia, patients in a coma or a state of reduced consciousness, and minors, particular questions may arise in considering whether the patient's request is voluntary and well considered.

> For further information on these situations, see Chapter 4

KEY ELEMENTS OF 'VOLUNTARY AND WELL-CONSIDERED REQUEST'

- Request made by patient himself
- 'External voluntariness': no undue influence from others
- 'Internal voluntariness' or decisional competence: insight into and understanding of the situation
- Well-considered request: well-informed, consistent, not on impulse
- Consistence apparent from patient's repeated request or other utterances
- Advance directive may take place of oral request (see section 4.1)
- Exercise particular caution in certain situations (see chapter 4)

3.3. UNBEARABLE SUFFERING WITHOUT PROSPECT OF IMPROVEMENT

General factors

Suffering is a broad concept. It can result from pain and shortness of breath, extreme exhaustion and fatigue, physical decline, or the fact that there is no prospect of improvement, but it can also be caused by growing dependence, or feelings of humiliation and loss of dignity. In the 1984 Schoonheim case, the Supreme Court ruled that suffering can consist of (the fear of) progressive degradation of quality of life or the prospect of no longer being able to die with dignity.

There is seldom only one dimension to the burden of suffering experienced by the patient. In practice, it is almost always a combination of aspects, including the absence of any prospect of improvement, which determines whether suffering is unbearable. The physician must therefore investigate all aspects that together make the patient's suffering unbearable.

A patient must be conscious of suffering. There are situations where this is not (or no longer) the case, as with coma, or where this is uncertain, as with reduced consciousness. Either of these situations can arise as a result of palliative sedation. In principle, if the patient is in a situation where he is no longer conscious of suffering, euthanasia may not be performed, irrespective of whether the patient's immediate family find his situation distressing or humiliating.

> For more on coma and reduced consciousness, see section 4.7

> For more on the relationship between euthanasia and palliative sedation, see section 4.8

The patient's consciousness of his suffering may be apparent from what he says, or from his other utterances or physical reactions. In cases where a patient can no longer express his suffering in words, the physician must be alert to other signals that may reveal the patient's burden of suffering.

Medical dimension to suffering

The physician must be satisfied that the patient is suffering unbearably and that there is no prospect of improvement. It is evident from the parliamentary history of the Act that there must be a medical dimension to the suffering.²⁴ The concept of a 'completed life'²⁵ falls outside the scope of the Act as it goes beyond the medical domain. Physicians do not have the specific expertise that is necessary to be able to form a judgment on this matter.

In its 2002 Brongersma judgment, the Supreme Court, citing the parliamentary history of the Act, held that the patient's suffering must on the whole be the result of one or more medically recognised diseases or conditions. The Supreme Court also reiterated the opinion it held in the 1994 Chabot judgment, i.e. that the condition may be either somatic or psychiatric. Since then, the KNMG has adopted the position that in assessing suffering in the context of termination of life by a physician, the suffering must (at least) have a medical dimension.²⁶ In view of the Brongersma judgment and the KNMG's position, the guiding principle for the RTEs is that the suffering must have a medical dimension: it must fall within the physician's domain, that is to say within the scope of his responsibility and expertise. There must be a state that can be described as a disease or a medical condition. However, there need not be a single, dominant or life-threatening medical problem. For instance, the patient could be suffering from two (or more) diseases. The medical dimension to the suffering then lies in the combination of these medical conditions.

Multiple geriatric syndromes

As we have seen, for a patient's request for euthanasia to be considered, his suffering must have a medical dimension. However, it is not a requirement that there be a *life-threatening* medical condition. Multiple geriatric syndromes – such as sight impairment, hearing

24 Memorandum of Reply, Parliamentary Papers, Senate, 2000-2001, 26691, no. 137b, pp. 32-34.

25 See Proceedings of the House of Representatives, 23 November 2000, TK 27-2254, which makes reference to 'completed life'.

26 *De rol van de arts bij het zelfgekozen levenseinde* [The role of the doctor in termination of life at the patient's request], KNMG, Utrecht, 2011, section 2.5 *Medische grondslag* [Medical dimension], pp. 27 ff. (in Dutch).

impairment, osteoporosis, osteoarthritis, balance problems or cognitive deterioration – may cause unbearable suffering without prospect of improvement.

These syndromes, which are often degenerative in nature, generally occur in elderly patients. It is the sum of these problems, in conjunction with the patient's medical history, life history, personality, values and stamina, that may give rise to suffering which that particular patient experiences as being unbearable and without prospect of improvement.

This is where the distinction lies between multiple, largely degenerative syndromes and the issue of 'completed life', insofar as the latter refers to suffering that has no medical dimension. Multiple geriatric syndromes, conversely, do have a medical dimension.

> For 'completed life', see section 4.9

No prospect of improvement

A patient is regarded as suffering with *no prospect of improvement* if the disease or disorder causing the suffering is incurable and there are no means of alleviating the symptoms so that the suffering is no longer unbearable. This must be determined in the light of the diagnosis and prognosis, and of whether there are realistic options, other than euthanasia, that would end or alleviate the symptoms. In considering whether there is any realistic prospect of alleviating the symptoms, account must be taken both of the improvement that can be achieved by treatment and of the burden such treatment would place on the patient. 'No prospect of improvement' must be seen in relation to the patient's disease or disorder and its symptoms. There is no prospect of improvement if there are no realistic curative or palliative treatment options that may – from the patient's point of view – be considered reasonable. It is thus clear that the assessment of the prospect of improvement is closely linked to determining whether there is a reasonable alternative that would alleviate or end the suffering (section 2 (1) (d) of the Act).

> See also section 3.5

Patients sometimes also use equivalent terminology to indicate that the fact that there is no longer any prospect of improvement makes their suffering unbearable to them, and that they therefore want their suffering to end. In that sense, the patient's perception that the situation is hopeless is part of what makes his suffering unbearable.

Unbearable nature of suffering

It is sometimes hard to establish whether suffering is unbearable, for this is a subjective notion. What is bearable for one patient may be unbearable for another. This depends on the individual patient's perception of his situation, his life history and medical history, personality, values and physical and mental stamina. It must be palpable to the physician, also in light of what has happened so far, that this particular patient's suffering is unbearable. The physician must therefore not only be able to empathise with the patient's situation, but also see it from the patient's point of view.

The fear of an imminent decline in health can be a major factor in the patient's suffering. The patient may fear increasing pain, further humiliation, shortness of breath or nausea, or situations in which his core values (such as independence and dignity) are undermined. In such cases the patient's current suffering is connected with the realisation that his situation will only deteriorate further and that values and circumstances that are important to him will come under increasing pressure. This is the case with diseases like cancer, but also with progressive ALS, multiple sclerosis, dementia and Parkinson's disease.

KEY ELEMENTS OF 'UNBEARABLE SUFFERING WITH NO PROSPECT OF IMPROVEMENT'

- There must be a medical dimension to the suffering
- Suffering can result from an accumulation of psychological and physical factors
- Suffering can result from symptoms caused by a combination of disorders
- Suffering can result from symptoms caused by multiple geriatric syndromes
- No prospect of improvement: there is no reasonable alternative to euthanasia (see also section 3.5)
- Unbearable suffering: it is about the suffering of this specific patient (in relation to his life history, medical history, personality, values and stamina). The suffering must be palpable and understandable to the physician
- Suffering may also be caused by fear of future deterioration
- Patient must be aware of the suffering

3.4. INFORMING THE PATIENT

The physician must inform the patient about his situation and prognosis. A well-considered request as referred to in section 2 (1) (a) of the Act can be made only if the patient has a full understanding of his situation (disease, diagnosis, prognosis, treatment options). The committee assesses whether the physician informed the patient adequately. The physician must ascertain whether the patient is adequately informed and has understood the information provided. He may not simply assume this to be the case, even when other physicians were involved in the case prior to the request.

A patient suffering a long-term illness will generally have a good understanding of his situation and prognosis. He may even have discussed euthanasia on more than one occasion. In other cases, a request for euthanasia may come as something of a surprise to the physician. It is then particularly important that he establish satisfactorily that the patient has understood all the relevant information, in view of the irrevocability of euthanasia.

KEY ELEMENTS OF 'INFORMING THE PATIENT'

- Patient must be informed about his situation and prognosis
- Physician must ascertain that patient has understood the information

25

3.5. NO REASONABLE ALTERNATIVE

The physician and the patient must together come to the conclusion that there is no reasonable alternative in the patient's situation. This due care criterion, which must be seen in relation to suffering with no prospect of improvement, is necessary in view of the profound and irrevocable nature of euthanasia. If there are less drastic ways of ending or considerably reducing the patient's unbearable suffering, these must be given preference.

The question of whether there is a reasonable alternative must be assessed in light of the diagnosis and prognosis. Where the physician lacks the expertise to assess whether reasonable alternatives exist, he should ascertain whether other physicians who do have that expertise have been involved in the patient's treatment, or he should consult a specialist in the medical field in question. He must also record such consultations in his report to the committee.

The physician and the patient must *together* arrive at the conclusion that no reasonable alternatives are available to the patient. The

perception and wishes of the patient are important. There is an alternative to euthanasia if there is a realistic way of alleviating or ending the suffering (not necessarily limited to medical intervention) which may – from the patient’s point of view – be considered reasonable. The advantages of the alternative must outweigh the drawbacks: ‘reasonable’ from the patient’s perspective means, among other things, that there is a favourable relationship between the outcome to be achieved through the alternative and the burden on the patient, while the positive effects must be achievable in the short term. The patient’s life expectancy also plays a role in this regard. The burden must be assessed in light of the patient’s individual circumstances, including the number of treatments he has already undergone, any side effects of the treatment, the stage of the disease and the patient’s age, medical situation and physical and mental stamina. It is not necessary to try all possible alternatives. Sometimes, ‘enough is enough’.

An invasive or lengthy intervention with limited results will not generally be regarded as a ‘reasonable alternative’. Generally, ‘a reasonable alternative’ intervention or treatment can end or substantially alleviate the patient’s suffering over a longer period. A patient who is decisionally competent may of course refuse such treatment, although as a consequence it may not be possible to grant the patient’s request for euthanasia at that moment.

Palliative care (which includes both pain relief and palliative sedation) plays an important role towards the end of life. In cases where the patient’s suffering is largely due to pain, pain relief may be an alternative to euthanasia. However, a patient may have good reason to refuse palliative care, for example because he does not wish to become drowsy (due to higher doses of morphine) or lose consciousness (through palliative sedation). It is important that the physician fully inform the patient about the benefits and disadvantages of palliative care, as the decision whether or not to use this option ultimately lies with the patient.

In summary, there is a reasonable alternative if:

- a. the proposed treatment/intervention significantly alleviates the patient’s unbearable suffering
- b. the proposed treatment/intervention has positive effects within a reasonable period of time
- c. any drawbacks are outweighed by the benefits (effect versus burden).

The patient has a large say in determining whether an alternative is ‘reasonable’.

In his report to the committee, the physician must indicate whether alternatives were available, how he discussed them with the patient and why the patient did not consider them reasonable.

KEY ELEMENTS OF 'NO REASONABLE ALTERNATIVE'

- Conclusion arrived at by physician and patient together
- Reasonable alternative has significant positive impact on suffering, takes effect fairly quickly, is long-lasting, has more benefits than disadvantages
- Burden on patient should be assessed in light of his specific circumstances
- Patient may always refuse treatment, including palliative treatment. If such treatment would end the patient's suffering, such a refusal may preclude granting a request for euthanasia
- Refusing palliative sedation will generally not preclude granting a request for euthanasia

3.6. INDEPENDENT PHYSICIAN

Before performing euthanasia, the physician must consult at least one other, independent physician who must see the patient and assess whether statutory due care criteria (a) to (d), discussed in sections 3.2 to 3.5, have been complied with. The Act does not require the independent physician to give his opinion on the exercise of due medical care in performing euthanasia, in relation to due care criterion (f) (see section 3.7 below). However, there is no reason why the independent physician should not advise the physician about this matter.

The independent physician forms an independent opinion on whether the first four due care criteria – (a) to (d) – have been complied with, and informs the physician in a written report. The purpose of this consultation is to ensure that the physician's decision is reached as carefully as possible. The independent physician's assessment helps the physician ascertain whether all the due care criteria have been met and reflect on matters before deciding to grant the request and perform euthanasia. The independent physician's report is also essential for the committee in reaching its decision on whether all due care criteria have been complied with. The committees believe it is important for the physician performing euthanasia to request a consultation. If this is not the case, the committee will expect the physician to explain the reasons for this in his report.

For instance, the patient may be being treated by several physicians working together and it may be the case that one physician requests the consultation and another actually performs euthanasia. In such cases, too, the independent physician will have to affirm his independence in relation to the physician performing euthanasia.

The independent physician should not assess the physician, nor is it his task to give the physician ‘permission’. The independent physician must make his own assessment of whether the due care criteria have been met and inform the physician accordingly, stating reasons. If the physician acts contrary to the independent physician’s assessment, he must clearly substantiate this in his report.

In the vast majority of cases the independent physician consulted is a SCEN physician.²⁷ SCEN physicians are trained by the KNMG and are available to make an independent, expert assessment in the context of a request for euthanasia. SCEN physicians also offer support and provide information. Only physicians may consult a SCEN physician.

Information needs of the physician in the early stages

The independent physician as referred to in the Act is the person to whom the physician turns for a ‘broad’ assessment of the case: have the due care criteria referred to in section 2 (1) (a) to (d) of the Act been met (request, suffering, information, alternatives)? The physician will not generally consult an independent physician until he is seriously considering granting the patient’s request for euthanasia.

The physician may also ask a SCEN physician or other physician for advice if he has questions before the euthanasia process actually commences. These questions may concern the process (‘what steps do I need to take?’), for instance if the physician has little or no experience of euthanasia, or the patient (‘is there reason to have the patient’s decisional competence assessed?’, ‘are there any treatment alternatives?’). Asking support from a SCEN physician or other physician on such matters is not a consultation within the meaning of the Act. It is merely a request for advice prior to the ‘statutory consultation’.

²⁷ SCEN refers to the Euthanasia in the Netherlands Support and Assessment Programme, which falls under the KNMG. The KNMG drew up a guideline for SCEN physicians in 2011, entitled *Goede steun en consultatie bij euthanasie* [‘Good euthanasia support and independent assessment’], which can be found on www.scen.nl. SCEN physicians are organised into regional divisions. One of the aims of the SCEN organisation is to guarantee quality through peer supervision.

The physician's responsibility in relation to the independent physician

The physician is expected to take note of the independent physician's findings before making a final decision on the request for euthanasia. The physician must take the independent physician's opinion very seriously. If there is a difference of opinion between the two, the physician may nevertheless decide to grant the patient's request, but he will have to be able to provide adequate grounds for his decision. Alternatively, he may consult another independent physician, though the idea is not that he should continue searching until he finds an independent physician who agrees with him.²⁸ A physician who has consulted multiple independent physicians must submit all the independent physicians' written reports to the committee, via the pathologist.

It is in the interests of the physician performing euthanasia that the independent physician write a comprehensive report.²⁹ Sometimes the quality of the report is questionable because, for instance, the independent physician has not assessed compliance with all the due care criteria or has not presented enough arguments in support of his conclusion, or the report may contain internal inconsistencies. One example of internal inconsistency, for instance, is if the independent physician states in his report that the patient's suffering is not yet unbearable, or that he has not yet made a specific request, but still concludes that all the due care criteria have been met. The physician must ensure that the independent physician's report is of the necessary standard. It is he, after all, who is obliged to demonstrate convincingly that all the due care criteria have been met. If the independent physician's report is substandard, the physician may have to ask the independent physician for more information. If necessary, the physician can refer to the guidelines drawn up by the KNMG/SCEN on the independent physician's responsibilities and the reporting checklist.³⁰

The independent physician's independence

The Act requires consultation with at least one other, independent physician. The independent physician must be in a position to form his own opinion. The concept of independence refers to his relationship with both the physician and the patient.³¹ Any suggestion

28 See section 23 of the KNMG guideline *Goede steun en consultatie bij euthanasie* (2011).

29 The SCEN has drawn up a checklist for the independent physician's report.

30 The KNMG guideline *Goede steun en consultatie bij euthanasie* (2011) and the checklist for the independent physician's report drawn up by the SCEN (2015).

31 See also *Standpunt inzake euthanasie* ['Position paper on euthanasia']. KNMG, Utrecht, 2003, pp. 14-16.

that he is not independent must be avoided. It is therefore important that the independent physician explain his relationship to the physician and the patient in his report.

The requirement of independence on the part of the independent physician *in relation to the physician* means that there must be no personal, organisational, hierarchical or financial relationship between the two. For instance, if the independent physician is from the same medical practice or partnership, if there is a financial or other relationship of dependence with the physician (for instance, if the independent physician is a registrar), or if there is a family relationship between them, he cannot act as the independent physician. Nor can the independent physician be the physician's patient or physician.

In addition, if both physicians regularly act as independent physicians for each other, or if they know each other socially, the physician brought in for consultation may not in fact be independent, or appear not to be independent. This also applies to a SCEN physician who has provided support that goes beyond mere advice or information in the period before euthanasia is performed. It is possible that the physician and the independent physician know each other, perhaps as members of a peer supervision group. This need not present a problem as such. Whether or not independent assessment is possible where both physicians are members of the same locum group depends on the circumstances. What matters is that the physician and the independent physician should be aware of this and clearly explain and substantiate their opinion on the matter in their reports to the committee.

The independence of the independent physician *in relation to the patient* implies among other things that there is no family relationship or friendship between the independent physician and the patient, and that the independent physician is not currently treating the patient, and has not done so in the recent past. Contact on a single occasion in the capacity of locum need not present any problem, although this will depend on the nature of the contact and when it occurred.

Sometimes, both members of a couple may make simultaneous requests for euthanasia. If both requests are granted, this is sometimes referred to as 'double euthanasia'. In such cases, the committees expect the physician or physicians to consult a different independent physician for each of the partners. This is necessary to ensure that the two cases are assessed separately. Both independent physicians must be satisfied that neither of the partners is exerting undue pressure on the other (in relation to their request for euthanasia).

The independent physician's expertise

The committees prefer an independent physician to be assigned 'at random', on the basis of the SCEN physicians' duty roster. Generally speaking the independent physician will have sufficient expertise to properly assess the case in question. If the independent physician has doubts about this, it is important that he discuss them with the physician.

In some cases, it may be necessary for the physician performing euthanasia to seek the advice of a physician with specific expertise (psychiatrist, geriatrician etc.) in addition to the normal SCEN physician in order to make a good assessment of compliance with the due care criteria, particularly with regard to decisional competence, the lack of prospect of improvement and/or a reasonable alternative. This will mainly be the case if the patient has a psychiatric disorder, dementia or an intellectual disability, but there may also be other reasons (for instance, if the physician has reasonable doubts about the patient's decisional competence).

> For more on consulting an expert with regard to patients with a psychiatric disorder, dementia or an intellectual disability, see sections 4.3 to 4.5

In principle, the independent physician must see and speak with the patient

According to the Act, the independent physician must see the patient.³² In the vast majority of cases, this will involve both seeing and speaking with the patient. In principle, the independent physician should also see the patient alone. It is possible that the patient is no longer capable of conversation by the time he is visited by the independent physician. If the physician sees such a situation developing, he would do well to ask the independent physician to come sooner. If necessary, the physician and independent physician can contact each other by telephone afterwards. If the independent physician is no longer able to communicate with the patient during his visit, he must provide an assessment based on all other available and relevant facts and circumstances. It can be useful to obtain further information from the physician and any family members of the patient. The Act therefore does not require that the independent physician is always able to communicate with the patient (either verbally or non-verbally). This also follows from the scope provided

32 'Seeing' the patient will normally mean 'visiting' the patient. This can lead to practical problems on Bonaire, St Eustatius and Saba, so the independent physician and patient may speak to each other via an online video link.

by the Act for performing euthanasia on the basis of the patient's advance directive when a patient is no longer able to communicate.

> For more on advance directives, see section 4.1

> For more on coma and reduced consciousness, see section 4.7

In some cases the independent physician visits the patient very shortly before euthanasia is to be performed, sometimes even on the day of the patient's death. The circumstances of the case, and particularly any unexpected and severe deterioration in the patient's situation, may make this unavoidable. The physician's report must then make it clear that he was aware of the independent physician's findings before performing euthanasia.

Consulting the independent physician for a second time

It is not unusual for some time to pass between the independent physician's visit to the patient and the performance of euthanasia. This is not usually a problem. The Act says nothing about the 'shelf life' of the independent physician's report. Generally speaking, the report will remain valid as long as there is no fundamental change in the patient's circumstances and in the course of the disease. The time between the independent physician's visit and the performance of euthanasia is more likely to be a matter of days and weeks than of months. The more time elapses, the more logical it becomes for the physician to contact the independent physician again, and failure to do so will raise questions with the committee. In some cases, the independent physician will have to see the patient a second time. Sometimes a telephone call between the physician and the independent physician, or between the independent physician and the patient, will suffice. It is not possible to give a specific rule for such cases. It is up to the physician to decide, based on the independent physician's earlier findings and developments in the patient's circumstances. The physician will have to be able to explain his decision to the committee if necessary.

Quite often the independent physician will visit the patient at a time when the patient's request is not immediately relevant and his suffering is not yet unbearable. In such cases the independent physician must conclude that not all the due care criteria have yet been met. In certain cases the independent physician will be able to say with a high degree of certainty how the situation will progress and when all the due care criteria will have been met. It is then generally sufficient for the physician and the independent physician to speak on the phone when the request has become immediately relevant and the patient's suffering unbearable. If the situation is less clear-cut, it makes sense for the independent physician to visit the patient again.

In some cases, contact by phone between the independent physician and the patient may suffice.

The independent physician will generally need to visit the patient a second time if he:

- visited the patient at an early stage and found that the patient was not yet suffering unbearably;
- determined that all the criteria had been met, but a lot of time has elapsed since, or the patient's condition has changed in a way that was not foreseen when he drafted his report.

If the physician is unable to contact the original independent physician, another independent physician may be consulted. In principle, the latter will need to see the patient himself and if possible speak with the patient. A report must also be drawn up of this second contact, possibly as an addendum to the first report.

The committees and the independent physician

The committees review the actions of the notifying physician, not those of the independent physician.³³ The independent physician may however be asked to answer questions from the committee, either in writing or in person. This does occasionally occur.

Once a year the committees and the KNMG/SCEN discuss the quality of the consultations and the independent physicians' reports in general.

If a committee is severely critical of the quality of an independent physician's report, it can provide the independent physician in question with feedback directly by phone or in writing. This will usually only be necessary if an independent physician repeatedly produces reports that raise (similar) questions. As it is the notifying physician who is ultimately responsible for the quality of the consultation and the independent physician's report, he receives a copy of any such feedback. If the quality of the independent physician's reports continues to be insufficient, even after feedback, the committee can raise the issue with the KNMG/SCEN, giving the independent physician's name.

³³ The KNMG has set up a complaints committee on SCEN physicians, to which any of the parties involved in a euthanasia case may submit a complaint about the actions of a SCEN physician.

KEY ELEMENTS OF 'INDEPENDENT PHYSICIAN'

- Consulting another physician for advice on a specific matter relating to the criteria is not formal consultation within the meaning of the Act
- Formal consultation: physician consulted must be independent, and any suggestion that he is not independent must be avoided
- In principle, independent physician must see and speak with patient; if communication is not possible, simply 'seeing' may suffice
- In certain circumstances, particularly if a long time has elapsed, independent physician may need to be consulted a second time (or, if he is unavailable, another independent physician)
- The physician performing euthanasia must read independent physician's report and consider it carefully

3.7. DUE MEDICAL CARE

The physician must exercise due medical care in performing euthanasia. Two aspects of this are the substances and doses administered, and appropriate checks to determine the depth of the induced coma. In assessing compliance with this due care criterion, the committees refer to the KNMG/KNMP 'Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide' of 2012 (referred to below as the Guidelines). These Guidelines advise physicians and pharmacists on practical and effective methods of performing euthanasia and assisting suicide. They list preferred substances, and also explicitly advise against using certain other substances.

General

Below, a distinction is drawn between termination of life on request (when the physician administers the substances) and assisted suicide (when the patient himself takes the substances given to him by the physician). Certain standards must be observed in both cases. It is, for example, important that the physician's report describe the substances administered, the doses and method of administration, and how long the procedure took. According to the Guidelines, the physician must have an emergency set of substances available in case something goes wrong with the first set. The physician may not leave the euthanatic with the patient prior to termination of life on request or assisted suicide, giving the patient or a third person the opportunity to take or administer the substance in the physician's absence.

Termination of life on request: order in which substances must be administered, and dose

In cases of termination of life on request, the Guidelines advise intravenous administration of a coma-inducing substance, followed by intravenous administration of a muscle relaxant. The Guideline lists substances that may be used and their recommended doses. If the physician deviates from the Guidelines, he will have to present convincing arguments in support of his actions. It is advisable for the physician to inform the patient and his family beforehand what effects the substances will have. He should also comply with the patient's individual wishes as far as possible, provided they fall within the scope provided by the Guidelines.

Termination of life on request: checking the depth of coma

The muscle relaxant must not be administered until the patient is in a deep coma, as he might otherwise perceive the effects of the muscle relaxant. To this end, it is vital that the physician establish that the coma is sufficiently deep before administering the muscle relaxant. When it comes to filling in the model reporting form, the physician will have to explain specifically how he checked the depth of the coma, i.e. by applying a pain stimulus and/or checking for the presence of protective reflexes (eyelash reflex, corneal reflex). If the committee has any doubts about this, it will ask the physician about the depth of the coma and how he established this.

Termination of life on request must be performed by physician

The physician may not allow a relative or other person to administer the euthanatics in his presence, not even using a PEG tube. The physician must perform every step of the procedure himself. This also means that the physician must remain present until death occurs and the consultation with the pathologist has ended.

Assisted suicide: substance and dose

In the case of assisted suicide, the physician dissolves the substance (a barbiturate) in a potion and hands this to the patient, who ingests it himself. The two steps described above (first inducing coma, then administering a muscle relaxant) are not applicable in assisted suicide. However, the physician must administer premedication to prevent vomiting and accelerate the passage of the substance through the stomach. The Guidelines list the type of substances, and their doses, to be used in assisted suicide.

Assisted suicide: physician must remain in immediate vicinity

If the patient wishes, the physician may leave the room after the patient has taken the euthanatic. He must however remain in the patient's immediate vicinity in order to intervene quickly if complications arise (e.g. if the patient vomits the potion back up). In that case the physician may have to terminate the patient's life after all. Sometimes, the patient does not die after drinking the barbiturate potion. The physician will then have to terminate the patient's life after a certain length of time. He must discuss this possibility beforehand with the patient and his family, and agree with the patient how long he will wait before terminating his life. The physician must prepare for this eventuality, and insert an IV cannula prior to assisting with suicide and bring along the substances needed to terminate the patient's life. Again, the physician must remain present until death occurs and the consultation with the pathologist has ended.

Relationship between physician and pharmacist

The physician bears final responsibility for exercising due medical care. His actions are assessed by the committees. If the pharmacist prepares the syringe or potion beforehand, he has an individual responsibility for its preparation and labelling. The physician must check whether he has received the correct substances in the correct doses.

It is important that the pharmacist have sufficient time to carefully consider the pharmaceutical aspects of the case, such as the most appropriate substances and method to be used. It is therefore important that the physician contact the pharmacist in good time.

It is not the pharmacist's task to assess whether all the statutory due care criteria for euthanasia have been met. This is the responsibility of the physician. However, like physicians, pharmacists are not obliged to assist with euthanasia. This is another reason why timely contact between the physician and the pharmacist is advisable, in order to prevent problems in the final stages.

KEY ELEMENTS OF 'DUE MEDICAL CARE IN TERMINATION OF LIFE ON REQUEST'

- Sequence of events:
 - physician administers coma-inducing substance
 - checks depth of coma
 - physician administers muscle relaxant
 - physician remains present until he has confirmed the patient's death, the pathologist has attended, and the consultation with the latter has ended
- Recommended substances, doses, methods of administration and coma check method: KNMG/KNMP Guidelines 2012
- Physician must have emergency set of intravenous substances to hand

KEY ELEMENTS OF 'DUE MEDICAL CARE IN ASSISTED SUICIDE'

- Sequence of events:
 - insert IV cannula and administer anti-nausea premedication
 - discuss with patient and family length of time to wait before terminating life, if necessary
 - physician hands barbiturate potion to patient
 - physician remains present or in immediate vicinity until he has confirmed the patient's death, the pathologist has attended, and the consultation with the latter has ended
- Recommended substances, doses, methods of administration: KNMG/KNMP Guidelines 2012
- Physician must have emergency set of intravenous substances to hand

4 SPECIFIC ISSUES

4.1. ADVANCE DIRECTIVE

Section 2 (2) of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act stipulates that a patient aged 16 or over who is decisionally competent in the matter may draw up an advance directive setting out a request for euthanasia. If at some point the patient is no longer capable of expressing his will, the physician may accept the advance directive as a request pursuant to section 2 (1) (a) of the Act. The advance directive thus has the same status as an oral request for euthanasia.³⁴

Content of the advance directive

The advance directive can replace an oral request, but it can also help the physician determine when to carry out the patient's request. This depends on what the patient has specified in his advance directive. It is important that the patient indicate as clearly as possible the specific circumstances in which his request should be acted upon. These must be circumstances in which the patient can be said to be suffering unbearably.³⁵ The content of the advance directive plays an important role in assessing whether the suffering is unbearable for the patient in question, in addition to the patient's behaviour and prevailing medical opinion on the impact of a particular disease process on the patient.

The Act does not limit the validity of an advance directive, nor does it require the directive to be regularly updated. However, the older the directive, the more doubt there may be as to whether it still reflects the patient's actual wishes. The directive will carry more weight if the patient has updated his advance directive, or orally reaffirmed its content. It is important that the patient draw up any advance directive in good time and update it regularly, describing as specifically as possible the circumstances in which he would wish his life to be terminated. It is the responsibility of the patient to discuss his advance directive with his physician when he drafts or updates it. The physician should include this information in his medical records. A personal directive drawn up by the patient in which he gives a description in his own words will generally be regarded as more significant than a pre-printed, standard form.

34 See the letter from the Minister of Health, Welfare and Sport of 4 July 2014 on the advance directive with regard to euthanasia.

35 An exception to the criterion requiring physicians to establish that the patient is suffering unbearably is described in section 4.7.

The following aspects are therefore important.

- a. To what degree or in what way did the patient reaffirm his written directive (either orally or otherwise) when he was still decisionally competent?
- b. If the patient is no longer capable of (effective) communication, has there been anything in his behaviour or utterances that contradicts his wishes as set out in the advance directive?
- c. Immediately prior to termination of life, is the patient's state one that he described in his advance directive as being a situation in which he would wish for his life to be terminated?

All things considered, the patient's request for euthanasia must have been made so consistently over time that the advance directive can reasonably be regarded as expressing the will of the patient at the time of termination of life.

Other due care criteria apply *mutatis mutandis*

Section 2 (2) of the Act states that, in the event of an advance directive, the due care criteria mentioned in the Act apply *mutatis mutandis*. This means, in accordance with the legislative history, that the due care criteria apply to the greatest extent possible in the given situation.³⁶ In other words, in assessing the due care criteria the physician must take account of the specific circumstances of the case; for instance, the patient may no longer be capable of communicating or responding to questions. The physician will generally have spoken with the patient when he was still capable of expressing his will. If a situation subsequently arises in which the patient's advance directive comes into play, information obtained in previous conversations with the patient will be particularly useful to the physician.

When the advance directive replaces an oral request, the other due care criteria apply *mutatis mutandis*. The following general points should be noted.

- a. The patient's request must be voluntary and well considered: the physician will be able to assess on the basis of his previous communication with the patient whether the request made in the advance directive is 'voluntary and well considered'. The fact that the patient drew up an advance directive (and probably repeated and confirmed the wishes set out in it as long as he was able) can be considered a clear indication that the request is voluntary and well considered. The physician can also base his conclusion on conversations with the patient's family or representatives.

³⁶ This is set out in the explanatory memorandum to the amendment of the Act, concerning the addition of the second sentence to section 2 (2) (Parliamentary Papers, House of Representatives, 26 691, no. 35).

- b. The patient must be suffering unbearably, with no prospect of improvement: though the advance directive replaces an oral request, the physician must still be satisfied that the patient is experiencing unbearable suffering immediately prior to the termination of life on request.
- c. The patient must be informed of his situation and prospects: the physician must know that the patient was informed of his situation and prospects when oral communication with the latter was still possible.
- d. There must be no reasonable alternative: as stated above (section 3.5) this is a conclusion that the physician and patient must arrive at together. It is therefore important that the physician carefully consider what the patient has written about this matter in his advance directive and what he said when he was still able to communicate.
- e. The independent physician: the Act stipulates that the independent physician must see the patient. This is also possible in this situation, even though there will be little or no possibility of communication between the independent physician and the patient. That means that, in addition to his own observations, the independent physician will have to base his decision and his opinion on information from the physician and other sources. This may include the patient's medical records, oral information from the physician, letters from specialists, the content of the advance directive, and conversations with family members and/or carers.
> See also sections 3.6 and 4.7
- f. Due medical care: there are no specific issues with regard to this due care criterion in situations where termination of life is performed on the basis of an advance directive. However, in a situation where the patient is no longer aware of the fact that euthanasia is being performed (for instance patients in a very advanced stage of dementia), the patient may give a pain or startle response, thus giving the appearance of resistance. As neither the Act nor the legislative history provides guidance on how to proceed in such cases, no general rules can be given. If a physician expects that the patient might exhibit a pain or startle response during the performance of euthanasia, it is not uncommon to administer premedication (for instance midazolam). This may be part of exercising due medical care. Nevertheless, this must be assessed in each specific case, taking into account the particular circumstances of that case, and one of the questions to be asked is with what purpose the premedication was administered. It is important that the physician keep meticulous records so that these points can be properly assessed.

The advance directive as provided for under section 2 (2) of the Act is deemed to reflect the will of the patient. In cases where the advance directive is consistent with statements made orally by the patient when he was still decisionally competent, no questions will generally arise. Even if the patient is no longer able to communicate normally, it may be possible to establish from his behaviour and utterances that his current wishes are consistent with wishes previously expressed, confirming the advance directive. A patient who is decisionally incompetent and who drew up an advance directive when he was still decisionally competent, and who is in a situation which he described in his advance directive and in which all due care criteria have been met, may be unaware of the performance of termination of life. The physician must then be alert to any behaviour and utterances that indicate objection to termination of life. If this is the case, euthanasia cannot be performed.

> See also section 4.4 Patients with dementia

> See also section 4.6 Patients with aphasia

> See also section 4.7 Coma/reduced consciousness

> See also section 4.8 Euthanasia and palliative sedation

ADVANCE DIRECTIVE: POINTS TO CONSIDER

- How clear is the advance directive?
- Did the patient reaffirm the advance directive when he was still decisionally competent?
- All things considered, can the advance directive be said to express the patient's will?
- Do the patient's behaviour and utterances in any way contradict the content of the advance directive?
- Have the other due care criteria been met to the greatest extent possible in the given situation?

4.2. MINORS

The Act applies to euthanasia for individuals aged 12 and over, but it does impose a number of additional requirements with regard to requests from minors:

- if the patient is a minor between the ages of 12 and 16, termination of life at the patient's request may only be carried out with the consent of the parent(s) or guardian (section 2 (4) of the Act);
- if the patient is a minor aged 16 or 17, the parent(s) or guardian must be consulted in the decision-making process, but their consent is not required (section 2 (3) of the Act).

The due care criteria described in section 3 of this Code are of course applicable in both cases. The statutory requirements concerning the involvement of the parent(s) or guardian in the decision-making process also apply if the minor's request is made in the form of an advance directive.³⁷

Notifications of euthanasia involving minors aged between 12 and 18 are rare. Between 2002 and 2017 the RTEs received only eight such notifications.

4.3. PATIENTS WITH A PSYCHIATRIC DISORDER

In line with the Supreme Court judgment in the 1994 Chabot case, physicians must exercise particular caution when a euthanasia request results (largely) from suffering arising from a psychiatric disorder.³⁸ Such cases often involve complex psychiatric problems, and require specific expertise.³⁹ Particular caution must be exercised when assessing the voluntary and well-considered nature of the request, the absence of any prospect of improvement, and the lack of a reasonable alternative.

It must be ruled out that the patient's psychiatric disorder has impaired his powers of judgment. If the patient is not decisionally competent with regard to euthanasia, his request cannot be regarded as voluntary and well considered. The physician must take particular note of whether the patient shows he is able to grasp relevant information, understands his disease and is consistent in his deliberations.

> See also section 3.2

As regards suffering with no prospect of improvement and the absence of a reasonable alternative, the possibility of other treatment options for the patient must be carefully explored. This is particularly so in cases where the patient is relatively young and might still have

- 37 The minimum age stated in section 2 (2) of the Act is 16. On the basis of the last sentence of section 2 (4), patients between the ages of 12 and 16 may also draw up a legally valid advance directive.
- 38 Specifically, the Supreme Court ordered physicians to exercise particular caution in all cases where patients' suffering is not demonstrably the result of a somatic disease or disorder and does not consist solely of the perception of pain and loss of physical function (Supreme Court 21 June 1994, NJ 1994/656).
- 39 See also the guidelines of the Dutch psychiatry association (Nederlandse Vereniging voor Psychiatrie) *Omgaan met het verzoek om hulp bij zelfdoding door patiënten met een psychiatrische stoornis* ['Dealing with requests for assisted suicide from patients with a psychiatric disorder'], Utrecht, 2009. At the time of writing, a review of these guidelines was under preparation.

many years to live.⁴⁰ If the physician does not have the expertise to assess whether alternatives are available, he will have to consult physicians who do have this specific expertise. If the patient refuses a reasonable alternative, he cannot be said to be suffering with no prospect of improvement. At the same time, patients are not obliged to undergo every conceivable form of treatment.

> See section 3.5

Consulting an independent physician and a physician with the required expertise

In regard to requests from patients with a psychiatric disorder the physician must always consult not only an independent physician who must give his opinion on compliance with all the due care criteria mentioned in sections 3.2 to 3.5, but also an independent psychiatrist. The latter should assess in particular whether the patient is decisionally competent regarding his request, whether the patient's suffering is without prospect of improvement and whether there are no reasonable alternatives. Unlike the independent physician, he may recommend treatment where appropriate. If contact with both an independent physician and a psychiatrist poses an unacceptable burden to the patient, it may be sufficient to consult an independent (SCEN) physician who is also a psychiatrist. In that case the physician must realise, however, that the independent physician must not only give his opinion on due care criteria (a) to (d), but also serve as an expert. As such he must give an opinion, based if necessary on his own examination of the patient, on specific aspects such as the patient's decisional competence regarding his request, whether he is suffering with no prospect of improvement, and possible reasonable alternatives.

> See also section 4.4

Combination of somatic and psychiatric disorders

The above refers to patients who request euthanasia because of suffering associated with a psychiatric disorder. Patients whose suffering is caused largely by a somatic disorder may also have mental problems which can aggravate their suffering. In these cases, too, the physician and the independent physician must explicitly consider whether the patient's mental problems preclude a voluntary and well-considered request. If the independent physician is not a psychiatrist, it may also be necessary to seek the advice of a psychiatrist. It should

40 See cases 2016-41 and 2016-78 in the 2016 annual report of the RTEs. Both cases have been published on the website of the RTEs: www.euthanasiecommissie.nl. They involved a woman in her forties and a man in his thirties. In both cases, the committee found that all the due care criteria had been complied with.

be said, however, that it is not uncommon for patients to be in low spirits in the circumstances in which they make a request for euthanasia, so that this in itself is not necessarily a sign of depression.

PATIENTS WITH A PSYCHIATRIC DISORDER: POINTS TO CONSIDER

- Can the patient's wish to die be considered a voluntary and well-considered request, or is it a symptom of his illness?
- Has it been established that the patient is suffering with no prospect of improvement and that there is no reasonable alternative?
- Has an independent psychiatrist been consulted in addition to the independent physician, or is the independent physician himself a psychiatrist?

4.4. PATIENTS WITH DEMENTIA

In cases involving patients with dementia, there is also reason to exercise particular caution when considering whether the statutory due care criteria have been met. This is especially true of the criteria relating to decisional competence and unbearable suffering. As a patient's dementia progresses, his decisional competence will decline. After a time, the patient may become completely decisionally incompetent.

Early-stage dementia

In nearly all the cases so far notified to the committees, the patient was in the early stages of dementia. At this stage the patient generally has sufficient understanding of his disease and is decisionally competent in relation to his request for euthanasia. Besides the actual decline in cognitive ability and functioning, the patient's suffering is often partly determined by their fear of further decline and the negative impact on their autonomy and dignity in particular (see also section 3.3). The key factor is the patient's perception of the progressive loss of personality, functions and skills, and the realisation that this process is unstoppable. This prospect can cause profound suffering in the present moment.

Late-stage dementia

It is still possible to grant a request for euthanasia at the stage where dementia has progressed to such an extent that the patient is no longer decisionally competent and is no longer able to communicate

(or is able to communicate only by simple utterances or gestures),⁴¹ provided the patient drew up an advance directive when he was still decisionally competent.⁴² The directive must be clear, and evidently applicable to the current situation.

> For more on advance directives, see section 4.1

The physician must take the entire course of the disease and all other specific circumstances of the case into account when reaching a decision. He must interpret the patient's behaviour and utterances, both during the disease process and shortly before euthanasia is performed. At that moment the physician must be satisfied that carrying out euthanasia is in line with the patient's advance directive, and that there are no contraindications (such as clear signs that the patient no longer wishes his life to be terminated). The physician must also be satisfied that the patient is suffering unbearably at that point. As noted above, the assessment of the content of the advance directive will have a bearing on this matter. The other due care criteria must be met to the greatest extent possible in the given situation.

Consulting an independent physician and a physician with the required expertise

The regular procedure of consulting an independent physician will generally suffice if a patient in the early stages of dementia requests euthanasia. The patient does not have to have been diagnosed with dementia according to prevailing medical practice. If there are any doubts as to the patient's decisional competence, it is wise for the physician to seek the advice of another physician with relevant expertise.

When euthanasia is to be performed in the late stages of dementia, the physician must consult both a regular independent physician (SCEN physician), to assess the due care criteria described in sections 3.2 to 3.5, and a physician specialised in dementia (such as a geriatrician, an elderly-care specialist or an internist specialising in geriatrics). The latter must assess whether the patient is still decisionally competent regarding his request. If he concludes that the patient is not decisionally competent in this respect, an advance directive is required. He must also assess whether the patient is suffering unbearably with no prospect of improvement, and whether there are indeed no reasonable alternatives. Again, if contact with both an independent physician and an expert poses an unacceptable burden to the patient, it may be sufficient to consult an independent (SCEN)

41 In such cases the review committees always invite the physician to give an oral explanation.

42 The RTEs have very limited experience of such cases: three cases in 2016 and three in 2017. Opinions are still being formed on these matters.

physician who is also an expert. Then too, the physician must realise that the independent physician must not only give his opinion on due care criteria (a) to (d), but also serve as an expert. As such he must give an opinion, based if necessary on his own examination of the patient, on specific aspects such as the patient's decisional competence regarding his request, whether he is suffering unbearably with no prospect of improvement, and possible reasonable alternatives.

In the late stages of dementia the independent physician will not always be able to speak with the patient. The independent physician must then base his assessment on all other facts and circumstances. The advance directive drawn up by the patient – which is required in such cases – and further information from the physician or the family can support this process.

> See also section 4.3

PATIENTS WITH DEMENTIA: POINTS TO CONSIDER

- Is the patient still capable of determining and expressing his will?
- If not, is there an advance directive?
- Is the patient still able to communicate at the point when euthanasia is to be performed?
If not:
 - is the situation obviously one referred to in the advance directive?
 - is the patient experiencing unbearable suffering?
 - are there clear signs that the patient does not wish his life to be terminated?
- In addition to the independent physician, has a physician been consulted who is an expert in the field, or is the independent physician himself an expert in the field?

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4.5. PATIENTS WITH AN INTELLECTUAL DISABILITY

Notifications of cases of euthanasia involving patients with an intellectual disability are rare.⁴³ There are cases where patients with a mild intellectual disability are capable of making a voluntary and well-considered request for euthanasia, and where all the other due care criteria have been met.⁴⁴ In these cases, particular attention must be paid to the patient's decisional competence with regard to a request for euthanasia.

⁴³ See case 2016-03 on www.euthanasiecommissie.nl.

⁴⁴ See also *Medische beslissingen rond het levenseinde bij mensen met een verstandelijke beperking* ['Medical decisions at end-of-life in people with intellectual disabilities'], by the Dutch association of physicians for people with intellectual disabilities (NVAVG), 2007.

Consulting an independent physician and a physician with the required expertise

In addition to the regular independent physician, who assesses the due care criteria described in sections 3.2 to 3.5, the physician will also, in principle, have to consult a physician with the expertise required to assess the patient's decisional competence (such as a physician specialising in the care of people with intellectual disabilities). Again, if contact with both an independent physician and an expert poses an unacceptable burden to the patient, it may be sufficient to consult an independent (SCEN) physician who is also an expert. In this situation too, the physician must realise that the independent physician must not only give his opinion on due care criteria (a) to (d), but also serve as an expert. As such he must give an opinion, based if necessary on his own examination of the patient, on specific aspects, particularly the patient's decisional competence regarding his request.

4.6. PATIENTS WITH APHASIA

Aphasia is a language disorder. Patients with aphasia have trouble using and/or understanding language. A patient with aphasia may be able to make a voluntary and well-considered request, but he will generally have difficulty expressing his views and wishes orally. A patient with aphasia will often be able to express his will or answer questions in another way, for example by squeezing someone's hand or through facial expressions or gestures. Another option would be to ask only questions requiring a yes or no answer, which the patient could also answer using gestures or signs. In this way, despite the patient's language disorder, it is possible to form a good impression of his request for euthanasia and the decisional competence required. If the other due care criteria are satisfied, the request for euthanasia may be carried out.

An advance directive drawn up by the patient can be used in support of and in addition to the patient's limited oral utterances.

4.7. COMA/REDUCED CONSCIOUSNESS

The suffering experienced by the patient is of particular importance when considering whether euthanasia is permissible for a patient in a coma or state of reduced consciousness not resulting from palliative sedation.

> See also section 4.8 on euthanasia and palliative sedation

Coma:

Suffering assumes a conscious state. If a patient is in a coma, i.e. a state of complete unconsciousness, he is unable to experience suffering.

Reduced consciousness:

If a patient is in a state of reduced consciousness, the possibility that he is suffering (perhaps unbearably) cannot be ruled out.⁴⁵

When coma/reduced consciousness sets in before euthanasia is to be performed

It is possible for a patient to fall into a coma or a state of reduced consciousness before the intended time that euthanasia is to be performed. This is a difficult situation, as it raises the question of whether euthanasia can still be performed.

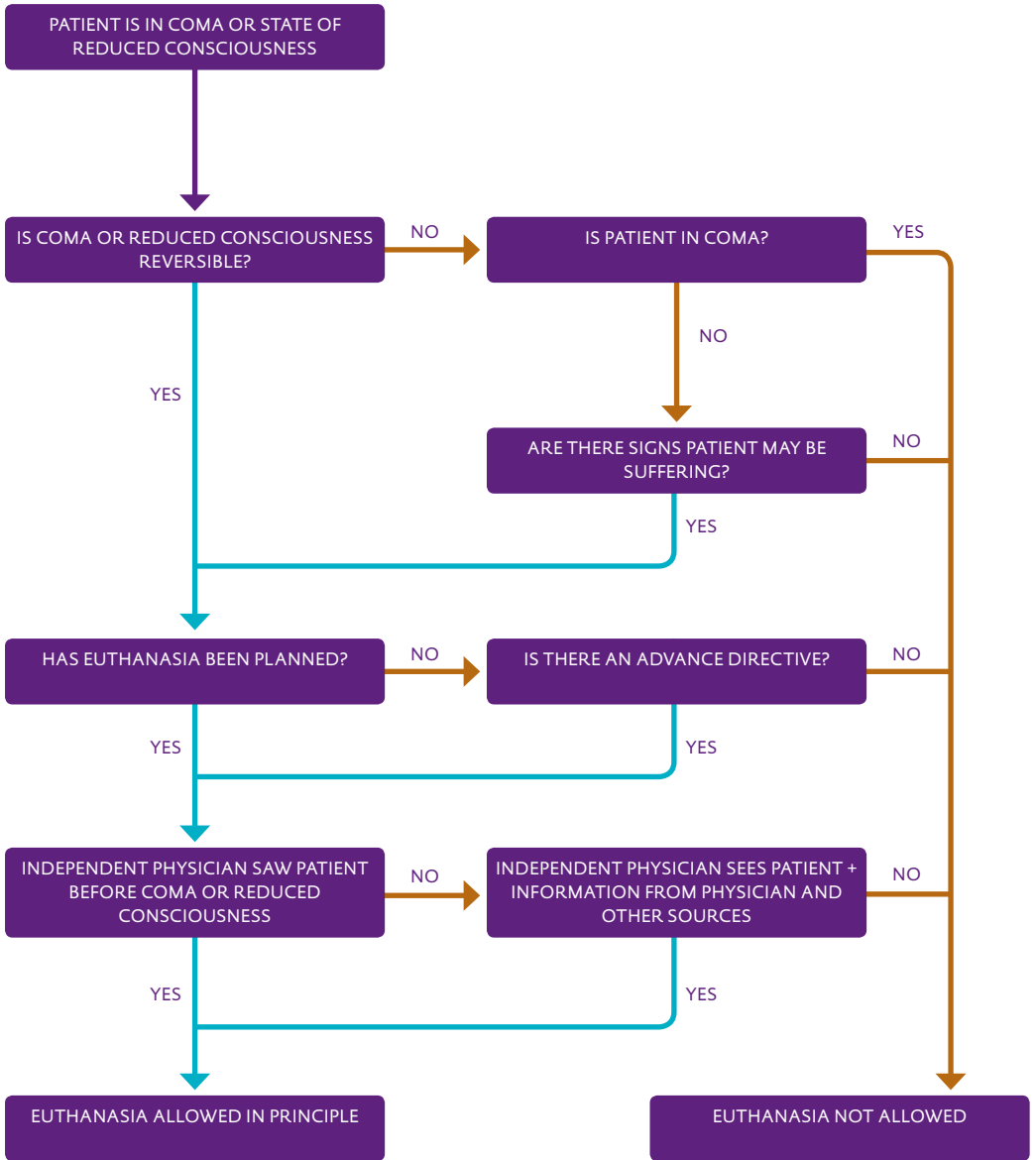
In answering this question, it is necessary to distinguish between a number of different situations.

Coma/reduced consciousness irreversible or reversible

- coma is irreversible (caused by disease, patient cannot be aroused)
The patient may spontaneously fall into a coma in the final stages of his disease. Since the patient can no longer experience suffering in this state, the physician may not proceed with euthanasia, even if he had already agreed to perform it.
- reduced consciousness is irreversible (caused by disease, patient cannot be aroused), but there are signs the patient may be suffering
The patient may spontaneously fall into a state of reduced consciousness from which he cannot be aroused, and may show signs of possible suffering. Such signs include, in particular, moaning, shortness of breath with or without stridor, and grimacing. Other symptoms may include restlessness, confusion and (faecal) vomiting.⁴⁶ In this situation, the physician may proceed with euthanasia. If there are no signs that the patient may be suffering, euthanasia cannot be performed.

⁴⁵ The Glasgow Coma Scale (GCS) provides guidance in determining the extent of a patient's reduced consciousness – and therefore also potential suffering. See also KNMG, 'Euthanasia for patients in a state of reduced consciousness', Utrecht, 2010.

⁴⁶ See also KNMG, 'Euthanasia for patients in a state of reduced consciousness', Utrecht, 2010, p. 28.



- coma or reduced consciousness is reversible (medically induced, can be reversed by withdrawing medication)

If the patient is in a coma or state of reduced consciousness that has not occurred spontaneously but has been caused by medication, he could potentially be aroused in order to ascertain whether he is still suffering. However, the committees consider this to be inhumane. In such a situation, therefore, the physician may perform euthanasia if the patient had requested it previously, either orally or in an advance directive. The patient need not be aroused from the reversible coma or state of reduced consciousness (even without signs of possible suffering) simply to confirm to the physician and/or independent physician that he is still suffering unbearably.

Coma/reduced consciousness occurring before or after consultation

- coma or reduced consciousness occurs before consultation has taken place

The patient may also enter a state of reduced consciousness or reversible coma before the independent physician has been able to see him. In this case, the independent physician can no longer communicate with the patient and must base his assessment of the patient's request on information provided by the physician, an advance directive (if there is one), the medical records and information from others. He will have to assess the patient's suffering on the basis of his own observations, physician notes and information provided orally by the physician, but also on information from other sources, such as letters from specialists and information from the patient's family or carers. In this situation, no advance directive is required.

- coma or reduced consciousness occurs after consultation has taken place

If the patient enters a state of reduced consciousness or reversible coma after the independent physician has visited the patient and communicated with him, the independent physician need, in principle, not be called in again. In this situation an advance directive is not required either, even if the patient is no longer capable of expressing his will at the point when euthanasia is to be performed.⁴⁷

Coma/reduced consciousness occurs before euthanasia is planned

A patient may fall into a coma or state of reduced consciousness before the physician and the patient have completed, or even started, the euthanasia process. In order to proceed with euthanasia, there must at least be an advance directive drawn up by the patient. The independent physician will have to see the patient. Here too, he will have to base his opinion partly on information from the physician,

⁴⁷ See also KNMG, 'Euthanasia for patients in a state of reduced consciousness', Utrecht, 2010.

the medical records and information from other sources. If the state of reduced consciousness is irreversible, there must also be signs that the patient is or may be suffering.

> See also sections 3.6 and 4.1

COMA/REDUCED CONSCIOUSNESS: POINTS TO CONSIDER

- Coma/reduced consciousness sets in shortly before planned euthanasia is to be performed:
 - has the physician established the depth of coma or reduced consciousness? Has he used the GCS?
 - is the coma or state of reduced consciousness reversible?
 - if reduced consciousness is irreversible, is the patient showing signs that he is or may be suffering?
 - if the independent physician did not see the patient before the coma or state of reduced consciousness set in, does he have enough information to form an opinion?
- Coma/reduced consciousness before euthanasia is planned:
 - in addition to the above: did the patient draw up an advance directive?

4.8. EUTHANASIA AND PALLIATIVE SEDATION

Euthanasia and palliative sedation are two different ways of ending or alleviating a patient's unbearable suffering. In the case of euthanasia, the patient's life is terminated. With palliative sedation, the patient is brought into a state of reduced consciousness until his death. Unlike euthanasia, palliative sedation is normal medical practice, though it is subject to specific conditions. One of these is a life expectancy of two weeks or less.⁴⁸

Patients who are suffering unbearably may make a request for euthanasia, but they can also opt for palliative sedation. Some patients do not want euthanasia, and palliative sedation may be a good alternative for them. Others refuse palliative sedation because they want to remain conscious until the very end. Patients are entitled to conclude that palliative sedation is not a 'reasonable alternative'. Refusing palliative sedation is not therefore an obstacle to euthanasia.

> See also section 3.5

Sometimes a patient may make a 'conditional' request for euthanasia. In this case, the patient is initially palliatively sedated, but the

48 See *Richtlijn palliatieve sedatie* ['Guideline on palliative sedation'], KNMG, Utrecht, 2009.

physician and the patient agree that euthanasia will be carried out should certain circumstances arise. For instance:

- it may take longer for the patient to die than he wished;⁴⁹
- the patient still shows signs of suffering, despite being in a state of reduced consciousness.

The committees emphasise that it is essential that the patient inform the attending physician of the specific situations in which his agreement to palliative sedation no longer applies and he wants his request for euthanasia to be carried out. In such situations, the physician will also have to determine the best time to consult the independent physician; in principle this should be before palliative sedation is administered. There are also cases in which the decision to grant a patient's request for euthanasia has been made, but sedation is administered prior to carrying out the procedure. This may be the case if the patient's symptoms suddenly worsen, but euthanasia cannot be performed yet, for instance because the physician is away and his locum cannot or does not wish to perform euthanasia, or because the physician has not yet received the euthanatics.

The patient is then sedated, so that he enters a state of reduced consciousness and as a result is no longer able to repeat or reaffirm his request for euthanasia immediately before euthanasia is performed. Euthanasia can be performed if the patient reaffirmed his request for euthanasia before he was sedated and only wished to be sedated to bridge the period until it becomes possible to perform euthanasia. It may also be performed if a situation has arisen that the patient has previously described – orally or in an advance directive – as one in which he would ask for the request for euthanasia he had already made to be carried out. In these cases, too, it is the committees' view that it would be inhumane to wake the patient solely for the purpose of having him confirm the unbearable nature of his suffering for the physician and/or independent physician.

4.9. 'COMPLETED LIFE'

As the legislative history of the Act makes clear, the expression 'completed life' (also referred to as 'finished with life') refers to the situation of people who, often at an advanced age and without the medical profession having established that they have a disease or disorder that is accompanied by great suffering, have come to the conclusion that the value of their lives to them has decreased to the

⁴⁹ In this case, it can be concluded that the patient has not given consent for palliative sedation to continue. This concerns consent within the meaning of the Medical Treatment Contracts Act (article 450 (1) of Book 7 of the Civil Code)

point where they would rather die than carry on living. The ‘completed life’ issue has been the subject of public debate for some years. The question is whether euthanasia should be allowed in such cases.⁵⁰ This is not currently the case. As the case law and legislative history show, unbearable suffering must have a medical dimension (see also section 3.3). However there is no requirement that the medical condition should be life-threatening. Multiple geriatric syndromes can also involve unbearable suffering with no prospect of improvement.⁵¹

> For more on multiple geriatric syndromes, see section 3.3

4.10. ORGAN AND TISSUE DONATION AFTER EUTHANASIA⁵²

The Act does not prescribe what can be done with the body after euthanasia, so it does not preclude organ and tissue donation after euthanasia. However, any planned donation procedure must not affect the due care to be exercised in the euthanasia process.

Organ or tissue donation is formally separate from the euthanasia process, but does have implications for that process. For instance, for organ donation to be possible, euthanasia will generally have to be performed in hospital. In other cases, like tissue donation, the patient’s body will usually have to be taken to hospital after euthanasia has been performed.

A physician who finds himself faced with this combination of euthanasia and organ or tissue donation should discuss the patient’s wishes with respect to donation with him. Then, before euthanasia is performed, he must discuss the procedure in detail with the transplant coordinator at the hospital. Then he must inform the patient and the patient’s family about what will happen. Guidelines have been drawn up on this subject, which can help the physician’s decision-making. These can be obtained from the transplant coordinator at the nearest university hospital.⁵³

50 See the report by the Schnabel Committee, entitled *Voltooid leven. Over hulp bij zelfdoding aan mensen die hun leven voltooid achten* [‘Completed life. On assisted suicide for people who regard their life as completed’], The Hague, January 2016, and the government response and vision on ‘completed life’, Letter to the House of Representatives, 12 October 2016.

51 See also *De rol van de arts bij het zelfgekozen levenseinde* [‘The role of the doctor in termination of life at the patient’s request’], KNMG, Utrecht, 2011, pp. 21-23.

52 *Richtlijn Orgaandonatie na euthanasie* [‘Guidelines on organ donation after euthanasia’], Dutch Foundation for Transplants, November 2017.

53 For more information (in Dutch) see www.transplantatiestichting.nl.

4.11. REQUIREMENTS NOT SET BY THE ACT

Some misconceptions exist regarding the criteria and conditions applying to euthanasia. The notifications received by the committees show that physicians and independent physicians sometimes set requirements that are not mentioned in the Act. The requirements laid down in the Act have been discussed and explained in this Code. Below is a list of conditions that are *not* laid down in the Act. A summary:

- There is no requirement that the patient's medical condition be life-threatening (see sections 2.1 and 3.3).
- The patient is not required to be in the terminal stage of his illness (see section 2.2).
- The physician and the patient do not need to be in a treatment relationship (see section 3.1).
- The patient is not required to provide a request for euthanasia in writing in addition to his oral request (section 3.2).
- The patient's request must be well considered but it need not, in principle, be persistent (section 3.2).
- The 'permission' of the independent physician is not required for euthanasia to be performed (section 3.6).
- A physician with expertise in assessing a patient's decisional competence need not always be consulted, but only if there are reasonable doubts as to the patient's decisional competence (see also sections 4.2 to 4.5).
- Palliative sedation is not a 'reasonable alternative' within the meaning of section 2 (1) (d) of the Act (section 4.8).
- It is generally desirable, as well as self-evident, for the patient's family to be involved in a euthanasia request, but this is not a requirement; nor is the family's consent required for euthanasia.⁵⁴

⁵⁴ The situation is different when the patient requesting euthanasia is a minor; see section 4.2.

5 USEFUL REFERENCES

5.1. THE COMMITTEES' WEBSITE

The committees' website can be found at www.euthanasiecommissie.nl. The site provides detailed information on the committees' procedures, as well as a selection of the committees' findings and their joint annual reports. The annual reports contain case descriptions.

The website also has:

- a model form for physicians to use when notifying the municipal pathologist;
- a model reporting form for physicians, which must accompany the notification;
- a model form for municipal pathologists to use when notifying the committee;
- the complaints regulations.

5.2. THE SCEN ORGANISATION

The SCEN organisation, which falls under the KNMG, fulfils a key role in relation to the due care criterion on consultation with an independent physician (see section 3.6). In the vast majority of cases, physicians consult a trained SCEN physician. For more information (in Dutch), see www.scen.nl.

5.3. EVALUATIONS OF THE ACT

The Termination of Life on Request and Assisted Suicide (Review Procedures) Act has been evaluated three times, in 2007, 2012 and 2017. The evaluation reports can be found (in Dutch) at www.zonmw.nl.

5.4. PUBLIC PROSECUTION SERVICE POLICY RULES

Notifications of euthanasia where the committees have found that the physician failed to comply with one or more of the due care criteria are passed on to the Public Prosecution Service and the new Health and Youth Care Inspectorate. The procedure followed by the Public Prosecution Service in such cases is set out in the *Aanwijzing vervolgingsbeslissing inzake actieve levensbeëindiging op verzoek (euthanasie en hulp bij zelfdoding)* [‘Instructions on prosecution decisions in the matter of active termination of life on request and assisted suicide’], which can be found (in Dutch) at wetten.overheid.nl/BWBR0039555/2017-05-17.

ANNEXE

RELEVANT STATUTORY PROVISIONS

Bulletin of Acts and Decrees 2001, no. 194

Act of 12 April 2001, containing review procedures for the termination of life on request and assisted suicide and amending the Criminal Code and the Burial and Cremation Act (Termination of Life on Request and Assisted Suicide (Review Procedures) Act)¹

TERMINATION OF LIFE ON REQUEST AND ASSISTED SUICIDE (REVIEW PROCEDURES) ACT

CHAPTER I. DEFINITIONS

Section 1

For the purposes of this Act, the following definitions apply:

- a. Our Ministers: the Minister of Justice and the Minister of Health, Welfare and Sport;
- b. assisted suicide: intentionally helping another person to commit suicide or providing him with the means to do so as referred to in article 294, paragraph 2, second sentence of the Criminal Code;
- c. the physician: the physician who, according to the notification, has terminated life on request or has provided assistance with suicide;
- d. the independent physician: the physician who has been consulted about the physician's intention to terminate life on request or to provide assistance with suicide;
- e. the care providers: the persons referred to in article 446, paragraph 1, of Book 7 of the Civil Code;
- f. the committee: a regional review committee as referred to in section 3;
- g. regional inspector: a regional inspector employed by the Healthcare Inspectorate of the Public Health Supervisory Service.

¹ See for proceedings in the States General: Parliamentary Papers, House of Representatives, 1998/1999, 2000/2001, 26 691. Proceedings of the House of Representatives, 2000/2001, pp. 2001-2072; 2107-2139; 2202-2223; 2233-2260; 2372-2375. Parliamentary Papers, Senate, 2000/2001, 26 691 (137, 137a, 137b, 137c (reprint), 137d, 137e, 137f, 137g, 137h). Proceedings of the Senate, 2000/2001, see session of 10 April 2001.

CHAPTER II. DUE CARE CRITERIA

Section 2

1. In order to comply with the due care criteria referred to in article 293, paragraph 2 of the Criminal Code, the physician must:
 - a. be satisfied that the patient's request is voluntary and well considered;
 - b. be satisfied that the patient's suffering is unbearable, with no prospect of improvement;
 - c. have informed the patient about his situation and his prognosis;
 - d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;
 - e. have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled;
 - f. have exercised due medical care and attention in terminating the patient's life or assisting in the patient's suicide.
2. If a patient aged sixteen or over who is no longer capable of expressing his will, but before reaching this state was deemed capable of making a reasonable appraisal of his own interests, has made a written declaration requesting that his life be terminated, the physician may comply with this request. The due care criteria in subsection 1 apply *mutatis mutandis*.
3. If the patient is a minor aged between sixteen and eighteen and is deemed to be capable of making a reasonable appraisal of his own interests, the physician may comply with a request made by the patient to terminate his life or provide assistance with suicide, after the parent or parents who have responsibility for him, or else his guardian, has or have been consulted.
4. If the patient is a minor aged between twelve and sixteen and is deemed to be capable of making a reasonable appraisal of his own interests, the physician may, if a parent or the parents who have responsibility for him, or else his guardian, can agree to the termination of life or to assisted suicide, comply with the patient's request. Subsection 2 applies *mutatis mutandis*.

CHAPTER III. REGIONAL REVIEW COMMITTEES FOR THE TERMINATION OF LIFE ON REQUEST AND ASSISTED SUICIDE

Division 1: Establishment, composition and appointment

Section 3

1. There are regional committees to review reported cases of the termination of life on request or assisted suicide as referred to in article 293, paragraph 2 and article 294, paragraph 2, second sentence, respectively, of the Criminal Code.
2. A committee consists of an odd number of members, including in any event one legal expert who also chairs the committee, one physician and one expert on ethical or moral issues. A committee also comprises alternate members from each of the categories mentioned in the first sentence.

Section 4

1. The chair, the members and the alternate members are appointed by Our Ministers for a period of six years. They may be reappointed once for a period of six years.
2. A committee has a secretary and one or more deputy secretaries, all of whom must be legal experts appointed by Our Ministers. The secretary attends the committee's meetings in an advisory capacity.
3. The secretary is accountable to the committee alone in respect of his work for the committee.

Division 2: Resignation and dismissal

Section 5

The chair, the members and the alternate members may tender their resignation to Our Ministers at any time.

Section 6

The chair, the members and the alternate members may be dismissed by Our Ministers on the grounds of unsuitability or incompetence or for other compelling reasons.

Division 3: Remuneration

Section 7

The chair, the members and the alternate members are paid an attendance fee and a travel and subsistence allowance in accordance with current government regulations, in so far as these expenses are not covered in any other way from the public purse.

Division 4: Duties and responsibilities

Section 8

1. The committee assesses, on the basis of the report referred to in section 7, subsection 2 of the Burial and Cremation Act, whether a physician, in terminating life on request or in assisting with suicide, acted in accordance with the due care criteria set out in section 2.
2. The committee may request the physician to supplement his report either orally or in writing, if this is necessary for a proper assessment of the physician's conduct.
3. The committee may obtain information from the municipal pathologist, the independent physician or the relevant care providers, if this is necessary for a proper assessment of the physician's conduct.

Section 9

1. The committee notifies the physician of its findings in writing within six weeks of receiving the report referred to in section 8, subsection 1, giving reasons.
2. The committee notifies the Board of Procurators General and the regional health care inspector of its findings:
 - a. if the attending physician, in the committee's opinion, did not act in accordance with the due care criteria set out in section 2; or
 - b. if a situation occurs as referred to in section 12, last sentence of the Burial and Cremation Act.The committee notifies the physician accordingly.
3. The time limit defined in the first subsection may be extended once for a maximum of six weeks.
The committee notifies the physician accordingly.
4. The committee is empowered to explain its findings to the physician orally. This oral explanation may be provided at the request of the committee or the physician.

Section 10

The committee is obliged to provide the public prosecutor with all the information that he may request:

- 1o for the purpose of assessing the physician's conduct in a case as referred to in section 9, subsection 2; or
- 2o for the purposes of a criminal investigation.

The committee notifies the physician that it has supplied information to the public prosecutor.

Division 6: Procedures

Section 11

The committee is responsible for making a record of all reported cases of termination of life on request or assisted suicide. Our Ministers may lay down further rules on this point by ministerial order.

Section 12

1. The committee adopts its findings by a simple majority of votes.
2. The committee may adopt findings only if all its members have taken part in the vote.

Section 13

The chairs of the regional review committees meet at least twice a year in order to discuss the methods and operations of the committees. A representative of the Board of Procurators General and a representative of the Health Care Inspectorate, which falls under the public health inspectorates, will be invited to attend these meetings.

Division 7: Confidentiality and disqualification

Section 14

The members and alternate members of the committee are obliged to maintain confidentiality with regard to all the information that comes to their attention in the course of their duties, unless they are required by a statutory regulation to disclose the information in question or unless the need to disclose the information in question is a logical consequence of their responsibilities.

Section 15

A member of the committee sitting to review a particular case must disqualify himself and may be challenged if there are any facts or circumstances which could jeopardise the impartiality of his judgment.

Section 16

Any member or alternate member or the secretary of the committee must refrain from giving any opinion on an intention expressed by a physician to terminate life on request or to provide assistance with suicide.

Division 8: Reporting requirements

Section 17

1. By 1 April of each year, the committees must submit to Our Ministers a joint report on their activities during the preceding calendar year. Our Ministers lay down the format of such a report by ministerial order.
2. The report referred to in subsection 1 must state in any event:
 - a. the number of cases of termination of life on request and assisted suicide of which the committee has been notified and which the committee has assessed;
 - b. the nature of these cases;
 - c. the committee's findings and its reasons.

Section 18

Each year, when they present their budgets to the States General, Our Ministers must report on the operation of the committees on the basis of the report referred to in section 17, subsection 1.

Section 19

1. On the recommendation of Our Ministers, rules are laid down by order in council on:
 - a. the number of committees and their territorial jurisdiction;
 - b. their locations.
2. Further rules may be laid down by Our Ministers by or pursuant to order in council with regard to:
 - a. the size and composition of the committees;
 - b. their working methods and reporting procedures.

CHAPTER IIIA. BONAIRE, ST EUSTATIUS AND SABA

Section 19a

This Act also applies in the territories of the public bodies Bonaire, St Eustatius and Saba in accordance with the provisions of this chapter.

Section 19b

1. For the purposes of:
 - section 1 (b), ‘article 294, paragraph 2, second sentence, of the Criminal Code’ is replaced by: ‘article 307, paragraph 2, second sentence, of the Criminal Code of Bonaire, St Eustatius and Saba’.
 - section 1 (f), ‘a regional review committee as referred to in section 3’ is replaced by: ‘a committee as referred to in section 19c’.
 - section 2, subsection 1, opening words, ‘article 293, paragraph 2, second sentence of the Criminal Code’ is replaced by: ‘article 306, paragraph 2, second sentence of the Criminal Code of Bonaire, St Eustatius and Saba’;
 - section 8, subsection 1, ‘section 7, subsection 2 of the Burial and Cremation Act’ is replaced by: ‘section 1, subsection 3 of the Death Certificates (Bonaire, St Eustatius and Saba) Act’.
 - section 8, subsection 3, ‘or the relevant care providers’ lapses.
 - section 9, subsection 2, opening words, ‘the Board of Procurators General is replaced by ‘the Procurator General’.
2. Section 1 (e) does not apply.

Section 19c

Notwithstanding section 3, subsection 1, a committee will be appointed by Our Ministers that is competent to review reported cases of termination of life on request or assisted suicide as referred to in article 306, paragraph 2 and article 307, paragraph 2, second sentence of the Criminal Code of Bonaire, St Eustatius and Saba.

Section 19d

The chair of the committee referred to in section 19c takes part in the meetings referred to in section 13. The Procurator General or a representative appointed by him and a representative of the Health Care Inspectorate also take part.

CRIMINAL CODE

Article 293

1. Anyone who terminates another person's life at that person's express and earnest request is liable to a term of imprisonment not exceeding twelve years or a fifth-category fine.
2. The act referred to in paragraph 1 is not an offence if it is committed by a physician who fulfils the due care criteria set out in section 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, and if the physician notifies the municipal pathologist of this act in accordance with the provisions of section 7, subsection 2 of the Burial and Cremation Act.

Article 294

1. Anyone who intentionally incites another to commit suicide is, if suicide follows, liable to a term of imprisonment not exceeding three years or to a fourth-category fine.
2. Anyone who intentionally assists another to commit suicide or provides him with the means to do so is, if suicide follows, liable to a term of imprisonment not exceeding three years or a fourth-category fine. Article 293, paragraph 2 applies *mutatis mutandis*.

BURIAL AND CREMATION ACT

Section 7

1. The person who conducted the post-mortem examination issues a death certificate if he is satisfied that the death was due to natural causes.
2. If death was the result of the termination of life on request or assisted suicide as referred to in article 293, paragraph 2 or article 294, paragraph 2, second sentence of the Criminal Code respectively, the physician does not issue a death certificate and immediately notifies the municipal pathologist or one of the municipal pathologists of the cause of death by completing a report form. The physician encloses with the form a substantiated report on compliance with the due care criteria set out in section 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.
3. If the physician decides, in cases other than those referred to in subsection 2, that he is unable to issue a death certificate, he immediately notifies the municipal pathologist or one of the municipal pathologists accordingly by completing a report form.

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REGIONAL
EUTHANASIA
REVIEW COMMITTEES

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