



**Regional
euthanasia
review committees**

—
Annual report 2010

Contents

<i>Foreword</i>	3
<i>Chapter I Developments in 2010</i>	
Notifications	5
Website	5
Due medical care	6
‘Finished with life’	6
<i>Chapter II Due care criteria</i>	
Due care criteria: general	8
Due care criteria: specific	10
a Voluntary and well-considered request	10
Mental illness or disorder	10
Depression	10
Dementia	10
Advance directive	11
b Unbearable suffering with no prospect of improvement	17
Unbearable suffering with no prospect of improvement in special cases	22
Dementia	22
Mental illness or disorder	22
Coma	23
Palliative sedation	23
c Informing the patient	23
d No reasonable alternative	23
e Independent assessment	24
f Due medical care	27
<i>Chapter III Committee activities</i>	
Statutory framework	32
Role of the committees	32
<i>Overview of notifications</i>	34

Foreword

This is the 2010 annual report of the five regional euthanasia review committees. In our annual reports we account for the way in which we review cases on the basis of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. The report provides details of the number of notifications received, the nature of the cases reported, the committees' findings and the considerations on which these were based.

As in the previous six years, the number of notifications under the Act rose in 2010, from 2,636 in 2009 to 3,136 in 2010 – a sharp increase (19%). The cause of this continuing increase in the number of notifications from year to year is not known. The year under review saw the start of a second evaluation (mentioned in earlier annual reports) of how the Act operates. The results are due in late 2012.

In 2010 the committees were able to reach conclusions on 2,667 of the 3,136 notifications. In 2010 the Ministry of Health, Welfare and Sport gave the committees the go-ahead to take on more staff. Despite this, their work fell even further behind schedule. As a result, the statutory deadline for issuing their findings on notifications was seriously exceeded in a number of cases. This is not only undesirable, but unlawful.

The committees greatly regret this state of affairs, which they also made known to the attending physicians. Both the members and the secretariats of the committees have made every effort to tackle these problems. An internal working group on working procedures has made a number of proposals designed to make the review of notifications by the committees more efficient, without of course impairing its quality. The proposals will be assessed by conducting pilot projects in two regions. These will start in mid-2011.

The considerable public focus on voluntary euthanasia is reflected in a number of initiatives that were launched in 2010. The initiative group Uit Vrije Wil ('Of one's own free will') presented a proposal for legislation, the Dutch Voluntary Euthanasia Society (now Right to Die-NL) conducted a study on the feasibility of an 'end-of-life clinic' and the Royal Dutch Medical Association initiated a debate, based on a published draft position paper, on the role of physicians in termination of life at the patient's request. The members of the committees have, of course, noted these initiatives with interest. However, given their own responsibilities, their independent status and their role in reviewing cases, the committees do not feel it is appropriate for them to express an opinion on the initiatives. Their task is to review the actions of attending physicians, in the light of the due care criteria laid down in section 2 of the Act, and to consider whether, in accordance with prevailing medical opinion and standards of medical ethics, the criteria have been complied with.

One matter of continuing concern to the committees is that their reviews of notifications should be unequivocal. While taking account of the principle that every notification should be reviewed according to the specific circumstances of the case, the committees are always at pains to harmonise their findings. In 2010 they again held meetings on this particular subject, which were attended by the lawyers (including the secretaries), physicians and ethicists on the committees. For more on this, readers are referred to Chapter I.

Of the 2,667 notifications on which the committees were able to reach conclusions in the year under review, they found in nine cases that the physician had not acted in accordance with

the due care criteria. In five of these cases, it was the way in which the euthanasia or assisted suicide procedure was performed that was deemed not to comply with the criteria – sufficient reason to devote a symposium marking the departure of coordinating chair J.J.H. Suyver in December 2010 to the topic ‘Performance of euthanasia and assisted suicide with due medical care’.

The committees are always pleased to receive feedback.

W.J.C. Swildens-Rozendaal

Coordinating chair of the regional euthanasia review committees

The Hague, August 2011

Chapter I Developments in 2010

The following developments took place in 2010.

Notifications

In 2010, the regional euthanasia review committees ('the committees') received 3,136 notifications of termination of life on request (often referred to as 'euthanasia') or assisted suicide.¹ This constitutes an increase of 19% over the 2009 figure (2,636). The Termination of Life on Request and Assisted Suicide (Review Procedures) Act ('the Act') will be evaluated again; the evaluation, which has already started, will also investigate the sharp rise in notifications.

In 2010, the committees reviewed 2,667 of the 3,136 notifications. The proportion of notifications actually reviewed has been a matter of great concern to the committees for some time. The substantial increase in the number of notifications (which has been going on for some years now) and the resulting capacity problems, especially in the secretariats, have caused the committees to fall behind schedule. In spring 2010 the Ministry of Health, Welfare and Sport allowed some more staff to be taken on, but still not enough. At the same time, unfortunately, some secretariat staff were on extended sick leave, with the result that the existing backlog of work, far from being reduced, continued to increase. The period within which notifications are dealt with has therefore become unacceptably long. The committees consider this a highly regrettable situation; dealing with notifications in good time and complying with the law is essential if they are to enjoy continuing confidence.

Together with the secretariats, the committee members are therefore doing all they can to tackle these problems. Among other things, a working group on working procedures has been set up, and in early 2011 it made proposals designed to make the committee's working procedures even more efficient, although obviously subject to the constraints imposed by the Act.

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 the Act. In nine cases the committees found that the physician had not acted in accordance with the Act. The most relevant elements of these cases – as well as a number of cases in which the committees found that the physician had acted in accordance with the due care criteria – are described in Chapter II (Due care criteria: specific) under the criterion concerned.²

Website

The committees aim to publish in full all the findings in which they conclude that the physician had not acted in accordance with the Act on the website www.euthanasiecommissie.nl. Findings in which the committees conclude that the physician had acted in accordance with the due care criteria are also published on the website. Only findings whose publication might jeopardise the patient's anonymity are withheld.

Unfortunately, since the increase in the number of notifications over the past few years has not been matched by a similar increase in the number of staff working for the committees, they were again unable to process any findings for publication in 2010. Consequently, none were published.

The committees hope to resume publishing findings on the website (which has been completely redesigned) in the course of 2011.

¹ See 'Overview of notifications' for the national figures.

² The passages included here as cases mainly concern the due care criterion that is being discussed at that point. A few cases in which the committees found that the procedure had not been performed in accordance with the due care criteria – owing to almost identical failings – are also given as examples.

Due medical care

In assessing compliance with the due medical care criterion, the committees carefully consider the current standard in medical and pharmaceutical research and practice, normally taking the method, substances and dosage recommended by the Pharmacy Research Institute (WINAP) of the Royal Dutch Association for the Advancement of Pharmacy (KNMP) as their guide. The Institute's *Standaard Euthanatica, toepassing en bereiding 2007* ('*Standaard Euthanatica*') also states which substances – and dosages – the KNMP does or does not recommend for use in cases of termination of life on request or assisted suicide.

In 2008, in the journal *Medisch Contact*, the committees referred to *Standaard Euthanatica* and announced that they would continue to take it as their guide.³

The committees note that more attending physicians followed *Standaard Euthanatica* in 2010. However, the committees again came across the use of substances that are not recommended in *Standaard Euthanatica*, and notifications in which the dosage was not specified or was not in accordance with the recommendations in *Standaard Euthanatica*.

In such cases the committees always asked the physician to explain why *Standaard Euthanatica* was not followed.

Unfortunately, they note that not all the physicians were able to give adequate reasons. In the year under review there were five cases in which the committees found that the physician had not acted in accordance with the due care criteria regarding the choice or dosage of substances. A number of these almost identical cases are described below.

In 2010, a joint KNMP/WINAP and Royal Dutch Medical Association (KNMG) working group began drawing up a new version of *Standaard Euthanatica*. On request, the committees provided the working group with information on their experience in assessing how the euthanasia procedure was performed (of course, always in general terms, and hence anonymously).

In December 2010 the committees held a symposium on the subject, which was also attended by representatives of KNMP/WINAP and the KNMG. The symposium reconfirmed that the committees will take the 2007 version of *Standaard Euthanatica* as their guide until a new version is published, and that physicians who do not follow *Standaard Euthanatica* must give adequate reasons for doing so.

'Finished with life'

In the year under review the committees also received notifications in which physicians described the unbearable nature of the patient's suffering in terms of being 'finished with life'. However, the physicians do not appear to be using the term in quite the same way as it is used in the public debate on the subject. What they want to express is that the patient perceived his suffering – and hence his life – as unbearable, and therefore wished to end it.

As discussed in more detail in Chapter II (Due care criteria: specific, under (b)), the unbearable nature of the patient's suffering is determined not only by his present situation but also by his perception of the future, his physical and mental stamina and his own personality. What is still bearable to one patient may be unbearable to another.

In the light of the public debate on being what is commonly termed 'finished with life',⁴ plus the fact that physicians also use this or similar terms fairly regularly to express the unbearable nature of suffering when reporting cases of euthanasia or assisted suicide, the committees felt a need to discuss the matter jointly. In autumn 2010 a meeting attended by physicians, ethicists and lawyers from all the committees was held on the subject. One main reason to hold such meetings regularly is to harmonise the committees' findings.

The committees review the physician's actions in the light of the due care criteria laid down in the Act. The intended purpose of this legislation was to codify the Supreme Court's case law and the due care criteria that had evolved from it. The committees take account of this case law when interpreting the criteria.

The Supreme Court's Brongersma ruling is of particular relevance to the 'finished with life' debate.⁵ The actual case occurred before the Act came into force, but the ruling was handed down afterwards. The ruling stated that suffering must chiefly be caused by a medically recognised disease or disorder. According to the Court, which referred to the preparatory work on the Act, a physician does not have the expertise to assess suffering caused by being 'tired of living', for this does not fall within the field of medicine ('Since the physician is then entering a field that lies beyond his professional competence, he may not, as a medical expert, assess the unbearable nature, hopelessness or untreatability of that suffering').

3 *Medisch Contact*, no. 4, November 2008.

4 The committees themselves do not use this term.

5 Supreme Court, 24 December 2002, *Nederlandse Jurisprudentie* (NJ) 2003, 167.

It is clear that the legislator did not intend the Act to be applicable to euthanasia on grounds of being ‘finished with life’, particularly since the public debate on the subject had not yet taken place.⁶

The government referred in a variety of terms to the lack of an unequivocal view within the medical profession on the concept of being ‘finished with life’, and indicated that there had not yet been a public debate on the subject (‘however, this is not yet an issue that has been fully discussed in Dutch society’).⁷ The committees consider the parliamentary history of the Act an important factor.

Since euthanasia and assisted suicide were in all cases criminal offences at the time when Mr Brongersma died, the Supreme Court had to decide whether the physician could successfully invoke *force majeure* in the sense of necessity, arising from a conflict of duty. When the Act came into force, euthanasia and assisted suicide ceased to be an offence if performed by a physician who reported the procedure and complied with the statutory due care criteria. Unlike a court’s evaluation of the defence of necessity, review by the committees under the Act is a test of reasonableness: could the attending physician reasonably be satisfied that the patient’s suffering was unbearable with no prospect of improvement? The physician must make clear to the committees that this was the case. The committees then decide whether, in the light of prevailing medical opinion and the standards of medical ethics, the due care criteria were complied with.

In all the notifications that were reviewed by the committees, the patient’s unbearable suffering with no prospect of improvement was chiefly due to a recognised disease or disorder (see, for example, case 11).

⁶ See Proceedings of the House of Representatives, 23 November 2000, Memorandum of Reply 27-2254; Parliamentary Papers, Senate 2000-2001, 26691, no. 137b, p. 32; Response, Parliamentary Papers, Senate 2000-2001, 26691, no. 137b, p. 34 ff.

⁷ See, inter alia, Parliamentary Papers, House of Representatives 2000-2001, 26691, no. 22, p. 76.

Chapter II Due care criteria

Due care criteria: general

The committees assess whether the attending physician has acted in accordance with all the statutory due care criteria. These criteria, as laid down in section 2 of the Act, are as follows.

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 inform 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;
- e consult 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 physician other than the regular attending physician, as a locum in the latter's absence, because the patient's situation rapidly deteriorates or because the attending physician does not wish to carry out the procedure himself, for instance because of his religious or ethical views.

In such situations it is important that the physician who carries out the procedure, and hence submits the notification, should obtain sound information in advance about the patient's situation and be personally satisfied that the due care criteria have been complied with.

Occasionally, physicians are unclear as to their (respective) roles in the termination of life. If, for example, a case of euthanasia is reported by a physician who did not perform

the procedure himself, the physician who actually performed the procedure will still have to sign the notification, and will be regarded by the committee as the attending physician.⁸

The information provided by attending physicians is of crucial importance to the committees' reviews. 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 committees note that an increasing number of physicians are using the new report form. The questions in it provide attending physicians with a better guide as to how to 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 decision-making process at the end of the patient's life or what happened when the procedure was performed.

The committees are aware that such an interview, besides taking up the physician's time, may be distressing to him. They wish to emphasise that the purpose of the interview is to give the physician an opportunity to provide further details regarding a notification which the committee still has its doubts about even after the physician has provided further information by telephone or in writing. In the absence of such details, the committee would be unable to find that the physician acted in accordance with the statutory due care criteria. The interview also gives the physician an opportunity to answer questions about his actions (which can, of course, be expected of him).

In 2010, the great majority of notifications again gave no grounds for further discussion or questions when they came before the committees. In those cases the committees could swiftly conclude that the physician had acted in accordance with the due care criteria (case 1 is included as an example of such a notification).

⁸ See article 3 (1) of the guidelines on the committees' working procedures, which were adopted on 21 September 2006.

Case 1

The due care criteria were complied with; no special particulars

Finding: criteria complied with

In early 2009 the patient, a man in his twenties, developed symptoms that were caused by a form of juvenile cancer. The tumour was located in the thoracic wall, and there was metastasis in the bone marrow.

The patient was given high doses of chemotherapy, and in autumn 2009 the tumour was surgically removed. The patient was then given more chemotherapy, followed by stem cell transplantation in late 2009 and radiotherapy in early 2010.

Despite this, he again suffered severe pain due to metastasis throughout the body. These were treated with palliative chemotherapy and radiotherapy. The pain control treatment had unpleasant side effects.

The patient was given fentanyl patches, methadone and Oramorph, but was still suffering unbearable pain. His condition deteriorated rapidly, and by the final week he was completely bedridden. Owing to urine retention he was fitted with a permanent catheter during the last few days.

His suffering was caused by severe pain throughout his body, general debilitation and total dependence on care by others. The patient found this suffering unbearable, and the physician was satisfied that this suffering was unbearable to the patient.

Apart from the palliative measures that had already been taken, there were no other ways to relieve the suffering. The patient refused palliative sedation. He did not want to be given higher doses of painkillers and sedatives and then lie in bed waiting to die.

Two days before he died, he had made his first specific request for euthanasia to the physician. He had subsequently repeated the request. There was an advance directive. An independent specialist who was also a SCEN physician was consulted as an independent physician. He saw the patient a day before he died. The patient had not yet taken any methadone, since he wanted to be as lucid as possible. He was lucid while explaining the reasons for his request for euthanasia.

He looked pallid. The independent physician saw the patient's face contort with pain several times. According to the independent physician, the patient's suffering mainly consisted of the increasingly severe pain and the fact that he could no longer get out of bed. Together with the prospect that things would only get worse, this made the patient's suffering unbearable to him. There was no prospect of any improvement in his suffering, nor were there any alternative ways to relieve the suffering.

According to the independent physician, the patient was decisionally competent. He was able to understand the implications of his wish for euthanasia and to express that wish in words. The request was voluntary and well-considered. The independent physician was satisfied that the due care criteria had been complied with.

The attending physician performed euthanasia by administering 2000 mg of Pentothal and 20 mg of Pavulon intravenously.

The committee assessed the physician's actions for compliance with the due care criteria laid down in section 2 of the Act, and considered whether, in accordance with prevailing medical opinion and the standards of medical ethics, the criteria had been 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 his suffering was unbearable with no prospect of improvement. The physician gave the patient sufficient information about his 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 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.

In a number of cases, however, the notification gave rise to in-depth, lengthy discussions within the committee. The remaining cases included in this chapter are examples of cases that gave rise to discussion and, usually, further questions. Unlike case 1, in which the committee's findings regarding all the due care criteria are discussed, in the other cases the description usually focuses on the relevant sections that serve as examples for a review of compliance with a specific criterion.

Due care criteria: specific

a Voluntary and well-considered request

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. The patient's request must be specific and made to the physician.

Three elements are crucial here:

- 1 The request for termination of life or assisted suicide must have been made by the patient himself.
- 2 It must be voluntary.
There are two aspects to this. The request must be internally voluntary, i.e. the patient must have the mental capacity to determine his own wishes freely, and externally voluntary, i.e. he must not have made his request under pressure or unacceptable influence from those around him.
- 3 In order to make a well-considered request, the patient must be fully informed and have a clear understanding of his disease. The patient is considered decisionally competent if he is capable of making an internally voluntary, well-considered request.

Mental illness or disorder

In general, requests for termination of life or assisted suicide because of unbearable suffering with no prospect of improvement that arises from a mental illness or disorder should be treated with great caution. If such a request is made by a psychiatric patient, even greater consideration

must be given to the question of whether the request is voluntary and well-considered. A mental illness or disorder may make it impossible for the patient to determine his own wishes freely. The physician must then ascertain, or obtain confirmation, that the patient is decisionally competent. Among other things, he must look at 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.

If other medical practitioners have been consulted, it is important to make their findings known to the committee. In 2010 there were two notifications of euthanasia or assisted suicide based on psychiatric problems, in both cases depression (see, for example, case 5).

Depression

In the year under review, there were again notifications in which the patient was suffering from depression in addition to one or more somatic conditions. Depression often adds to the patient's suffering (see, for example, case 13). The possibility that it will also adversely affect 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. The attending physician must therefore ascertain, or obtain confirmation, that the patient is decisionally competent. 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 therefore not generally a sign of depression.

Dementia

All twenty-five notifications, dealt with in 2010, concerning termination of life on request or assisted suicide involving patients suffering from dementia were found by the committees to have been handled with due care. The patients were in the initial stages of the disorder and still had insight into the 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. Cases 6, 7 and 8 serve as illustrations.

The committees adhere to the principle that physicians should normally treat requests for termination of life from patients suffering from dementia with additional caution. They must take the stage of the disorder and the other specific circumstances of the case into account when reaching a decision. Patients at a more advanced stage of the disorder are less likely to be decisionally competent. If a patient is in the initial stages of dementia, it is advisable to consult one or more experts, preferably including a geriatrician or a psychiatrist, in addition to the independent physician. 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 in all such cases.

The physician must take additional care in reaching his decision and must make clear to the committee how it was reached.

Advance directive

The Act requires the physician to be satisfied that the patient has made a voluntary and well-considered request. The request is almost always made during a conversation between the physician and the patient, and hence is made orally. What matters most is that the physician and the patient should be in no doubt about the patient's request.

The Act makes specific provision for a written directive. This replaces an oral request in cases where a patient who used to be decisionally competent is no longer capable of expressing his wishes when the time comes to consider ending his life. The due care criteria likewise apply here, which is why it is so important that the physician to whom the request is made in a specific situation should be in no doubt regarding the directive. 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 clearer and more specific the directive is, the firmer the basis it provides for the physician's decision. The latter, as well as the independent physician, will have to decide in the light of both the described and the current situation – and having regard to the process that the physician has gone through with the patient – whether the patient has made a voluntary and well-considered request, whether he is suffering unbearably with no prospect of improvement and whether he has no reasonable alternative.

If, on the other hand, the patient is capable of expressing his wishes and can request that his life be terminated, a written directive can help eliminate any uncertainty and confirm the oral request. A handwritten directive drawn up by the patient in which he describes the circumstances in his own words often provides additional personal confirmation, and is therefore more significant than a standard form, particularly one that is conditionally worded.

Contrary to popular belief, the Act does not require an advance directive to be drawn up. In practice, the existence of such a directive does make it easier to subsequently assess the case, but the committees wish to emphasise that it is not the intention that people be put under unnecessary pressure to draw up such a directive in difficult circumstances, in some cases only shortly before they die.

By recording details of a patient's wish for euthanasia and the physician's and patient's decision-making process concerning the end of his life in the patient's records, the physician can also help eliminate any uncertainty. This may, for example, be of help to locums and others involved in reaching a decision.

Case 2 (not included here)

Case 3

The patient's request was voluntary and well-considered; despite limited capacity for communication during the visit by the independent physician, this could still be determined with sufficient certainty

Finding: criteria complied with

In 2008 the patient, a man in his sixties, was diagnosed with a melanoma which had metastasised into the lymph glands. There was no prospect of recovery. Surgery was performed. By early 2010 there was diffuse metastasis in the upper and lower back. Despite various therapies, the patient was in great pain.

In mid-2010 the patient began to have difficulty in finding words. This proved to be caused by

metastases in the brain. He then began to have epileptic seizures, for which he was treated with dexamethasone and Depakine.

Towards the end the patient deteriorated very rapidly. He had headaches, and became bedridden, incontinent and dependent as a result of repeated seizures. One day before he died he was given Dormicum to make him less restless, but even in his sleep he had epileptic attacks.

The patient's unbearable suffering was caused by pain and seizures, plus the fact that he was now barely able to communicate. Confinement to bed, dependency and loss of dignity contributed to a state of suffering with no prospect of improvement.

Apart from the measures already taken, there were no other ways to alleviate the suffering. The documents make clear that the physician gave the patient sufficient information about his situation and prognosis.

After being diagnosed with diffuse metastasis, the patient had discussed euthanasia with the physician in general terms. Three days before he died he specifically requested euthanasia, and he repeated the request several times. Towards the end he could still indicate that he wanted euthanasia, but he was no longer able to substantiate his request.

There was a recent advance directive in which the patient had indicated which situation would mean unbearable suffering to him. According to the attending physician there was no pressure on the patient from those around him, and he was aware of the implications of his request and his physical situation.

An independent specialist, who was also a SCEN physician, was consulted as an independent physician. He saw the patient on the day of the euthanasia procedure, after being informed about him by the attending physician and examining the medical records. According to his report, the patient was in bed and was sleeping.

The independent physician was able to shake the patient awake, but the only thing he could make out was that the patient wanted to die. The patient was no longer able to make anything else clear.

The patient was restless, and because he was rubbing his abdomen with his hand he seemed to be in pain. His wife and children said that he was now in a situation he had wanted to avoid: he was in great pain, with loss of dignity. His family said he was a very independent, strong man who, when his disease proved to have metastasised, had made quite clear that he wanted euthanasia in such circumstances.

The independent physician's summary was that the patient, in the terminal stage of a now untreatable melanoma, was in great pain and having numerous seizures. He had been treated with high doses of painkillers, antiepileptics and Dormicum. The independent physician was satisfied that, despite the patient's drowsiness, he was still suffering unbearably with no prospect of improvement. The patient could still indicate his wish for euthanasia, but could no longer substantiate it. The statements by the patient's wife and children, the physician's notes and the patient's advance directive made clear that the request was well-considered and voluntary. There were no realistic alternative ways to alleviate the suffering. The independent physician was satisfied that the due care criteria had been complied with.

The committee found that the physician had acted in accordance with the statutory due care criteria.

Case 4 (not included here)

Mental illness or disorder

In 2010 the committees received two notifications concerning patients whose unbearable suffering was due to a mental illness or disorder.

In these cases the physicians proved to have paid special attention to the question of whether the request was voluntary and well-considered and whether the patient's suffering was unbearable with no prospect of improvement (case 5 is included below as an example).

Case 5

A voluntary, well-considered request by a patient who was suffering unbearably with no prospect of improvement owing to a psychiatric condition (depression)

Finding: criteria complied with

More than four years before the patient died,⁹ she was diagnosed with vital depression. Her medical history reveals recurring episodes of depression, which were difficult to treat, from 1980 onwards. Apart from a period of several months, she was in hospital from 2005 until she died. Since her depression failed to respond to the various treatments, a psychiatrist working at a teaching hospital was asked for a second opinion. He examined the patient himself, and on his advice she was given treatment based on anti-depressant medication, assistance in finding ways to keep her mind occupied during the day, assistance in keeping her as independent as possible and use of physiotherapy to improve her mobility. Lack of energy and initiative, and despondency made it very difficult for her to cooperate with the treatment. She found it distressing, and seemed constantly unable to cope. When it became clear that this treatment was as unsuccessful as the rest, the medication was phased out and all further treatment terminated (in consultation with the psychiatrist). It was decided to prevent or treat the patient's physical symptoms as far as possible.

Her suffering was due to the fact that she perceived her inability to feel anything as distressing; she had lost touch with, and all sense of, her surroundings and life in general. The various treatments over the previous years had not helped. She had been suffering from therapy-resistant depression for years, and did not wish to continue living in what she perceived as a highly distressing way. The fact that there was no prospect of improvement in her situation, and her increasing physical deterioration, made her suffering unbearable to her. The physician found this palpable.

He had seen her cooperating as best she could with the treatment and continuing to hope that she would get better. He now could understand that after four years of treatment in which her condition, far from improving, had merely deteriorated, and with no way to alleviate her suffering, she did not want to continue living. Apart from the measures already taken there were no ways left to alleviate her suffering.

The documents show that the physician and the attending specialists, the general practitioner and the registrars gave the patient sufficient information about her situation and prognosis.

Some considerable time before she died she had repeatedly told the physician that she wanted to die, had repeatedly discussed the possibility of euthanasia with him and one of his colleagues, and on several occasions had asked him to perform the procedure.

The patient had drawn up an advance directive. According to the physician there was no pressure on the patient from those around her, and she was aware of the implications of her request and of her physical situation.

The physician consulted three independent fellow psychiatrists as independent physicians. The first saw the patient just over five weeks before she died. The second, who was also a SCEN physician, saw her just over four weeks before she died. The third, who was likewise a SCEN physician, saw her a week before she died. The physician informed the three

⁹ To prevent possible identification, the patient's age is not indicated.

independent physicians about the patient and let them examine her medical records. In their reports they confirmed her case history and described their visits to her. In their opinion her suffering was unbearable, with no prospect of improvement.

According to the first independent physician the patient had been informed about her situation and prognosis. There were no alternative ways to alleviate her suffering. The documents made clear that all the medically indicated biological treatments had been tried and that electroshock therapy was no longer indicated, since it had had no effect in the past. There had been careful consultation with the medical team, the previous attending psychiatrist, another independent psychiatrist who had been consulted on the subject of mood disorders, and the general practitioner.

The independent physician's report stated that the patient was in a wheelchair because she had difficulty in walking. Her appetite was poor, causing her to lose weight. She was sleeping badly. She was lucid, and the physician was able to communicate with her, and eventually to establish a degree of rapport. His first impression was that she was severely depressed. Her thinking was not abnormal, nor did she have serious cognitive problems. The physician was able to draw and keep her attention, and her observation was intact. Her mood was depressive, but not psychotic. She was emotionally unstable, crying all the time and constantly talking about how miserable she felt and how empty, hopeless and unbearable her life was. She had had enough of phasing in new medication and then phasing it out again. She no longer enjoyed anything, she had no energy or feelings left and she had not laughed for four years. She had considered suicide, but did not know how to go about it. She stated that she could no longer cope with reality, since she no longer felt part of it.

The committee's findings were as follows. On the question of whether the patient's request was voluntary and well-considered, the committee noted that she had wanted to die for a long time. Before her interview on admission to hospital seven months before she died, she had spoken at length to her relatives about her wish for euthanasia. Both she and her relatives assumed that this was not an option because she was mentally ill. When she indicated during the interview that she wanted to die, the physician informed her about the due care criteria in the Act. In the months that followed she repeatedly stated that she wanted to die. Once it became clear that the last treatment had failed, she was no longer willing to try further treatments, and she stated that she had had enough and wanted to die now. She was aware that there was no prospect of improvement in her situation and that things would only get worse. She no longer wanted to live in isolation from the people she loved. She expressly asked for help in dying. In an interview with another psychiatrist two months before she died, her wish to die was again quite clear. The physician stated that the patient was always able to talk about her situation in an appropriate, differentiated way, and that there was mutual contact. She was lucid, and the physician could draw her attention, but not always keep it. Her orientation to time, place and person was normal. She had minor memory disorders that were appropriate to her age and condition. Her judgment was not impaired, and she was well aware of her situation. She had a realistic picture of her disease. The physician was satisfied that her request was voluntary and well-considered.

Insofar as this is relevant to an assessment of compliance with this due care criterion, the committee's findings regarding the three independent physicians were as follows. The first physician was satisfied that the patient's request was voluntary and well-considered. The second was satisfied that her request was voluntary and persistent. However, he felt that the patient's judgement was so strongly affected by her depressive symptoms that her request could not be regarded as well-considered. He based this opinion on her presentation, which was dominated by complaints about her symptoms. He felt that her thoughts went in one direction only, and that she was unable to consider the pros and cons of her request.

After this visit by a second independent physician, the attending physician reviewed his assessment of whether the patient's request was well-considered and discussed this at length with a fellow psychiatrist. He was eventually satisfied that the patient was indeed

capable of weighing things up; she had considered palliative care and sedation, only to refuse them, and she had had thoughts about suicide, but did not want to burden her relatives with them. Despite having wanted to die for a long time, she had made well-considered decisions to cooperate with each course of treatment. Only when it became clear to her that there were no realistic alternative treatments left did she begin to think of death as her only option. All these factors made the physician decide to consult a third independent physician. The third independent physician concluded that the patient had initially kept her request for euthanasia to herself for a long time, since she did not want to burden her relatives. She was very pleased that the physician had obtained so much advice about possible types of treatment. After it had become clear that the last treatment had failed, she had finally, after due deliberation and consideration, made her final request for euthanasia. She made it clear that this was entirely what she wanted, half-rising to indicate just how serious her request was. She was very well aware that, if the procedure was performed, it would be irreversible. The third independent physician was satisfied that the patient's request was well-considered. Some weeks before the patient died she had set out her wishes in a signed directive. On the question of whether the patient's request was well-considered, the committee noted that the physician was satisfied that the patient definitely wanted to die, that she had weighed up the options of living or dying and that she had a persistent wish to die. In the light of the above facts and circumstances, the committee found that the physician could be satisfied that the patient's request was voluntary and well-considered. On the question of whether (as confirmed by the three independent physicians) the patient's suffering was unbearable, with no prospect of improvement, the committee notes with regard to the patient's prospects of improvement that in the past four years she had not only undergone all possible medication treatment in accordance with the relevant guidelines but had also cooperated with further treatment; yet nothing had helped. The severity of her depression ruled out appropriate use of psychotherapy. A second opinion by an independent psychiatrist confirmed that there were no other realistic treatments left. The patient's depression had proved therapy-resistant. Nor had hospitalisation and living in sheltered accommodation made any difference to her situation.

Regarding the unbearable nature of the patient's suffering, the committee notes that the physician had been involved in her treatment for a period of time nearly four years before she died. After four years he was again involved in her treatment. This enabled him to assess the development in her attitude and approach to her situation. According to his report, the patient had said she found it very distressing not to be able to feel anything any longer; she had lost touch with her surroundings and life in general. She felt that she was no longer in her right mind, and she hated having so much difficulty in communicating with others. Looking back on her life with satisfaction did not give her enough consolation and support to want to carry on living. None of the treatments in the previous years had helped. The fact that there was no prospect of improvement in her situation, and the accompanying physical symptoms, added to the patient's suffering.

The committee concluded that the physician could be satisfied that the patient's suffering was unbearable, with no prospect of improvement. It therefore found that the physician had acted in accordance with the statutory due care criteria.

Dementia

Cases 6, 7 and 8 are examples of notifications concerning patients suffering from dementia. In these cases the physician proved to have paid special attention to the question of whether the request was voluntary and well-

considered and whether the patient's suffering was unbearable with no prospect of improvement.

Case 6 (not included here)

Case 7

The physician could make it clear that he found an Alzheimer patient's suffering palpably unbearable

Finding: criteria complied with

Since mid-2009 the patient, a woman in her eighties, had felt that she was becoming forgetful. She had to write things down in order to remember them, but soon after reading them she had forgotten them again. Watching television was also more and more difficult, as it was all getting too fast for her. In early 2010, at her own request, she was examined by a psychiatrist, who found her to be decisionally competent. She then underwent a neuropsychological examination to determine whether there was cognitive deterioration. Several functional disorders and general cognitive deterioration were found, and it was concluded that she was suffering from incipient dementia, possibly Alzheimer's disease. This was confirmed by a geriatrician who was consulted by the attending physician. The patient suffered from the future prospect of humiliation and loss of dignity. She was already losing her sense of time, and saying the same things twice. She realised she was already suffering from slight dementia, and was afraid of a further decline which, among other things, would lead her to become dependent and incontinent, and to lose her way. She was also afraid of being unable to request euthanasia because she was no longer decisionally competent. She wanted to die with dignity, while she 'still had all her faculties'.

The patient had experienced at close hand what Alzheimer's disease could be like. Her mother, sisters and brother had all had the disease in later life, and had eventually died in nursing homes. Whenever she had gone to visit them there, she had felt sad and helpless. The loss of dignity that accompanied the disease had made a deep impression on her. She had perceived the way in which people were looked after in nursing homes as degrading. By exercising her brain the patient had done what she could to prevent dementia. She did not want to experience undignified deterioration as a result of dementia, and had therefore signed an advance directive back in 1993. Her disease was incurable, and there was no prospect of improvement in her suffering. This was unbearable to her.

She had always told the physician that she wanted euthanasia if she developed dementia. Some six weeks before she died, when it was becoming increasingly clear that she was suffering from dementia, she asked the physician for euthanasia, and she repeated her request several times thereafter. In addition to the earlier advance directive, she had also signed a recent one. At the physician's request, one of her daughters had also written down the story she had told of her own life.

According to the physician there was no pressure on her from those around her, and she was aware of the implications of her request and her physical situation. This had been confirmed by a psychiatrist.

An independent specialist, who was also a SCEN physician, was consulted as an independent physician. He saw the patient just over a week before she died. According to his report she was lucid during the interview. She told him of her long-time fear of developing dementia and her experience with her relatives who had suffered from it. She felt disillusioned: she had developed the disease despite her efforts to keep abreast of things and exercise her brain. She was afraid of the future, since she knew exactly what was going to happen to her. Physically, too, she had deteriorated a great deal. Since she was unsteady on her feet, she could no longer walk her dog, and she was finding stairs more and more difficult. She was afraid of falling while going to the lavatory at night and not being able to alert anyone because she had forgotten to put her alarm on. She was still living alone, but her daughters took turns to stay with her because of her fear and panic at losing her sense of time. She was afraid of losing touch with reality before long and eventually being unable to request euthanasia because she was no longer decisionally competent. She did not want to experience the total humiliation and loss of dignity that the disease would eventually lead to.

The independent physician's report confirmed that the patient's suffering was unbearable with no prospect of improvement, and stated that her fear of the future was realistic. There were no alternative ways to alleviate her suffering.

The committee found that the physician could be satisfied that the patient's request was voluntary and well-considered, that her suffering was unbearable with no prospect of improvement, and that the physician had acted in accordance with the statutory due care criteria.

Case 8 (not included here)

b *Unbearable suffering with no 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 condition that is causing the patient's suffering is incurable and alleviation of the symptoms to such an extent that the suffering is no longer unbearable is also impossible. 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 condition 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 fact that there is no longer 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 essentially an individual notion. 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, and his own personality. What is still bearable to one patient may be unbearable to another.

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 – all based on the patient's own statements. In practice, a combination of aspects of suffering almost always determines whether it 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 9 (not included here)

Case 10

The patient, who was in a coma, could no longer express the unbearable nature of his suffering. In the case of a reversible coma induced by medication, it is inhuman to wake the patient simply so that he can state that he is again, or still, suffering unbearably
Finding: criteria complied with

In autumn 2008 the patient, a man in his eighties, was diagnosed with a progressive, untreatable brain condition. He was gradually losing a number of functions. By spring 2010 there was a risk of laryngeal paralysis. The condition was incurable.

The patient was suffering as a result of his progressive loss of function, which among other things caused him problems with his memory, speech and ability to swallow. He was also suffering from the knowledge that he could suffocate and that there was no prospect of improvement in his situation. The patient, who had always been in control of his life, was suffering from his physical loss of dignity, his total dependence, his loss of control and the hopelessness of his situation. This suffering, which could no longer be alleviated, was unbearable to him. He did not want palliative sedation, but clearly preferred euthanasia. Just over two months before he died, he had asked the physician for euthanasia, and he had repeated this request several weeks before he died. Two days before he died, in the presence of his family, he had specifically asked the duty physicians from the out-of-hours service to perform euthanasia. There was an advance directive in which he said he wanted euthanasia if he was suffering unbearably with no prospect of improvement, if he was in a state that allowed no prospect of returning to what he considered a dignified way of living or if he was suffering extreme loss of dignity.

Two days before he died his condition deteriorated dramatically, causing severe pain and extreme shortness of breath. Since the physician could not be reached, the physicians on weekend duty administered morphine and Dormicum subcutaneously. This stabilised the patient's condition, but he was no longer able to communicate.

The general practitioner (who was also a SCEN physician) who was consulted as an independent physician saw the patient on the day that he died, after consulting the attending physician and examining the medical records. The independent physician confirmed the patient's history and the diagnosis of a condition that could not be treated with medication. According to his report he found the patient in bed. A morphine pump had been put in place and Dormicum was being administered every four hours. Owing to the medication he could not be fully woken and was unable to communicate clearly. The interview took place with his wife and children. Since no SCEN physician had been available during the weekend, it had not been possible to start the euthanasia procedure.

The independent physician's report confirmed that, given the disease he was suffering from, the patient's life was meaningless and hopeless. The independent physician felt that the patient was not suffering unbearably at the time of his visit, since he was being kept in a coma by medication. In effect this was palliative sedation. Although as a result of the sudden dramatic deterioration in his condition at this point the patient was no longer able to express his wishes, he was known to have stated that he wanted euthanasia on many previous occasions. Two days earlier he had expressed this wish several times to the duty physicians. There was an advance directive. The patient's request had been voluntary and well-considered. The independent physician concluded that euthanasia could be performed, or else that palliative sedation could be continued.

The committee found that the physician could be satisfied that the patient's request was voluntary and well-considered and that he was suffering unbearably with no prospect of improvement. The fact that he was suffering unbearably was apparent from the documents, and was confirmed by the need to administer so much morphine and Dormicum that, in effect, palliative sedation was being applied. The committee was able to determine this from the written documents supplied by the physician, including his report and his records concerning the weekend before the patient died; this information was confirmed by the independent physician's report. The patient was being given so much morphine and Dormicum for his acute, extreme shortness of breath that he could not be fully woken. It is deemed inhuman to wake a patient from medically indicated sedation (a reversible coma) in order to determine whether he perceives his suffering to be unbearable.

The committee found that the physician had acted in accordance with the due care criteria.

Case 11

Unbearable suffering due to macular degeneration

Finding: criteria complied with

The patient, a woman in her eighties, could no longer do the things that made life worthwhile to her. She lived on her own. She had always enjoyed intellectual challenges in her life, she used the computer and email and she liked reading, philosophising, debating, politics, art and so on. She had always been very independent and had considered this her greatest asset. Physically, however, she was deteriorating. In recent years her vision had got worse owing to macular degeneration, she suffered from dizziness, her hearing was poor and she sometimes had faecal incontinence. At first she had tried to find all kinds of ways to cope with her limitations, but these had not proved sufficient for her to perceive her life as worthwhile. She felt trapped in her deteriorating body. Her present situation was due to her advancing age, and little or nothing could be done about it. She felt her life had lost all meaning. However, her mind was still active, and she thirsted for information.

The possibility of withholding food and fluids had been discussed, but this would involve a period of dependence. The patient considered this the most dreadful thing that could happen to her, and she rejected this alternative. She considered it a blessing that she could end her life with the help of euthanasia and would not have to become dependent.

The unbearable nature of her suffering was due to her loss of the ability to live a meaningful life, her loss of contact with the outside world and the prospect of dependence, which she saw as the worst possible fate. Given her philosophy of life, the physician found her suffering palpably unbearable. The patient was also suffering from the fact that there was no prospect of improvement in her situation.

Apart from the palliative measures that had already been taken, there were no alternative ways to alleviate her suffering. The documents make clear that the physician and the specialists gave her sufficient information about her situation and prognosis.

When the patient came to the physician's surgery in 2007 she discussed euthanasia with him in general terms. They had several conversations about it thereafter. From late 2009 onwards her request for euthanasia, which she repeated on a number of subsequent occasions, became more and more specific. There was a recent advance directive.

Four months before the euthanasia procedure was performed, the patient was seen by a psychiatrist (at the physician's request) to determine whether she was suffering from depression or another form of mental illness that might have given rise to her wish for euthanasia, and whether she was decisionally competent.

The psychiatrist, the first independent physician to be consulted, noted that despite the patient's poor hearing he was able to interview her successfully. She was lucid and was well oriented to time, place and person. The interview did not reveal any memory problems. The patient was coherent and responded appropriately to questions. She was able to explain why her disabilities (deafness, impaired vision and dizziness) prevented her from living her life as she had always done.

The first independent physician found that the patient was not suffering from depression or any other mental illness. He considered her fully decisionally competent regarding her wish for euthanasia, which he found palpable.

The second independent physician consulted by the attending physician was an independent general practitioner, who was also a SCEN physician. He first saw the patient nine weeks before the euthanasia procedure was performed.

The woman he saw was thin, tough-minded and sharp-witted. She told him of the rich and satisfying life she had had, and the spiritual and intellectual impoverishment she was now experiencing. There was so much more she might still have wanted, but her impaired vision and her deafness made this almost impossible. She was able to make quite clear that her disabilities prevented her from making something of her life as she would have wanted to do.

She used hearing aids and a magnifying glass and had always tried to find ways of alleviating her suffering, but in vain.

According to the second independent physician's report, the patient wanted to end her life (or have it ended) because she was suffering from being alive. She was an intelligent woman with broad interests. However, her disabilities prevented her from doing the things that made life worthwhile to her. She felt lonely, and could no longer find anything to help her get through the day. She felt trapped within herself, and perceived her situation as hopeless and without any meaning.

Once every two weeks she was visited by people she could talk to, which she greatly enjoyed, but apart from that she felt she no longer had any quality of life. She had been a member of Right to Die-NL for nearly thirty years, and two years earlier, when her vision had become very poor, she had expressed her wish for euthanasia. Since autumn 2009 she had specifically indicated that she wanted euthanasia as of now. The second independent physician concluded that she was suffering from being alive. She felt her life was over, and had lost all meaning. She perceived the suffering caused by her disabilities and deterioration as unbearable, with no prospect of improvement, and the independent physician found this palpable. She had expressed her wish consistently and voluntarily. The second independent physician was satisfied that the due care criteria had been complied with.

Five days before the euthanasia procedure was performed, the second independent physician saw the patient again. The patient, who had been waiting for a granddaughter to return from abroad, still indicated with total conviction that she wanted euthanasia. The independent physician remained of the opinion that the due care criteria had been complied with.

The committee invited the attending physician for an oral interview, in particular to ascertain whether the patient's suffering was unbearable with no prospect of improvement, and what the cause of this was. He said that he had known the patient for some considerable time, ever since he had started in the practice.

On receiving the letter from the review committee he had reread the records, and with hindsight it had occurred to him that it might not have been such a good idea to say so explicitly that the patient was 'finished with life'. The independent physician had used this expression in his report, and the attending physician had felt it was a good description. However, such terminology is inapplicable to the patient in the sense of 'tired of life'. The attending physician stated that he meant the patient's suffering was due to her physical deterioration and the resulting dependence. But for these factors, she would have been happy to stay alive. That was how the term 'finished with life' should be interpreted. The patient was a highly intelligent woman who only considered her life meaningful if she could function intellectually. Particularly as a result of her macular degeneration, however, she found it increasingly difficult to read, watch television and do all kinds of everyday things. This created dangerous situations, for instance when crossing roads, dealing with gas appliances and so on.

At first the physician found it hard to determine that the patient's suffering was unbearable. He had hesitated for a long time before granting her request for euthanasia, and had also spoken to her daughters. When she had made her first specific request, he had initially been cautious and had told her he would probably be unable to grant it. One day she had also said that she would commit suicide if her request for euthanasia was turned down. The physician was sure that she would do so, and that she would make detailed arrangements for it. However, she only discussed this intention with the physician at a very late stage, but he did not feel that this was being used to pressure him into performing euthanasia. What it meant to the physician was that the patient's suffering was unbearable. However, when the patient mentioned suicide, he called in a psychiatrist to determine whether she was decisionally competent. Her increasing dependence was an unbearable threat to her. Alternative forms of treatment such as home adaptations, use of audio books and so on were discussed at length.

The patient had made use of audio books and a magnifying glass. Alternatives were discussed with her daughters, one of whom wanted her mother to move in with her. However, the patient's independence was very important to her. She was not yet entirely dependent, but dangerous situations were starting to arise – in fact, she already required a certain amount of supervision. However, the mere idea of home care was a nightmare as far as the patient was concerned, and she refused to countenance alternatives that would cause her to lose her independence.

In addition to blindness due to macular degeneration, the patient suffered from faecal incontinence and pruritus. No further diagnosis of these symptoms was made, since it would make no difference to the patient's attitude. She would only want to carry on living if her blindness could be cured. Unfortunately her eye disorder was unstable, and her vision had deteriorated so severely within a short period of time that she could no longer even read large print. She did not find audio books sufficiently satisfying.

As far as the physician was concerned, the macular degeneration, the medical problem, was the reason why he wanted to grant the patient's request.

At first he had not been able to empathise with her request, but the longer and more often he saw her the more he was convinced that her suffering was unbearable. Her intelligence was such that she was perfectly capable of expressing what she wanted, and she knew how to get her own way. The physician was well aware of this and had therefore been particularly cautious; that is why it took him longer to be convinced that her suffering was unbearable. The unbearable nature of her suffering was also increasingly apparent to her daughters, especially when out walking with her; she stumbled frequently, and could not cross the road by herself. The misery she was feeling was written all over her face. What the physician was seeing was not just injured pride.

The independent physician had seen the patient twice, because several weeks elapsed between his first visit and the euthanasia procedure. The attending physician stated that the independent physician had noted on both occasions that the patient perceived her suffering as unbearable with no prospect of improvement, and that the independent physician found this palpable.

The patient's mother had died in a nursing home (after an illness and a failed attempt to end her life) and the patient had always said she did not want the same thing to happen to her; she had been a member of Right to Die-NL for years. She had also regularly discussed the matter with the physician for many years. The physician was convinced that euthanasia was in keeping with her outlook on life.

The committee wondered 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 disease or medical condition. Partly in view of his written and oral statements and the independent physician's report, the committee considered at length whether this was a 'finished with life' situation. As the preparatory work on the Act makes clear, the expression 'finished with life' refers to the situation of people who, often at an advanced age and without it having been established by the medical profession 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. 'The patient's situation must be definable as suffering from the point of view of medical ethics. It must therefore include a medical dimension [...] Suffering arising in a non-medical context should not be assessed by physicians, for it lies beyond the medical field.'

The committee must therefore decide whether the patient's suffering was caused by a medically recognised condition. In this connection it notes that, under the existing due care criteria, suffering that is unbearable with no prospect of improvement must be largely due to a medically recognised condition. However, there is no requirement that this should be a serious condition.

The patient's suffering was largely due to her near-blindness, which had resulted from macular degeneration. She was a highly intelligent woman who only considered her life meaningful if she could function intellectually. Especially as a result of her macular degeneration, however, she found it increasingly difficult to read, watch television and do all kinds of everyday things. She could no longer live her life in a way that was meaningful to her. What particularly upset her was the fact that because of her blindness she was becoming more and more dependent. She therefore rejected proposals to help her carry on living, such as daily nursing and other help, moving in with one of her daughters and so on. Her hearing was also deteriorating, she had occasional faecal incontinence and she suffered from dizziness. The committee was of the opinion that these symptoms were part of what made her perceive her suffering as unbearable.

The committee noted that macular degeneration is a medically recognised condition. There is no effective treatment for it, or any prospect of improvement. What this means is that this case is not a 'finished with life' situation as defined above, and that the physician's actions lay within the medical field.

The patient said her suffering had become so unbearable that she wanted euthanasia. In this connection the committee noted that there was also a substantial degree of existential suffering due to the situation the patient now found herself in. Given her advanced age, life history and character, this combination of factors resulted in suffering that was unbearable to her. The committee also noted [...] that it can only assess the reasonableness of the physician's conclusion in this respect. The committee found that the physician could be satisfied that the patient was suffering unbearably with no prospect of improvement. The committee observed that this patient's autonomy and life history had played an important part in the physician's decision. Given the patient's advanced age and attitude to life, the committee could understand her refusal of alternatives such as learning Braille or admission to a nursing home. The committee therefore found that the physician and the patient could together conclude that there were no reasonable alternative ways left to alleviate her suffering.

The committee found that the physician acted in accordance with the statutory due care criteria.

Case 12 (not included here)

Unbearable suffering with no prospect of improvement in special cases

Dementia

As already 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 in their personality, functions and skills that is already taking place, coupled with the realisation that this will get worse and worse and will 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. In that sense, 'fear of future suffering' is a realistic assessment of the prospect of further deterioration. Here again, the specific circumstances of the case will determine whether the physician feels the patient's suffering to be palpably unbearable. (Cases 6, 7 and 8 serve as examples.)

Mental illness or disorder

The fact that a wish for euthanasia or assisted suicide expressed by a patient suffering from a mental illness or disorder generally requires the physician to be especially cautious has already been discussed in this report. Apart from the question of decisional competence – whether the patient can be deemed capable of making a voluntary, well-considered request – a key question is whether his suffering is unbearable, with no prospect of improvement; the question of whether there is no prospect of improvement in

the suffering that the patient perceives as unbearable is another issue to which the physician must pay particular attention (see case 5).

Coma

Another key issue is whether comatose patients can be said to be suffering unbearably. Since a patient in a coma is not suffering – because he is not conscious – he cannot be said to be suffering unbearably. Euthanasia may not therefore be performed.

Unlike in cases where coma has occurred spontaneously as the result of illness or complications associated with illness, euthanasia may be justified if the coma is the result of medical treatment (the administration of medication to alleviate symptoms) and is therefore in principle reversible. If a patient is in a state of reduced consciousness (but not in a coma), the physician may, in the light of the patient's responses, reach the conclusion that the patient is indeed suffering unbearably. To assist physicians in determining the level of consciousness – and thus also in answering the question of whether the patient is indeed comatose – and to minimise interpretation problems, at the request of the Board of Procurators General the Royal Dutch Medical Association (KNMG) has drawn up a set of guidelines entitled 'Euthanasia for patients in a state of reduced consciousness', which was published in mid-June 2010. 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.

Palliative sedation

Palliative sedation means deliberate reduction of the patient's consciousness in order to eliminate untreatable suffering in the final stage of his life. Palliative sedation can only be considered if the patient is expected to die soon.¹⁰ The possibility of palliative sedation does not always rule out euthanasia.

There are patients who expressly refuse palliative sedation and indicate that they wish to remain conscious to the very end. In such situations, the physician and patient may conclude that palliative sedation is not a reasonable alternative.

c Informing the patient

Physicians must inform 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, have 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.

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.

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. One factor that can lead a patient to refuse palliative or other treatment is, for example, that it may have side effects which he finds hard to tolerate and/or unacceptable. In that case, he does not consider that the effect of the treatment outweighs its disadvantages.

There are also patients who refuse an increased dose 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, for such feelings of drowsiness and confusion often pass quickly.

Refusal of palliative treatment or other care is an important subject for discussion between physicians and patients. If the physician and the patient then reach a joint decision, the physician will be expected to indicate in his report to the committee why other alternatives were not deemed reasonable or acceptable in this specific case.

Case 13 (not included here)

¹⁰ See the KNMG's guidelines on palliative sedation (revised in 2009).

e Independent assessment

Physicians must consult 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 a second, independent physician who will give an independent expert opinion on whether the due care criteria set out under (a) to (d) have been fulfilled before the termination of life on request or the assisted suicide takes place, and draw up a written report. 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 to reflect on matters before granting the request. The independent physician sees the patient to determine whether the physician who intends to perform the procedure has not overlooked anything regarding the due care criteria under (a) to (d); the same applies to any other independent physicians who are consulted.

If an independent physician who has been consulted earlier is consulted again, this consultation may, depending on the circumstances described below, take place by telephone. The consultation must be formal, and specific questions must be answered. 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 independent physician must be independent of the attending physician and the patient. The KNMG's 2003 Position Paper on Euthanasia also explicitly stated (p. 15) that the physician's independence must be guaranteed. According to the KNMG, this implied that a member of the same group practice, a registrar, a relative or a physician who was otherwise in a position of dependence in relation to the physician who called him in could not normally be deemed independent. The need to avoid anything that might suggest the physician was not independent was once again emphasised.

What this means, in sum, is that there must not be any family or working relationship between the two physicians, or in principle any other form of partnership.

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 feel that, if a physician

always consults the same independent physician, the latter's independence can easily be jeopardised. As stated above, it is vital to avoid anything that may suggest the physician is not independent.

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 does call the physician's independence into question. 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 case of the patient there must, among other things, be no family relationship or friendship between them, 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.

The independent physician's written report¹¹ is of great importance when assessing notifications. A report describing the patient's situation when seen by the physician and the way in which the patient 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. He should also specifically mention his relationship 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.

Sometimes an independent physician concludes on seeing the patient that one of the due care criteria has 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. This might, for example, occur in the following situations.

If 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,

¹¹ The checklist for reporting by independent physicians on euthanasia and assisted suicide can be used as a guide (see www.euthanasiacommissie.nl).

he will usually have to see the patient a second time. If he has indicated that the patient's suffering will very soon become 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. However, it may still be advisable for the two physicians to consult by telephone or in some other manner.

If 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 a longer period of time is involved or if the prognosis is less predictable, the independent physician will normally have to see the patient a second time. If there has been further consultation between the attending physician and the independent physician, or if the independent physician has seen the patient a second time, it is important that this be mentioned in the notification.

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

Case 3 shows the importance of consulting the independent physician in good time.

The 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 ultimately reach his own decision, for it is his own actions that the committees will be assessing. The Euthanasia in the Netherlands Support and Assessment Programme (SCEN) trains physicians to make independent assessments in such cases. In most cases it is 'SCEN physicians' who are called in as independent physicians. The committees note that this is also increasingly done when euthanasia is performed by a hospital specialist, and that more and more specialists are themselves SCEN physicians. SCEN physicians also have a part to play in providing support, for example by giving advice.

The committees note that by no means all physicians consult the independent physician about how the euthanasia or assisted suicide procedure is 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 intends to perform the procedure.

The committees also note that some SCEN physicians offer to advise the attending physician on the performance of the procedure – an excellent example of the support component of the SCEN programme.

Case 14 (not included here)

Case 15

Failure to consult an independent physician

Finding: failure to comply with the criteria

In spring 2009 the patient, a woman in her seventies, was diagnosed with non-Hodgkin's lymphoma after a longer period of abdominal trouble. A large mass was pressing on the colon and causing a serious obstruction. The patient was given chemotherapy, and a stent was placed in the colon to relieve the obstruction. She was fed parenterally. By mid-2009 it was clear that the tumour was not responding to the chemotherapy. The patient could no longer be treated, and her condition deteriorated daily. She was given morphine for the pain and Dormicum to help her sleep.

Her suffering was caused by nausea, vomiting, abdominal and back pain, increasing debilitation and loss of dignity.

After earlier conversations with the physician about the possibility of euthanasia, she requested it several times from mid-2009 onwards. On the day that euthanasia was performed, the patient was drowsy but still able to communicate. There was a recent advance directive.

The physician did not consult an independent physician. According to his report the patient had deteriorated unexpectedly fast, and palliative treatment was not always effective. She

was looking forward to a festive occasion. The physician felt that it would be premature to have her seen by an independent physician before the occasion, and undesirable to do so around the time of it. Afterwards the patient became drowsy, and the physician felt that a visit by an independent physician would no longer be feasible.

Because the physician had failed to consult an independent physician, the committee invited him for a personal interview to provide further information.

The physician said that, despite serious complications caused by her disease, the patient had been doing well for quite some time. She was being fed parenterally because of a blockage of the colon, and so was still in a reasonable state. However, when her condition eventually continued to deteriorate and she had said she wanted euthanasia fairly soon, the physician delayed consulting an independent physician because of a festive occasion that the patient was greatly looking forward to. He felt it would be disrespectful to his patient to have her seen by an independent physician at that point. He planned to consult an independent physician after the occasion in question, but the rapid deterioration in the patient's condition meant that it was too late to do so. She was still able to communicate but no longer entirely lucid, and in any case in too poor a state to be interviewed by an independent physician. She was now in the situation she had wanted to avoid. The physician had previously considered palliative sedation and discussed it with her, but she had said she wanted to die at a time of her own choosing. The euthanasia had been performed satisfactorily, in the way that the patient had wanted.

The physician stated that he wanted to learn something from this case. He said that, if asked to perform euthanasia in the future, he planned to consult an independent physician immediately, and to consult him a second time if too much time were to elapse between the consultation and the euthanasia procedure.

The committee noted the following in connection with the consultation procedure.

The physician is legally required to consult another physician who, before the euthanasia or assisted suicide procedure is performed, must give an independent expert opinion (in writing) on whether the due care criteria have been complied with. The purpose of this is to ensure that the physician reaches a decision with all due care. It helps him not only to determine whether the due care criteria have been complied with but also to reflect on the factors that have played a part in his decision before he decides to grant the request for euthanasia.

The committee believes it is important for a physician to get in touch with an independent physician in good time, so that arrangements can be made without haste for him to see the patient. It is also important for the attending physician to inform the patient of the need for such a visit in good time and explain further details of this. In this particular case the physician failed to consult an independent physician.

Particularly in view of the patient's long case history (in which serious complications had already occurred and there was a risk of even more occurring) and the patient's earlier specific and well-considered request for euthanasia, the committee felt that the physician should and could have consulted an independent physician at an earlier stage. By failing to do so, he put himself in a difficult position that could have been avoided. The committee was aware that it might be hard to determine how soon an independent physician should be consulted. If there is a risk of declining cognitive or communicative ability (for example, owing to rapid deterioration in the patient's condition or the side effects of medication), it may therefore be wise to consult an independent physician at an early stage. This can be followed later on by a brief additional consultation (if necessary by telephone), on which the independent physician must again make a written report.

The independent physician should normally see the patient in person. This is a firm rule which can only be set aside in very exceptional cases. A visit by an independent physician may occasionally no longer be feasible because, on objective medical grounds, the patient's

condition no longer permits it. A possible example is this particular case, in which the patient was no longer able to communicate properly owing to her rapidly deteriorating condition. But even in such a situation, there is still a duty to consult an independent physician. The attending physician's report must then explain clearly why this was not done. Although the independent assessment criterion (consultation with an independent physician who has seen the patient) may just conceivably be complied with even if the independent physician has not interviewed the patient in person, the committee found that in this particular case such consultation could and should have taken place.

In view of all this, the committee could only conclude that the physician failed to comply with the independent assessment criterion, and hence with the statutory due care criteria.

f Due medical care

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

Termination of life on request or assisted suicide is normally carried out using the method, substances and dosage recommended in *Standaard Euthanatica* (2007), the guidelines drawn up by the KNMP/WINAP.¹² In cases of termination of life on request, the report recommends intravenous administration of a coma-inducing substance, followed by intravenous administration of a muscle relaxant. In the guidelines, the KNMP indicates which substances should be used to terminate life on request. It makes a distinction here between 'first-choice' substances¹³ and 'second-choice' substances.¹⁴ Physicians have less experience with the latter category of substances. *Standaard Euthanatica* also lists substances that are not alternatives to first-choice substances, and substances that should not be used at all.

If a physician does not use a first-choice substance and fails to give grounds for having used the other substance, the committees will ask him further questions. When assessing whether the due medical care criterion has been complied with, the committees act on the principle that second-choice substances are permitted, provided that the physician gives sufficient grounds for having used them. The committees will certainly ask further questions if the physician uses substances that are not listed as alternatives or should not be used at all.

The use of non-recommended substances may have negative consequences for the patient. This can be avoided by using the appropriate substances. There must be a guarantee that a patient is in a deep coma when the muscle relaxant is administered.

The committees have no objection to the use of a substance such as midazolam as pre-medication before a

recommended coma-inducing substance is administered. 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 KNMP's recommendations in *Standaard Euthanatica*, it is important to fulfil patients' personal wishes as far as possible.

Standaard Euthanatica also states which dosages the KNMP recommends for termination of life on request and assisted suicide. The committees will ask the physician further questions if the dosage is not mentioned or if it differs from the dosage indicated in *Standaard Euthanatica*. If the method of administration is not mentioned, the committees will also enquire about this.

As already indicated, there must be a guarantee that a patient is in a deep coma when the muscle relaxant is administered. The use of a coma-inducing substance recommended in *Standaard Euthanatica*, as well as the correct dosage, is crucial in order to ensure that the patient cannot perceive the effects of the muscle relaxant. In cases 16 and 18 the physicians used a lower dosage than recommended in *Standaard Euthanatica*. In case 16 the physician had taken advice from a pharmacist. The committee notes that it is the physician, not the pharmacist, who bears responsibility for performing the life-terminating procedure with due care, and hence for the choice and dosage of the substances used.

In five cases it was found that the physician had not acted in accordance with the due medical care criterion because, owing to the low dosage used, there was no guarantee that the patients were in a deep coma when the muscle relaxant was administered.

The physician must check the depth of the coma in an appropriate manner before administering the muscle relaxant. The joint KNMP/WINAP and KNMG working

¹² *Standaard Euthanatica: toepassing en bereiding 2007*.

¹³ Listed in the table on page 22 of *Standaard Euthanatica*.

¹⁴ Listed in the table on page 26 of *Standaard Euthanatica*.

group (referred to in Chapter 1) will draw up guidelines on the subject.

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. 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. In that case the physician may perform euthanasia. Nor may the physician leave the patient alone with the euthanatics. This may be hazardous, to other people as well as to the patient.

Case 16

Euthanasia performed using a dose of thiopental that is not recommended in *Standaard Euthanatica*, and depth of coma not properly verified. Despite having taken a pharmacist's advice, the physician remains responsible

Finding: failure to comply with the criteria

In 2009 the patient, a man in his seventies, was diagnosed with lung cancer that had metastasised into the brain, causing hemiplegia on the left-hand side of the body. The condition was incurable. The patient was given palliative chemotherapy, but this did not help. He was admitted to a hospice.

The patient, who was suffering unbearably from the increasing deterioration in his condition, the accompanying dependence and the hopelessness of his situation, had asked the physician to perform euthanasia. According to the general practitioner who was consulted as an independent physician, and was also a SCEN physician, the due care criteria had been complied with.

The physician performed euthanasia by intravenous administration of 500 mg of thiopental and 12 mg of Pavulon.

The committee asked the physician to provide further information regarding the dosage of euthanatics used. The physician explained in writing that he had been unable to obtain the euthanatics from his usual pharmacist, who was on holiday. The pharmacist to whom he was referred instead had given him a euthanasia kit containing 500 mg of thiopental and 12 mg of Pavulon. The pharmacist had assured him that 500 mg of thiopental would be sufficient to put the patient into a deep coma. He gave the physician a second kit in case of breakages or spillage of the euthanatics in the first one.

While performing the euthanasia procedure, the physician saw that the patient was already going into a coma after the thiopental was injected. The patient, who was very emaciated, was in a deep coma, but he was still just about breathing and had a detectable pulse. Since the physician was clinically satisfied that the patient was already in a deep coma after 500 mg of thiopental had been administered, he decided not to give him another 500 mg of thiopental. After 12 mg of Pavulon was injected, the patient died within one minute. The physician also explained that he had always administered 1000 mg of thiopental when performing euthanasia on previous occasions, whereupon the patients had stopped breathing and died. He considered it self-evident that the 500 mg dose of thiopental would not have been enough to put a less cachectic patient into a sufficiently deep coma. In cases of doubt, 1000 mg or even 2000 mg of thiopental would need to be administered, since a patient must be in a deep coma before being injected with a substance containing curare. However, the physician was satisfied that this particular patient was in a deep coma after 500 mg of thiopental had been injected.

On being invited to give further details in a personal interview, the physician stated that in his experience patients lost consciousness after receiving even a small dose of thiopental. This had also happened in this particular case: the patient's head had lolled immediately after the thiopental was injected, he was barely breathing and his pulse was only just detectable. The physician stated that he had been in practice for over thirty years and had no doubts

whatever about the coma. He admitted that he had not tested the corneal reflex or checked the depth of the coma in any other way. He had not done so because relatives of the patient were present.

He stated that, before performing euthanasia, he always informed the patient's relatives about the method that would be used. When giving this information, he would indicate that, to be on the safe side, a second substance (Pavulon) would be administered as a muscle relaxant. The physician stated that he disliked having to administer Pavulon to a dead body if – contrary to his explanation – the patient had already died because of the thiopental. The physician stated that in this case about one minute elapsed between the administration of the thiopental and the Pavulon. The patient then died within one minute.

Conversations with fellow physicians had indicated that one or two 500 mg ampoules of thiopental were sufficient if the patient was cachectic (very emaciated). If he had had any doubts about the depth of the coma he would have used a second 500 mg ampoule.

However, he had been utterly convinced that the patient was in a deep coma.

The physician stated that he had performed euthanasia about thirteen times using 1000 mg of thiopental and had never had any problems. This had strengthened his conviction that 1000 mg was sufficient. He was unaware that the WINAP had recommended increasing the dose to more than 1000 mg. He stated that he was of course willing to comply with this recommendation.

The committee noted the following in connection with the performance of the procedure. When determining whether euthanasia was performed in accordance with prevailing medical opinion, the committee normally takes 2007 *Standaard Euthanatica* as its guide. This recommends using a 2000 mg dose of thiopental to induce a coma; the reason for this is that the 1500 mg dosage recommended in the previous (1998) version of *Standaard Euthanatica* had in some cases proved too low.

The committee adhered to the principle that there must be a guarantee that the patient cannot come round from the coma and perceive the effects of the subsequently administered muscle relaxant. This is why it considered the dosage of the coma-inducing substance so important.

The committee emphasised that the physician is responsible for performing the euthanasia with due care, even if he has obtained his information from an expert, in this case a pharmacist. The committee noted that the physician administered the muscle relaxant one minute after administering the coma-inducing substance, and that the patient died one minute later. The administration of Pavulon paralysed the patient's muscles, leaving him incapable of any further response. If the patient had not been in a coma at that point, the muscle paralysis would have prevented him from making this clear. Given the low dosage of thiopental (500 mg), there is no guarantee that the patient was actually in a coma throughout the euthanasia procedure. This is all the more worrying because the physician had determined that the patient was only just breathing and had a barely detectable pulse, but had failed to check the depth of the coma by testing the corneal reflex.

The committee was of the opinion that, by using a 500 mg dose of thiopental to induce the coma, the physician took the risk that the patient might not be in a coma during the euthanasia procedure. It did not doubt the good intentions of the physician, who believed he could rely on the expertise of the pharmacist he had consulted. Nevertheless, the committee could only conclude that the euthanasia procedure was not performed in accordance with due medical care, and hence that the physician did not act in accordance with the statutory due care criteria.

Case 18

Coma induced by administering thiopental in stages, and in a dosage not recommended in *Standaard Euthanatica*

Finding: failure to comply with the criteria

In autumn 2004 the patient, a woman in her eighties, was diagnosed with a form of leukaemia, for which she was given medication. The treatment was stopped in autumn 2009 because of side effects, and it was decided to let nature take its course. The patient was suffering from increasing fatigue and listlessness, possibly due to anaemia. Her suffering consisted of severe fatigue that prevented her from doing anything, and above all her dependence on care by others and loss of control over her life. This suffering was unbearable to her, with no prospect of improvement, and the physician found this palpable. During the first few months of 2009 the patient had already talked about her wish for euthanasia, and had drawn up advance directives describing in detail what she meant by unbearable suffering and when she would want euthanasia. In the month before she died she regularly asked the physician for euthanasia. A few days before she died she indicated that she wanted it at that point in time.

The general practitioner who was consulted as an independent physician, and who was also a SCEN physician, was satisfied that the due care criteria had been complied with.

The attending physician performed euthanasia by intravenous administration of 750 mg of thiopental and 20 mg of Pavulon, followed by another 750 mg of thiopental.

Because the committee had questions about the way in which the euthanasia was performed, it asked the physician to provide further information about this. The physician did so both orally and in writing.

With regard to the way in which the euthanasia procedure was performed, the physician stated that he was familiar with *Standaard Euthanatica*. However, he disagreed with the recommendations it made, such as the use of 2000 mg of thiopental to induce a coma. He believed that in that case patients would die of an overdose of thiopental. He quoted an article by an anaesthetist recommending that thiopental be administered to cachectic patients in stages. On being questioned further, the physician said that he strongly disliked the idea of a patient dying while the substances were being injected. He was also afraid that the patient might suffocate if 2000 mg of thiopental were administered in a single dose. Another factor was that he wanted to keep to the method of performing euthanasia that he had previously discussed with the patient. He finally stated that he did not consider the recommendation in *Standaard Euthanatica* sufficiently well founded. The patient weighed about 65 kg. After administering 750 mg of thiopental he had used a pain stimulus to determine the depth of the coma, and had then injected 20 mg of Pavulon. He had then administered the remaining 750 mg of thiopental. The patient had died two minutes later. He had decided to administer the thiopental in stages so that the patient would not die of this, but would remain in a coma long enough. He said that no problems had arisen with the euthanasia procedure.

The committee noted that the physician terminated the patient's life by administering euthanatics in stages. He first administered 750 mg of thiopental, then 20 mg of Pavulon and finally another 750 mg of thiopental. He preferred this method to the one recommended by the KNMP/WINAP.

The committee could well imagine that the physician might dislike the idea of a patient dying while the substances were being injected. In assessing whether euthanasia has been performed with due medical care, the committee takes 2007 *Standaard Euthanatica* as its guide. This publication increased the 1500 mg dosage of thiopental that had been recommended previously (in 1998) to 2000 mg, because the 1500 mg dosage had in some cases proved too low.

The committee noted that the physician had not followed the recommendations made by KNMP/WINAP regarding the administered dosage of thiopental and the method of administration.

The committee also noted that the physician had used a non-recommended method of euthanasia in an earlier case that he had reported. In the light of this earlier notification the Healthcare Inspectorate had, among other things, objected to the way in which he had performed euthanasia. The Inspectorate had told him that, by titrating the dose of thiopental until the patient lost consciousness, he was taking the risk that the patient would not be in a deep coma before Pavulon was injected, and hence might suffocate while still to some extent conscious. The Inspectorate had also strongly urged the physician to comply strictly with the KNMG's 'Points of concern regarding euthanasia and assisted suicide' and *Standaard Euthanatica* and urged him to make sure he acted differently in future.

In this particular case the physician proved not to have done so.

The committee was of the opinion that, by administering the coma-inducing substances in stages, the physician took the risk that the patient might only remain in a coma for a very short time, or would not be in a sufficiently deep coma. Administration of Pavulon paralyzes the patient's muscles, leaving him incapable of any further response. If this particular patient had already been coming round from the coma or had not yet been in a complete coma when the Pavulon was administered, the muscle paralysis would have prevented her from making this clear. Given the low dosage of thiopental, there was no guarantee that the patient was actually in a deep coma while the muscle relaxant was being administered. The subsequent injection of more thiopental did not reduce the risk that the patient might initially have perceived something without being able to make this clear. The committee found the physician's stated reasons for using an unrecommended method of euthanasia and an unrecommended dosage unconvincing and unacceptable.

The committee found that the physician did not perform the euthanasia procedure with due medical care, and hence did not act in accordance with the statutory due care criteria.

Case 19 (not included here)

Chapter III Committee activities

Statutory framework

Termination of life on request and assisted suicide are criminal offences in the Netherlands (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. If the physician satisfies both conditions, the procedure he has performed is not treated as a criminal offence. 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 the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, and the physician's duty to notify the municipal pathologist is dealt with in the Burial and Cremation Act.

The Termination of Life on Request and Assisted Suicide (Review Procedures) Act also states that it is the task of the regional euthanasia review committees to determine, in the light of the physician's report and other documents accompanying the notification, whether a physician who has terminated a patient's life on request or assisted in his suicide has fulfilled the due care criteria referred to in section 2 of the Act.

Role of the committees

When a physician has terminated the life of a patient on request or assisted in his suicide, he notifies the municipal pathologist. When doing so, he submits a detailed report showing that he has complied with the due care criteria.¹⁵ The pathologist performs an external examination and ascertains how the patient died and what substances were used to terminate his life. He then establishes whether the physician's report is complete. The report by the independent physician and, if applicable, an advance directive drawn up by the deceased are added to the file.

The pathologist notifies the committee, submitting all the required documents and any other relevant documents provided by the physician, such as the patient's medical file and letters from specialists. Once the committee has received the documents, both the pathologist and the physician are sent an acknowledgement of receipt.

In the light of prevailing medical opinion and standards of medical ethics, the committees decide whether the physician has acted in accordance with the statutory due care criteria. If a committee has any questions following a notification, the physician will be informed. Physicians are sometimes asked to respond in writing to additional questions.¹⁶ The committees sometimes contact physicians by telephone if they need extra information. If the information thus provided by the physician is insufficient, he may then be invited to provide further information in person. This gives him an opportunity to explain in more detail what took place in this particular case.

The physician is notified of the committee's findings within six weeks. This period may be extended once, for instance if the committee has asked further questions.

For some years now capacity at the committee secretariats has not kept pace with the increase in the number of notifications. Some new staff were taken on in 2010, but owing to the increasing backlog, the need to train the new staff and the fact that secretariat staff were on extended sick leave, it was unfortunately still not possible to meet the six-week deadline in a large number of cases.

As mentioned in the introduction, the committees are examining their working procedures to determine whether these can be made more efficient subject to the statutory provisions and without impairing the quality of their findings.

The committees issue findings on the notifications they assess. In almost every case they conclude that the physician

¹⁵ A standard report form is available as an aid in drawing up the report. It can be filled in as it stands or used as a guide, and can be found at www.euthanasiecommissie.nl.

¹⁶ According to the evaluation of the Act, this happened in some 6% of the cases reported in 2005.

has acted in accordance with the statutory due care criteria. In such cases, only the attending physician is informed.

If the committee is of the opinion [...] its proposed findings to all the members and alternate members of its own and other committees for their advice and comments. This helps ensure harmonisation and consistency of assessment. The ultimate decision is reached by the competent committee.

In 2010, nine physicians were found not to have acted in accordance with the criteria. In such cases, the findings are not only sent to the attending physician but are also, in accordance with the Act, referred to the Board of Procurators General and the Healthcare Inspectorate. The Board decides whether or not the physician in question should be prosecuted.¹⁷ The Inspectorate decides in the light of its own tasks and responsibilities whether any further action should be taken. This may range from interviewing the physician to disciplinary action. The coordinating chair and the alternate coordinating chair of the committees hold consultations with the Board and the Inspectorate every year.

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. They each have an alternate. Each committee also has a secretary, who is also a lawyer, with an advisory vote at committee meetings. The committees act as committees of experts; it should be noted here that, in cases where physicians are found to have acted with due care, their findings are final. The secretariats are responsible for assisting the committees in their work.

For organisational purposes the secretariats form part of the Central Information Unit on Healthcare Professions (CIBG) in The Hague, which is an executive organisation of the Ministry of Health, Welfare and Sport. The secretariats have offices in Groningen, Arnhem and The Hague, and the committees meet there every month.

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

The committees see all the reports by the independent physicians consulted by the attending physicians, and thus have an overall picture of the quality of these reports. The

quality of reporting needs to be constantly monitored, but the committees are very pleased to have noted a definite improvement in this regard. The committees' general findings are forwarded to SCEN each year.

Committee members also give presentations to municipal health services, associations of general practitioners, community organisations, hospitals, foreign delegations and so on, using examples from practice to provide information on applicable procedures and the due care criteria.

¹⁷ Instructions on prosecution decisions in the matter of termination of life on request and assisted suicide, Government Gazette, 6 March 2007, no. 46, p. 14.

Overview of notifications

1 January 2010 to 31 December 2010

Notifications

The committee received 3,136 notifications in the year under review.

Euthanasia and assisted suicide

There were 2,910 cases of euthanasia (i.e. active termination of life at the patient's request), 182 cases of assisted suicide and 44 cases involving a combination of the two.

Physicians

In 2,819 cases the attending physician was a general practitioner, in 193 cases a medical specialist working in a hospital, in 115 cases a geriatrician and in 9 cases a registrar.

Conditions involved

The conditions involved were as follows:

Cancer	2,548
Cardiovascular disease	158
Neurological disorders	75
Other conditions	237
Combination of conditions	118

Location

In 2,499 cases patients died at home, in 182 cases in hospital, in 109 cases in a nursing home, in 127 cases in a care home, and in 219 cases elsewhere (e.g. in a hospice or at the home of a relative).

Competence and findings

In all cases the committee deemed itself competent to deal with the notification. In the year under review there were nine 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 63 days.