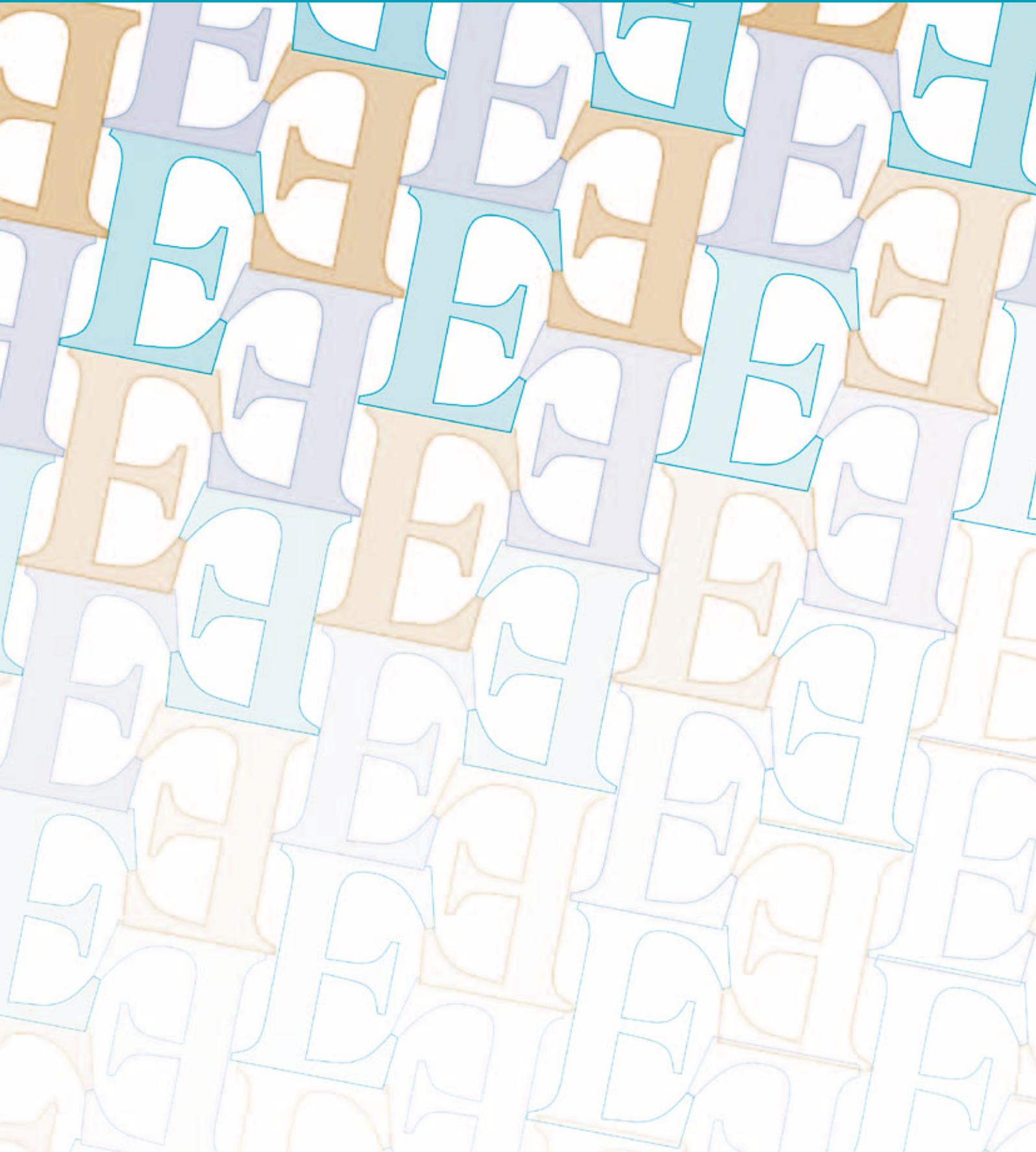


REGIONAL
EUTHANASIA
REVIEW COMMITTEES

ANNUAL REPORT 2013



CONTENTS

FOREWORD

CHAPTER I DEVELOPMENTS IN 2013

Notifications	7
Increase in number of notifications continues	7
Dementia	9
Mental disorders	9
Notifications from End-of-Life Clinic	9
Harmonisation	11
Transparency	11
Requirements not set by the Act	11
Complaints regulations	11
Regional committee secretariats incorporated in the Disciplinary Boards and Review Committees Secretariats Unit (ESTT)	11

CHAPTER II DUE CARE CRITERIA

Due care criteria: general	12
Due care criteria: specific	14
a. Voluntary, well-considered request	14
Mental disorder	16
Depressive symptoms	17
Written directive not a prerequisite	17
Advance directive and decisional incompetence	17
Decisional incompetence in relation to dementia and disorders affecting communication	18
Decisional incompetence in relation to reduced consciousness and coma	19
Dementia	19
b. Unbearable suffering without prospect of improvement	20
Suffering must have medical dimension	21
Dementia	23
Mental disorder	23
Coma and reduced consciousness (non-comatose)	25
Guideline on euthanasia for patients in a state of reduced consciousness	25
When the Guideline on euthanasia for patients in a state of reduced consciousness does not apply	
Euthanasia based on an advance directive	25
Palliative sedation	28
c. Informing the patient	28
d. No reasonable alternative	28
e. Independent assessment	29
Independent physician	29
When must an independent physician be consulted for a second time?	30
Assessing a decisionally incompetent patient	31
Independent physician's report	31
SCEN	33
f. Due medical care	33

KNMG/KNMP Guideline ‘Performing euthanasia and assisted suicide procedures’ of August 2012	34
Termination of life on request	34
Assisted suicide	34

CHAPTER III ACTIVITIES OF THE REGIONAL EUTHANASIA REVIEW COMMITTEES

Statutory framework	36
Role of the committees	36
Statutory tasks, powers and methods	36
Composition and organisation of the committees	37
Transparency and communication	37

ANNEXES

I Overview of notifications	39
II Overview of disposal by the Public Prosecution Service and the Healthcare Inspectorate of notified cases in which the committees found that the physician did not act 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 (Not included)	
III Termination of Life on Request and Assisted Suicide (Review Procedures) Act	41

FOREWORD

In this annual report for 2013, the five regional euthanasia review committees account for the way in which they review cases on the basis of the due care criteria laid down in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. The report provides details of the number of notifications received, which increased once again (by 15%), the nature of the cases, the committees' findings and the considerations on which these were based.

The dramatic events in Tuitjenhorn affected us all deeply. This case did not concern a euthanasia notification, and the committees were therefore not involved. Nevertheless, we could see (for instance from reports by notifying physicians) the impact these events had on physicians and how difficult they made it for some of them to reach a decision on whether or not to comply with euthanasia requests.

The committees again made great efforts to reduce the backlog of the past years – caused by capacity shortfalls – and inform the physicians of their findings within the statutory time limit. In most cases they succeeded. In the more complex cases, however, such as euthanasia for patients suffering from a mental disorder or dementia, exceeding the time limit is often unavoidable. Before a committee reaches its final decision, the members of all committees almost always hold a plenary discussion about such cases, aimed at harmonising their views. It is usually not possible to complete the plenary discussion and reach a decision within the statutory time limit of 2 x 6 weeks.

The committees examine the actions of the notifying physician in the context of the law, the legislative history of the Act and the relevant case law. They also take previous committee findings into account. When interpreting the due care criteria, they always strive to achieve uniformity in their assessments, bearing in mind that every case must be assessed within its own specific context.

The 'case law' thus created by the committees and the relevant considerations are explained in further detail in Chapter 2 of the annual report and illustrated with specific cases and findings. The actual findings are published in full on the website.

The findings which are important for the development of standards (in particular all cases in which the committees found that the physician had not complied with the due care criteria) are published on the website, so that they are accessible to physicians and other interested parties. Much of the backlog in this respect was cleared in 2013. The findings in question have now been published on the website (www.euthanasiecommissie.nl) in a logical order and with a short summary. A start was made on the establishment of a code of practice, as advocated by the medical profession. It will be completed in early 2015.

By making their 'case law' accessible in this way, the committees want to make clear what options the law gives physicians. In addition, publishing the findings adds to the transparency and auditability of the way in which euthanasia and assisted suicide procedures are performed by physicians in practice.

By providing this information, the committees also aim to make a positive contribution to the regularly recurring public debate regarding termination of life at the patient's request.

To remove existing misconceptions and prevent new ones arising, for instance with regard to the legal status of the advance directive in carrying out a request for euthanasia from a patient who has since become decisionally incompetent, the Minister of Health, Welfare and Sport and the Minister of Security and Justice set up the 'Advance directive and euthanasia' working group, which will present its final report in 2014. The ministers also appointed an advisory committee to assess the possibilities for assisted suicide in the event of a 'completed life'.

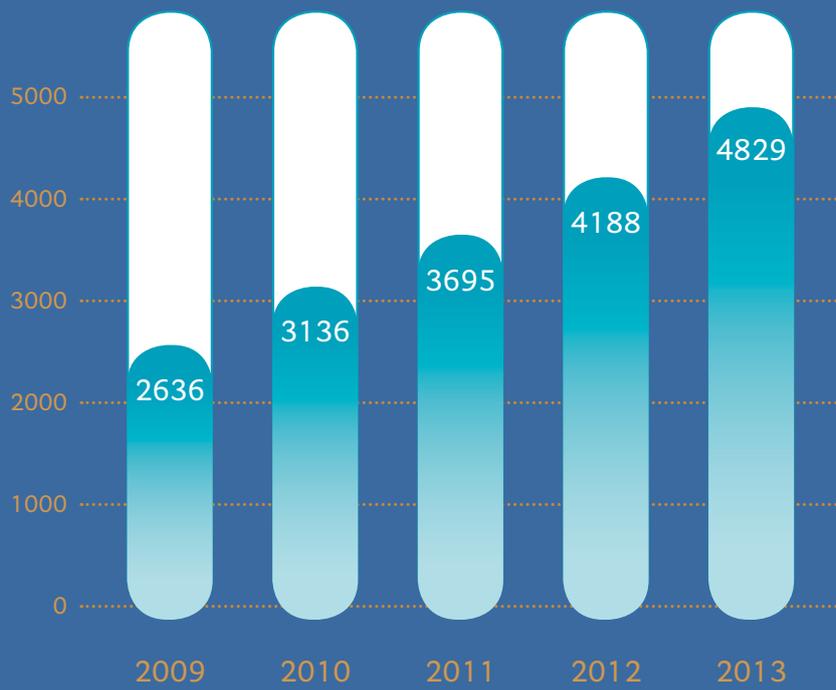
2013 was again a busy year for the committees and for their new members, appointed in December 2012.

I would like to thank the committees' members, the general secretary, the secretaries and the staff of the secretariats for their great commitment and efforts.

The committees are always pleased to receive feedback, which can be sent by email to the general secretary: n.visee@toetscie.nl.

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

The Hague, September 2014



TOTAL NO. OF NOTIFICATIONS
EUTHANASIA AND ASSISTED SUICIDE

Ch. 1

DEVELOPMENTS IN 2013

NOTIFICATIONS

In 2013, the regional euthanasia review committees received 4,829 notifications of termination of life on request or assisted suicide. Annexe 1 gives an 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 the procedure had acted in accordance with the due care criteria set out in section 2 (1) of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act ('the Act'). In 5 cases, around 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 2, under the relevant due care criterion. In all other cases, around 99.9 % of the total, the committees found that the physician had acted in accordance with all due care criteria. Several of these findings, mainly in the more complex cases, are described in Chapter 2.

Increase in number of notifications continues

The number of notifications received by the committees in 2013 (4,829) again showed an increase (15%) compared to 2012 (4,188). Thanks to a new working procedure adopted in 2012 and the expansion of the number of committee members and secretariat staff, the backlog of the past years was cleared in 2013 and most of the notifications were processed within the statutory time limit of 2 x 6 weeks.

The expectation in 2012 that around 75% of the notifications would concern 'straightforward' notifications was largely correct.

Notifications were considered straightforward if the committee secretary, on receiving the papers, could establish with a high degree of certainty that the due care criteria had been complied with and that the information provided was so comprehensive 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 finalised without delay.

The notifications that did raise questions and therefore were preferably to be discussed in person were reviewed at the monthly committee meetings.

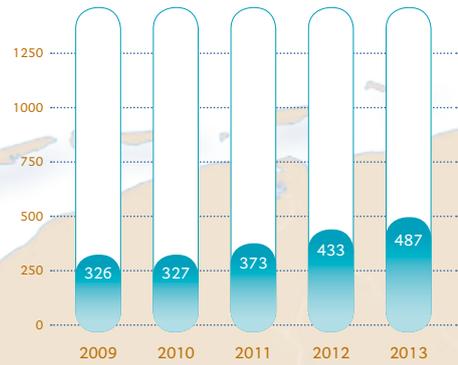
TOTAL NUMBER OF NOTIFICATIONS EUTHANASIA AND ASSISTED SUICIDE BY REGION



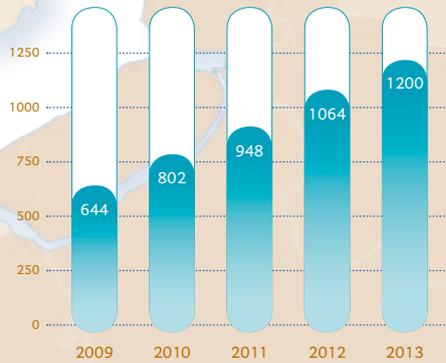
REGION 3
NORTH HOLLAND



REGION 4
SOUTH HOLLAND AND ZEELAND



REGION 1
GRONINGEN, FRIESLAND, DRENTHE
AND BONAIRE, ST EUSTATIUS AND SABA



REGION 2
OVERIJSEL, GELDERLAND,
UTRECHT AND FLEVOLAND



REGION 5
NORTH BRABANT AND LIMBURG

DEMENTIA

Patients' suffering was caused by a form of dementia in 97 cases notified to the committees, compared with 42 in 2012. 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 because they could fully grasp the implications of their request.

In a number of cases the patients were in an advanced stage of dementia and had often for years been discussing with their physicians their desire to terminate their lives if their suffering became unbearable. In one case the patient was compelled to turn to a physician of the End-of-Life Clinic (SLK).

All 97 dementia cases were found by the committee to have been handled with due care.

MENTAL DISORDERS

Patients' suffering was caused by a mental disorder in 42 cases, compared with 14 in 2012 and 13 in 2011. Of the 42 cases notified to the committees in 2013, 32 were reviewed. All were found to have been handled with due care. In 14 cases the notifying physician was a psychiatrist, in 14 cases a general practitioner, in 2 cases a geriatrician, in one case an internal specialist and in one a medically qualified psychotherapist. In six cases the notifying physician was affiliated with the End-of-Life Clinic. In view of the continuing public interest in the subject, these 32 cases were anonymised and given priority for publication on the committee website, along with summaries.¹

The committees have established that there appears to be an increase in willingness among physicians to carry out euthanasia and assisted suicide in cases involving a mental disorder.

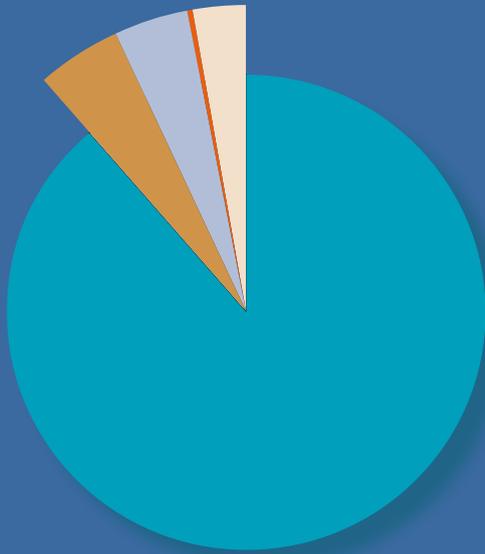
This may be explained by physicians' awareness of the fact that in 2011 and 2012 the review committees found 27 cases to have been handled with due care. In addition, physicians' views on the regulatory standards in this respect have clearly changed. The same conclusion was reached in the second evaluation report on the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, which was carried out at the request of the Minister of Health, Welfare and Sport in 2012.²

NOTIFICATIONS FROM END-OF-LIFE CLINIC

In the course of the reporting year, the committees received 107 notifications from the End-of-Life Clinic (SLK). As the handover of the patient from the attending physician to the SLK physician and the relatively short duration of the SLK physician-patient relationship are by definition points for concern, the committees decided in 2013 to consider all SLK notifications as non-straightforward cases, to be discussed at the monthly committee meetings. The committees established that on the whole the SLK physicians clearly described in their reports the process they had gone through with the patient, the attending physician and – usually – the family before complying with the patient's request for euthanasia. In 2013 the committees found in all cases notified by SLK physicians that the physicians had complied with the statutory due care criteria. Chapter 2 of this report describes a number of these cases.

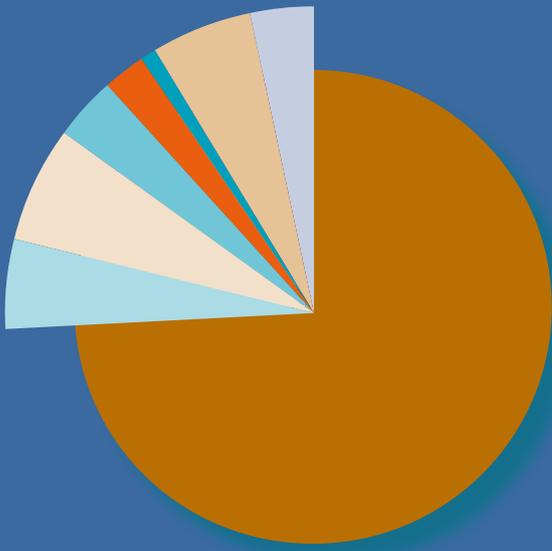
1. www.euthanasiecommissie.nl

2. Second evaluation report on the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, The Hague, Netherlands Organisation for Health Research and Development (ZonMw), December 2012.



NOTIFYING PHYSICIANS IN 2013

General practitioner	4281
Specialist working in a hospital	213
Geriatrician	193
Registrar	13
Other physician (e.g. a doctor affiliated with the End-of-Life Clinic, a junior doctor, non-practising physician or hospice physician)	129



DISORDERS INVOLVED IN 2013

cancer	3,588
cardiovascular disease	223
neurological disorders	294
pulmonary disorders	174
dementia	97
mental disorders	42
multiple geriatric syndromes	251
other disorders	160

It also includes a case in which, after consulting with the SLK physician, the patient's own physician complied with the request for euthanasia (case 32).

HARMONISATION

In 2013, all committee members discussed several complex cases in detail on a secure, restricted website. All cases in which the committees intended to conclude that the due care criteria had not been complied with were discussed, as well as a number of cases in which the proposed finding was that the criteria had been complied with. In the latter cases, the committee which initiated the discussion wanted to hear the views of the other committee members regarding its draft findings or the considerations on which the findings were based. This plenary 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 the 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. In addition to these plenary discussions on individual cases, the committees also regularly hold meetings on current topics, to discuss developments in the field more generally. In February 2013, a workshop was held to discuss initial experiences with notifications from the SLK.

TRANSPARENCY

To provide physicians and other interested parties with a good, up-to-date overview of the committees' views and to make their interpretation of the key concepts of the due care criteria more accessible, the committees established a Publication Committee (PC). Its task is to select cases relevant to the development of standards and publish them in an accessible way on the review committees' website. Thanks to the PC's efforts, all important decisions from 2012 and 2013 have now been published on the website. It is expected that the PC will soon be able to complete the publication of cases for 2012, 2013 and part of 2014. They will then be able to regularly publish interesting cases in the current calendar year. Their efforts are also aimed at developing a future-proof website which meets all the requirements of the modern age.

REQUIREMENTS NOT SET BY THE ACT

(not included here)

COMPLAINTS REGULATIONS

(not included here)

COMMITTEE SECRETARIATS INCORPORATED IN THE DISCIPLINARY BOARDS AND REVIEW COMMITTEES SECRETARIATS UNIT (ESTT)

(not included here)

Ch.2

DUE CARE CRITERIA

DUE CARE CRITERIA: GENERAL

The committees examine retrospectively whether the attending physician acted in accordance with 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. exercise due medical care and attention in terminating the patient's life or assisting in his suicide.

Procedures for termination of life on request and assisted suicide are almost always carried out by the attending physician; in practice, this is often the patient's general practitioner. In some cases the procedures are performed by a locum because the patient's situation rapidly deteriorates while the attending physician is absent or if the attending physician does not wish to carry out the procedure himself, because of his religious or ethical views or for other reasons. Timely handover of the patient is to be preferred (see case 14).

If the attending physician does not wish to carry out the procedure, it may be done by a physician affiliated with Stichting Vrijwillig Leven (SVL, 'Living is a Choice') or the End-of-Life Clinic (SLK) (see cases 4, 5 and 7). The committees also receive notifications of cases in which the attending physician performs the euthanasia or assisted suicide procedure himself after involving the SLK (see case 3).

It is important in these cases for the physician who performs the procedure, who is therefore the notifying physician, to first obtain reliable information about the patient's situation and be personally satisfied that the due care criteria have been fulfilled.

The information provided by notifying physicians is of crucial importance to the committees' reviews (see case 19). If the physician gives an account of the entire decision-making process in his notification, he may not be required to answer further questions at a later stage. The physician is expected to use the model notification form as revised in 2009, preferably the digital version. The questions in it help notifying physicians make it clear to the committee that they have complied with the due care criteria.

The committees sometimes require further information, which can often be provided by telephone or in writing. In some situations, however, the committees prefer to interview the physician in person in order to obtain a clearer picture of the physician's and patient's shared decision-making process at the end of the patient's life or obtain answers to questions.

The committees are aware that such an interview with a committee is burdensome for the physician. It often requires the physician to relive a complex and distressing process months after the fact, and the physician often feels as if he is being called to account by the committee. It is also time-consuming. The committees would like to emphasise that a personal interview is often useful to clarify matters and that without it they would often be unable to make a sound assessment.

In 2013 the great majority of notifications gave no grounds for further discussion or questions when they came before the committees. These were cases in which the information provided by the notifying physician and the independent physician was sufficient for the committee to find that the physician had acted in accordance with the due care criteria. The committee then does not include any further considerations in its findings. Case 1 illustrates such a straightforward situation.

CASE 1

FINDING: CRITERIA COMPLIED WITH

Summary: the patient, a woman in her forties, had been suffering from multiple sclerosis for many years. She was severely disabled, had dysphagia and was hardly able to speak. Her independence was severely threatened and she was likely to become entirely helpless. The patient did not want to go into a nursing home. She communicated with the independent physician by pointing at letters on a letter board with her finger and using slight head movements to indicate yes or no.

The patient, a woman in her forties, had been diagnosed with multiple sclerosis many years before. In the ten years before her death, she developed bulbar dysarthria. Her condition was incurable. She could only be treated palliatively. The patient's suffering consisted of severe disability and dysphagia. The patient was hardly able to speak. Communication was difficult due to her limited motor skills. She was suffering from the deterioration in the motor skills she still had. This threatened her independence, which she absolutely did not want to lose, and was making her totally helpless. Her situation was without prospect of improvement. She did not want to go into a nursing home. The patient felt her suffering was unbearable.

The physician was satisfied that the patient's suffering was unbearable, with no prospect of improvement according to prevailing medical opinion. There was no longer any way to alleviate it.

The documents make 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. On two occasions, one several months and one two weeks 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 visited the patient ten days before the termination of life was performed, after he had been told about the patient's situation by the attending physician and had examined the relevant medical records. In his report the independent physician gave a summary of the patient's medical history and the nature of her suffering. The patient

was unable to communicate orally. She communicated by pointing at letters on a letter board with her finger. She was assisted in this, at her request and unrequested, by nursing assistants. The independent physician did not consider this communication method to be sufficiently objective.

Using slight head movements, the patient proved able to answer the independent physician's questions with a nod or shake of the head. The independent physician was of the opinion that the patient was thus able express her request objectively and indicate that she understood the consequences of her request. The independent physician concluded, partly on the basis of his interview with the patient, that the due care criteria had been satisfied.

The attending 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 committee examined retrospectively whether the attending physician had acted in accordance with the statutory due care criteria laid down in section 2 of the Act. The committee then decided whether, in the light of prevailing medical opinion and standards of medical ethics, the due care criteria were complied with.

In view of the above facts and circumstances, the committee found that the attending 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 committee found that the physician had acted in accordance with the statutory due care criteria laid down in section 2 (1) of the Act.

DUE CARE CRITERIA: SPECIFIC

a. Voluntary, well-considered request

The physician must be satisfied that the patient's request is voluntary and well-considered.

The physician must be satisfied that the patient's request is voluntary and well-considered. Key elements in the contact between the physician and the patient include willingness to discuss the (possibly imminent) end of the patient's life, the patient's wishes, and ways in which they can or cannot be fulfilled.³ The patient's request must be specific and made to the physician who will perform the procedure.

Three elements are crucial here:

1. The request for termination of life or assisted suicide must have been made by the patient himself.
2. The request must be voluntary. There are two aspects to this.
 - The patient must be decisionally competent (internal voluntariness), that is he must have

3. Parliamentary Papers, Senate, 2000/2001 session, 26691, no 137b, pp. 16 and 54.

- a clear understanding of relevant information about his situation and prognosis, be able to consider any possible alternatives and understand the consequences of his decision.
- He must not have made his request under pressure or unacceptable influence from those around him (external voluntariness).
3. The request must be *well-considered*. In order to make a well-considered request, the patient must be fully informed and have a clear understanding of his disease.

CASE 2

FINDING: CRITERIA COMPLIED WITH

Summary: the patient was almost completely paralysed and could no longer speak. He could communicate by eye contact and head movements. By making a 'stop sign' with his left arm he could indicate in discussions that he disagreed. The patient was decisionally competent and able to make his voluntary and well-considered request clear to the attending physician and the independent physician.

The patient, a man in his fifties, was diagnosed with squamous-cell carcinoma of the tongue base two months before his death. A curative course of chemotherapy and radiotherapy was started. The patient was given a PEG tube. Several weeks before his death, the patient suffered an ischemic CVA as a result of basilar artery thrombosis. Thrombolysis produced no result. The patient was almost completely paralysed and could no longer speak. In view of the poor prognosis, it was decided he would be given fluids only. After a week there were slight functional improvements. The patient's lucid moments were more frequent and he was able to use eye contact and head movements (nodding and shaking his head, turning his head towards someone) to communicate. He was also able to lift his left arm a little, to make a 'stop sign' in a conversation to indicate disagreement. Given the severe damage to his brain stem, the attending neurologist did not expect any further functional improvement. In addition, further treatment of the tongue base carcinoma had been rendered impossible by the CVA. There was no prospect of recovery. He could only be treated palliatively.

The patient's suffering consisted of his complete dependence on others and his severely limited ability to communicate. He also suffered from the knowledge that the tongue base carcinoma would increasingly cause problems, his condition would only deteriorate further and his situation was without prospect of improvement. The patient experienced his suffering as unbearable. The physician was satisfied that this suffering was unbearable to the patient and that there was no prospect of improvement according to prevailing medical opinion. A week before his death, the patient communicated with the physician regarding euthanasia and asked her to perform the procedure to terminate his life. During further contact he repeated the request.

The patient communicated with the physician in the manner described above. The clarity and decisiveness of the patient's facial expressions made it clear to the physician that he was fully aware of what was being discussed and what his opinion was. The physician included a CD with her notification, recorded four days before the patient's death, with a 'conversation' between the patient and his wife about his wishes.

The physician concluded that the request was voluntary and well-considered. The physician felt this was supported by the findings of a fellow GP, whom she had asked to support her in this euthanasia process due to her own relatively limited experience as a GP and given the complexity of the situation, and who had also been present during one of the visits to the patient. The SCEN physician who was consulted by the attending physician and who visited the patient four days before his death indicated in his report that the patient tried to greet him with his left hand when he entered the room and that they had definite eye contact. The patient knew exactly why the independent physician was there and nodded his head

affirmatively. According to the independent physician, it became clear during the interview that the patient was decisionally competent and that he made his euthanasia request voluntarily. The independent physician concluded, in part on the basis of his interview with the patient, that the due care criteria had been complied with.

CASE 3

FINDING: CRITERIA COMPLIED WITH

Summary: the End-of-Life Clinic (SLK) involved the attending physician in the euthanasia process, as a result of which the physician eventually took over from the SLK.

The patient, a woman in her forties, had been suffering for several years from terminal COPD and severe arterial disease. A year before her death, she underwent breast surgery after developing severe intertrigo. As a result of the operation and due to poor circulation, the patient's breasts became necrotic. There was no prospect of recovery. She could only be treated palliatively. The patient's suffering consisted of severe pain in her necrotic breasts. She suffered from dyspnoea and was dependent on supplemental oxygen. The patient was hardly able to get out of bed and had to be washed and changed by her partner. She suffered from her dependence on others, the deterioration in her condition and the futility of her bedridden existence. The patient regarded her suffering as unbearable. The attending physician, her own GP, was convinced that the patient's suffering was unbearable, 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 physician and the specialists gave the patient sufficient information about her situation and prognosis.

The patient had discussed euthanasia with the physician before. The patient had been wanting euthanasia for six years, but the circumstances precluded the physician from complying with that wish. When the patient's health deteriorated sharply in 2013, the physician referred her to the End-of-Life Clinic (SLK) for further guidance in the euthanasia process. The SLK physician involved the GP in the process in view of the long-standing physician-patient relationship. During this process, the GP became willing to assist the patient again in the euthanasia process. It was agreed that assisted suicide would be performed. The GP then took over control of the euthanasia process from the SLK physician, with the latter remaining involved in the procedure, but to a lesser extent.

In the last months before her death, the patient repeatedly asked her GP and the SLK physician to perform the procedure to terminate her life. The physician concluded that the request was voluntary and well-considered. The independent SCEN physician concluded, in part on the basis of his interview with the patient, that the due care criteria had been satisfied. The committee found that the physician acted in accordance with the due care criteria laid down in section 2 (1) of the Act.

CASE 4

(not included here)

Mental disorder

When a physician receives a request for termination of life or assisted suicide due to unbearable suffering without prospect of improvement resulting from a mental disorder, particular caution must be exercised. The physician will have to assess whether the request is *voluntary and well-considered*. A mental disorder may make it impossible for the patient to determine his own wishes freely. The attending physician must then ascertain whether the patient appears capable of grasping relevant information, understanding his condition and advancing consistent arguments. In such cases it is important to consult not only the

independent physician but also one or more experts, including a psychiatrist (see cases 11 and 12). Their findings too must be made known to the committee.

Of the 42 cases of euthanasia or assisted suicide notified in 2013 which involved patients with psychiatric problems, 32 were reviewed in the reporting year, and in all cases the due care criteria were found to have been complied with. Whether or not a patient suffering from a mental disorder *lacks all prospect of improvement* is something that must be considered especially carefully. For that reason we have included two such cases in this report, cases 11 and 12 below, under **b. Unbearable suffering without prospect of improvement**.

Depressive symptoms

In addition to suffering from one or more somatic conditions, a patient can also have symptoms of depression, which often exacerbate his suffering. The possibility that depression is adversely affecting his *decisional competence* cannot be ruled out. If there is any doubt about whether the patient is depressed, a psychiatrist will in practice often be consulted in addition to the independent physician. If other medical practitioners have been consulted, it is important to make this known to the committee. It should also be noted that it is normal for patients to be in low spirits in the circumstances in which they make a request for euthanasia, and that this is not in itself a sign of depression.

Written directive not a prerequisite

The Act requires the physician to be satisfied that the patient has made a voluntary and well-considered request. The request for termination of life is almost always made during a conversation between the physician and the patient, and hence is made orally. Contrary to popular belief, the Act does not require an advance directive or living will to be drawn up.

On the other hand, even if the patient is capable of expressing his wishes, a written directive can help eliminate any uncertainty and confirm the oral request. Although in practice such a directive makes it easier to assess the case, the committees wish to emphasise that it is not the intention that people be put under unnecessary pressure to draw up and sign such a directive in difficult circumstances, in some cases only shortly before they die.

Advance directive and decisional incompetence

The Act makes specific provision for a physician to carry out a patient's request for euthanasia in cases where the patient is no longer capable of expressing his wishes, provided these wishes were written down in an advance directive at a time when the patient was still decisionally competent (section 2 (2) of the Act). In cases like these, an advance directive can replace an oral request. The due care criteria referred to in subsection 1 apply *mutatis mutandis*. That means that the due care criteria apply to the greatest extent possible in the given situation.⁴ As the government put it in the parliamentary debate on the Act, the due care criteria must be applied 'in so far as the actual situation allows it'.⁵

4. The patient's family also have a significant role to play. In his letter of 5 November 1999, at the time of the debate on the euthanasia legislation, concerning the legal status of advance directives in healthcare (Parliamentary Papers, House of Representatives, 1999/2000 session, 26885, no. 1), Minister of Justice Benk Korthals also discussed the role of close family in interpreting the wishes set out by the patient in written directives.

5. Govert den Hartogh, 'Wilsverklaring vergt onderhoud' (Advance directive needs maintenance), Medisch Contact no. 39, 25 September 2012.

Decisional incompetence in relation to dementia and disorders affecting communication

Unlike patients in a state of reduced consciousness or coma, patients who are unable to express their wishes or are decisionally incompetent due to, for instance, advanced dementia, Huntington's disease, aphasia etc. are usually still capable of some communication, either verbal or non-verbal, however poor. In these cases, the attending physician and the independent physician – if they were unable to talk with the patient at an earlier stage of the disease – must establish what the patient's current wishes are from his behaviour and utterances. Both physicians will have to decide in the light of the patient's advance directive and the current situation whether the patient has made a voluntary and well-considered request, whether he is suffering unbearably and whether there is no prospect of improvement or reasonable alternative in the patient's situation. The entire process that the attending physician has gone through with the patient and has recorded in the file contributes to that decision. Both physicians will have to be satisfied that the patient's current state is one that he had previously described and expressed as being unbearable. Contrary to the usual situation, the independent physician will not be able to speak with the patient. He will have to determine whether the request is well-considered and voluntary on the basis of the patient's advance directive, the information provided by the attending physician, the attending physician's file, the patient's behaviour and utterances and the statements made by others, for instance the patient's family.⁶

To be able to comply with the patient's request, the physician must be convinced that the patient still wishes his life to be terminated. If, when euthanasia is about to be performed, it is evident from the patient's behaviour that he no longer has this wish, the physician cannot go through with the procedure.

Although it is difficult to make any general statements as to the circumstances under which euthanasia may be performed in such situations, the possibility may not be excluded, bearing in mind the tenor of the Act. This will always have to be assessed based on the specific circumstances in each individual case.

In making a decision on a request for euthanasia laid down in an advance directive, the physician must consider the patient's current situation and compare it with his wishes as laid down in the directive and discussed previously with the physician. To avoid problems of interpretation at a later stage, it is therefore advisable to draw up the directive in good time and update it at regular intervals. It should describe as specifically as possible the circumstances in which the patient would wish his life to be terminated. The patient is responsible for discussing the advance directive with the physician at the time it is drawn up and whenever it is updated.⁷ A directive drawn up by the patient himself in which he describes the circumstances in his own words often provides additional confirmation, and is therefore more significant than a standard form, particularly one that is conditionally worded.

The physician can help eliminate uncertainty by recording details of a patient's wish for euthanasia and the patient's and his decision-making process concerning the end of life in the patient's records. The physician is responsible for keeping a record.

The clearer and more specific the advance directive and the better the records kept, the firmer the basis they provide for everyone involved, such as the attending physician, the independent physician and observers, if any.

6. See the guidelines on 'Dealing with requests for assisted suicide by patients with a psychiatric disorder', NVVP, 2009.

7. KNMG Guideline for Palliative Sedation, 2009.

Decisional incompetence in relation to reduced consciousness and coma

The legal status of advance directives for euthanasia in the event of *reduced consciousness* or coma is discussed in the section on [Coma and reduced consciousness](#), under [b. Unbearable suffering without prospect of improvement](#).

Dementia

All 97 notified cases which were reviewed in 2013 and which concerned termination of life on request or assisted suicide for patients with demential syndrome were found by the committee to have been handled with due care. In the vast majority of these cases, 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 because they could fully grasp the implications of their request.

Patients at a more advanced stage of the disorder are less likely to be decisionally competent. The committees adhere to the principle that physicians should normally treat requests for termination of life from patients suffering from dementia with additional caution. In these cases, it is essential that there is a record of the patient expressing the wish for euthanasia in the past, namely a clear advance directive written by the patient when still decisionally competent, which incontrovertibly applies to the situation at hand. They must take the entire course of the disease and the other specific circumstances of the case into account when reaching a decision.

CASE 5

(not included here)

CASE 6

FINDING: CRITERIA COMPLIED WITH

Summary: decisional competence of an Alzheimer's patient.

The patient, a woman in her eighties, had been diagnosed with Alzheimer's disease three years before her death. She was being monitored by a neurologist and did not want to be assisted by a psychogeriatric team. Until recently, the patient had been able to enjoy everyday activities, such as cycling, walking and doing puzzles. These activities had compensated for the loss of depth in personal conversations. She was now deteriorating, however. The patient suffered from restlessness, including at night, insomnia, memory loss, aggressive mood swings, sadness and her complete dependence on care. She felt unwell and lightheaded. Sometimes she would not recognise her family. She was desperate and was suffering from a realistic fear of the suffering that lay ahead of her. Six years before her death, the patient had already discussed euthanasia in general terms with her physician. Shortly after her diagnosis she discussed her euthanasia wish again. She had witnessed the sickbed of a family member with Alzheimer's and absolutely did not want to go through that herself. She flatly refused to go into a nursing home. The patient discussed her euthanasia wish several times with her attending specialist. She also had an advance directive, dated four years earlier, and a document in which she gave a family member power of attorney to make decisions for her if she was unable to do so herself. In these documents she explicitly mentioned her euthanasia request. Lastly, there was a video recording dating back to two years before her death, in which the patient confirmed her euthanasia wish orally. In all these expressions of her wishes, she named going into a nursing home as the ultimate boundary: if that were to become necessary, she wanted euthanasia.

Three weeks before her death, the patient asked her GP to perform the euthanasia procedure. Every time she requested euthanasia, she would remove her wedding ring and

her watch. She did this on every occasion until she died. The physician was convinced that her request was voluntary and well-considered. The GP consulted a SCEN physician as the independent physician. The SCEN physician took note of all the information about the patient and her euthanasia request, including the video recording. During the interview with the patient, the independent physician noted that she was consistent in her wish for euthanasia, but that she had difficulty answering other questions. Initially, the independent physician concluded that the patient was decisionally incompetent at the time of the interview. He qualified that conclusion when giving a personal explanation to the committee. According to the independent physician, the patient was decisionally competent with regard to her request for termination of life, but incompetent in all other areas. He also considered the patient to have been decisionally competent when she wrote the advance directive and recorded the video. The independent physician found that the due care criteria had been complied with.

Two of the patient's family members were present when euthanasia was performed. Despite her increasing dysphasia, the patient was able until the end to communicate the essence of her wish to be allowed to die to her family as well. Before performing euthanasia, the physician asked the patient again what she wanted. She confirmed that she wanted euthanasia and was aware that the euthanatics would be administered.

The attending physician was later invited to an interview with the committee, where he explained that it was possible, if you did not know the patient well, to doubt her decisional competence, because the patient needed rest and concentration to be able to communicate verbally. The physician was afraid that if her illness progressed further she would no longer be able to repeat her request. In response to questions from the committee, the independent physician said that he had doubts in particular about the patient's decisional competence in other areas. He had no doubts as to her decisional competence with regard to her euthanasia request. He based this in part on the patient's decisional competence when she drew up the advance directive, recorded the video and 'maintained' the written request as was apparent from the file.

The patient knew why the independent physician was there and was able to make clear how much she was suffering from losing control of the situation, and that she did not want to live like that any longer. The committee found, partly on the basis of the explanations given by the attending physician and the independent physician, that the statutory due care criteria had been satisfied.

Apart from whether or not the request is voluntary and well-considered, the question of whether there is *no prospect of improvement* in the patient's suffering, and above all whether his suffering is *unbearable*, should be key elements in the physician's decision. Before the physician can proceed with the euthanasia procedure, he must be satisfied that the patient's unbearable suffering without prospect of improvement in the current situation has been described by the patient in his advance directive as being unbearable and without prospect of improvement.

If a patient is suffering from dementia, it is advisable to consult one or more experts, preferably including a geriatrician or a psychiatrist, in addition to the independent physician.

b. Unbearable suffering without prospect of improvement

The physician must be satisfied that the patient's suffering is unbearable, with no prospect of improvement.

There is *no prospect of improvement* if the disease or disorder that is causing the patient's suffering is incurable and the symptoms cannot be alleviated to the extent that the suffering is no longer unbearable. It is up to the physician to decide whether this is the case, in the light of the diagnosis and the prognosis. In answering the question of whether there is any realistic prospect of alleviating the symptoms, account must be taken both of the improvement that can be achieved by palliative care or other treatment and of the burden such care or treatment places on the patient. In this sense, 'no prospect of improvement' refers to the disease or disorder and its symptoms, for which there are no realistic curative or palliative treatment options that may – from the patient's point of view – be considered reasonable.

Patients also use equivalent terminology to indicate that the absence of any prospect of improvement is unacceptable to them, and that they want their suffering to end. In that sense, this perception of the situation by the patient is part of what makes suffering unbearable.

It is harder to decide whether suffering is *unbearable*, for this is a subjective notion. What is still bearable to one patient may be unbearable to another. Whether suffering is unbearable is determined not only by the patient's current situation, but also by his perception of the future, his physical and mental stamina, his personality and his life history.

Notifications often describe unbearable suffering in terms of physical symptoms such as pain, nausea and shortness of breath, and feelings of exhaustion, increasing humiliation and dependence, and loss of dignity. In practice, it is almost always a combination of aspects of suffering that determines whether suffering is unbearable. The degree of suffering cannot be determined merely by looking at the symptoms themselves; it is ultimately a matter of what they mean to the patient, in the context of his life history and values. The physician must find the patient's suffering to be palpably unbearable. The question here is not whether people in general or the physician himself would find suffering such as the patient's unbearable, but whether it is unbearable to this specific patient. The physician must therefore be able to empathise not only with the patient's situation, but also with the patient's point of view.

A crucial factor when the committees make their assessments is whether the physician is able to make it clear that he found the patient's suffering to be palpably unbearable.

CASE 7

(not included here)

CASE 8

(not included here)

CASE 9

(not included here)

Suffering must have medical dimension

As the legislative history of the Act makes clear, the expression 'finished with life' refers to the situation of people who, often at an advanced age and without the medical profession having established that they have an untreatable disease or disorder that is accompanied by great suffering, have come to the conclusion that the value of their lives to them has decreased to the point where they would rather die than carry on living. Suffering within the meaning of the Act must therefore include a medical dimension. Suffering that arises in a non-medical context should not be assessed by physicians, for it lies beyond the medical field.

The committee must therefore investigate whether the physician could be satisfied not only that the patient's suffering was unbearable with no prospect of improvement, but also that it was mainly due to a recognised disease or medical condition, i.e. that there was a medical dimension. However there is no requirement that the medical condition should be serious or life-threatening. Multiple geriatric syndromes can also cause unbearable suffering with no prospect of improvement.

CASE 10

FINDING: CRITERIA COMPLIED WITH

Summary: multiple geriatric syndromes in a patient in his nineties who was hearing impaired, visually impaired and partially mobile, and who was suffering from sleeping problems, low spirits, traumatic war memories and the fear of further deterioration and dependence.

The patient was a man in his nineties who was severely hearing impaired and severely visually impaired as a result of macular degeneration. In addition he had for years had problems as a result of osteoarthritis. Despite treatment by an orthopaedist and in a pain clinic, the patient became increasingly less mobile and was increasingly dependent on help from others. He felt his life was empty and futile.

In the two years before his death, the patient regularly discussed euthanasia with his physician and asked his physician to perform euthanasia. On the advice of his physician, he moved to a care home in 2011, in the hope that he would be able to rebuild his social life there. This was not a success, however. The patient was unable to connect with the other residents. The patient was suffering from sleeping problems, low spirits and traumatic war memories and expressed a wish to die. He felt his life was over and he was afraid of further deterioration. In early 2013, he was seen by a psychiatrist who established that he was not suffering from major depressive disorder. The psychiatrist attributed the low spirits to the sleeping problems and the social isolation resulting from his physical disability. The patient's personality also played a part.

In the following months, a mental health nurse helped the patient to build up social contacts and give more meaning to his daily life. The patient was also given medication, including medication to help him sleep better. None of this helped, however. The patient still wished to die. In the summer of 2013 the same psychiatrist established that all treatment options had been exhausted. He found that the patient was still not suffering from a depressive or cognitive disorder. The patient was decisionally competent and his request for euthanasia was consistent and well-considered, the psychiatrist concluded.

The patient's suffering consisted of his inability to engage in independent activity or build up meaningful relationships with other people, as a result of his severely impaired eyesight, hearing and mobility. He was no longer able to watch television or read the newspaper, and felt his days were very empty. The patient suffered from the prospect of sitting on the couch without any purpose for years to come. He also suffered from his insomnia, his war memories and a fear of further deterioration and dependence. The patient experienced his suffering as unbearable. The physician and the patient discussed the situation and the patient's prospects at length on several occasions. The physician was satisfied that this suffering was unbearable to the patient and that there was no prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate the patient's suffering that were acceptable to him. In the opinion of the physician, and taking account of the psychiatrist's assessment, the patient's euthanasia request was voluntary and well-considered. The SCEN physician who was consulted by the attending physician visited the patient three days before his death. The SCEN physician, too, established that the

patient's request did not result from an underlying depression and concluded that the due care criteria had been complied with.

The physician acted in accordance with the due care criteria.

Dementia

As indicated in the section on [voluntary and well-considered requests](#), requests for euthanasia made by patients suffering from dementia should normally be treated with great caution. The question of decisional competence has already been discussed. Another key issue is whether dementia patients can be said to be suffering unbearably. What makes their suffering unbearable is often their perception of the deterioration that is already taking place in their personality, functions and skills, coupled with the realisation that this will only worsen and eventually lead to utter dependence and total loss of self. Being aware of their disease and its consequences may cause patients great and immediate suffering. A realistic assessment of how the illness is likely to progress may also lead to a fear of future suffering. The specific circumstances of the case will determine whether the physician finds the patient's suffering to be palpably unbearable. In the case of dementia, there is a close connection between both aspects, i.e. assessing whether the request is *voluntary and well-considered* and assessing whether suffering is *unbearable with no prospect of improvement*. Cases 5 and 6 were therefore included as examples, above, in the section on [Dementia](#), under [a. Voluntary and well-considered request](#).

Mental disorder

It has already been emphasised elsewhere in this report that a request for euthanasia or assisted suicide by a patient suffering from a mental disorder requires the attending physician to exercise particular caution. Apart from the question of decisional competence and whether the patient can be deemed capable of making a *voluntary, well-considered request*, a key question is whether the suffering considered unbearable by the patient is *without prospect of improvement*. This is illustrated in the two cases below (11, 12). Given the complexity of the issue and the specific expertise required, and in view of the caution that should be observed when dealing with a psychiatric patient's wish to die, it is strongly recommended that, in addition to an independent physician, one or more independent psychiatrists be consulted. The latter's advice will focus on the patient's decisional competence and the degree to which his suffering is without prospect of improvement, whilst the independent physician will assess whether the due care criteria have been complied with.⁸

CASE 11

(not included here)

8. KNMG/KNMP Guideline 'Performing euthanasia and assisted suicide procedures' of August 2012.

CASE 12

FINDING: CRITERIA COMPLIED WITH

Summary: the patient, a woman in her thirties, had had a range of psychiatric problems since the age of 18, which had become more severe over the past years. Despite extensive treatment, her condition was deteriorating. She also developed somatic problems. The attending physician (her attending psychiatrist) consulted two independent psychiatrists on the advice of a SCEN physician. They considered the patient to be decisionally competent with regard to her euthanasia request and considered her suffering to be without prospect of improvement. The physician then consulted a SCEN physician who, after speaking with the patient and on the basis of the findings of the two independent psychiatrists, established that the due care criteria had been complied with.

The patient, a woman in her thirties, had had multiple psychiatric problems since the age of 18. She suffered from borderline personality disorder, an eating disorder, obsessive compulsive disorder and kleptomania, and was a compulsive hoarder. The patient was well-educated and fully aware of her disorders. From getting up in the morning to going to sleep at night, her life consisted of obsessive compulsive behaviour. She stole large amounts of food to store for her prolonged and extensive eating and vomiting rituals. She was continuously and increasingly anxious. In the final months before her death, she had lost a lot of weight and was physically exhausted.

In the summer of 2013, she was severely underweight. The patient then sustained a double pelvic fracture due to her compulsive movements in combination with her poor health. The patient had tried every conceivable psychotherapy and drug treatment. She was suffering from all the abovementioned complaints and experienced her suffering as unbearable. The attending physician, her attending psychiatrist, was satisfied that the patient's suffering was unbearable, with no prospect of improvement according to prevailing medical opinion.

More than six months before her death, the patient specifically asked the attending physician to ascertain whether her request complied with the due care criteria for euthanasia. The physician first consulted a SCEN physician for advice on what procedure to follow. On the advice of this SCEN physician, the physician consulted two independent psychiatrists to have them assess the patient's psychiatric condition and decisional competence. Both spoke separately with the patient and came independently to the conclusion that the patient was suffering from severe personality issues with intense anxiety, a chronically depressed mood and a very restricted life. The patient's suffering was severe and had not improved despite extensive and prolonged treatment.

The psychiatrists consulted by the attending physician established that nothing pointed to an impaired ability to form judgments and that the patient was decisionally competent with regard to her euthanasia request. After they had submitted their reports, the attending physician consulted an independent SCEN physician, who was also a geriatrician. The independent physician found that the suffering, which consisted of a combination of mental and physical suffering, was palpably unbearable. The independent physician established that the multiple psychiatric problems had proven resistant to therapy and that the patient's suffering was therefore without prospect of improvement. The patient had sufficient cognitive skills to be able to understand the scope of her decision. The independent physician deemed her to be decisionally competent, also referring to the findings of the independent psychiatrists who had been consulted previously. The independent physician concluded, partly on the basis of his interview with the patient, that the due care criteria had been satisfied.

The committee established that the attending physician had approached this special case with great care and caution, and they appreciated his actions. That approach was evident

from the fact that he first consulted a SCEN physician for advice on how to proceed. On that physician's advice, he then asked two independent psychiatrists for a second opinion regarding the patient's psychiatric condition and her decisional competence, before asking a second SCEN physician to serve as the independent physician and assess whether the statutory due care criteria had been complied with. In view of the above facts and circumstances, the committee found that the due care criteria had been complied with in this case.

Coma and reduced consciousness (non-comatose)

Suffering assumes a conscious state. Since a patient in a coma is in a state of complete unconsciousness, he cannot be said to be suffering. In this situation, euthanasia cannot be performed.

One exception can be made to this principle: unlike in cases where coma has occurred spontaneously as the result of illness or complications associated with illness, euthanasia may be justified in the case of medically induced coma, resulting from the administration of medication to alleviate pain and symptoms and therefore in principle reversible. Euthanasia may then be justified. In this case, it is considered inhuman to wake the patient simply so that he can confirm that he is again, or still, suffering unbearably.

If a patient is in a state of reduced consciousness (but not in a coma) – either spontaneously or as a result of medication to reduce pain or symptoms – it cannot be ruled out that he is suffering and that the suffering is unbearable, in which case euthanasia is possible. The physician can establish whether this is the case by assessing the patient's response. The Glasgow Coma Scale can provide useful guidance in determining the extent of a patient's reduced consciousness (and thus the possible suffering), or to establish that the patient is in a coma.

Guideline on euthanasia for patients in a state of reduced consciousness

The KNMG Guideline 'Euthanasia for patients in a state of reduced consciousness', published in June 2010, deals specifically with the situation where, after the attending physician has consulted an independent physician and is ready to carry out euthanasia, the patient – spontaneously or *unintentionally*, as a result of medication to reduce pain or dyspnoea – falls into a state of reduced consciousness. According to the Guideline, the physician may proceed with the euthanasia if the patient can still experience suffering, possibly unbearable suffering. This is determined using the Glasgow Coma Scale (GCS). The Guideline also allows the physician to proceed if the patient *unintentionally* falls into a coma resulting from the administration of medication to alleviate pain or dyspnoea. While such a coma is in principle reversible, it is not necessary to wake the patient simply so that he can confirm that he is again, or still, suffering unbearably. In these situations set out in the Guideline, the physician may proceed with the euthanasia without again consulting an independent physician. Although the patient is no longer able to express his wishes immediately prior to euthanasia, an advance directive is not required.

When the Guideline on euthanasia for patients in a state of reduced consciousness does not apply

Euthanasia based on an advance directive

In cases where the Guideline does not apply, a physician may – on the basis of section 2 (2) of the Act – carry out a patient's request for euthanasia, which the patient can no longer express because he is in a state of reduced consciousness or *reversible coma*, but which is stated in

an advance directive. For instance, the patient's condition may suddenly deteriorate to the extent that he spontaneously enters a state of reduced consciousness *before* an *independent physician* has been consulted. Or a patient's condition may suddenly decline so sharply that the attending physician has to administer medication to alleviate the pain and/or other symptoms, causing the patient to enter a state of reduced consciousness or a reversible coma, again *before* an *independent physician* has been consulted. In both cases, the abovementioned Guideline *does not* apply. And in both situations, the independent physician can conclude that the patient's request for euthanasia was voluntary and well-considered, based on the advance directive. Whether the patient's suffering was unbearable with no prospect of improvement must be assessed through observation (seeing the patient), information and medical records provided by the attending physician, and (if available) information from the patient's immediate family (case 13). Again, the Glasgow Coma Scale can provide useful guidance in determining the extent of a patient's reduced consciousness (and thus the possible suffering), or to establish that the patient is in a coma. If the coma is reversible, in this situation it is also considered inhuman to first wake the patient simply so that he can confirm to the independent physician that he is suffering unbearably (see case 14).

Cases involving semi-conscious patients usually lead the committees to ask further questions. The committees then examine the specific facts and circumstances. In the light of these, a committee may find in such cases that the physician has acted in accordance with the due care criteria.

CASE 13

(not included here)

CASE 14

FINDING: CRITERIA COMPLIED WITH

Summary: the patient was handed over to the physician who carried out the euthanasia procedure by her own GP, who announced two days before her death that he was unwilling to perform the termination of life, on grounds of principle. The patient was given palliative sedation, but during the physician's visits she was able to communicate one last time. When the independent physician visited, the patient was in a reversible coma. Waking her from the coma in order to communicate with the SCEN physician was considered to be inhuman. Her GP would have done better to have handed her over earlier than he actually did.

The patient, a woman in her seventies, was diagnosed 18 months before her death with urethral carcinoma of the bladder, with tumour growth and metastases in the pelvis, as turned out later. There was no prospect of recovery. She could only be treated palliatively. Two months before her death, the patient received radiotherapy to reduce the pain caused by the metastases, but this was without the desired result. In the following weeks, the pain gradually became more severe despite increasing doses of pain medication. Three days before her death, the pain had become so severe that she was given morphine and Dormicum using a pump. This did not provide enough relief either.

The patient's suffering consisted of pain which could not be relieved. In the last few days before her death, the patient was (partially) sedated. Calm periods alternated with periods of crying, moaning and restlessness. The patient screamed when touched, making washing her and providing other care almost impossible. The patient, who also vomited frequently and could hardly eat or drink anything, experienced her suffering as unbearable. The physician was satisfied that the patient's suffering was unbearable, with no prospect of improvement according to prevailing medical opinion.

The patient had discussed euthanasia with her GP more than a month before her death. On

that occasion, she also presented him with an advance directive. In the five days before her death, the patient indicated to her family and her home carers on several occasions that she could not cope any longer and wanted euthanasia. The patient kept asking when 'the doctor' was coming to put her out of her misery. When the patient's GP received her euthanasia request, two days before her death, he was unwilling to carry out the procedure on grounds of principle, but he knew that the patient's request was realistic and sustained. He then asked another physician to take over the euthanasia procedure. That physician visited the patient on the day of her death, and the day before. On the day of her death, the patient indicated unequivocally, when she was conscious, that she wanted to die and that she wanted him to help her die.

The physician concluded that the request was voluntary and well-considered. An independent SCEN physician visited the patient on the day when the procedure to terminate her life was performed, after he had been told about the patient's situation by the physician and had examined her medical records. He also knew that there was an advance directive. When the independent physician visited, the patient was sedated and could not be woken. Her breathing was rapid and shallow, and she moaned from time to time. In those moments the patient did not appear comfortable. The independent physician considered it inhuman to bring her out of sedation for consultation. As a result, he was unable to communicate with her. On the basis of his own observations, his conversations with the family members present, the home carer and the physician, as well as the GP's notes and the care record, the independent physician was able to assess the patient's suffering and her request. The independent physician concluded, in part on the basis of these sources, that the due care criteria had been satisfied.

The committee assesses cases on the principle that to comply with the due care criteria, the independent physician must be able to speak with the patient, preferably in private. If the independent physician cannot speak with the patient because the patient is in a state of reduced consciousness, he must see the patient and, on the basis of the facts and circumstances, form an opinion as to whether the due care criteria have been satisfied.

In this case the independent physician visited and saw the patient, but was unable to communicate with her, because she had been given medication and was in a state of reduced consciousness as a result. Nonetheless, on the basis of conversations with the physician responsible for her, the family and the home carer, as well as the medical record, the care record and the advance directive, the independent physician was able to form a sound opinion as to the degree to which the patient's euthanasia request was voluntary and well-considered, and the degree to which her suffering was unbearable and without prospect of improvement. The independent physician was also able to establish for himself that, despite being sedated, the patient did not appear comfortable. In the opinion of the committee, it would have been inhuman to wake the patient just to allow the independent physician to communicate with her.

The committee also noted that the situation should be avoided in which a consultation takes place but the independent physician cannot speak with the patient. In the opinion of the committee, it stands to reason, partly in view of the above, that the patient's GP, who knew her wishes, should have handed the patient over to the attending physician earlier than was done in this case.

Palliative sedation

The Act does not apply to palliative sedation, which is a normal medical procedure. Palliative sedation means deliberately reducing the patient's consciousness in order to eliminate untreatable suffering in the final stage of his life. Palliative sedation may only be administered if the patient is expected to die within two weeks and is experiencing symptoms which cannot be treated any other way. These symptoms are referred to as refractory symptoms.⁹ While the decision to administer palliative sedation is made by the attending physician, it may only be done if the patient (or his representative) agrees to it.

There are patients who expressly refuse palliative sedation and indicate that they wish to remain conscious to the very end. The physician and patient may together conclude that palliative sedation is not a reasonable alternative if the patient in question wishes euthanasia. In other words, the possibility of palliative sedation does not always rule out euthanasia.

Sometimes a patient may make a conditional request for euthanasia. In this case, the patient is initially palliatively sedated, but the physician and the patient agree that euthanasia will be carried out should certain circumstances arise. For instance it may take longer for the patient to die than he wishes and/or the patient may still show symptoms of suffering despite being in a state of reduced consciousness. The patient may wish to avoid putting his loved ones through such an ordeal, or his wish to die with dignity may be put at risk.

The committees emphasise that it is essential that the patient inform the attending physician of the specific situations in which his agreement to palliative sedation no longer applies and he wants his request for euthanasia to be carried out.

c. Informing the patient

The physician must have informed the patient about his situation and prognosis.

In assessing compliance with this criterion, the committees determine whether, and how, the physician, or other attending physicians, informed the patient about his disease and prognosis.

In order to make a well-considered request, the patient must have a full understanding of his disease, the diagnosis, the prognosis and the possible forms of treatment. It is the physician's responsibility to ensure that the patient is fully informed and to verify that this is the case. This criterion did not lead the committees to comment on any of the reported cases in 2013.

d. No reasonable alternative

The physician and the patient have together come to the conclusion that there is no reasonable alternative in the patient's situation.

It must be clear that there is no realistic alternative way of alleviating the patient's suffering, and that termination of life on request or assisted suicide is the only way left to end that suffering. The focus is on treating and caring for the patient and on limiting and where possible eliminating the suffering, even if curative therapy is no longer possible or the patient no longer wants it.

9. The KNMG/KNMP Guideline 'Performing euthanasia and assisted suicide procedures' of August 2012 recommends agreeing a maximum time limit of two hours until the patient's death with the patient and his family.

The emphasis in medical decisions at the end of life must be on providing satisfactory palliative care. However, this does not mean that the patient has to undergo every possible form of palliative care or other treatment. Even a patient who is suffering unbearably with no prospect of improvement can refuse palliative care or other treatment, for instance because he considers that the positive effects of treatment do not outweigh the negative effects, e.g. side effects which he finds unacceptable or hard to tolerate. For instance, there are patients who refuse an increased dosage of morphine because of a fear of becoming drowsy or losing consciousness. The physician must then ensure that the patient is properly informed and discuss with him whether this fear is justified.

Some forms of further care may also be unacceptable or hard to tolerate for a patient. In his view, the positive effect of the treatment or care then does not outweigh the negative effects. Refusal of palliative treatment or further nursing or care is an important subject for discussion between physicians and patients. The physician is expected to indicate in his report to the committee why the patient did not consider other alternatives reasonable or acceptable. Cases 4, 7 and 11 are examples of notified cases in which the physician was able to establish that there were no reasonable alternatives for the patient.

e. Independent assessment

The physician must 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.

The physician is legally required to consult another, independent physician who sees the patient to determine whether the physician who intends to perform the procedure has not overlooked anything regarding the due care criteria. The independent physician gives an independent expert opinion regarding the due care criteria set out in (a) to (d) and draws up a written report. This requirement also applies to any other independent physicians consulted by the attending physician.

The independent assessment is a formal consultation of a second physician and specific questions must be asked. The committee interprets the term 'consult' to mean considering the independent physician's findings and taking account of them when deciding whether to grant the patient's request for termination of life. The purpose of this is to ensure that the physician's decision is reached as carefully as possible. The independent assessment helps the physician confirm that he has complied with the due care criteria, and reflect on matters before granting the request.

The requirement to consult an independent physician does not imply that the attending physician needs the independent physician's 'permission' to carry out euthanasia. Naturally, the attending physician should take the independent physician's opinion very seriously, but if there is a difference of opinion between the two, the attending physician must reach his own decision, for it is his actions that the committees will be assessing. If he is of the opinion that the due care criteria have been satisfied but the independent physician disagrees, he will have to provide convincing arguments for the committee that the criteria were indeed fulfilled.

Independent physician

The independent physician must be independent of the attending physician and the patient. The KNMG's 2003 Position Paper on Euthanasia explicitly states (p. 15) that the physician's independence must be guaranteed.

According to the KNMG, this implies that a member of the same group practice, a registrar,

a relative or a physician who is otherwise in a position of dependence in relation to the physician who has called him in cannot normally be deemed independent. It is important to avoid anything that might suggest the physician is not independent (see cases 15 and 16). The physician's independence may also appear open to question if the same two medical practitioners very often act as independent physicians on each other's behalf, thus effectively acting in tandem. This may create an undesirable situation, for their independence may then – rightly – be called into question. The committees believe that, if a physician always consults the same independent physician, the latter's independence can easily be jeopardised.

A notifying physician and an independent physician may also know each other privately, or as members of a peer supervision group. The fact that they know each other privately does not automatically rule out an independent assessment, but it may appear that the physician is not independent. Whether the fact that they know each other as members of a peer supervision group – a professional activity – rules out an independent assessment will depend on how the group is organised. What matters is that the attending physician and independent physician should be aware of this and make their opinion on the matter clear to the committee.

In the interests of an independent assessment, attending physicians are advised to – and usually do – consult a SCEN physician as independent physician, via the regional division of the Euthanasia in the Netherlands Support and Assessment Programme (SCEN) (see below).

Finally, there must, among other things, be no family relationship or friendship between the independent physician and the patient, the physician must not be helping to treat him (and must not have done so in the past) and he must not have come into contact with him in the capacity of locum.

When must an independent physician be consulted for a second time?

Questions are sometimes asked about the period that an independent physician's opinion is valid, i.e. at the most, how much time may there be between the independent physician visiting the patient and the euthanasia procedure? There is no simple answer to this question, although it is more likely to be weeks than months. Much depends on the independent physician's findings, expected and unexpected developments in the patient's situation, and other factors.

The following situations may occur.

- The independent physician is called in at an early stage and finds that the patient is not yet suffering unbearably or that a specific request for euthanasia has not yet been made. In such cases, he will usually have to visit the patient a second time (see case 18).
- The independent physician concludes that the due care criteria have been complied with, but the patient's condition turns out to be less predictable and/or a long period of time is involved. The independent physician will in principle have to visit the patient a second time.
- An independent physician who has been consulted earlier is consulted again. This consultation may, depending on the circumstances described above, take place by telephone (see case 17).
- The independent physician expects the patient's suffering will very soon become palpably unbearable and has specified what he believes that suffering will entail. A second visit or a second consultation by telephone or in any other manner will not normally be necessary if the patient's suffering does indeed become unbearable very soon.

- The unbearable nature of the patient's suffering is already palpable to the independent physician, but the patient has not yet made a specific request for euthanasia to be performed – in order to say goodbye to relatives, for example. A second visit or a second consultation by telephone or in any other manner will not normally be necessary.

If there has been further consultation between the attending physician and the independent physician, or if the independent physician has visited the patient a second time, it is important that this is mentioned in the notification. Sometimes an independent physician concludes on visiting the patient that one or more of the due care criteria have not yet been fulfilled. In such cases, it is not always clear to the committees what exactly happened subsequently, so that further questions have to be put to the notifying physician.

The committees also receive notifications in which the independent physician was consulted, visited the patient and made his report very shortly before the patient died, or even on the day of death. In such cases it is advisable for the attending physician to make clear when and how he received the independent physician's report.

Assessing a decisionally incompetent patient

The attending physician must consult an independent physician who must give his opinion on a decisionally incompetent patient's request for euthanasia. In accordance with section 2 (1) (e) of the Act, the independent physician must see the patient. The regional committees consider that, normally, the independent physician will not just see the patient but also speak with him.

However, there may be circumstances in which the patient is no longer capable of expressing his wishes. Section 2 (2) of the Act, which establishes the legal status of the advance directive, provides for the attending physician to carry out euthanasia in this situation.

If the independent physician has not visited the patient at an earlier stage in the physician's and patient's joint decision-making process, he will find himself facing a patient with whom he is unable to communicate, or only with great difficulty. Earlier parts of this report have dealt with these situations. The paragraphs entitled '[Advance directive and decisional incompetence](#)' and '[Coma and reduced consciousness](#)' also discuss the independent physician's position in this type of situation (see also cases 13 and 14).

The euthanasia procedure may be carried out in cases where a decisionally incompetent patient only 'communicates' non-verbally, provided the due care criteria are satisfied. The independent physician will no longer be able to speak with a patient in such a situation, but he will be able to establish that the request for euthanasia is voluntary and well-considered on the basis of the patient's advance directive. Whether the patient's suffering is unbearable with no prospect of improvement must be assessed on the basis of the advance directive and the patient's current condition, the relationship between the two, information and medical records of the attending physician, and (if available) information from the patient's immediate family (see also case 6, in which decisional competence was at issue).

Independent physician's report

The independent physician's written report is of great importance when assessing notifications. A report describing the patient's situation when visited by the physician and the way in which the patient – in so far as possible – talks about his situation and his wishes will give the committee a clearer picture. The independent physician must give his opinion on whether the due care criteria set out in (a) to (d) have been fulfilled. In order to establish

his independence, he should specifically mention what his relationship is to the attending physician and the patient.

The independent physician is responsible for his own report. However, the attending physician bears final responsibility for performing the life-terminating procedure and for complying with all the due care criteria. He must therefore determine whether the independent physician's report is of sufficient quality and whether the independent physician has given his opinion as to whether the due care criteria set out in (a) to (d) have been fulfilled. If necessary, he must ask the independent physician further questions. The committees regularly ask the independent physician to explain his report further, either orally or in writing.

CASE 15

(not included here)

CASE 16

FINDING: FAILURE TO COMPLY WITH THE CRITERIA

Summary: the attending physician and the independent physician were part of the same partnership, which means that no independent physician was consulted.

For the purpose of a euthanasia procedure, the attending physician had contacted the national SCEN phone number and had been given the name of the independent physician who was on duty in that region at the time. The attending physician and the independent physician were in the same partnership, but were both convinced that the independent physician was indeed sufficiently independent and able to assess whether the due care criteria had been satisfied, in part because the independent physician had never been involved in the patient's treatment. The attending physician and the independent physician were aware of the fact that there must be no conflict of interests between them. They had taken this to mean two colleagues in the same GP practice, rather than two specialists who are part of the same hospital-based partnership, which was the case in their situation.

The committee established that the attending physician and the independent physician had interpreted the term 'independent' too narrowly, by looking only at the absence of a treatment relationship between the independent physician and the patient, and by focusing insufficiently on the conflict of interest factor, which may jeopardise that independence. The attending physician has indicated that measures have been taken within the partnership and rules have been drawn up to guarantee the independence of the independent physician in the future.

Nonetheless, the committee found that the physician had not acted in accordance with the due care criterion of independent assessment.

CASE 17

FINDING: CRITERIA COMPLIED WITH

Summary: two years after the independent physician's visit to the patient, a second visit, if only a brief one, would have been necessary prior to euthanasia. However, the attending physician and the independent physician were able to convince the committee that the chances of the independent physician reaching a different conclusion after his second visit were zero.

In 2008, the patient was diagnosed with progressive muscular atrophy. The condition was incurable. The attending physician consulted an independent physician in 2010, who

visited the patient and concluded that the due care criteria had largely been satisfied. At the time, the patient had not yet actually made a specific request for euthanasia, nor was he suffering unbearably. When the patient requested euthanasia, some days before his death, the attending physician phoned the independent physician and explained the patient's current situation. The patient was exhausted and could no longer speak. He had endured a great deal of suffering, purely through willpower. His situation was so distressing that the attending physician was in no doubt as to whether the due care criteria had been satisfied. To the independent physician, the patient's situation had already been fully clear during his visit. He did not want to impose a second visit on the patient, or in any case wanted to spare him that burden. The independent physician indicated to the attending physician that this consultation by phone would be sufficient and that he did not need to visit the patient a second time. The attending physician, who had never performed euthanasia before, thought he could rely on the experienced independent physician's assessment. In the opinion of the committee, it would have been better if the experienced independent physician had advised the attending physician, who had no experience of euthanasia, that a second visit would be better.

CASE 18

(not included here)

CASE 19

(not included here)

SCEN

The Euthanasia in the Netherlands Support and Assessment Programme (SCEN) trains physicians to make independent assessments. In most cases, physicians consult a SCEN physician as an independent physician, by calling the regional SCEN telephone number. The committees are pleased to note that specialists these days almost always call in a SCEN physician when euthanasia is performed in a hospital. Increasingly, they are themselves trained SCEN physicians.

SCEN physicians also have a part to play in providing support, for example by giving advice (see cases 7 and 12).

The committees note that by no means all physicians consult the SCEN physician about how the euthanasia or assisted suicide procedure is to be performed. Although section 2 (1) (e) of the Act only requires the independent physician to give an opinion on compliance with criteria (a) to (d), there is no reason why the attending physician should not discuss with the independent physician (who is usually a SCEN physician) how he proposes to perform the procedure. The committees have noted that some SCEN physicians offer of their own accord to advise the attending physician on how to perform the procedure. This is a good example of the support component of the SCEN programme.

f. Due medical care

The physician must exercise due medical care and attention in terminating the patient's life or assisting in his suicide.

In the case of euthanasia, i.e. termination of life on request, the physician actively terminates the patient's life by administering the euthanatics to the patient intravenously. In the case of assisted suicide, the physician gives the euthanatic to the patient, who ingests it himself.

KNMG/KNMP Guideline 'Performing euthanasia and assisted suicide procedures' of August 2012

In assessing the criterion of due medical care, the committees generally took as their guide the method, substances and dosage recommended in the Guideline 'Performing euthanasia and assisted suicide procedures' published by the Royal Dutch Medical Association (KNMG) and the Royal Dutch Association for the Advancement of Pharmacy (KNMP).¹⁰ The Guideline provides physicians and pharmacists with advice on 'the practical and effective performance of euthanasia and assisted suicide'.

This Guideline lists which substances, doses and/or methods should be used. It also explicitly lists a number of substances, doses and methods which should not be used. If a physician does not use the substances listed in annexes I and IV of the Guideline and fails to give grounds in his report for having used another substance, the committees will ask him further questions. The committees will certainly ask questions if substances have been used which are advised against. The committees will also ask the physician further questions if he has omitted to state the dosage in his report or if it differs from the dosage indicated in the Guideline.

The physician may not let someone else administer or give the euthanatic to the patient, nor may he leave the patient alone with the euthanatic. This may be hazardous, to other people as well as to the patient.

The physician must obtain the euthanatic directly from the pharmacist, in person.

Before performing euthanasia, physicians are advised to discuss with the patient and his relatives what effect the substances will have. Subject to the constraints imposed by the Guideline, it is important to fulfil patients' personal wishes as far as possible.

Termination of life on request

In cases of termination of life on request, the Guideline recommends intravenous administration of a coma-inducing substance, followed by intravenous administration of a muscle relaxant. It must be absolutely certain that a patient is in a deep coma when the muscle relaxant is administered. The use of a coma-inducing substance recommended in the Guideline in the correct dosage is crucial in order to ensure that the patient cannot perceive the effects of the muscle relaxant. The use of non-recommended substances may have negative consequences for the patient. This can be avoided by using the appropriate substances. If there is any doubt, the committees will ask questions about the depth of the coma and how the physician established this.

A substance such as midazolam may be used as pre-medication before a recommended coma-inducing substance is administered.

Assisted suicide

In the event of assisted suicide, the physician must remain with the patient or in his immediate vicinity until the patient is dead. This is because there may be complications; for example, the patient may vomit the potion back up or death may not ensue as quickly as expected. The physician must discuss these possible events with the patient and his family beforehand.¹¹ If the patient does not die within the prescribed time, the physician must perform euthanasia. As it cannot be predicted what course the assisted suicide will take, an intravenous cannula must always be inserted before the procedure is performed.

10. See the KNMG/KNMP Guideline 'Performing euthanasia and assisted suicide procedures' of August 2012, pp. 18, 32 and 33.

11 The KNMG/KNMP Guideline 'Performing euthanasia and assisted suicide procedures' of August 2012 recommends agreeing a maximum time limit of two hours until the patient's death with the patient and his family.

The physician must also ensure he has all the necessary materials and substances ready for intravenous administration.¹²

CASE 20

(not included here)

¹² See the KNMG/KNMP Guideline 'Performing euthanasia and assisted suicide procedures' of August 2012, pp. 18, 32 and 33.

Ch.3

ACTIVITIES OF 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 (under articles 293 and 294 of the Criminal Code). The only exception is when the procedure is 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 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 the Burial and Cremation Act.

The pathologist reports the termination of life to the committee and submits the attending physician's report, the independent physician's report and, if applicable, the patient's advance directive with his report. He also submits any other relevant documents provided by the attending 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. The physician must convince the committee that he has indeed acted in accordance with those criteria.

If, on the basis of all the information received, the committee reaches the preliminary conclusion that the physician did *not* act in accordance with the due care criteria, the physician will be invited to explain his actions in person before the committee reaches its final conclusion.

The committees issue written findings on the notifications they assess. If the committee finds that the physician acted in accordance with the statutory due care criteria, that finding is final and the case is automatically closed. If the committee finds that the physician did not act in accordance with the due care criteria, the finding and the relevant file are sent to the Board of

Procurators General and the Healthcare Inspectorate, as well as to the physician. The Board will decide, again 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 to take other measures.

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. Each member has two alternates, so in each region there are nine committee members. Each committee is assisted by a secretary (a lawyer) who makes the preparations for the monthly committee meeting and has an advisory vote at the meetings. The secretariats provide support to the committees.

Transparency and communication

To provide physicians and other interested parties with a good, up-to-date overview of the committees' views and to make their interpretation of the key concepts of the due care criteria more accessible, the findings which are deemed relevant to the development of standards – in particular all cases in which the committee found that the due care criteria had not been satisfied – are published in an accessible format on the website of the committees.

The committees also have a public information task and help the KNMG's Euthanasia in the Netherlands Support and Assessment Programme (SCEN) to train physicians to perform independent assessments.

ANNEXE 1

OVERVIEW OF NOTIFICATIONS



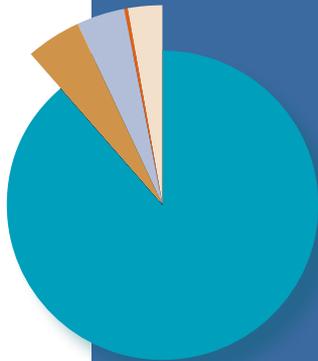
OVERVIEW OF NOTIFICATIONS, TOTAL

Overview of notifications, 1 January 2013 to 31 December 2013

NOTIFICATIONS The committees received 4,829 notifications in the year under review.

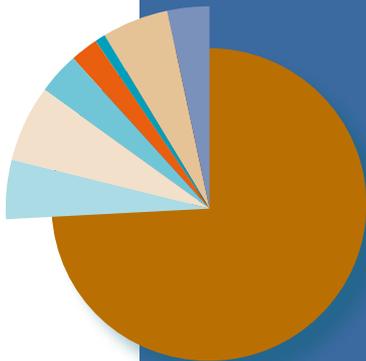
EUTHANASIA AND ASSISTED SUICIDE There were 4,501 cases of euthanasia (i.e. active termination of life at the patient's request), 286 cases of assisted suicide and 42 cases involving a combination of the two.

PHYSICIANS



● General practitioner	4281
● Specialist working in a hospital	213
● Geriatrician	193
● Registrar	13
● Other physician (e.g. a doctor affiliated with the End-of-Life Clinic, a junior doctor, non-practising physician or hospice physician)	129

DISORDERS INVOLVED



● cancer	3,588
● cardiovascular disease	223
● neurological disorders	294
● pulmonary disorders	174
● dementia	97
● mental disorders	42
● multiple geriatric syndromes	251
● other disorders	160

SETTINGS In 3,800 cases patients died at home, in 240 cases in hospital, in 160 cases in a nursing home, in 268 cases in a care home, in 295 cases in a hospice and in 66 cases elsewhere (e.g. at a family member's home).

END-OF-LIFE CLINIC (SLK) In the course of the reporting year, the committees received 107 notifications from the End-of-Life Clinic (SLK).

BONAIRE, ST EUSTATIUS AND SABA In the course of the reporting year, the committees received no notifications from Bonaire, St Eustatius or Saba.

COMPETENCE AND FINDINGS In all cases the committee deemed itself competent to deal with the notification. In the year under review there were 5 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 59 days.

ANNEXE 3

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



Bulletin of Acts and Decrees 2001, 194

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

We Beatrix, by the grace of God Queen of the Netherlands, Princess of Orange-Nassau, etc., etc., etc.

Greetings to all who see or hear these presents! Be it known:

Whereas We have considered that it is desirable to include in the Criminal Code grounds for granting immunity to a physician who, acting in accordance with the statutory due care criteria laid down in this Act, terminates life on request or provides assistance with suicide, and also that it is desirable to create a statutory notification and review procedure;

We, therefore, having heard the Council of State, and in consultation with the States General, have approved and decreed as We hereby approve and decree:

CHAPTER I. DEFINITIONS

Section 1

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

- a. Our Ministers: the Minister of Justice and the Minister of Health, Welfare and Sport;
- b. assisted suicide: intentionally helping another person to commit suicide or providing him with the means to do so as referred to in article 294, paragraph 2, second sentence, of the Criminal Code;
- c. the attending 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 attending 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 attending 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 prognosis;
 - d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation;

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

- 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. exercise 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 attending physician may, in accordance with the provisions of subsection 1, comply with this request unless he has well-founded reasons for declining to do so.
 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 attending 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 attending physician may, if a parent or the parents who have responsibility for him, or else his guardian, is or are unable to agree to the termination of life or to assisted suicide, comply with the patient's request provided that the attending physician is satisfied that ending the patient's life will prevent the patient from suffering profound distress. 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, 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 an attending 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 attending physician to supplement his report either orally or in writing, if this is necessary for a proper assessment of the attending 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 attending physician's conduct.

Section 9

1. The committee notifies the attending physician within six weeks of receiving the report referred to in section 8, subsection 1, of its findings, giving reasons.
2. The committee notifies the Board of Procurators General and the regional health care inspector of its findings:
 - a. if the attending physician, in the committee's opinion, did not act in accordance with the due care criteria set out in section 2; or
 - b. if a situation occurs as referred to in section 12, last sentence, of the Burial and Cremation Act. The committee notifies the attending 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 attending physician accordingly.
4. The committee is empowered to explain its findings to the attending physician orally. This oral explanation may be provided at the request of the committee or the attending 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 attending physician's conduct in a case as referred to in section 9, subsection 2; or
2. for the purposes of a criminal investigation.

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 of the Public Health Supervisory Service 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 an attending 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 committee must submit to Our Ministers a report on its activities during the preceding calendar year. Our Ministers may 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 will be 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 IIIA. BONAIRE, ST EUSTATIUS AND SABA

Section 19a

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

Section 19b

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

Section 19c

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

Section 19d

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

CHAPTER IV. AMENDMENTS TO OTHER LEGISLATION

Section 20

The Criminal Code² is amended as follows.

A

Section 293 is amended to read as follows:

Section 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 the first paragraph 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.

2. Last amended by the Act of Parliament of 26 January 2001, Bulletin of Acts and Decrees, 70.

B

Section 294 is amended to read as follows:

Section 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.

C

The following is inserted in article 295, after '293': , first paragraph,.

D

The following is inserted in article 422, after '293': , first paragraph,.

Section 21

The Burial and Cremation Act³ is amended as follows.

A

Section 7 is amended to read as follows:

Section 7

1. The person who conducted the post-mortem examination must issue 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 attending physician must not issue a death certificate and must immediately notify the municipal pathologist or one of the municipal pathologists of the cause of death by completing a report form. The attending physician must enclose with the form a detailed 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 attending physician decides, in cases other than those referred to in subsection 2, that he is unable to issue a death certificate, he must immediately notify the municipal pathologist or one of the municipal pathologists accordingly by completing a report form.

B

Section 9 is amended to read as follows:

Section 9

1. The form and layout of the models for the death certificates to be issued by the attending physician and the municipal pathologist must be laid down by order in council.
2. 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, must be laid down by order in council on the recommendation of Our Minister of Justice and Our Minister of Health, Welfare and Sport.

3. Bulletin of Acts and Decrees 1991, 133, last amended by the Act of Parliament of 1 July 1998, Bulletin of Acts and Decrees, 466.

C

Section 10 is amended to read as follows:

Section 10

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

D

The following sentence is added to section 12: If the public prosecutor decides, in cases as referred to in section 7, subsection 2, that he is unable to issue a certificate of no objection to burial or cremation, he must immediately notify the municipal pathologist and the regional review committee as referred to in section 3 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

E

In section 81, first point, '7, subsection 1' is replaced by: 7, subsections 1 and 2.

Section 22

The General Administrative Law Act⁴ is amended as follows. In section 1:6, the full stop at the end of point (d) is replaced by a semi-colon, and a fifth point is inserted as follows: e. orders and actions implementing the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

4. Bulletin of Acts and Decrees 1998, 1, last amended by the Act of Parliament of 26 January 2001, Bulletin of Acts and Decrees, 71.

CHAPTER V. CONCLUDING PROVISIONS

Section 23

This Act enters into force on a date to be determined by Royal Decree.

Section 24

This Act may be cited as the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

We order and command that this Act be published in the Bulletin of Acts and Decrees and that all ministries, authorities, bodies and officials whom it may concern diligently implement it.

Done at The Hague on 12 April 2001

Beatrix

A.H. Korthals,
Minister of Justice

E. Borst-Eilers,
Minister of Health, Welfare and Sport

Published on the twenty-sixth of April 2001

A.H. Korthals,
Minister of Justice