## REGIONAL EUTHANASIA REVIEW COMMITTEES

# ANNUAL REPORT 2014



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## FOREWORD

This is the 2014 annual report of the five regional euthanasia review committees (RTEs). In their annual reports the committees account for the way in which they fulfil their statutory task of reviewing cases on the basis of the due care criteria laid down in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

This year's report differs from the customary format.

In April 2015 the RTEs published a Code of Practice. The Code outlines the issues that the committees regard as relevant in connection with the statutory due care criteria and is intended as a summary of the considerations that the committees have published in their annual reports and findings over the past few years.

The committees examine the actions of the notifying physician in the context of the Act, its legislative history and the relevant case law. They also take their own previous findings into account, as well as the decisions of the Public Prosecution Service and the Health Care Inspectorate listed in Annexe I to the annual reports. Previously, the annual reports explained in detail how the RTEs interpret and apply the statutory due care criteria, as reflected in their 'case law' and the considerations it contains. This is no longer the case.

Chapter I describes relevant developments, followed by an overview in Chapter II of the number of notifications received in 2014 (5,306; a 10% increase compared to 2013) and their nature. Chapter III describes a number of cases, but no longer provides further explanations.

For each case it is specified which of the due care criteria it illustrates, what key points the committee in question had to consider and, of course, what the committee's findings were. All findings that have been described in the form of cases can be found in full on the website.

The various case descriptions now refer to the relevant considerations in the Code of Practice, which can be found on the RTEs' website (www.euthanasiecommissie.nl).

Findings that are deemed important for the development of standards are published on the website. They include all cases in which the committees found that the physician had not complied with one or more of the due care criteria. There were four such cases in 2014, all of which have been included in the annual report, as is customary.

Notifications of more complex cases concerning, for example, patients who have a psychiatric disorder or patients who are in an advanced stage of dementia are nearly always first put to the members of all the committees before the competent committee makes a final decision. The often lively internal discussions are aimed at harmonising the findings of the various committees. While taking account of the principle that every notification should be reviewed according to the specific circumstances of the 'case', the committees as always strive for consistency with regard to their findings.

With the Code of Practice, the annual reports, and the findings published on the website, the committees aim to provide clarity on the scope provided by the law to physicians, independent physicians, patients intending to request euthanasia and other interested parties.

The RTEs held several constructive consultations in this reporting year with the Royal Dutch Medical Association (KNMG), which likewise aims to improve clarity. We greatly appreciated these consultations, characterised as they were by an open atmosphere and cooperative attitudes.

In addition to the activities outlined above, in 2014 a considerable amount of time and energy was put into the reorganisation, in which the RTEs' secretariats were incorporated into the Disciplinary Boards and Review Committees Secretariats Unit (ESTT).

The 2014 reporting year was an inspiring and, once again, challenging year for the committees.

I would like to thank the committee members, the general secretary, the secretaries and the staff of the secretariats for their great commitment and effort. A special word of thanks goes to the members of the supervisory committee for the Code of Practice.

The committees would be pleased to receive feedback via their general secretary (email: n.visee@toetscie.nl).

W.J.C. Swildens-Rozendaal, LLM *Coordinating chair of the regional euthanasia review committees* 

The Hague, August 2015

# DEVELOPMENTS IN 2014

## CODE OF PRACTICE

The joint annual reports of the regional euthanasia review committees (RTEs) and the findings published on their website give an impression of how the committees apply and interpret the statutory due care criteria for euthanasia as set out in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (*Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*). The second evaluation of the Act (2012) recommended that a Code of Practice be published to make this information more accessible. This recommendation was endorsed by several organisations closely concerned with the issue, including the Royal Dutch Medical Association (KNMG). The Minister of Health, Welfare and Sport and the Minister of Security and Justice also informed the House of Representatives that they concurred with the conclusion that a Code of Practice was desirable.

Professor J. Legemaate, professor of health law at AMC/University of Amsterdam, was willing to assist the committees in drafting the Code of Practice. He was assisted by a supervisory committee of RTE members, consisting of Professor J.K.M. Gevers (chair), Dr E.F.M. Veldhuis (physician) and Professor A.R. Mackor (ethicist), and general secretary N.E.C. Visée, LLM. The draft Code was presented to all members and secretaries of the RTEs for their comments.

On 23 April 2015, the coordinating chair, W.J.C. Swildens-Rozendaal, LLM, presented the first copy of the Code of Practice to the president of the KNMG, Professor R.J. van der Gaag, at the KNMG symposium entitled 'The SCEN physician's puzzle' at Domus Medica in Utrecht.

The Code 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 over the past few years. The Code focuses on these considerations; it does not examine specific cases.

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

The Code of Practice can be found on the committees' website.<sup>1</sup>

1 www.euthanasiecommissie.nl.



TOTAL NO. OF NOTIFICATIONS EUTHANASIA AND ASSISTED SUICIDE

## NOTIFICATIONS

## Number of notifications

In 2014, the RTEs received 5,306 notifications of euthanasia, i.e. termination of life on request or assisted suicide. The number of notifications received in 2014 again showed an increase (10%) compared to 2013 (4,829). Chapter II gives a detailed overview of these notifications, both for the Netherlands as a whole and per region. In each case the committees examined whether the physician who had performed euthanasia had acted in accordance with the due care criteria set out in section 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. In four cases, less than 0.1% of the total, the committees found that the physician had not acted in accordance with the due care criteria. These cases are described in Chapter III. In all other cases the committees found that the physicians had acted in accordance with all the due care criteria. Several of these findings, which concerned complex cases, are also described in Chapter III. Chapter IV gives an overview of the RTEs' activities.

## **Psychiatric disorders**

Patients' suffering was caused by a psychiatric disorder in 41 notified cases of euthanasia. In 2012 and 2013 the figures were 14 and 42, respectively. It can be concluded that the previously observed increase in this number has not continued. Of the 41 cases notified to the committees in the reporting year, 36 were reviewed in 2014. In addition, 14 cases notified to the committees in 2013 were reviewed in 2014. A total of 50 notifications were therefore reviewed in 2014. In one case the committees found that the physician had not complied with the due care criteria (see *case 2014-01*). In all other cases the committee found that the due care criteria had been complied with. In 20 of the 50 cases reviewed the notifying physician was a psychiatrist, in 30 cases a general practitioner, another medical specialist, an elderly-care specialist or another physician. In 19 cases the physician was affiliated with the End-of-Life Clinic (SLK).

In 2014 the increase in the number of notifications of psychiatric cases attracted considerable interest. The KNMG published a factsheet entitled '*Euthanasie bij patiënten met een psychiatrische aandoening*' [Euthanasia for patients with a psychiatric disorder] in February 2014. In response to questions in the House of Representatives, the Minister of Health, Welfare and Sport said she wanted to encourage online publication of the RTEs' findings in psychiatric cases.<sup>2</sup>

In view of the continuing public interest in the subject, a large number of these cases were anonymised and published on the committees' website, along with summaries.<sup>3</sup> In 2014, all cases reviewed in 2013 were prioritised for publication on the committees' website.<sup>4</sup>

On 4 June 2014, a round table discussion was held on the subject of euthanasia and psychiatry.  $^{\rm 5}$ 

At a meeting with the permanent parliamentary committee in November 2014, the Minister of Health, Welfare and Sport indicated a desire to have the guidelines of the National Psychiatry Association (NVVP) declared applicable to all physicians and for psychiatric

<sup>2</sup> Parliamentary Papers, House of Representatives, 2013/2014, 32 647, no. 20.

<sup>3</sup> See footnote 1.

<sup>4</sup> See footnote 1.

<sup>5</sup> Parliamentary Papers, House of Representatives, 2013/2014, 32 647, no. 28.

## NOTIFYING PHYSICIANS IN 2014

General practitioner	4678
Specialist working in a hospital	175
Geriatrician	191
Registrar	25
Other physician	237
(e.g. a doctor affiliated with the End-of-	
Life Clinic, a junior doctor, non-practising	g
physician or hospice physician)	



## DISORDERS INVOLVED IN 2014

cancer	3888
neurological disorders	317
oother disorders	291
multiple geriatric syndromes	257
cardiovascular disease	247
pulmonary disorders	184
dementia	81
psychiatric disorders	41

expertise to be embedded in the RTEs.<sup>6</sup> In the spring of 2015, the committees appointed a psychiatrist to fill a vacancy for a physician-member of the RTEs.

The RTEs' annual seminar on 3 April 2014, to which external experts were also invited, included detailed discussion of the topic of euthanasia and psychiatry.

Chapter III describes three cases in which the patient's suffering was caused by psychiatric problems: *cases 2014-01, 2014-70* and *2014-72*. In case *2014-37* (not included in the English translation) a psychiatric disorder played a role in the patient's suffering, in addition to a somatic disorder.

#### Dementia

Patients' suffering was caused by dementia in 81 cases notified to the committees in 2014. In 2013 the figure was 97. In the vast majority of these cases, the patients were in the initial stages of the disorder and still had insight into their condition and its symptoms (loss of bearings and personality changes). They were deemed decisionally competent with regard to their request because they could still grasp its implications. In 14 cases the physician was affiliated with the End-of-Life Clinic (SLK). All 81 dementia cases were found by the committees to have been handled with due care. In addition to these 81 cases, there were 12 cases in which dementia played a part in addition to another disorder, such as cancer or Parkinson's disease. In these cases, too, the committees found that the physicians had acted in accordance with the due care criteria. Chapter III discusses cases 2014-03 (not included in the English translation) and 2014-35, in which the patient's suffering was caused by dementia.

## **COMMITTEE PROCEDURES – DEVELOPMENTS**

#### Straightforward and non-straightforward cases

In 2014, 80% of the notifications received concerned straightforward cases. Notifications were considered straightforward if the committee secretary could establish that the information provided was so comprehensive and the likelihood that the due care criteria had been complied with was so great that the committee would be able to review the notification digitally. The straightforward notifications could almost all be discussed and reviewed digitally by the committees and therefore disposed of without delay. See, for instance, cases 2014-12 and 2014-16. A small number of notifications that were initially considered straightforward were later deemed to be non-straightforward, and as a result were discussed in a committee meeting.

The other 20% of the notifications received did raise questions that required discussion in person and were reviewed at the monthly committee meetings.

Thanks to the working method introduced in 2012 and the increase in the number of committee members and secretariat staff, the backlog of the previous years was cleared in 2013 and 2014. The average time that elapses between the notification being received and the committee's findings being sent to the physician is now 47 days.<sup>7</sup>

<sup>6</sup> Parliamentary Papers, House of Representatives, 2013/2014, 32 647, no. 40.

<sup>7</sup> Section 9 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act states that the committees must notify the physician within six weeks of receiving the report of their findings, giving reasons. This period may be extended once by six weeks.

In 2014 the committees received no complaints concerning the way notifications were dealt with. As announced in last year's annual report, the committees have decided to establish an independent complaints committee. The final touches are currently being added to the complaints regulations, which set out in detail the complaints committee's procedures, powers and composition. The complaints regulations are expected to be published on the committees' website this autumn.

#### Harmonisation

In 2014, if a committee intended to find that a physician had *not* acted in accordance with one or more due care criteria, the provisional findings and the accompanying file were submitted – digitally – to the members and alternate members of all the committees for their advice and comments. Similarly, the draft findings on a number of notifications concerning complex cases, stating that the physician *had* acted in accordance with the due care criteria, were submitted to all members and alternate members of the committees as well. In all these cases, the committee which initiated the discussion wanted to hear the views of the other committee members regarding its draft findings and the considerations on which the findings were based. This internal exchange of views and considerations has proven to be a valuable tool for the harmonisation of findings. It also creates support within the committees for the decisions in more complex cases. After the discussion has been closed, it is up to the *original committee of three* (physician, ethicist and lawyer) to take all factors into consideration and reach a final decision.

The notifications from the Health Care Inspectorate and the Public Prosecution Service and the considerations they contain (see Annexe 1) also contribute to the harmonisation of findings. In addition to the aforementioned internal discussions on individual cases, the committees also regularly hold meetings on current topics to discuss developments in the field more generally.

## Regional committee secretariats incorporated into the Disciplinary Boards and Review Committees Secretariats Unit (ESTT)

As of 1 July 2014, the secretariats of the RTEs and the secretariat of the Central Committee on Termination of Life (Neonates) and Late-term Abortions (LZA-LP committee) were incorporated into a new department at the Ministry of Health, Welfare and Sport, the Disciplinary Boards and Review Committees Secretariats Unit (ESTT). This department also comprises the secretariats of the Healthcare Disciplinary Boards. Each secretariat is organised separately. The independent nature of the reviews conducted by the RTEs, the LZA-LP committee and the Disciplinary Boards remains guaranteed. The management team of the ESTT comprises Iris van den Hauten-Hinnen, director, and Rik Poelstra, deputy director.

## OTHER DEVELOPMENTS

#### The significance of the advance directive

Following the public debate on the significance and value of the advance directive with regard to euthanasia, in mid-2013 the Minister of Health, Welfare and Sport established the 'Advance directive and euthanasia' working group, consisting of staff members from the Ministry of Health, Welfare and Sport, the Ministry of Security and Justice and the KNMG.<sup>8</sup>

8 Parliamentary Papers, House of Representatives, 2012/2013, 32 647, no. 16.

The working group was tasked with providing legal and practical clarity concerning the significance of the advance directive in the context of decisionally incompetent patients, as laid down in section 2 (2) of the Act.9

The working group's activities were divided into three phases. In her letter of 4 July 201410 the Minister of Health, Welfare and Sport informed the House of Representatives of the results of the first and second phases, comprising an analysis of the parliamentary debate, the legislative history of section 2 (2) of the Act and an analysis of the relevant case law.11 The analysis of the legislative history was performed by the working group itself and the case law analysis by the Criminal Law Department of Erasmus University Rotterdam (EUR), at the request of the Research and Documentation Centre (WODC) of the Ministry of Security and Justice. The third phase aimed to identify practical problems, and was carried out by the Netherlands Organisation for Health Research and Development (ZonMw). The RTEs contributed to both analyses and to ZonMw's study.

The working group's ultimate aim is to draw up two guidelines, one for physicians and other care professionals and one for patients and members of the public. The RTEs will also contribute to these guidelines if requested. The guideline for patients and the public is expected to be published in the autumn of 2015.

## Organ donation after euthanasia

Physicians regularly encounter patients wanting to donate organs after euthanasia. Most patients who die as a result of euthanasia cannot donate organs due to their condition (often a malignancy). However in some situations it is possible, particularly for patients with neurodegenerative disorders, such as motor neurone disease or MS, or a psychiatric disorder. To date, this combination of procedures has been performed more than 10 times in the Netherlands. Belgium has more experience in this field.

The Act contains no provisions on what can be done with the body after euthanasia, so it does not preclude organ donation after euthanasia. To prevent the request for euthanasia from being influenced by the possibility of organ donation, it is important that physicians assess any request for organ donation only after it is clear that the due care criteria for euthanasia have been complied with.

Organ donation after euthanasia involves a complex combination of procedures, as it requires, among other things, that the euthanasia procedure be performed in hospital. This generally means the patient has to be taken to hospital for the euthanasia procedure. The two procedures must also be strictly separated, but at the same time closely coordinated in view of the speed required. This calls for close cooperation and coordination.

To achieve that coordination and to ensure the procedure is carried out with due care, a working group initiated by various universities is working on a guideline for physicians. It describes how physicians can respond to a patient's request that his organs be donated after euthanasia. The committees have given feedback on a draft version of the guideline.

- 9 Section 2 (2) of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act reads as follows: '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 referred to in subsection 1 apply *mutatis mutandis*'.
- 10 Parliamentary Papers, House of Representatives, 2013/2014, 32 647, no. 16.
- 11 For the purpose of the analysis by WODC/EUR, case law includes cases brought before criminal and civil courts, and medical disciplinary boards, as well as the findings of the regional euthanasia review committees.

## Digital model notification form

In view of the increase in the number of notifications and therefore also in the number of straightforward notifications that can be reviewed digitally (and thus more quickly), it is important for the physician to provide sufficient, clearly legible information when submitting the notification.

In 2014 the RTEs asked a number of physicians to complete the model notification form again, because it was illegible and/or contained insufficient information to assess it in light of all the due care criteria. Case 2014-23 is an example.

When sending their findings to physicians who had completed the notification form on paper, the committees asked those physicians to do so digitally for any subsequent notifications.

The model notification form can be downloaded from the following websites: www.euthanasiecommissie.nl and www.knmg.nl.

# Ch.2

## NATIONAL OVERVIEW OF NOTIFICATIONS 2014

Overview of notifications from1 January 2014 to 31 December 2014

NOTIFICATIONS The committees received 5,306 notifications in the year under review.

- EUTHANASIA AND ASSISTED SUICIDE There were 5,033 cases of euthanasia (i.e. active termination of life at the patient's request), 242 cases of assisted suicide and 31 cases involving a combination of the two.
- LOCATIONS In 4,309 cases patients died at home, in 171 cases in hospital, in 184 cases in a nursing home, in 239 cases in a care home, in 326 cases in a hospice and in 77 cases elsewhere (e.g. at a family member's home).
- CARIBBEAN NETHERLANDS In the course of the reporting year, the committees received no notifications from the Caribbean Netherlands.
- COMPETENCE AND FINAL DECISION In all cases the committee deemed itself competent to deal with the notification. In the year under review there were 4 cases in which the physician was found not to have acted in accordance with the due care criteria.

LENGTH OF ASSESSMENT PERIOD The average time that elapsed between the notification being received and the committee's findings being sent to the physician was 47 days.

## NOTIFYING PHYSICIANS IN 2014

<ul> <li>General practitioner</li> </ul>	4,678
Specialist working in a hospital	175
Elderly-care specialist	191
🛑 Registrar	25
<ul> <li>Other physician</li> </ul>	237
End-of-Life Clinic	227

#### CONDITIONS INVOLVED IN 2014

	Cancer	3,888
	Neurological disorders	317
igodol	Other conditions	291
	Multiple geriatric syndromes	257
	Cardiovascular disease	247
	Pulmonary disorders	184
	Dementia	81
	Psychiatric disorders	41

## TOTAL NUMBER OF NOTIFICATIONS EUTHANASIA AND ASSISTED SUICIDE BY REGION



Total number of notifications in 2014 by region (not included here)

15



## DUE CARE CRITERIA

Up to 2013, Chapter 2 of the annual report provided an overview of how the committees apply and interpret the statutory due care criteria for euthanasia as set out in the Act and the most important developments, illustrated by cases. The Code of Practice published in April 2015 now serves as the committees' policy line, so besides descriptions of cases, this chapter now only gives references to the Code.<sup>12</sup>

The committees assess whether the notifying physician has acted in accordance with all the statutory due care criteria laid down in section 2 of the Act. These criteria determine that physicians 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.

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 into account, and previous decisions of the Public Prosecution Service and the Health Care Inspectorate in cases where a committee found that the physician had not acted in accordance with the due care criteria. This means that it must be clear that the physician complied with due care criteria (c), (e) and (f) above, and that he can plausibly argue that, given the circumstances of the case, he was reasonably able to conclude that he had complied with due care criteria (a), (b) and (d). To this end, the physician must include with his notification to the pathologist a substantiated report (section 7 (2) of the Burial and Cremation Act).

12 See footnote 1.

16

## SELECTED CASES

The first two cases are examples of a straightforward case. The other cases are nonstraightforward. The selected cases deal, respectively, with the requirement to submit a substantiated report and with the various due care criteria set out in the Act. The cases are described in the form of summarised findings and focus on key aspects of the notifications and the committee's considerations. Lastly, several euthanasia cases that involved psychiatric disorders and dementia are discussed separately. This is done in view of the great interest in such cases among the public. The full text of the findings on these cases can be found – under the same numbers – on the committees' website, under year of publication 2014.<sup>13</sup>

## STRAIGHTFORWARD NOTIFICATIONS

Nearly all the straightforward notifications in 2014 could be discussed and reviewed digitally by the committees. As mentioned in Chapter I, around 80% of all notifications fell in this category. To provide insight into these notifications, the findings are given for two of the straightforward cases.

## CASE 2014-12

See case 2014-12 on the website for the full text. FINDING: due care criteria complied with

**KEY POINT:** straightforward notification

SUMMARY: The patient, a man in his fifties, had been suffering from motor neurone disease for two years. He suffered from loss of muscular control, shortness of breath, hypoventilation, hypersalivation and increasing difficulty in communicating and swallowing. The patient was extremely fatigued, wheelchair-bound and entirely dependent on care. He was also afraid of suffocating. The patient wanted to be in control of the situation and to end his life consciously and with dignity. As he could no longer speak, he communicated via a voice output communication aid on his computer.

Two years before his death, the patient, a man in his fifties, was diagnosed with motor neurone disease. Since then, the patient's condition had continued to deteriorate; in the weeks before his death this process accelerated. His condition was incurable. He could only be treated palliatively.

The patient's suffering consisted of loss of muscular control, progressive shortness of breath and hypoventilation. He also suffered from hypersalivation and experienced increasing difficulty in communicating and swallowing. The patient was extremely fatigued and lacked energy. He had become wheelchair-bound and was entirely dependent on care. He was suffering from the progressive nature of his symptoms and the fear of suffocating. The patient indicated he was 'worn out'. He wanted to be in control of the situation and to end his life consciously and with dignity.

The patient experienced his suffering as unbearable. The physician was satisfied that this suffering was unbearable to him and with no prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate his suffering that were acceptable to him. The documents made it clear that the physician and the specialists

13 See footnote 1.

gave him sufficient information about his situation and prognosis. The patient had discussed euthanasia with the physician before.

More than a week before his death, the patient asked the physician to actually perform the procedure to terminate his life. The physician concluded that the request was voluntary and well-considered. The physician consulted an independent physician who was also a SCEN physician. The independent physician saw the patient five days before the termination of life was performed, after she had been informed of the patient's situation by the physician and had examined his medical records. As the patient could no longer speak, he communicated via a voice output communication aid on his computer.

In her report the independent physician gave a summary of the patient's medical history and the nature of his suffering. She concluded, partly on the basis of her interview with the patient, that the due care criteria had been met.

The physician performed the termination of life on request using the method, substances and dosage recommended in the KNMG/KNMP's Guideline 'Performing euthanasia and assisted suicide procedures' of August 2012.

The committees examine retrospectively whether the physician has acted in accordance with the statutory due care criteria laid down in section 2 of the Act. They consider whether the due care criteria have been complied with in the light of prevailing medical opinion and standards of medical ethics.

In view of the above facts and circumstances, the committee found that the physician could be satisfied that the patient's request was voluntary and well-considered, and that his suffering was unbearable, with no prospect of improvement. The physician informed the patient sufficiently about his situation and his prognosis. The physician came to the conclusion, together with the patient, that there was no reasonable alternative in the patient's situation. The physician consulted at least one other, independent physician, who saw the patient and gave a written opinion on whether the due care criteria had been complied with. The physician performed the euthanasia with due medical care. The physician acted in accordance with the statutory due care criteria laid down in section 2 (1) of the Act.

## CASE 2014-16

FINDING: due care criteria complied with

**KEY POINT:** straightforward notification

SUMMARY: The patient, a woman in her seventies, had been diagnosed with a pericardial effusion, a pleural effusion, heart failure and pulmonary hypertension. The patient's suffering consisted of severe shortness of breath brought on by minimal physical exertion. She could no longer do anything, was bedridden and fully dependent on care, and felt powerless. The patient was also suffering from the lack of quality of life, a fear of suffocating and the absence of any prospect of improvement in her situation.

For the last nine years before her death, the patient, a woman in her seventies, had suffered from a pericardial and pleural effusion. In the last eight years before her death she suffered from heart failure. Her condition was deteriorating gradually and progressively and she suffered from recurrent pleural effusions. A year before her death she was diagnosed with pulmonary hypertension. The patient's condition deteriorated in the months preceding her death. Her condition was incurable. She could only be treated palliatively.

See case 2014-16 on the website for the full text. The patient's suffering consisted of severe shortness of breath brought on by minimal physical exertion. She could no longer do anything and felt powerless. She was bedridden and had become entirely dependent on others for her personal care. The patient was suffering from the lack of quality of life and a fear of suffocating. She was also suffering from the absence of any prospect of improvement in her situation.

The patient experienced her suffering as unbearable. The physician was satisfied that this suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate her suffering that were acceptable to her. The documents made it clear that the physician and the specialists gave her sufficient information about her situation and prognosis. The patient had discussed euthanasia with the physician before.

More than a week before her death, the patient asked the physician to actually perform the procedure to terminate her life. The physician concluded that the request was voluntary and well-considered. The physician consulted an independent physician who was also a SCEN physician. The independent physician saw the patient two days before the termination of life was performed, after he had been informed of the patient's situation by the physician and had examined her medical records.

In his report the independent physician gave a summary of the patient's medical history and the nature of her suffering. He concluded, partly on the basis of his interview with the patient, that the due care criteria had been met.

The physician performed the termination of life on request using the method, substances and dosage recommended in the KNMG/KNMP's Guideline 'Performing euthanasia and assisted suicide procedures' of August 2012.

The committees examine retrospectively whether the physician has acted in accordance with the statutory due care criteria laid down in section 2 of the Act. They consider whether the due care criteria have been complied with in the light of prevailing medical opinion and standards of medical ethics.

In view of the above facts and circumstances, the committee found that the physician could be satisfied that the patient's request was voluntary and well-considered, and that her suffering was unbearable, with no prospect of improvement. The physician gave the patient sufficient information about her situation and prognosis. Together, the physician and the patient could be satisfied that there was no reasonable alternative in the patient's situation. The physician consulted at least one other, independent physician, who saw the patient and gave a written opinion on whether the due care criteria had been complied with. The physician performed the euthanasia with due medical care. The physician acted in accordance with the statutory due care criteria laid down in section 2 (1) of the Act.

## SUBSTANTIATED REPORT

CASE 2014-23 (NOT INCLUDED HERE)

## VOLUNTARY, WELL-CONSIDERED REQUEST

## CASE 2014-25

In this case, the patient's state of reduced consciousness was medically induced and therefore, in principle, reversible. It is the committees' view that it would be inhumane in such cases to reverse the patient's state of reduced consciousness solely for the purpose of having him confirm the unbearable nature of his suffering. In such a situation, therefore, the physician may perform euthanasia if the patient had requested it previously, either orally or in an advance directive. For more information on reduced consciousness, see pages 29 ff of the Code of Practice. See case 2014-25 on the website for the full text.

FINDING: due care criteria complied with

DUE CARE CRITERION: voluntary and well-considered request

**KEY POINT:** reduced consciousness

SUMMARY: The patient, a woman in her fifties who was suffering from metastasised uterine cancer, was suffering from severe shortness of breath. She had indicated orally and in writing that if she were to be sedated for that reason, she wanted euthanasia. On the day of her death, the patient's situation had deteriorated, and she asked for euthanasia to be performed as soon as possible. Several hours before performing euthanasia the physician administered midazolam, and the patient said she did not want to wake up again. Eventually she fell into a restless sleep. In accordance with the patient's euthanasia request and her signed directive concerning her wish for euthanasia in the event of reduced consciousness, the physician then performed the procedure for termination of life.

About a year before her death, the patient, a woman in her fifties, was diagnosed with uterine leiomyosarcoma. The patient underwent surgery, but six months before her death pulmonary and peritoneal metastases were discovered. Her condition was incurable. She could only be treated palliatively.

The patient's suffering consisted of severe dyspnoea, despite maximum therapy, as a result of tumour growth in her lungs. The patient could only sit up straight and was unable to rest. Because she was coughing a lot, she was not sleeping well. She became increasingly exhausted. In addition she was suffering from severe oedema. After she had coughed up blood several times, the patient became afraid of suffering a fatal pulmonary haemorrhage. The patient experienced her suffering as unbearable. She wanted to be allowed to die with dignity. The patient had discussed euthanasia with the physician before.

Around two and a half weeks before her death, the patient asked the physician to actually perform the procedure to terminate her life. She repeated her request several times. The physician concluded that the request was voluntary and well-considered.

The physician twice consulted the same independent physician who was also a SCEN physician. In the first consultation, the independent physician saw the patient two weeks before the termination of life was performed, after having been informed of the patient's situation by the physician and examining her medical records.

In the report the independent physician gave a summary of the patient's medical history and the nature of her suffering. At the time of the independent physician's visit, the patient said she was not yet suffering unbearably. However, if the shortness of breath and pain became more severe, and she became dependent, that would be the limit for her. If she needed to be sedated in connection with dyspnoea or a haemorrhage, she also wanted euthanasia. In the first report, the independent physician concluded, partly on the basis of the interview with the patient, that the due care criteria had not yet been met.

On the day of the patient's death, the physician consulted the independent physician again, by telephone. The physician informed the independent physician of the deterioration in the

patient's condition. The physician said that the patient was bedridden and no longer able to speak or sleep due to the dyspnoea. The physician said that the patient had asked that day for euthanasia to be performed as soon as possible.

In the second report, the independent physician concluded, partly on the basis of the conversation with the physician, that the due care criteria had been met.

Several hours before performing the termination of life procedure, the physician administered 15mg of midazolam because the patient was having severe difficulty breathing. The patient indicated that she absolutely did not want to wake up again. Half an hour later, the patient was somewhat drowsy, but could still communicate. Around two hours after the first dose, the patient was given another 15mg of midazolam. She then fell into a restless sleep. The patient was gasping for breath, looked ashen and was sitting with her upper body bent half forward. In accordance with the patient's euthanasia request and her signed directive concerning her wish for euthanasia in the event of reduced consciousness, the physician performed the termination of life on request around an hour and a half after administering the second dose of midazolam, using the method, substances and dosage recommended in the KNMG/KNMP's Guideline 'Performing euthanasia and assisted suicide procedures' of August 2012.

In view of the above facts and circumstances, the committee found that the physician could be satisfied that the patient's request was voluntary and well-considered.

#### CASE 2014-89 (NOT INCLUDED HERE)

## UNBEARABLE SUFFERING WITHOUT PROSPECT OF IMPROVEMENT

#### CASE 2014-02 (NOT INCLUDED HERE)

## CASE 2014-36

FINDING: due care criteria complied with

DUE CARE CRITERION: unbearable suffering without prospect of improvement

**KEY POINT:** medical dimension to suffering

SUMMARY: The patient, a man in his eighties, felt that life had nothing more to offer him. A registered general psychologist who was consulted concluded that he had a consistent wish for euthanasia. The patient's suffering was caused by geriatric syndromes which caused increasing debilitation. Due to his functional decline and dependence on others, the patient no longer considered his life meaningful. Living in this way was more than he could bear. The physician and the independent physician established satisfactorily that the patient's suffering had a medical dimension and that this was palpably unbearable. There were no reasonable alternatives available.

Due to his advanced age, the patient, a man in his eighties, was suffering from a combination of physical symptoms and the feeling that life had nothing more to offer him. The patient and his wife had been together for many years. The bond between them had been extremely close and they needed no one else. They had no children. The patient had cared for his wife for years when she was ill. That had given him a final purpose in life. Around six months before

As noted on pages 13, 31 and 32 of the Code of Practice, the patient's suffering must have a medical dimension. It may be the result of an accumulation of serious and minor health problems. See case 2014-36 on the website for the full text. his death, his wife died and from then on he lost interest in the world. He had always been a loner. He had never had any real friends and he felt like an outsider.

The patient could no longer follow the radio or television. He also no longer internalised anything he read. The patient was tired and felt drained, and no longer wanted to do anything. His motor skills were deteriorating, partly as a result of arthrosis and osteoporosis. He was having difficulty walking and his hands had become clumsy, which meant he could no longer perform certain actions, such as making a sandwich. The patient was afraid he would end up in a wheelchair and become even more dependent. He also had urinary problems and always wore incontinence pads. The patient did not want any more psychosocial support or involvement with others. His condition was incurable. There were no more treatment options.

The patient's suffering consisted of the feeling that continuing to live this way was completely devoid of meaning and quality. He was increasingly debilitated due to old age, and could no longer do very much. But his suffering was mainly made unbearable by the feeling that he had nothing more to expect from life. The patient regarded his life as completed. He experienced his suffering as unbearable.

The patient had discussed euthanasia with the physician before. More than two months before his death, the patient asked the physician to actually perform the procedure to terminate his life. The physician had known the patient for many years and understood the patient's perspective. On the independent physician's advice, the patient spoke several times with a registered general psychologist, who concluded that the patient's wish was consistent.

At the request of the committee, the physician gave a further, oral explanation concerning the question of whether the unbearable nature of the patient's suffering could to a sufficient degree be found to be caused by a recognised disease or medical condition.

In the last few years of his life, the patient could hardly do anything anymore. He was suffering from osteoporosis. He was in pain from vertebral compression fractures. He fell frequently, causing large haematomas. Following a CVA one year before his death, the left side of his body was partially paralysed. He suffered from frequent headaches. He had decreased kidney function, which made it difficult to treat the pain with medication. The patient suffered from urinary incontinence. He could only walk a few steps, partly due to arthrosis of the knee. He also suffered from atrial fibrillation. The patient's eyesight was poor and he could no longer read. The patient's mental health was good.

His wife had been his reason for living. His loyalty and devotion to her had kept him going, despite all his physical problems. He had looked after her as long as he could, even though she no longer recognised him because she was suffering from Alzheimer's disease. After her death, the patient regarded his life and suffering as meaningless.

The physician was convinced that this suffering was unbearable to him and that there was no prospect of improvement. The unbearable nature of his suffering, which was palpable to the physician, was caused by untreatable pain, incontinence, a high risk of falling, increasing disability, loss of autonomy and dependence on care. He had been suffering for some time, but after his wife's death (they had no children) the patient could not and did not want to go on.

At the request of the committee, the independent physician gave a further, oral explanation. The independent physician thought the patient was a very nice man who was easy to talk to. However, the patient did not want close social contacts. This was partly due to his physical disabilities, such as deafness and impaired eyesight. His motor skills were deteriorating and he could hardly walk at all. He rarely went outside. Incontinence also contributed to his considerable disability. After the patient's wife died, he requested euthanasia. When the independent physician first visited him, the patient said that he wanted to see his next birthday before dying. The independent physician then wanted to know how consistent the patient's wish was. The patient subsequently spoke with a registered general psychologist several times. During his second visit to the patient, the independent physician became convinced that the patient really wanted euthanasia. He certainly found the patient to be decisionally competent. After his wife's death, the patient wanted no more involvement with others in the form of care, therapy or family visits. He did not want to be dependent on other people.

The independent physician was satisfied that the patient's suffering had a physical component, but believed that the patient's personality certainly contributed to the way he experienced his suffering.

The committee considered whether the unbearable nature of the patient's suffering was to a sufficient degree caused by a recognised disease or medical condition. After reading the patient's medical record and speaking to the physician and the independent physician, the committee concluded that the patient's suffering was caused by geriatric syndromes which caused increasing debilitation. These aging-related conditions, including arthrosis of the knee, pain from vertebral compression fractures caused by osteoporosis, headaches, poor kidney function, incontinence, impaired vision, atrial fibrillation and hemiparesis following a CVA, were closely related to the medical domain. After the patient's wife died, he felt his life no longer had any meaning. He had felt his suffering was unbearable for some time, but he had kept on going to support his wife in her illness.

Due to his functional decline and increasing dependence on others, and in view of his past life and personal values, the patient could no longer give his life meaning. Living in this way was more than he could bear. The committee found that the physician and the independent physician had established satisfactorily that the patient's suffering had a medical dimension and that it was palpably unbearable. There were no reasonable alternatives available.

## **INFORMING THE PATIENT**

No cases concerning this due care criterion have been included here. See, for instance, *case* 2014-02.

## NO REASONABLE ALTERNATIVE

CASE 2014-05 (NOT INCLUDED HERE)

## CONSULTING AN INDEPENDENT PHYSICIAN

CASE 2014-56 (NOT INCLUDED HERE)

## CASE 2014-47

FINDING: due care criteria complied with

DUE CARE CRITERIA: voluntary and well-considered request, no prospect of improvement, unbearable suffering, consulting an independent physician

KEY POINTS: simultaneous performance of euthanasia on a couple, voluntary request, medical dimension, independent physician's opinion

SUMMARY: A married couple requested simultaneous assisted suicide. The female patient had substantial medical problems and physical disabilities. She was dependent on care, which in the past had always been provided by her husband. He too had severe health problems and would have euthanasia performed soon. The physician was able to conclude that in view of the patient's past life, her close relationship with her husband and the lack of a social network of her own, the prospect for this patient of a life in which she would be dependent on other people for her physical care, probably in a nursing home, meant unbearable suffering without prospect of improvement. The suffering had a predominantly medical dimension.

In the event of simultaneous euthanasia requests by a couple, the physician must consider carefully whether it is preferable to consult one independent physician for both partners or a separate independent physician for each. If one independent physician is asked to assess both requests, that physician will have to be extra alert to the question of whether he is able to form an independent judgment in both cases. In principle, the independent physician will have to speak with each partner separately. In this particular case the physician consulted the same independent physician for both euthanasia requests. The independent physician believed he was capable of forming an independent judgment in each case. However, he did not speak to the patient and her husband separately. Particularly in view of the patient's dependence on her husband, it would have been better if the independent physician had done so. Nevertheless, partly in view of the findings of a psychiatrist consulted on the matter, there is no reason to doubt the accuracy of the independent physician's conclusions.

\* This concerns two separate notifications, which were reviewed separately. The finding described here concerns only the notification of the woman's assisted suicide.

In 2014, as in 2013 (see 2013 annual report, case 9), the committees received several notifications of cases in which euthanasia had been performed simultaneously on a couple. In all these cases, the committee found that the due care criteria had been complied with. For information on voluntary and well-considered requests see page 11 of the Code of Practice, on unbearable suffering without prospect of improvement see page 13 and on the independent physician see page 16. See *case 2014-47* on the website for the full text.

More than 25 years before her death, the patient, a woman in her eighties, had suffered a brainstem stroke. Despite lengthy rehabilitation, she continued to have difficulty walking, even when using a rollator. Five years before her death, the patient was diagnosed with osteoporosis, with various vertebral compression fractures, severe arthrosis of the knee and a rotator cuff tear in the right shoulder. As a result, walking became even more difficult. Two years before her death, a heart valve was found to be defective and she was thought to have aortic sclerosis. Over the years, the patient suffered several TIAs and lost more and more weight. Eventually she only weighed 45kg. The patient also suffered from hypertension and presbycusis. Her condition was incurable. She could only be treated palliatively.

In addition to her having to live with her many medical problems and her physical disabilities, the patient suffered because of the knowledge that she was not self-reliant and that when her husband died (he had severe health problems and was to have euthanasia performed soon), she would be dependent on other people and would probably have to go into a nursing home. For many years, partly due to residual symptoms of the brainstem stroke, the patient had to some extent been dependent on her husband's care and had developed a symbiotic relationship with him. The patient had still been living with her parents when they married and had lived abroad with her husband for a long time. They had always done everything together. One time when she had to spend a couple of weeks alone, which had been necessary in connection with her husband's job, she had found it disastrous. She did not want to go through that again. A life without her husband, in which she would be dependent on care provided by other people, was inconceivable for her. The patient, who had no children and had not built up her own social network, experienced her current and expected suffering as unbearable. The patient had on several occasions discussed her wish for euthanasia in the event of her husband's death with the physician.

One day before her death, the patient asked the physician to actually perform the procedure to terminate her life, almost immediately after her husband had made the same request for himself. The patient later repeated her request.

At the request of the physician a psychiatrist assessed whether the patient's request was influenced by a psychiatric disorder or dementia and whether she was decisionally competent with regard to her request. The psychiatrist established that the patient's wish for euthanasia was palpable and could be explained in view of her intensive and dependent relationship with her husband, as well as her life prospects without her husband due to her severe motor disability. Her wish was not caused by an irrational fear of the future or depression. It was not based on loyalty to her husband, nor was she influenced by him. According to the psychiatrist the patient concluded independently that she did not want to go on living and that her wishes were consistent. The psychiatrist concluded that the patient had no psychiatric symptoms and that she was decisionally competent in relation to her request. The physician concluded that the request was voluntary and well-considered. He established that the patient was not depressed and that she had not been influenced by her husband. The physician felt this was supported by the psychiatrist's findings. The independent physician concluded in his report, partly on the basis of his interview with the patient, that the due care criteria had been met.

At the committee's request, the physician gave an oral explanation, in which he stated that the euthanasia process had been very rapid. While the physician was on holiday, the patient's husband's condition had deteriorated very fast. He had been admitted to hospital, probably with sepsis. When his condition had improved slightly, his attending physicians told him his lower leg had to be amputated, otherwise he could develop sepsis again very quickly, within one or two weeks. The patient's husband refused to have his lower leg amputated, however. When the physician returned from his holiday, the husband had a 'volcano' in his foot.

The patient's husband was used to being in charge. Over the years, the patient had said on several occasions that she did not want to be left behind on her own and asked the physician to help her if this was imminent. The physician had told her he would probably be unable to do anything for her. He hoped that she would die before her husband. When the physician returned from holiday the patient said she could not bear the new situation. She had seen with her own parents what happened to the surviving partner when the other one died. The physician concluded that the patient had her own substantial medical problems. When her husband died she would no longer have anyone to help her. She was already practically fully dependent on care due to her physical complaints. This dependence was a nightmare scenario for the patient.

With regard to the symbiotic relationship between the patient and her husband, the physician said that it was not the case that one partner dominated the other. The patient's husband had not influenced her.

When asked about the matter, the physician explained that there had been no time to find different independent physicians for the patient and her husband. He had not considered doing so either. The physician was of the opinion that it would only be necessary to consult two separate independent physicians in exceptional cases. He thought it was up to the independent physician, in such cases, to identify that necessity. The physician believed it would have been possible for the independent physician to assess both the patient's case and her husband's and then make a negative recommendation concerning one of them. He would have been able to do that himself. When the physician was driving to meet the couple he'd thought, 'This is the right thing to do'.

At the committee's request, the independent physician gave an oral explanation, which included the following. When asked about the matter, the independent physician said the symbiotic relationship between the patient and her husband formed the basis of the patient's suffering. He met the patient and her husband at the hospital where the husband had been admitted. He did not speak to them separately because the room in the hospital was not suitable for that. The husband did the talking. The patient gave the impression she was fully dependent on him. All their lives the couple had been focused on each other. They had both signed an advance directive years ago. Their requests for assisted suicide were linked. The independent physician remarked that during their meeting the patient was focused on her husband, but did answer the independent physician without involving her husband. It was easy to get her attention. The independent physician had not considered involving a second independent physician.

The independent physician described the patient's dependence. The patient was certainly physically dependent on care as a result of the residual symptoms of the CVA. The independent physician confirmed that the patient's wish to die was voluntary and not influenced by external factors. Her wish to die was very clear. The independent physician was satisfied that she was able to make that choice herself. The underlying reason was her husband's illness. He did not decide for her that she had to die too. Within the framework of his illness, she had made her own choice. When asked about the matter, the independent physician explained that in the event of a new, comparable case he would reach the same conclusion. He would, however, want to speak to the two partners separately, but in this case the circumstances had not allowed it.

In view of the above facts and circumstances, the committee found that the physician could be satisfied that the patient's request was voluntary and well-considered. The patient had discussed her wish for euthanasia in the event of her husband's death with the physician on several occasions and had been very consistent about it. Partly in view of the findings of the abovementioned psychiatrist, the committee was also satisfied that the patient had come to her own conclusions and had not been influenced by her husband.

The committee also considered with regard to the patient's suffering that it was sufficiently clear from her medical record and the oral explanations given by the physician and the independent physician that she was suffering from serious medical problems and physical disabilities. As a result she was dependent to a great extent on other people for care. Her husband had always provided that care. The committee found that the physician could conclude that in view of her past life, her close relationship with her husband and the lack of a social network of her own, the prospect for this patient of a life in which she would be highly dependent on other people for her physical care, probably in a nursing home, meant

unbearable suffering without prospect of improvement. In the opinion of the committee, her suffering had a predominantly medical dimension. The physician had informed the patient sufficiently about her situation and her prognosis. Together, the physician and the patient could be satisfied that there was no reasonable alternative in the patient's situation. With regard to the requirement that the physician must have consulted at least one other, independent physician, the committee considered as follows. In the event of simultaneous euthanasia requests by a couple, the committee deems it important for the physician to consider carefully whether it is preferable to consult one independent physician for both partners or a separate independent physician for each.

If, after deliberation, the conclusion is that one independent physician will be asked to assess both requests, that physician will have to be extra alert to the question of whether he is able to form an independent judgment in both cases. After all, such situations can be tricky. The independent physician can find himself in a difficult situation if he finds that the due care criteria have been met in one case, but not in the other. In principle, the independent physician will have to speak with each partner separately to establish whether all the due care criteria have been met.

The committee noted that the physician consulted one independent physician with regard to both requests for euthanasia. This independent physician visited the patient and her husband at the same time. There was one interview between the independent physician and the couple, and on the basis of that interview the independent physician concluded in two separate reports that the due care criteria had been met. The independent physician did not speak to the patient and her husband separately. The committee concluded from his further, oral explanation that the independent physician deemed himself capable of making an independent judgment in both cases. In view of the above considerations and in particular of the patient's dependence on her husband and the possibility that he might have influenced her wish for euthanasia, the committee believes it would have been better if the independent physician had spoken with each partner separately. Taking into account the findings of the aforementioned psychiatrist, who did speak with the patient without the husband present and who discussed the possibility of her being influenced by her husband in his report, the committee nonetheless in this case saw no reason to doubt the accuracy of the independent physician's conclusions. The committee found that the physician had fulfilled the requirement of consulting at least one other, independent physician.

## DUE MEDICAL CARE

CASE 2014-04 (NOT INCLUDED HERE)

## **PSYCHIATRIC DISORDERS**

For points to consider regarding patients with a psychiatric disorder, see pages 26 ff of the Code of Practice. See case 2014-01 on the website for the full text.

## CASE 2014-01

FINDING: due care criteria not complied with

DUE CARE CRITERIA: voluntary and well-considered request, no prospect of improvement, unbearable suffering, no reasonable alternative, consulting an independent physician

KEY POINT: psychiatric disorder

SUMMARY: The patient, a woman in her eighties, had been suffering from depression for around 30 years. She had been treated with electroconvulsive therapy (ECT) and antidepressants. When these became ineffective, the patient declined further treatment. The patient's general practitioner did not want to comply with her euthanasia request. She then turned to another physician, who was also a general practitioner, who spoke with the patient in the presence of her children on two occasions in quick succession, not long before her death. He consulted a SCEN physician who was also a general practitioner as the independent physician.

The committee found that the notifying physician had not exercised the degree of caution that may be expected in the case of a psychiatric patient who requests assisted suicide. In this case the physician should have taken more time to talk to the patient, and should have spoken to her without her children present. As both the physician and the independent physician lacked psychiatric expertise, the physician should have consulted an additional expert.

The patient, a woman in her eighties, had been suffering from depression for around 30 years. While in the earlier years periods of depression sometimes alternated with manic episodes, in later years she suffered only from chronic melancholic depression, which became more severe in the last two to three years. Between ten to eight years and three to two years before her death, the patient received extensive electroconvulsive therapy and was treated with antidepressants. In the early years these treatments had brought temporary relief. When the ECT treatment ceased to be effective and began causing memory problems, and when subsequently the antidepressants ceased to work, the patient declined these treatments. From then on she only took paracetamol and a sleeping tablet. The patient was briefly admitted to a care home, but she did not like it at all. She felt she had to make a huge effort to become part of the group, and she was unable to do that. In addition, the home was due to be demolished at some point, which was not a reassuring thought. The patient's suffering consisted of the fact that she no longer derived any pleasure at all from life, did not want her children or grandchildren to visit and was scared of everything. She was afraid to get up and afraid to go to bed, felt exhausted all day and did not have the energy to do anything. She had no hobbies; she just sat on the sofa all day. When she turned on the television she was unable to follow the programme. She saw nobody except her children. She was afraid to go outside because she feared the questions she might be asked. She was always worrying, had headaches (her head felt like a block of concrete), and suffered from palpitations and poor appetite. In the three years before her death she had lost 26kg in weight. The patient felt trapped in her home and in her body. She experienced her suffering as unbearable.

The patient had discussed euthanasia with her general practitioner before and signed an advance directive. As her general practitioner did not want to comply with her euthanasia request, she was registered with the End-of-Life Clinic (SLK) about a year before her death.

The SLK physician contacted the patient's general practitioner. Around three weeks before her death, the patient asked this physician to actually perform the procedure to terminate her life. She then repeated her request.

In an interview with the committee, the physician gave a further, oral explanation, which included the following. The medical record includes correspondence from a clinical geriatrician, dating from the year of the patient's death, a letter from a nurse practitioner at a psychiatric centre, dated two years before her death and a letter from a psychiatrist at the same psychiatric centre, dated eight years before her death, all of which the physician had been able to take note of. The patient had suffered from depression since menopause. She had been treated by psychiatrists for years with both medication and ECT treatment. In the three years before her death these treatments had ceased to be effective. The patient did, however, suffer memory loss as a result of the ECTs. The patient considered the ineffectiveness of these therapies and their side-effects sufficient reason to decline further treatment. Based on his own experience and on the outcome of the multidisciplinary consultation at the End-of-Life Clinic, the physician was in no doubt that the patient could no longer be treated and was decisionally competent, and that granting her euthanasia request could be considered.

The physician did not consider consulting a second expert in addition to the SCEN physician. The SCEN physician had agreed that the patient could no longer be treated, was suffering unbearably and was not suicidal, but decisionally competent. The physician said he was not familiar with the guidelines of the Dutch psychiatry association (Nederlandse Vereniging voor *Psychiatrie*) on dealing with requests for assisted suicide from patients with a psychiatric disorder. He considered depression to be a chronic disease and did not see why it would be necessary to consult an additional independent physician who was also a psychiatrist for a patient with depression. The physician explained that he had spoken on the phone with the patient's general practitioner. During that conversation, he understood that relations between the general practitioner and the patient were not good and that the general practitioner thought the patient was being overly dramatic. According to the general practitioner, the patient's wish for euthanasia was not sufficiently palpable for him to grant it. A close family member subsequently registered the patient with the End-of-Life Clinic. Around six months before her death, the patient was referred by her general practitioner to a clinical geriatrician, at the recommendation of the End-of-Life Clinic. The clinical geriatrician had been involved in the period before the SLK physician had been in contact with the patient. The physician had however spoken to the clinical geriatrician on the phone.

When asked about the matter, the physician explained that he had spoken with the patient twice, once more than three weeks before her death and again three days later. The first time they spoke, two of the patient's children had been present and the second time two other children of the patient's. On neither occasion did he speak with the patient in private. The children had not joined in the conversation, however, except when he asked them to.

With regard to the voluntary and well-considered nature of the request, the absence of any prospect of improvement, and the independent assessment criterion, the committee considered as follows. In the event of a request for euthanasia or assisted suicide from a psychiatric patient, it is important to consult not only the independent physician but also one or more other physicians, including a psychiatrist, who can give an expert opinion on, among other things, the patient's decisional competence and whether the patient's suffering is without prospect of improvement. Assessing the decisional competence of such a patient, including a patient with chronic melancholic depression as in this case, requires special expertise. The same applies to being able to answer the question of whether any treatment options remain, despite the patient's past medical history.

The notification details provided by the physician and the oral explanation he gave the committee did not demonstrate to the committee that he was sufficiently aware of this. He was not familiar with the guidelines of the Dutch psychiatry association on dealing with requests for assisted suicide from patients with a psychiatric disorder. Although he had taken note of correspondence from a psychiatrist dated eight years before the patient's death and correspondence from a mental health institution dated two years before her death, he did not consult a psychiatrist himself to verify whether there were currently any treatment options and whether the patient's request for euthanasia might be provoked by melancholic depression. The most recent correspondence found in the medical record was from a clinical geriatrician and consisted of advice concerning treatment. The contact by telephone with this expert two weeks before the patient's death can only partly be viewed as consulting an expert as part of a euthanasia process. The physician's explanation that he had not considered consulting a second independent physician because the SCEN physician had reached the same conclusion as he had, i.e. that the patient was decisionally competent, shows an underestimation of the requirements that an adequate assessment of the euthanasia request of a psychiatric patient must meet. This is especially relevant given that both he and the SCEN physician were general practitioners and as such had no specific psychiatric expertise. In this specific case, the committee also observed that the physician spoke with the patient only twice within a very short timeframe and that the period between those conversations and the assisted suicide was very short. Moreover, those conversations both took place in the presence of her children and the physician did not speak with the patient in private.

By proceeding in this way, the physician was unable to demonstrate satisfactorily that he had been able to form a sufficiently substantiated opinion, not only with regard to the question of whether any treatment options remained, but also, and in particular, with regard to the consistent, voluntary and well-considered nature of a request made by such a patient, who apparently experienced frequent changes in her moods and emotions (she had recently been suicidal, but had also greatly enjoyed a holiday two years previously).

The committee found that the physician had not exercised the degree of caution that may be expected in the case of a psychiatric patient who requests assisted suicide. He should have taken more time to speak with the patient (privately, as well as in her children's presence) and especially, since both he and the independent physician lacked psychiatric expertise, he should have consulted an additional expert, to ascertain in particular whether the patient was decisionally competent in relation to her request for assisted suicide.

The physician did *not* act in accordance with the statutory due care criteria laid down in section 2 (1) of the Act.

## CASE 2014-70

For points to consider regarding patients with a psychiatric disorder, see pages 26 ff of the Code of Practice. See case 2014-70 on the website for the full text. FINDING: due care criteria complied with

DUE CARE CRITERIA: voluntary and well-considered request, no prospect of improvement, unbearable suffering, no reasonable alternative

KEY POINT: psychiatric disorder

SUMMARY: The patient, a woman in her thirties, suffered from borderline personality disorder, post-traumatic stress disorder and a tendency to dissociate and self-harm that was related to the personality disorder. She also felt depressed, without suffering from clinical depression. The patient had spent years in psychiatric institutions in connection with suicide attempts, self-harm, feelings of depression, depersonalisation and helplessness. She underwent all treatments offered to her, but the symptoms did not improve. The physician, her attending psychiatrist, requested a second opinion from another psychiatrist. The second psychiatrist concluded that the patient's request was voluntary and well-considered, that her suffering was unbearable, and that there was no prospect of improvement. The independent physician confirmed the physician's assessment that the due care criteria had been complied with.

The patient, a woman in her thirties, suffered from borderline personality disorder, posttraumatic stress disorder and a tendency to dissociate and self-harm related to the personality disorder. She also felt depressed, without suffering from clinical depression.

In the 20 years before her death, the patient had spent 14 years in psychiatric institutions in connection with suicide attempts, self-harm, and strong feelings of depression, depersonalisation and helplessness. During that long period in the institutions there was no real improvement in her symptoms and her ability to function socially deteriorated rather than improved. She then moved to sheltered housing, where she was treated by a clinical psychologist/psychotherapist, a mental health nurse and the physician, a psychiatrist. In that period she received EMDR therapy, emotion regulation skills training, a stabilisation course and day treatments focusing on structure, and she was admitted several times, for instance to adjust her medication. She underwent all treatments offered to her, and made every effort to engage with therapy, but the symptoms did not improve.

About a year before her death the patient attempted suicide. After that she made a request for euthanasia to her attending physicians, including the notifying physician. The patient was then treated with lithium and quetiapine, but this did not have the desired effect. An intensive treatment was suggested for her personality disorder, but treatment was not possible in a setting that was feasible to the patient.

According to the physician, the patient had received all the necessary treatments focused on reducing the symptoms or gaining more control over them, but they had had no effect and in any event had not relieved her suffering. The physician requested a second opinion from another psychiatrist, who confirmed that the relevant treatments had been given. The patient's suffering consisted of almost constant tension, severe problems with emotion regulation and the reliving of events, such as bullying, which she was unable to manage and which overwhelmed her. She experienced feelings of emptiness and dissociation. She suffered from inner pain and reliving deep and severe traumas. She also suffered from nightmares and the noises in her head; as a result she never had any rest and had become exhausted. The patient felt inferior and was unable to correct her self-image. She often experienced contact with other people as a threat and everyday life to her was a constant, almost impossible challenge. She felt powerless to change her situation. She coped with stress and feelings of emptiness by self-harming. She also suffered from eating problems and compulsive thoughts and actions.

The patient had wanted to die for a very long time and had expressed that wish consistently over the past years. After she had decided not to commit suicide, she discussed euthanasia with the physician for the first time, eight months before her death.

A month and a half before her death, the patient asked the physician to perform the procedure to terminate her life. More than a month before the patient's death, the physician requested a second opinion from another psychiatrist. After examining the patient, the second psychiatrist concluded that the patient's request was voluntary and persistent, and that it was based on suffering experienced as unbearable, as a result of a psychiatric disorder that was without prospect of improvement in terms of treatment. According to the psychiatrist, the patient grasped the consequences of her request. After examining the medical record, the psychiatrist was satisfied that the relevant treatments had taken place. The patient's family backed her request and the psychiatrist believed that her request could be fulfilled.

The physician found that the patient was decisionally competent and the request was voluntary and well-considered. He was also satisfied that the patient's suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion.

The committee noted that physicians must exercise particular caution when dealing with a euthanasia request from a patient suffering from a psychiatric disorder. It found that in the case under review the physician did so. In addition to the SCEN physician, the physician consulted another psychiatrist, who gave his opinion on the patient's decisional competence and concluded that there were no relevant treatment options left. The patient was able to understand the consequences of her decision, her wish was consistent and it had existed for a long time.

The independent physician confirmed the physician's assessment that the statutory due care criteria had been complied with and that the patient's suffering was without prospect of improvement, particularly after a life in psychiatric institutions; he further confirmed that her wish had existed for a very long time and was well-considered, and that there were no longer any real alternatives in her situation.

## CASE 2014-72

For points to consider regarding patients with a psychiatric disorder, see pages 26 ff. of the Code of Practice. See case 2014-72 on the website for the full text. FINDING: due care criteria complied with

DUE CARE CRITERIA: voluntary and well-considered request, no prospect of improvement, unbearable suffering, no reasonable alternative

KEY POINT: psychiatric disorder

SUMMARY: In her youth the patient, a woman in her sixties, had had a traumatic experience and had been emotionally neglected and mentally abused. She was diagnosed with a personality disorder with borderline characteristics. The patient was treated by a psychiatrist and a psychologist. Eight years before her death, the patient developed severe pain as a result of a herniated disc. Even after surgery the pain never disappeared completely. In the years that followed she had recurrent periods of depression and was suicidal. The patient underwent all the treatments in the depression protocol, but to no lasting effect. Her attending physicians were not willing to fulfil her wish for euthanasia. The notifying physician, who was affiliated with the End-of-Life Clinic (SLK) and who was not a psychiatrist, consulted a psychiatrist/SCEN physician and a non-practising general practitioner/SCEN physician as independent physicians. The physician exercised great caution: on the one hand he consulted various attending physicians (a general practitioner, psychiatrist and registered general psychologist) and the patient's family, and on the other he consulted an independent psychiatrist to ascertain whether there were any realistic treatment options left and to establish whether the patient was decisionally competent in relation to her request for euthanasia.

In her youth the patient, a woman in her sixties, had had a traumatic experience and had been emotionally neglected and mentally abused. Twenty-three years before her death, she was diagnosed with a personality disorder with borderline characteristics. For several years around that period, the patient received outpatient treatment from a psychiatrist and a psychologist. She also took medication. The effects of these treatments were reasonably successful. The patient then experienced a relatively calm period lasting a decade, in which she did not seek psychiatric treatment, despite some angry outbursts and self-harm. Eight years before her death, the patient started to experience severe pain as a result of a lumbar disc herniation. She underwent surgery and was given pain relief. The pain never disappeared entirely, however. From that period onwards, the patient never felt well again. In the years that followed, the patient suffered from recurrent periods of severe depression and attempted suicide four times using medication. All four attempts were thwarted, against her wishes. One year before the patient's death, it was established that she was chronically and persistently suicidal, as a result of a severe personality disorder combined with recurrent periods of depression. The patient underwent all the treatments in the depression protocol, including electroconvulsive therapy, but to no lasting effect. She also received talk therapy. Her condition was incurable.

The patient's medical history also included skin carcinomas on her legs, which occurred two years before her death and for which she received appropriate treatment.

The patient's suffering consisted of complete exhaustion as a result of profound depressions, and pain and disability as a result of the herniated disc. Nothing interested her anymore. She no longer had the energy to watch television or read. She had to rest due to the exhaustion and the pain, but in those moments of rest she would start to worry. Every day was too much for her. She also suffered from the knowledge that there was no prospect whatsoever of improvement in her situation.

The patient had discussed euthanasia with several attending physicians before and also asked them to actually perform euthanasia. The last attending physicians did not want to fulfil her request, for reasons of their own. The patient subsequently registered with the End-of-Life Clinic about a year before her death. Four months before her death, the patient made her request to a psychiatrist from the clinic. More than six weeks before her death, the patient asked the physician, who was not a psychiatrist, to actually perform the procedure to terminate her life. She repeated her request during the next two visits by the physician and in telephone conversations.

The physician consulted two independent SCEN physicians, one of whom was an independent psychiatrist. The first independent physician – the independent psychiatrist – saw the patient four days before the termination of life was performed, after she had been informed of the patient's situation by the physician and had examined her medical records.

In her report the first independent physician gave a summary of the patient's medical history and the nature of her suffering. She also observed depressive characteristics during the interview. The independent physician concluded, partly on the basis of her interview with the patient, that there were no further alternative treatment options that would have a realistic chance of benefiting the patient. The patient was decisionally competent in relation to her request for euthanasia.

The second independent physician – a non-practising general practitioner – saw the patient two days before the termination of life was performed. He had previously been informed of the patient's situation by the physician and had examined her medical records, including the findings of the first independent physician. In his report the second independent physician gave a summary of the patient's medical history and the nature of her suffering. According to the second independent physician, the patient responded appropriately and her answers were clear. The patient was decisionally competent in relation to her request for euthanasia. The second independent physician concluded in his report, partly on the basis of his interview with the patient, that the due care criteria had been met.

In the event of euthanasia for a psychiatric patient, it is important to consult not only the independent physician but also one or more physicians, including a psychiatrist, who can give an expert opinion on, among other things, the patient's decisional competence and whether the patient's suffering is without prospect of improvement.

The documents provided by the physician made it sufficiently clear to the committee that he had exercised great caution. The physician consulted various attending physicians (a general practitioner, psychiatrist and registered general psychologist) and the patient's family; he also consulted an independent psychiatrist to ascertain whether there were any realistic treatment options left and to establish whether the patient was decisionally competent in relation to her request for euthanasia.

## CASE 2014-37 (NOT INCLUDED HERE)

## DEMENTIA

#### CASE 2014-03 (NOT INCLUDED HERE)

## CASE 2014-35

FINDING: due care criteria complied with

DUE CARE CRITERIA: voluntary and well-considered request, consulting an independent physician

KEY POINTS: dementia, role of the advance directive

SUMMARY: The patient, a woman in her seventies, suffered from Alzheimer's disease. The physician and the patient had repeatedly discussed euthanasia ever since she was diagnosed. The patient had drawn up a detailed and updated advance directive, with a provision on dementia. Right until the end she was able to express her euthanasia request to the physician, though not necessarily in words. The patient's suffering as observed by the physician matched what she had previously described orally and in the advance directive as unbearable to her. The patient could not express her request orally to the independent physician, but the independent physician was able to rely on the advance directive. The physician could be satisfied that the patient's request was voluntary and well-considered, and that her suffering was unbearable without prospect of improvement.

More than a year before her death, the patient, a woman in her seventies, was diagnosed with Alzheimer's disease. Her condition was incurable. She could only be treated palliatively. She was given medication. The patient and her family were supported by a dementia case manager (dementia case managers give professional advice and information and provide support to dementia patients and their families). The patient's cognitive and motor skills deteriorated rapidly. Two months before her death, the patient began receiving personal care at home. At that time the patient also started to go to day care.

The patient's suffering consisted of the fact that she was no longer able to function independently and needed help with everything. She had always been an independent person and the loss of control over her life made her very sad. When day care and home care became necessary, the patient had had enough. She had seen people around her become incapacitated as a result of Alzheimer's disease and she did not want to go through that process herself. The physician had known the patient for years and, partly in view of the patient's personality before her illness, was satisfied that the patient's suffering was unbearable to her. The patient's suffering was without prospect of improvement according to prevailing medical opinion.

The patient had discussed euthanasia with the physician before. Around 10 months before the termination of life was performed, the patient handed the physician an advance directive, including a provision on dementia.

A month before her death, the patient asked the physician to actually perform euthanasia. When speaking to the physician, the patient proved to have an understanding of her illness. She substantiated her request for euthanasia with reasons. The patient subsequently repeated her request to the physician on several occasions.

The physician was satisfied that the patient understood what euthanasia entailed, right up to the end, and that termination of her life was her express wish.

For points to consider regarding patients with dementia, see pages 27 ff of the Code of Practice.

For information on voluntary and wellconsidered requests, see page 11 of the Code of Practice, on patients with dementia, see page 27, on the advance directive see page 23 and on the independent physician see pages 16 ff. See case 2014-35 on the website for the full text. The physician consulted two independent physicians who were general practitioners and independent SCEN physicians. The first independent physician saw the patient two months before the termination of life was performed, after he had been informed of the patient's situation by the physician and had examined her medical records. At that time the patient had not yet requested that euthanasia be performed. In the opinion of the first independent physician, assessment of compliance with the due care criteria was not yet necessary.

The second independent physician saw the patient a month before the termination of life was performed, after she had been informed of the patient's situation by the physician and had examined her medical records. In her report the independent physician gave a summary of the patient's medical history and the nature of her suffering. The second independent physician concluded that the patient understood what euthanasia entailed and that she had requested euthanasia because she had dementia. The independent physician had doubts, however, as to the patient's decisional competence in relation to her current wish to die. The patient was unable to consistently express at what moment in time she wanted euthanasia to be performed. In addition, her understanding of her illness varied depending on the degree of fatigue or agitation and the phase of the disease. The independent physician advised the physician to consult a psychogeriatric physician to have the patient's decisional competence assessed.

Three days after the second independent physician's visit, a psychogeriatric physician visited the patient. According to the psychogeriatric physician the patient understood what euthanasia was and could say that a situation could arise in which she would request euthanasia. The patient was unable to specify what that situation would be. When her children talked about accepting home care and day care, however, she rejected this idea with vehemence and anger. The patient did not make a concrete request for euthanasia and could not remember having done so previously. She did say, however, that there were times when she thought life was no longer worth living and she would rather be dead. She could imagine requesting euthanasia one day.

Partly on the basis of the findings of the psychogeriatric physician, the second independent physician concluded that due to her loss of any concept of time the patient was no longer able to formulate a specific moment when the termination of life procedure was to be carried out. According to the second independent physician, the well-documented advance directive could replace the patient's oral consent. The independent physician concluded, partly on the basis of her interview with the patient, that the due care criteria had been met.

From the notification, it was insufficiently clear to the committee how the physician had ascertained that the patient's suffering was unbearable to her at the time of the termination of life. The committee also had questions about the voluntary and well-considered nature of the patient's request, partly in view of what the psychogeriatric physician and the SCEN physicians said in their reports.

The physician gave an oral explanation, which included the following. The patient was an upper middle class lady who knew exactly what she did and did not want. After she was diagnosed it was already clear to the physician that she would at some point request euthanasia. The physician said that the complicating factor in this patient's case was the fact that at the end she increasingly lost her sense of time. Her wish for euthanasia was clear, but it was not always clear at what moment she wanted her life to be terminated. On a good day she would know when her birthday was and say that she wanted to die on her birthday. On a bad day she would be confused and unable to express this. Moreover, the patient tended to put on a brave face in front of strangers. In the end, the physician found the case to be very clear and was satisfied that the due care criteria had been complied with.
A number of issues were still insufficiently clear to the committee after reading the file and hearing the physician's oral explanation. For instance, the committee wanted to ask the second independent physician some questions about her findings based on her second visit to the patient, at which the physician was also present. In particular, the committee wanted to hear from the second independent physician what her opinion was, after the second visit, regarding the patient's decisional competence, the voluntary and well-considered nature of the request and the unbearable nature of her suffering.

The independent physician gave an oral explanation, which included the following. The committee had noticed in the patient's medical record that the independent physician had visited the patient together with another SCEN physician. This was not apparent from the independent physician's report. When asked about the matter, the independent physician explained that the SCEN physician who had accompanied her worked at the same practice as she did. Although the independent physician had been a SCEN physician for a long time, she had never before had to assess compliance with the due care criteria for a patient with dementia. She wanted to exercise the greatest possible care and she felt supported by the presence of her colleague, who had specific expertise on euthanasia and dementia. The colleague did not take part in the conversation with the patient, but the independent physician and her colleague did discuss the case afterwards. The independent physician had not reported this course of events because she did not think it was relevant to the report. In the end the independent physician based her findings on the conversation with the patient, the conversation with the physician, the medical file, the assessment by the psychogeriatric physician and the patient's advance directive. The provision on dementia (drawn up 10 months before the patient's death) clearly stated what the patient absolutely did not want and what would be unbearable suffering for her. The independent physician was told that at that point the patient was already losing her sense of time. The independent physician could see that the patient was suffering, while the unbearable nature of the suffering was clear to her in part from the way the whole process had gone. The patient's situation matched the situation she had described in her advance directive as never wanting to experience. Her dependence and the loss of autonomy formed the key components of the unbearable suffering. What contributed to the unbearable nature of the suffering was the fear of future suffering; her symptoms were only going to get worse.

The committee initially questioned how the physician had become convinced that the patient's request for euthanasia was voluntary and well-considered and that she was suffering unbearably. It was clear from the file that at the end the patient was no longer able to properly express and substantiate her request orally, partly due to her lack of a sense of time caused by her illness. The oral explanations by the physician and the second independent physician made the course of events clear to the committee. The voluntary and well-considered nature of the request was mainly clear from the fact that the physician and the patient had discussed it from the moment she was diagnosed. The physician documented this process carefully in the patient's medical record. Moreover, at an earlier stage the patient had signed and handed over a detailed advance directive to the physician. The physician also said that the patient was able to indicate her request to the physician right to the last moment, though not necessarily in words. According to the physician this is not uncommon in patients with dementia. Under stress and social pressure, and as a result of fluctuations in the severity of symptoms, their decisional competence and/or communication skills may vary. On several occasions the physician saw the patient become angry and distressed when she realised that she had lost her autonomy and become dependent. That suffering matched the suffering that the patient had previously expressly indicated, both orally and in the advance directive, as being unbearable to her.

The independent physician based her findings on her own observations during her interview with the patient, but also on the entire process from the time of diagnosis, her knowledge of which was based on the medical records and conversations with the people involved. The independent physician felt she was supported by the psychogeriatric physician's findings. Although the patient could not express her request orally to the independent physician, the independent physician was able to rely on the patient's advance directive in this case. The advance directive included the patient's name, was dated and signed and had been updated and discussed with the physician regularly. It stated clearly what the patient would consider to be unbearable suffering.

# Ch.4

# THE REGIONAL EUTHANASIA REVIEW COMMITTEES

### STATUTORY FRAMEWORK

Termination of life on request and assisted suicide are criminal offences in the Netherlands and the islands of Bonaire, Saba and St Eustatius (articles 293 and 294 of the Criminal Code). The only exception is when the procedure has been performed by a *physician* who has fulfilled the statutory *due care criteria* and has *notified* the municipal pathologist. The aforementioned articles of the Criminal Code (articles 293 (2) and 294 (2)) identify compliance with these conditions as specific *grounds for exemption from criminal liability*. The due care criteria are set out in section 2 (1) of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, while the physician's duty to notify the municipal pathologist is dealt with in section 7 (2) of the Burial and Cremation Act.

The physician's notification to the pathologist must include a *substantiated report* in which he explains why he believes he has complied with the due care criteria (see *case* 2014-23 and annexe 1, case 19 of the 2013 annual report). A model report is available for the physician to fill in, preferably digitally.<sup>14</sup> The pathologist performs an external examination of the body and ascertains how the patient died and what substances were used to terminate his life. He then establishes whether the physician's report is complete. The pathologist notifies one of the regional euthanasia review committees of the euthanasia, i.e. the termination of life on request or the assisted suicide, and includes with that notification the physician's report, the findings of the independent physician concerning the due care criteria and – if there is one – the deceased person's advance directive. He also submits any other relevant documents provided by the physician, for instance the physician's notes and letters from specialists.

# ROLE OF THE COMMITTEES

#### Statutory tasks, powers and methods

The statutory basis for the regional committees is laid down in section 3 of the Act. Their task is to assess in retrospect whether the physician has acted in accordance with the due care criteria. This review takes place using the physician's report and all other documents submitted with the notification. The physician must convince the committee that he has indeed complied with those criteria.

14 See footnote 1.

Immediately after receiving the notification and a preliminary reading of the documents submitted with the notification, the experienced secretary of the committee in question makes an initial assessment of whether the notification is straightforward or not. A notification is considered straightforward if the assessment is that the statutory due care criteria have been complied with and the information submitted is sufficiently complete and thus does not raise any questions.

The straightforward notifications are sent digitally to the committee members (lawyer, physician and ethicist) and, in principle, reviewed digitally by them, which means they can be dealt with as quickly as possible. If any of the committee members thinks that the notification does raise questions, it is referred to the monthly committee meeting for discussion with the other non-straightforward notifications.

Euthanasia notifications that, during the first selection or the further review process, raise questions regarding one or more due care criteria are deemed to be non-straightforward. Non-straightforward notifications may also concern types of cases that the committees have decided always need further discussion, such as euthanasia notifications concerning patients whose suffering resulted from dementia, psychiatric disorders or multiple geriatric syndromes.

If the committee has any questions about a notification or requires more information or further explanation, it will contact the physician and/or the independent physician, either by telephone or in writing. If the information acquired in this way is insufficient to conduct a proper review of the physician's actions, the physician and/or the independent physician can be invited to explain their actions in person and answer questions from the committee (section 8 of the Act in conjunction with article 5 (2) (c) of the Decree of 6 March 2002 (Bulletin of Acts and Decrees 2002, no. 141) and the Guidelines on regional euthanasia review committee procedures of 21 November 2006).

During the interview, the committee asks questions and the physician can give a further, oral explanation before the committee makes its final decision. A report is made of this interview. Before the report is adopted, a draft is sent to the physician and he is asked whether the report correctly reflects the explanation he gave.

In cases in which the committee intends, on the basis of the documents submitted, to find that the physician did *not* act in accordance with one or more due care criteria, the physician is always invited for an interview with the committee.

The committees issue written findings on the notifications they review. In principle, the physician will receive the committee's findings within the statutory period of six weeks. This period may be extended by a further six weeks. These periods may be longer in cases where the committee requires further oral or written explanation or information from the notifying physician or the independent physician. In addition, further internal consultations for the purpose of *harmonisation* (discussed below) sometimes lead unavoidably to extension of these periods. The notifying physician is informed of this possibility in the confirmation of receipt of the notification, which states that the notification will, in principle, be dealt with within the statutory period of 6 (or 12) weeks.

If the committee finds that, in fulfilling the patient's request for euthanasia, the physician has complied with all the due care criteria, that finding is final. The case has then been disposed of de facto.

If the committee finds that the physician did *not* act in accordance with one or more of the due care criteria, the findings and the relevant file are sent, pursuant to the Act, to the Board of Procurators General and the Health Care Inspectorate, as well as to the physician. The Board

will decide, possibly after an interview with the physician, whether criminal charges will be brought. The Inspectorate will decide, again possibly after an interview with the physician, whether or not to institute a disciplinary case or take other measures.

The notifications of the Public Prosecution Service (the Board of Procurators General) and the Health Care Inspectorate and the considerations they contain are also relevant to harmonisation (discussed below).

The coordinating chair, the deputy coordinating chair and the general secretary of the committees consult annually with the Board and the Inspectorate.

#### Composition and organisation of committees

There are five regional euthanasia review committees. The place of death determines which committee is competent to review the case in question.

Each committee comprises three members: a lawyer, who is also the chair, a physician and an ethicist. In principle, a committee has two alternate members for each discipline, making a total of nine committee members for each region. Each member can serve as an alternate member on the other committees, both in the digital review of notifications and in discussing and reviewing notifications at the monthly committee meetings. Each committee is assisted by a secretary (a lawyer) who makes the preparations for the monthly committee meeting and attends the meetings in an advisory capacity.

The secretariats provide support to the committees. They have offices in Groningen, Arnhem and The Hague, which is where the committees meet. The secretariats are incorporated in the Disciplinary Boards and Review Committees Secretariats Unit (ESTT), which also comprises the secretariats of the Healthcare Disciplinary Boards. The secretariats are organised separately so as to guarantee the impartiality of review by the committees.

#### Harmonisation

If a committee intends to find that a physician has *not* acted in accordance with one or more due care criteria, it submits those findings and the accompanying file – digitally – to all members and alternate members of the committees for their advice and comments. The draft findings in complex cases stating that the physician *has* acted in accordance with the due care criteria are usually submitted to all members and alternate members of the committees as well. In very exceptional cases, after all the arguments submitted have been considered, draft findings are submitted to the national consultative council for an authoritative opinion. Even then, the final decision falls to the competent committee of three.

Every year a meeting is held on a complex and current topic for all members and secretaries. External experts are often invited to attend.

The national consultative council meets at least four times a year. Their meetings are also attended by the general secretary and the committee secretaries. This helps ensure harmonisation and consistency of assessment and decision-making.

#### Transparency and communication

To provide physicians and other interested parties with a good, up-to-date overview of the committees' considerations and to make their interpretation of the due care criteria more

accessible, the committees published a Code of Practice in 2015 which can be consulted online, like their annual reports.

The committees' Publication Committee (PC), established in 2013, is tasked with publishing findings that are deemed important for the development of standards in an accessible way on the committees' website. They in any case publish findings of all cases in which the committees found that the physician had *not* complied with one or more of the due care criteria. The publication of these cases on the committees' website has priority.<sup>15</sup>

The committees also fulfil their duty to inform<sup>16</sup> by giving presentations to municipal health services, associations of general practitioners, foreign delegations and so on. In these presentations, the committee members and secretaries discuss the statutory due care criteria and the review procedure, often using examples from practice.

The committees also help the KNMG's Euthanasia in the Netherlands Support and Assessment Programme (SCEN) to train physicians to perform independent assessments. At the request of SCEN physicians, members of the committees attend peer supervision meetings in their regions.

Findings with regard to independent physicians' reports are generally forwarded directly to the physician in question and sometimes in general terms, and therefore anonymised, to the SCEN organisation.

Annexe I (not included here)

15 See footnote 1.

<sup>16</sup> See article 4 (2) of the Decree of 6 March 2002 establishing rules regarding the committees referred to in section 19 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

# ANNEXE II

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)

# 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;
- 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 Health Care Inspectorate of the Public Health Supervisory Service.

# 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 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.
- 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:

if the physician, in the committee's opinion, did not act in accordance with the due care criteria set out in section 2; or

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:

- 1° for the purpose of assessing the physician's conduct in a case as referred to in section 9, subsection 2; or
- 2° 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 powers;
- 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 III A. 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' 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.

#### Section 9

1. The form and layout of the models for the death certificates to be issued by the physician and the municipal pathologist are laid down by order in council.

The form and layout of the models for the notification and the detailed report as referred to in section 7, subsection 2, for the notification as referred to in section 7, subsection 3 and for the forms referred to in section 10, subsections 1 and 2 are laid down by order in council on the recommendation of Our Minister of Justice and Our Minister of Health, Welfare and Sport.

#### Section 10

- If the municipal pathologist decides that he is unable to issue a death certificate, he immediately notifies the public prosecutor by completing a form and immediately notifies the Registrar of Births, Deaths and Marriages.
- 2. Without prejudice to subsection 1, the municipal pathologist, if notified as referred to in section 7, subsection 2, will report without delay to the regional review committees referred to in section 3 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act by completing a form. He will enclose a detailed report as referred to in section 7, subsection 2.

#### Section 81

Anyone who

- 1°.infringes the provisions laid down by or pursuant to sections (...) 7, subsections 1 and
- 2 (...) is liable to a term of imprisonment not exceeding one month or a second-category fine.