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Foreword

The regional euthanasia review committees publish an annual report in pursuance of Section 17 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. This seventh report deals with the work of the committees in 2005.

In the year under review there was considerable media interest in euthanasia in other countries. However, there were also some interesting developments in the Netherlands regarding procedures for the termination of life. Partly as a result of the Vencken court case, there was an extensive debate on the difference between euthanasia and palliative sedation (also known as terminal sedation). Guidelines on this were published by the Royal Dutch Medical Association at the beginning of December 2005. In autumn 2005 the government also agreed to set up a national review committee to deal with late termination of pregnancy and termination of life in newborn babies by physicians.

The number of notifications rose slightly. In 2005, 1,933 cases of euthanasia and assisted suicide were reported, as against 1,886 in 2004 and 1,815 in 2003. In 2005 there were three cases in which the committees found that the physician had not acted in accordance with the due care criteria.

As in previous years, this annual report discusses a number of the notifications received in 2005. This provides insight into the factors the committees took into consideration when making their assessments.

From May 2006 onwards you will be able to read the findings (from which all identifying details have removed) on the committees' updated website (www.toetsingscommissieseuthanasie.nl). The extensive work of building the website took place in 2005. It was no simple matter to remove identifying details from the findings and still preserve their information value. Highly specific information that may be traceable to a particular individual may no longer be included. It is important that readers be aware of this.

Like the State Secretary for Health, Welfare and Sport, we trust that publishing our findings will make physicians even more willing to report cases and will further improve the quality of procedures for the termination of life.

R.P. de Valk-van Marwijk Kooy

Coordinating chair of the regional euthanasia review committees

Arnhem, April 2006

Chapter I

Committee activities

1. Statutory framework and role of the committees

Under Dutch criminal law, it is an offence for anyone to take another person's life at that person's express and earnest request (article 293, paragraph 1 of the Criminal Code). However, it is not an offence for physicians to do so, provided they comply with the due care criteria specified in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (hereafter referred to as 'the Act') and notify the municipal pathologist of their actions. Article 294 of the Criminal Code contains similar provisions on assisted suicide. Under the Criminal Code, therefore, termination of life on request and assisted suicide do not constitute criminal offences in certain circumstances.

The Act provides for regional euthanasia review committees (hereafter referred to as 'the committees') to assess cases in which physicians have terminated the life of patients on request or assisted in their suicide. It also lists the due care criteria physicians must fulfil. The committees therefore carry out their main task on the basis of the Act. Euthanasia means that the physician administers the euthanatics to the patient. Assisted suicide means that he prescribes substances to be ingested by the patient himself.

Whenever a physician has terminated the life of a patient or assisted in his suicide, he is required to notify the municipal pathologist of his actions, using, if he wishes, the standard report form.¹ 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 and whether all the required documents are present. The report by the independent physician and, if applicable, the advance directive drawn up by the deceased are added to the file. The pathologist notifies the committee, submitting all the required documents and any others that may be relevant.

There are five regional euthanasia review committees in the Netherlands. The place of death determines which committee is competent to assess the case in question. Each committee comprises three members: a lawyer, who is also the chair, a physician and an expert on ethical issues. They each have an alternate. Each committee also has a secretary, with an

¹ This form can be downloaded from www.toetsingscommissieseuthanasie.nl

advisory vote at committee meetings. The secretaries and support staff form the secretariats, which are responsible for assisting the committees in their work.

The secretariats have offices in Groningen, Arnhem and The Hague, and the committees meet there every month.

If a committee has any questions about a report, the physician in question will be informed. He may then be invited to provide further information in person. More often, however, he will be asked to respond in writing. The committees also regularly contact physicians by telephone in order to obtain the required information.

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

The committees are competent to assess cases in which a physician has terminated a patient's life on request or assisted in his suicide. In a number of cases, however, they are not competent to do so.² If a physician has terminated the life of a patient without the patient having explicitly requested it, the municipal pathologist must refer the case directly to the public prosecutor. The review procedure set out in the Act is not intended for such cases.

The committees issue multidisciplinary findings on the cases they assess. In almost every case they conclude that the physician has acted in accordance with the due care criteria. In such cases, only the notifying physician is informed of the committee's findings. In a very few cases – three in 2005 – the committees find that the physician has not acted in accordance with one or more of the criteria. The committee will then refer the matter to the Board of Procurators General and the Health Care Inspectorate. The Board will decide whether or not to prosecute. 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 committees hold consultations with the Board and the Inspectorate every year.

The purpose of the legislation governing termination of life on request and assisted suicide is to safeguard and improve the quality of procedures followed by physicians in such cases. The main principle is that they should act openly. The legislation provides a framework for

² See Article 1, paragraph 2 of the guidelines on the working procedures of the regional euthanasia review committees, adopted on 18 June 2003.

assessment, in the form of due care criteria which the committees use to perform their main task (assessing notifications). In doing so, they help maintain standards of care.

The committees also help raise standards, for instance by providing information and helping the Euthanasia in the Netherlands Support and Assessment project (SCEN) train physicians to perform independent assessments. They also give presentations to municipal health services, associations of general practitioners and foreign delegations, using examples from practice to provide information on applicable procedures and the due care criteria.

In 2005 preparations were made to update the www.toetsingscommissieseuthanasie.nl website and publish the committees' findings on it (with all identifying details removed). The purpose of this is to provide a clearer picture of how the committees work. It is no simple matter for them to preserve the information value of the findings, since information that may be traceable to a particular individual may no longer be included. Close attention was paid to this during the preparations for publication of the findings on the website.

To ensure uniform assessments, the chairs of the committees and their alternates meet regularly. They also make agreements about working methods. If, for instance, a committee finds that a physician has not acted in accordance with the due care criteria, it submits its draft findings to all the chairs and their alternates for comment, which it takes into account when issuing its findings.

2. Developments in 2005

There were a number of developments that were of relevance to the work of the committees. Physicians' willingness to notify them of euthanasia or assisted suicide continued to be a key issue.

Willingness to notify and number of notifications in 2005

A high rate of notification sheds light on how euthanasia is being dealt with in practice. That is an important policy goal, in addition to ensuring that due care is taken. It should be noted here that a fall or rise in the number of notifications says nothing about physicians' willingness to notify the committees. In order to determine this, the number of notifications has to be compared with the total number of cases of euthanasia and assisted suicide in the Netherlands.

A 1998-2002 evaluation of the euthanasia review procedure revealed that in 1990, 18% of all cases of euthanasia and assisted suicide were reported and that this figure had risen to 41% by 1995 and to 54% by 2001.³ In the year under review the committees received 1,933 notifications of euthanasia and assisted suicide, as against 1,886 in 2004.

Palliative sedation

The public debate on the distinction between palliative sedation and euthanasia continued in the year under review. The Royal Dutch Medical Association's guidelines on palliative sedation, which were published in December 2005,⁴ make clear what the distinction is. The purpose of palliative sedation is to alleviate refractory symptoms accompanied by severe suffering that cannot be relieved in any other way. If performed in the right way, i.e. using the correct dose of sedatives (benzodiazepines), such sedation cannot serve to terminate life.

Accordingly, palliative sedation performed with due care is normal medical procedure and cannot be considered as euthanasia or unrequested termination of life. In cases of deep sedation that is meant to be continued until the patient dies, fluids and food are often

³ *Medische besluitvorming aan het einde van het leven: de praktijk en toetsingsprocedure euthanasie* ('Medical decisions at the end of life: practice and the euthanasia review procedure'), G. van der Wal, A. van der Heide, B.D. Onwuteaka-Philipsen and P.J. van der Maas, Amsterdam/Rotterdam, 2003.

⁴ The guidelines can be found on the Association's website (knmg.artsennet.nl).

withheld, as it would serve no medical purpose to administer them. According to the guidelines, this is acceptable if the patient is not expected to survive longer than one to two weeks.

In a number of situations where refractory symptoms are causing severe suffering, both palliative sedation and euthanasia can be considered as possible alternatives. There should then be a frank discussion between the physician and the patient. The patient may have good reasons to prefer euthanasia to palliative sedation. For example, he may wish to continue communicating with his loved ones during his final days and therefore not wish to end up in a state of reduced consciousness, or he may not want to die in a sedated condition.⁵

In spring 2005 all the committee members and their alternates met to discuss this subject.

In the year under review the committees received one notification from a physician who was giving a patient palliative sedation and withholding fluids and food. The committee that dealt with the notification declared itself incompetent on the grounds that this was not euthanasia, but normal medical procedure.

Euthanasia and dementia

In 2005 the committees received several notifications of euthanasia in patients with dementia (see Case 4). All were in a relatively early stage of the disease.

In general, it is difficult to perform euthanasia on dementia patients in accordance with the due care criteria. As in every individual case, careful consideration must be given to all the facts and circumstances. Of crucial importance here are the due care criteria that the request for euthanasia be voluntary and well-considered, and that the patient's suffering be unbearable, with no prospect of improvement. As the specific circumstances in this case show, review of these two criteria may lead to the conclusion that the physician acted in accordance with both of them, even if the patient in question was suffering from dementia.

Minors

⁵ See Dick Willems, *Preadvies Nederlandse Vereniging voor Bio-ethiek: Opvattingen over de goede dood*.

In 2005 the committees received one notification of euthanasia involving a twelve-year-old patient. This was the first-ever notification involving a patient under sixteen. The notification is discussed in Case 3.

Chapter II

Overview of notifications

1 January 2005 to 31 December 2005

Notifications

The committees received 1,933 notifications in the year under review.

Euthanasia and assisted suicide

There were 1,765 cases of euthanasia, 143 cases of assisted suicide and 25 cases involving a combination of the two.

Physicians

In 1,697 cases the notifying physician was a general practitioner, in 170 cases a medical specialist working in a hospital and in 66 cases a physician working in a nursing home.

Conditions involved

The conditions involved were as follows:

Cancer	1,713
Cardiovascular disease	23
Neurological disorders	85
Pulmonary disorders, other than cancer	29
Other conditions ⁶	27
Combination of conditions	56

Location

⁶ In previous years AIDS was mentioned separately, but in 2005 only one case involving AIDS was reported, so it is included under 'Other conditions'.

In 1,585 cases patients died at home, in 159 cases in hospital, in 73 cases in a nursing home, in 44 cases in a care home, in six cases in another institution and in 66 cases elsewhere (e.g. in a hospice or at the home of a relative).

Competence and findings

In one case a committee deemed itself incompetent to deal with the notification. In the year under review there were three cases in which the finding was that the physician had not acted in accordance with the due care criteria.⁷

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 28 days.

⁷ The overview is of all notifications received in 2005. Notifications received at the end of the year will be dealt with in 2006, because of the time needed to review them. The committees' findings on these notifications will therefore be included in next year's report. Two of the three cases referred to here were received in 2004. In all three cases the committees' findings were issued in 2005.

Chapter III

Due care criteria

1. General

In their findings the committees indicate whether or not, on the basis of their assessment, the physician has acted in accordance with the due care criteria. These criteria, as referred to in Article 293, paragraph 2 of the Criminal Code, 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.

The following two cases illustrate how notifications are assessed for fulfilment of these criteria. In practically every case, including these two, the committees find that the physician has acted in accordance with them.

As the cases show, a patient's suffering may involve various factors that can reinforce one another and combine to make the suffering unbearable. Apart from the patient's disease or condition, other factors arising from his personal circumstances or life history may contribute to his suffering. It is not always possible or necessary to make a sharp distinction between these factors.

One of the factors in suffering may be fear of future suffering (cf. Case 4). It is therefore important to determine whether that fear is realistic, and how soon such future suffering may be expected.

Case 1

In April 2001 the patient, a 35-year-old woman, was diagnosed with breast cancer. She underwent a radical mastectomy with axillary dissection. Metastases were found in the axillary glands. In 2003 metastases were also found in the skeleton, liver, lungs, lymph nodes and brain. There was no longer any prospect of recovery. The patient was given palliative chemotherapy and cranial radiotherapy.

From May 2005 onwards she had pain throughout her torso and suffered from severe fatigue. In June 2005 the brain metastases caused epileptic seizures. In July 2005 she was given palliative spinal radiotherapy to combat the pain.

Apart from the fact that she was increasingly bedridden, the patient was suffering from extreme fatigue, increasingly uncontrollable pain, inability to sit or walk unaided, mental confusion, inability to eat and exhaustion. She also suffered greatly from the realisation that she was losing control over herself. She found this suffering unbearable, and there was no longer any way to alleviate it. She refused palliative sedation. The physician expected her to die within a period ranging from several days to three weeks if her life was not terminated.

The patient first broached the subject of euthanasia with her physician in September 2004, and she first specifically asked him to terminate her life in early July 2005. She repeated her request every time he came to see her thereafter.

The physician called in an independent general practitioner who was also a SCEN physician. The independent physician saw the patient in mid-July 2005. The patient was increasingly tired and bedridden. She said she had always made it clear that she would request euthanasia as soon as she noticed she was starting to lose control of her life. In the previous few weeks the pain had become much worse despite increased medication, and the metastases were growing week by week. Two days before the independent physician came to see her she had spent a quarter of an hour watching her youngest daughter perform in a play. This had been the breaking point. She had collapsed immediately afterwards and decided she had reached the end. She had arranged her farewells and her funeral in detail weeks earlier. She was reasonably lucid and struck the independent physician as

determined. She expressed her wish for euthanasia very calmly and firmly several times. She was not depressed.

The independent physician concluded that the due care criteria had been fulfilled. The attending physician administered 2000 milligrams of pentothal and 20 milligrams of Pavulon intravenously. The procedure was performed with due medical care and attention. The committee found that the physician had acted in accordance with the due care criteria.

Case 2

In June 2005 the patient, a 58-year-old woman, was diagnosed with occlusive icterus due to a tumour in the head of the pancreas. Before a final diagnosis could be made she suffered a perforated intestine and peritonitis, for which she underwent surgery involving the insertion of a stent. The patient suffered severe post-operative complications. There was no prospect of recovery. Scans revealed that the tumour was getting larger and that the patient had pulmonary metastases. She was given maximum pain relief (300 micrograms of Durogesic a day, and extra morphine by nasal tube if necessary).

The patient was suffering from increasing pain despite efforts to relieve it, increasing nausea, ascites and the fact that she could only be fed by nasal tube. She found this suffering unbearable.

Apart from the palliative measures already taken, there was no longer any way to alleviate her suffering. The documents indicate that the physician gave her sufficient information about her situation and prognosis. He expected her to die soon.

The patient made her first specific request for euthanasia in September 2005, and repeated this request several times thereafter.

The physician called in an independent general practitioner who was also a SCEN physician. After obtaining information about the patient from the notifying physician, the independent physician saw her for the first time in late September 2005 and again a month later. In his report he described the patient's case history and confirmed that the specialists treating her had said she would not survive major surgery. His report stated that she was extremely debilitated, somewhat cachectic and bedridden. She could only just manage to go to the lavatory unaided. The patient said she was anxious to get her affairs properly organised, as she wanted to avoid a recurrence of such pain as she had suffered while in hospital. She

was also afraid that she would eventually no longer be able to make her wishes clear. She did not consider palliative sedation an acceptable alternative.

The patient could not yet clearly put into words what her suffering entailed, and she did not want to die at that point. The independent physician's findings were that the patient would die of her disease, that she did not have any specific wish for euthanasia at that time, and that if she were given sufficient palliative care there was no reason for her to seek euthanasia. He concluded that the criteria for euthanasia had not yet been fulfilled.

In his November 2005 report he noted that the patient had clearly deteriorated in the previous month. She was debilitated and looked fatigued. She said that she felt exhausted. Her total dependence and the extreme deterioration in her condition made her feel it was 'all over'. She felt she was being forced to wait for death to come, whereas she would sooner die now. Durogesic was keeping the pain reasonably under control, and her husband gave her occasional injections of morphine. The patient said she could no longer keep up her recent struggle. Now that her condition had clearly got worse – a fact confirmed by the most recent CIT scan – and the only prospect was further deterioration, she wanted euthanasia.

The independent physician concluded that the patient was suffering severely from her continuing deterioration. He said he found her suffering (fatigue, complete social deprivation and chronic physical discomfort) to be palpably unbearable. She clearly wished to die as soon as possible.

There were no alternative means, including palliative ones, of alleviating her suffering. The independent physician found that the due care criteria had been fulfilled. The attending physician performed euthanasia by administering 2000 milligrams of pentothal and 20 milligrams of Pavulon intravenously. The committee found that he had acted in accordance with the due care criteria.

2. Specific

This section indicates how notifications are assessed on the basis of the due care criteria, and what factors are important when making this assessment. The cases described below illustrate the issues that the committees were faced with in 2005. It should be noted here that most notifications give little ground for discussion in committee meetings.

(a) Voluntary and well-considered request

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

The request for euthanasia must have been made by the patient himself. It must also be voluntary. The physician must be certain that the patient has not made the request under pressure from those around him. In making their assessment, the committees consider when and how the patient made the request. The firmness and consistency of the request are relevant factors here. In order to make a well-considered request, the patient must have a clear picture of his disease, the situation he is in, the prognosis and any other ways of improving the situation.

Advance directive

On the standard report form the physician is asked whether there is an advance directive. This may suggest that such a directive is mandatory, but that is not so.

The physician must be satisfied that the patient's request is voluntary and well-considered. Such a request is usually made orally, but in most cases the physician asks the patient to record his request in writing.

Given the importance of an advance directive in the case of a patient who is no longer capable of expressing his wishes when the time comes to assess his request for euthanasia, it is important to update the directive at regular intervals and, where possible, describe the specific circumstances in which the patient wishes to undergo euthanasia. The clearer and more specific the directive is, the firmer the basis it provides for the physician's decision.

An advance directive that the patient has written himself gives the committees more information than a pre-printed statement formulated in general terms. However, an advance directive is not mandatory.

A physician cannot be compelled by an advance directive to grant a request for euthanasia. He must always make his own judgement, since he will have to account for his actions in cases of termination of life or assisted suicide. A patient's wish for euthanasia arises as the disease progresses. There must be no uncertainty between the physician and the patient as to what the patient's wishes are; even if the patient is perfectly capable of expressing his wishes and requests euthanasia orally, a written directive can help eliminate any uncertainty.

The physician must be satisfied that the request is voluntary and well-considered. Willingness to discuss the end of the patient's life, the patient's wishes and possible ways of fulfilling them are all part of the contact between the patient and the physician.

Minors

Relatives are often involved in discussing the patient's wishes. However, their consent is not required – it is the patient's wishes that count. A patient between twelve and sixteen years of age can request euthanasia if he is capable of informed consent. In such situations, however, the parents must agree with their child's wishes. This is illustrated in the following case.

Case 3 (voluntary and well-considered request)

The patient was a minor (12 years old). The parents agreed with their child's request for euthanasia.

In July 2003 the patient, a 12-year-old boy, was diagnosed with a rhabdomyosarcoma in his left foot. Metastases were found in the lymph nodes, bone marrow and skeleton. The patient was first given chemotherapy and radiotherapy, followed by more chemotherapy and autologous stem cell rescue. His recovery from the bone marrow transplantation was sluggish. In November 2004 the tumour was found not to be in remission. In December 2004 the patient's mediastinum and neck were irradiated. At the time of the diagnosis it was already clear that the prognosis was poor. Following the relapse, in October 2004, palliative care was the only alternative left. Morphine was used to combat the pain (the patient could not tolerate Durogesic). Although the pain was under control, the patient suffered from side effects. He was fed by tube, but this caused nausea, for which he was given medication. In February and March 2005 pleural punctures were performed to release fluid, but it rapidly accumulated once more.

After being informed about the benefits and drawbacks of pleural punctures, the patient decided to stop having them. He reached this decision after extensive discussions with his parents. He was increasingly short of breath. He started a course of Haldol and was given oxygen. The patient was also cachectic, and became exhausted and bedridden. Even slight changes in position made his dyspnoea worse, and he could no longer sit up supported by pillows – all he could do was lie flat on his back and concentrate on his breathing. However, he was able with effort to respond to conversation, and communication was adequate. The patient refused terminal sedation. He did not want to become a vegetable. His doctors had

always kept him fully informed about his situation and prognosis. For example, he would look at his gland specimens together with the pathologist. The physician expected the patient to die within a few days if his life was not terminated.

The patient was admitted to hospital at the end of May. From that point onwards his wish for euthanasia was discussed repeatedly and at length in the presence of his parents, the physician, the paediatrician and the nurse. In the course of a three-hour conversation he repeatedly indicated that he did not want to live any longer. The next morning he again made this clear to his mother. His condition had rapidly deteriorated over the previous four days, and he was now no longer capable of drawing up a euthanasia directive. The physician said that the patient was under no pressure from those around him and was aware of the implications of the request and of his physical situation. He was a highly gifted boy who had taken an interest in his disease and its progress from the very outset. Following his relapse in October 2004 he had been fully aware that he would die of his disease. He had never been depressed. The patient's parents had no doubts whatever about their son's decision. It had already been discussed, and they respected his wishes. The physician was able to account for the brief period that had elapsed between the explicit request for euthanasia and the performance of the procedure. The patient had fought against his disease for a long time and had tried to organise his life meaningfully. The physician also said that children are less distressed by the idea of life coming to an end. They are more capable of disregarding their imminent fate. Death is only discussed in the terminal stage of the disease.

An independent SCEN physician was called in, saw the patient on 28 May 2005 and drew up a detailed report on his case history. The report stated that the patient was thin, cachectic, fatigued and short of breath. He was lucid, but had to pause for breath every few sentences. He was bedridden. The pain was controlled by morphine, but the patient felt it was making him groggy. The only way to alleviate his suffering was a pleural puncture, which he refused, as it would only be effective for a few days. He knew that he would die from respiratory insufficiency. The independent physician stated that the reason for the request was that there was no prospect of improvement. The patient said he had spent some time considering the matter. Rather than die in his sleep, he wanted to remain completely conscious. The parents also found that their son's suffering was palpably unbearable, and they fully supported his request. The independent physician found that the request was voluntary. The patient was not depressed, and was capable of informed consent. The patient had made a request in the presence of the notifying physician just two days earlier. The notifying physician had hardly been involved in the initial stages of the patient's treatment.

The notifying physician, the parents and the patient discussed the patient's wish for euthanasia in detail at the end of May 2005. The patient was determined to proceed. The father had no doubts. The mother found the request harder to accept, but had no doubts that it was well-considered.

The independent physician considered that the patient was suffering unbearably. The patient came across as older than he was. Although the explicit request had been made only very recently, it was understandable given the severity of his suffering. The parents consented to the procedure. The independent physician found that the due care criteria had been fulfilled.

The notifying physician then performed the euthanasia with due medical care and attention. The committee found that the physician had acted in accordance with the due care criteria.

Case 4 (voluntary and well-considered request – dementia)

The attending physician called in a geriatric psychiatrist to determine whether the patient was capable of informed consent. The committee examined whether the request was voluntary and well-considered and whether the patient's suffering was unbearable, with no prospect of improvement. The due care criteria were fulfilled.

In June 2003 the patient, an 83-year-old woman, was diagnosed with Lewy body dementia, which is incurable. She was treated with Exelon and showed a good cognitive response. At the same time she was given medication for her hypokinetic rigid syndrome and her sleeping problems. Her motor symptoms became worse and she continued to be restless at night.

The patient was suffering from the fact that she could no longer function independently and had become ADL-dependent, that she was losing control of her body and hence was incontinent and could no longer walk properly, and that her cognitive functions were impaired so that she no longer had full control of her mind, especially at night. It was vital to the patient to be in control of her mental faculties. She knew that she was suffering from a progressive condition (Lewy body dementia) and was bound to deteriorate. She realised that she would eventually no longer be able to make her wish for euthanasia clear and that she would lose her autonomy and be admitted to a nursing home. The idea of consciously experiencing this unavoidable physical and mental decline, together with the fear of increasing loss of control over her mental faculties, was unbearable to her. Apart from the palliative measures already taken, there was no way to alleviate her suffering.

The patient first specifically requested euthanasia in July 2005, and repeated the request on a number of occasions thereafter. Two independent physicians were called in. The first was a psychiatrist and the second a SCEN general practitioner. They saw the patient in July 2005 and late September 2005 respectively. According to the report by the first independent physician, the patient described how she had noticed in the previous two-and-a-half years that her memory was failing and that she was finding it more difficult to speak and do sums. She had subsequently been diagnosed with Lewy body dementia. Since taking Exelon she had regained some control over her mind. She also said that she had difficulty in walking and was incontinent, which was a particular problem at night. She said that she became increasingly confused in the early evenings and usually slept badly at night. She then often felt frightened and despondent. In the afternoons she felt better and was still capable of enjoying things. The patient perceived her dependence as humiliating. She was finding life increasingly difficult, and she did not want to deteriorate any further. She would prefer to decide for herself when to die. She did not feel it was fair, especially to those around her, to take her own life or hasten death by refusing food and fluids. She had been a member of the Dutch Association for Voluntary Euthanasia (NVVE) for twenty years and had discussed her wish for euthanasia with her husband and five children. They found her decision hard to accept, but respected her choice.

According to the first independent physician, the patient's cognitive functions were reasonably good at the time when he saw her. It was evident that she was used to applying her powers of reasoning, but also that she had to concentrate very hard. The physician stated that the patient's depression and anxiety were appropriate in the circumstances. She had made her request for euthanasia voluntarily. Her ability to decide about this had not been influenced by her dementia or by depression. She was capable of informed consent, and her request was well-considered. Given the prospect that her symptoms would get worse and that she would eventually require nursing care, which she definitely did not want, there was no prospect of alleviating her suffering. The realisation that she was becoming more and more dependent on others and that she had less and less control over her body was unbearable to her.

The report by the second independent physician confirmed the patient's case history and the fact that in July 2005 she had been examined by a geriatric psychiatrist, who had found her capable of informed consent regarding her request for euthanasia. The second physician reported that the patient walked unsteadily and could scarcely move her neck. After half an hour she clearly became fatigued and unable to concentrate. She felt she was suffering unbearably because she was powerless to control her mind and because her body was so

feeble. She felt unable to decide things for herself, and knew that this would get worse as her disease progressed. She perceived her loss of ADL function owing to the rigidity of her muscles as humiliating. She also suffered from night-time restlessness and fears, as well as incontinence. As a result of all this she slept badly and was dependent on her husband. She suffered from the knowledge that her disease would make her cognitive and physical symptoms worse. She preferred euthanasia because she would not be able to commit suicide with modern sleeping tablets and she considered it undignified to hasten death by refusing food and fluids.

The second physician concluded that this was a voluntary, well-considered request for euthanasia by a patient who was fully informed about the nature of her disease. She was suffering unbearably, with no prospect of improvement and there was no other reasonable alternative. She had drawn up a euthanasia directive. He found that the due care criteria had been fulfilled, provided that the procedure for the termination of life was performed carefully. Euthanasia was performed in October 2005 with due medical care and attention.

In assessing whether the attending physician could be satisfied that the patient had made a voluntary and well-considered request, the committee considered the following factors. In her contacts with the patient, the physician had been aware of the patient's views on euthanasia from the very outset. The patient had regularly expressed her wish for euthanasia as the disease progressed. To rule out the possibility of depression and to determine whether the patient was capable of informed consent regarding her request for euthanasia, the physician had called in a geriatric psychiatrist, who had concluded that the patient was not depressed and was capable of informed consent. The SCEN physician had also concluded on the basis of his interview with the patient that her decision had been voluntary and well-considered. In view of these facts and circumstances, the committee found that the attending physician could be satisfied that the patient had made a voluntary, well-considered request.

In assessing whether the physician could be satisfied that the patient was suffering unbearably, with no prospect of improvement, the committee considered the following factors. The letters from the specialists stated that the patient was suffering from progressive cognitive disorders accompanied by parkinsonism and hallucinations, in all likelihood caused by Lewy body dementia. This condition is incurable and patients deteriorate progressively. The patient was therefore suffering with no prospect of improvement.

As to whether the patient's suffering was unbearable, the committee stated that she was suffering from her ADL-dependence and her loss of both physical and cognitive functions.

For a woman who had always been used to running her own life and being in control of her body, this physical decline was unbearable. She could not bear the thought that in a later stage of her disease she would require nursing care and would lose her autonomy. Her memories of the final stages of her parents' and parents-in-law's lives played a major part in this. She was also aware of what she would inevitably have to go through before very long. In view of all this, the committee found that the physician could reasonably have concluded that this particular patient was suffering unbearably. The physician had given the patient sufficient information about her situation and prognosis. The committee found that the physician had acted in accordance with the due care criteria.

(b) Unbearable suffering with no prospect of improvement

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

This criterion has two components: there must be no prospect of improvement, and the patient's suffering must be unbearable.

There is *no prospect of improvement* if there is no realistic means of treatment. The disease or condition that is causing the suffering is incurable and there is no realistic prospect of alleviating the symptoms. 'Realistic prospect' means that the improvement that can be achieved by palliative care or other treatment must be in reasonable proportion to the burden such treatment places on the patient.

It is more difficult to determine how *unbearable* a patient's suffering is, since in principle this is subjective. It is determined by the patient's point of view, 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 pain, nausea, shortness of breath, exhaustion, and increasing humiliation and dependence and loss of dignity. There are also other factors that can help to make suffering unbearable. The degree to which such symptoms and circumstances are perceived as suffering will differ from patient to patient. In order to determine whether suffering is unbearable, there has to be some kind of objective standard. In making their assessment, the committees therefore consider whether the physician found the patient's suffering to be palpably unbearable. In certain specific situations the 'unbearable suffering' criterion may create dilemmas, for instance where patients are comatose or suffering from Alzheimer's disease.

Physicians in general are of the opinion that deeply comatose patients do not suffer unbearably. In view of this, the committees feel that physicians should adopt an extremely cautious approach to patients who can no longer communicate.

The committees examine the specific facts and circumstances of each reported case. On the basis of this, a committee may find in a specific case that the physician has acted in accordance with the due care criteria. If a patient is in a shallow coma and displays outward symptoms of suffering, such as groaning, fluttering eyelids or visible shortness of breath, the physician may indeed be satisfied that the patient is suffering unbearably.

A dilemma may also arise if the physician has already promised the patient to cooperate in performing euthanasia. If a physician has made such a promise and is later confronted with what may be a sudden change in the situation, he may feel he is under moral or other pressure to proceed. It is therefore advisable for physicians to refrain from making unqualified promises to patients.

The possibility that patients who are no longer capable of informed consent drew up an advance directive at an earlier stage where they were still so capable has already been discussed in connection with the 'voluntary and well-considered request' criterion. A comatose patient may have drawn up such a directive. Although the patient's wishes will play an important role in the physician's decision whether or not to perform euthanasia, the 'unbearable suffering with no prospect of improvement' criterion remains fully applicable.

Not infrequently, the attending physician consults an independent physician who does not find that the patient is suffering unbearably. In many cases, the independent physician often indicates that he expects further deterioration to lead to unbearable suffering within a given period of time. In such cases, it is generally advisable for the physician to consult the independent physician again at a later stage to discuss whether the patient's suffering has since become unbearable. Depending on the circumstances of the case, the independent physician may need to see the patient again. In other cases it may be sufficient for the two physicians to consult by telephone. In such cases it is always advisable for the physician to mention in the file that there has been further consultation with the independent physician or that the latter has seen the patient a second time. This is discussed in more detail below in connection with the consultation criterion.

Cases 5 and 6 (not included here)

(c) Informing the patient

The physician must inform the patient about his situation and prognosis.

In assessing fulfilment of this criterion, the committees determine whether, and in what way, the physician has 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 this (see also Case 3).

(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 alternative available to the patient other than euthanasia. The criterion also makes clear that the decision must be reached jointly by the patient and the physician.

The focus is on treating and caring for the patient and on limiting and where possible eliminating the suffering, even if therapy is no longer possible or the patient no longer wants it. The emphasis must be on providing satisfactory palliative care before euthanasia can be considered.

However, this does not mean that the patient has to undergo every possible form of palliative care or other treatment. Just like any other patient, a patient who is suffering unbearably with no prospect of improvement is entirely free to refuse palliative care or other treatment.

One factor that can lead a patient to refuse palliative or other treatment is that it may have side effects which he finds hard to tolerate. Radiotherapy sometimes has side effects that are disproportionate to the benefit of the treatment.

There are also patients who refuse further palliative care (in the form of an increased dose of morphine) because of a fear – which is not always justified – of becoming drowsy or losing consciousness, which they definitely do not want.

If treatment is refused, the committees will assess whether there was a 'reasonable alternative' in the specific case.

Since this particular decision is reached jointly by the physician and the patient, the physician is expected to indicate in his report why it was reasonable for the patient to refuse alternative treatment in this particular situation.

Case 7 (not included here)

(e) Independent assessment

The physician must consult at least one other independent physician, who must see the patient and state in writing whether the due care criteria set out in (a) to (d) have been fulfilled.

A second, independent physician must see the patient and indicate in writing whether the due care criteria have been fulfilled. In this capacity, the second physician must make an independent assessment. Failure to consult an independent physician will lead the committees to find that the physician did not act in accordance with the due care criteria. This is illustrated in Case 8 below.

The second physician must be independent of the attending physician and the patient. In the case of the physician this means, for example, that there is no family or working relationship between the two physicians and that they are not members of the same group practice.

In practice, the committees are confronted with a number of different arrangements in which general practitioners work under the same roof. They are not members of the same group practice, but they do share facilities; for example, they may rent the same premises, share computer systems or share electronic patient files. It is not easy to decide in advance which particular arrangements will jeopardise a physician's independence. In cases of doubt, the committees will therefore always ask further questions when such working arrangements are involved.

An attending physician and an independent physician may also know each other personally, for example because they are both members of a professional group that meets to discuss medical cases. Here again, the specific circumstances will determine whether this jeopardises a physician's ability to make an independent assessment. Relevant factors here

are how often the two physicians meet and whether the patient's situation has been discussed in that particular group.

In the case of the patient, there must be no family relationship, the physician must not be helping to treat the patient (and must not have done so in the past) and he must not have come into contact with the patient in the capacity of locum. In Case 9 below the physician was the patient's own family doctor, and hence was not independent. This was one reason why the committee found that the physician who performed euthanasia in that particular case had not acted in accordance with the due care criteria.

The physicians' independence of the patient also played a part in Case 10. They had both been consulted by him in connection with treatment for a different condition. In that case the committee asked further questions. In Case 11 it found that the physician was not independent of the patient.

The independent physician's report is of great importance when assessing notifications.⁸ A report describing the patient's situation when seen by the physician and the way in which the patient talks about the situation and his wishes will give the committees a clearer picture. The independent physician must state that he has checked whether all the due care criteria have been fulfilled, and must indicate why they have or have not 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 fulfilling all the due care criteria. This means that he must also check that the independent physician has submitted a report and that the report is of a sufficiently high standard. If there is a difference of opinion between the two physicians, the attending physician must ultimately reach his own decision (cf. Case 7). In most cases, however, he will take extensive account of the independent physician's findings, for it is his own actions that the committees will be assessing.

Sometimes an independent physician concludes on seeing the patient that one of the due care criteria has not yet been fulfilled (see also 'Unbearable suffering with no prospect of improvement'). It is not always clear to the committees what exactly happened after that. In

⁸ The checklist for reporting by independent physicians on euthanasia and assisted suicide can be used as a guide (see www.toetsingscommissies euthanasie.nl).

such cases they ask the attending physician further questions. The independent physician should normally express an opinion regarding all the criteria.

If the independent physician is called in at an early stage and finds that the patient is not yet suffering unbearably or that the request for euthanasia is not based on the current situation, he will usually have to see the patient a second time. Sometimes, however, it will not be necessary, for example if the independent physician has indicated that the patient's suffering will very soon become unbearable and has specified what that suffering will entail. In that case it may be sufficient for the two physicians to consult by telephone. If a longer period of time is involved or if the prognosis is less predictable, the independent physician will have to interview 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 Euthanasia in the Netherlands Support and Assessment Project (SCEN) trains physicians to make independent assessments in cases of euthanasia. The course covers every aspect of independent assessment (medical, ethical and legal). In general, reporting by SCEN physicians has been excellent from the very outset. However, efforts must always be made to ensure that this remains so.

Case 8 (consultation)

The attending physician did not consult an independent physician and felt he was under a moral obligation to perform euthanasia. The committee found that he had not acted in accordance with the due care criteria.

In 2001 the patient, a 78-year-old man, was diagnosed with a Dukes' C colon carcinoma. He underwent hemicolectomy, followed by radiotherapy. When metastases were found he was given chemotherapy. In 2004 treatment was stopped following the discovery of metastases in the liver. The patient's condition gradually deteriorated, and in December 2004 he discussed the possibility of euthanasia with his physician. The subject came up again in March and May 2005, and in June the patient made a specific, emphatic request. He had indicated exactly where the limit of suffering lay as far as he was concerned. He always appeared lucid and rational. He did not want to be 'left high and dry'. He had seen relatives suffer for long periods, and he wanted to decide for himself when to die. The patient signed an NVVE euthanasia directive and gave it to the physician, who then indicated that an independent

physician would have to be called in. The patient accepted this and said he would talk about it 'when the time came'. In the weeks that followed the situation varied. The tumour grew steadily and the patient dealt with various matters, including his funeral arrangements. In the last week of May 2005 his condition was reasonable. His pain was under control, although he was gradually becoming dehydrated. His physician indicated that there were still some palliative options left. The patient said his suffering was not yet unbearable.

By the beginning of June 2005, however, the pain had become much more severe, and a phone call was made to the attending physician. When he saw the patient it was clear to him that the pain could no longer be controlled. The patient indicated that he had given up the struggle, and asked the physician to perform euthanasia the following week.

The physician said that an independent physician would have to be consulted. By then it was 5 o'clock on Friday afternoon and he could no longer get in touch with a SCEN physician. He promised the patient that he would call one in on Monday. During the weekend a locum prescribed increasing doses of morphine in combination with Dormicum. The attending physician saw the patient again on Monday morning. The patient was very short of breath, had a great deal of bronchial mucus, was restless and unable to communicate, but did respond to pain stimuli. The physician administered 60 milligrams of morphine and 15 milligrams of Dormicum, but the situation remained unchanged. Some hours later he administered 80 milligrams of morphine and 30 milligrams of Dormicum, but things still did not improve. According to the physician, the patient was now experiencing the kind of suffering he had always been so afraid of. In consultation with the patient's relatives, and despite not having called in an independent physician, the physician decided to perform euthanasia by administering 2 grams of thiopental and 16 milligrams of Pavulon. He felt he was under a moral obligation to do so. He was satisfied that the situation was degrading and unbearable for this particular patient. In his view there was no point in calling in an independent physician now that the patient could no longer communicate.

In an interview with the committee, the physician stated that he had regularly discussed the need to consult an independent physician with the patient. However, the patient had repeatedly postponed the decision, partly because he did not want his wife to have to cope with it. The committee found that, in failing to consult an independent physician, the attending physician had not acted in accordance with the due care criteria. Especially given the length of the patient's illness, the physician could and should have called in an independent physician at an earlier stage. He had acquiesced for too long in the patient's wish to postpone the consultation. The committee did not share his view that there was no point in

calling in an independent physician now that the patient could no longer communicate. Even in these circumstances, the committee found that the patient could and should have been seen by an independent physician. However, the committee was satisfied that the physician had acted conscientiously in this particular case. It found that he had not acted in accordance with the due care criteria, and referred the matter to the Board of Procurators General and the Health Care Inspectorate.

Cases 9, 10 and 11 (not included here)

(f) Due medical care

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

Euthanasia or assisted suicide are normally carried out in accordance with the advisory report by the Royal Dutch Pharmaceutical Society.⁹ In the case of euthanasia, the physician actively terminates the patient's life by administering the euthanatics, usually by intravenous injection. In the case of assisted suicide, the patient drinks a barbiturate potion.¹⁰ In principle, the physician must remain with the patient until the patient is dead. He must not leave the patient alone with the euthanatics. This is because the patient may vomit, in which case the physician may perform euthanasia. Furthermore, leaving such substances without medical supervision may pose a hazard to people other than the patient.

Different arrangements may be made in exceptional cases, but only for good reasons. The physician must always be on hand to intervene quickly if the euthanatics do not have the desired effect. Euthanasia must always be performed by the physician himself.

In practice, physicians are occasionally uncertain about their role in the euthanasia procedure. This uncertainty may concern the role of the notifying physician, the independent physician or the physician who performs the procedure. For example, if a case of euthanasia is reported by a physician who did not actually perform the procedure, the physician who

⁹ *Toepassing en bereiding van euthanatica* ('Application and preparation of euthanatics'), 1998.

¹⁰ Usually a 100-millilitre potion containing 9 grams of pentobarbital sodium or secobarbital sodium.

performed the procedure is deemed to be the notifying physician.¹¹, Case 14 involved such uncertainty about the roles of the various physicians involved.

Cases 12, 13 and 14 (not included here)

¹¹ Article 3 of the guidelines on the working procedures of the regional euthanasia review committees (adopted on 18 June 2003).