2004 ANNUAL REPORT

Contents

Foreword

I realised once again just how important it is that we in the Netherlands are able to deal openly with euthanasia after seeing the Spanish film Mar Adentro. Based on a true story, the film tells of a seriously disabled man and his long struggle to be allowed to die with dignity.

In the Netherlands, euthanasia has been the subject of an ongoing public debate for over thirty years. The entry into force of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act marked the end of a long process, but not of the debate. That has continued unabated, since new questions and problems constantly arise.

In 2004, the Royal Dutch Medical Association held an interesting symposium with the purpose of identifying these problems and suggesting ways of solving them. As a result, national guidelines are now being drafted for administering terminal sedation, dealing with medical grounds, substances to be used, decision-making procedures etc.

And every year the debate revives when the figures are published. There is evidence that the number of notifications has stabilised somewhat. In 2004, a total of 1,886 cases of euthanasia and assisted suicide were recorded. That was a slight rise from 2003, when 1,815 cases were reported to the committees. That figure was 1,882 in 2002.

There were four cases in 2004 in which the committees decided that the attending physician had failed to act in accordance with the due care criteria.

This year, the follow-up study announced by the State Secretary for Health, Welfare and Sport will be launched. It will examine the willingness of physicians to notify the committees of euthanasia or assisted suicide. Another question it will address is whether physicians' increasing knowledge of palliative care has had an influence on the incidence of euthanasia. The study should also help explain why physicians are unwilling to notify the committees.

It remains important to keep track of new trends, and of physicians' conduct with regard to notifying the committees.

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Coordinating chair of the regional euthanasia review committees

Arnhem, March 2005

Chapter 1 Committee activities

Statutory framework and role of the committees

Under Dutch criminal law, it is an offence for any person to take another person's life at that person's express and earnest request (Criminal Code article 293, paragraph 1). 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 provisions of 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 where 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 work on the basis of the Act**.** Termination of life on request – euthanasia – means that the physician administers the lethal drug to the patient. In the case of assisted suicide, he prescribes the drug for the patient to administer himself.

Whenever physicians have terminated the life of a patient or assisted in their suicide, they are required to notify the municipal pathologist of their actions. They do so using a model report.[1] The pathologist performs an external examination to ascertain how the patient died, and what substances were used to terminate their life. He then establishes whether the physician's report is complete, and if all the necessary appendices are present. The report by the independent physician and, if applicable, the advance directive drawn up by the deceased are also enclosed. The pathologist notifies the committee, submitting all the documents required, and any others that might be relevant.

There are five regional euthanasia review committees in the Netherlands. Place of death is decisive in determining 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 has a secretary, with an advisory vote in the committee meetings. The secretaries and support staff form the secretariats, which are responsible for assisting the committees in their work.

The secretariats fall under the Central Information Unit on Health Care Professions**,** an agency of the Ministry of Health, Welfare and Sport. The Unit has offices in Groningen, Arnhem and The Hague, where the committees meet every month.

If a committee has any questions about a report, the physician in question will be informed. He may then be invited to give further information in person. More often, however, he will be asked to respond in writing. The physician must receive notification of the committee's findings within six weeks. If the committee has further questions, this period may be extended once.

The committees are competent to assess cases in which a physician has terminated a patient's life on request, or assisted in their suicide. But there are a number of cases in which they are not competent.[2] If a physician has terminated the life of a patient without their having explicitly requested it, the municipal pathologist must submit the case directly to the public prosecutor. The review procedure set down in the Act is not intended for such cases.

The committees give multidisciplinary findings on the cases they assess. In the majority, they conclude that the physician has acted in accordance with the due care criteria. In such cases, only the physician is informed of the committee's findings. In very few cases – four in 2004 – the committees find that the physician has not acted in accordance with one or more of these criteria. The committee will then submit its findings 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 standards of physicians' intervention in such cases. The main principle is to ensure that they act in all openness. The due care criteria are the parameters within which the committees perform their main task, i.e. assessing cases in which a physician has terminated the life of a patient on request, or assisted them in committing suicide. In doing so, the committees are instrumental in safeguarding standards.

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[1] This form can be viewed on www.toetsingscommissieseuthanasie.nl

The committees also help to raise standards, for instance by providing information and helping the Euthanasia in the Netherlands Support and Assessment Project (SCEN) to train physicians to perform independent assessments. They also give presentations to Municipal Health Services, GPs and foreign delegations, using examples from practice to provide information on applicable procedures and the due care criteria.

To ensure uniformity, the chairs of the committees and their deputies regularly hold meetings. There are also agreements about working methods. If, for instance, a committee finds that a physician has not acted in accordance with the due care criteria, it will pass on its draft findings to the chairs of all the committees for their comments. The committee in question will take these comments into account when issuing its findings.

Developments in 2004

A number of developments were relevant to the committees' work. They included the debate on terminal sedation and on the issue of dementia in relation to euthanasia. Physicians' willingness to notify them of euthanasia or assisted suicide continued to be a concern.

Willingness to notify and number of notifications in 2004

A high percentage of notifications helps to shed light on how physicians are dealing in practice with the issue of euthanasia. That is an important aim of policy, along with ensuring that due care is taken. It should be noted here that a fall or rise in the number of notifications does not necessarily mean that physicians are less or more willing to notify the committees, as is sometimes mistakenly implied in the press. After all, to determine the degree of willingness, the number of notifications would have to be compared with the total number of cases of euthanasia and assisted suicide in the Netherlands.

In 2004, the committees received 1,886 notifications of euthanasia and assisted suicide. This meant that the falling trend in number of notifications, which began in 1999, came to a halt in 2004. The committees were also looking into ways to increase physicians' willingness to notify them. As the study conducted by Van der Wal and Van der Maas concluded, it is important for physicians to know exactly how they should be fulfilling the due care criteria.[3]

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[2] See article 1, paragraph 2 of the guidelines on the work of the regional euthanasia review committees, adopted on 18 June 2003

[3] *Medische besluitvorming aan het einde van het leven*. *De praktijk en de toetsingsprocedure* (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

There is considerable interest in how the committees reach their conclusions in individual cases, and the considerations involved. This report examines each due care criterion in turn, using cases to illustrate how the committee in question reached its conclusion. If more is known about this, it is likely that physicians will be more willing to notify the committees of their actions.

This is also the reason why the State Secretary for Health, Welfare and Sport has decided to publish the committees' findings. Preparations are now under way.

Terminal sedation

In 2004, the public debate on terminal sedation, partly in relation to euthanasia, flared up again. The medical profession is currently drafting guidelines on sedating patients. Given current interest in the subject, and the importance of harmonisation and of exchanging views on the matter, the committees will be holding a special meeting on this theme for all their members and alternates in 2005.

It is important to distinguish between terminal sedation, where the intention is to relieve suffering, and euthanasia, where the intention is to end life. Terminal sedation, accompanied in most cases by a decision no longer to administer fluids or food, is a normal medical procedure, and the patient usually dies of natural causes. In determining whether due care has been taken, the medical grounds for terminal sedation are of particular importance, together with the degree of sedation needed, the life expectancy of the patient when he is sedated, the type of sedative and dosage chosen, and the decision-making procedure, including informing the patient. The study by Van der Wal et al. devotes attention to this issue. It concludes that euthanasia was discussed in approximately half the cases in which terminal sedation was decided on, that in 14% of cases the patient opted for terminal sedation instead of euthanasia, and that in 10% of cases terminal sedation was decided on because the patient had made no explicit request for euthanasia.[4]

There are some exceptional situations in which terminal sedation is not effective. Patients sometimes continue to be agitated, in pain or short of breath or suffer a loss of dignity they had indicated beforehand would be intolerable to them. If the patient had requested euthanasia on an earlier occasion, and if an independent physician had already been consulted before sedation was administered, euthanasia could still be performed, provided the patient had already been informed that this situation could arise.

Euthanasia and dementia

The committees received one notification in 2004 involving the problem of euthanasia and dementia. In this case, the North Holland committee found that the physician who had performed euthanasia on this patient acted in accordance with the due care criteria. Generally speaking, it is not always possible to perform euthanasia in accordance with the due care criteria when the patient in question is suffering from Alzheimer's disease. As applies in every individual case, careful consideration will have to be given to all the facts and circumstances. Of crucial importance are the due care criteria that the request for euthanasia was voluntary and well-considered, and that the patient's suffering was 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, even when the patient in question is suffering from Alzheimer's. Chapter 3 looks at this subject in more detail under the heading "Unbearable suffering with no prospect of improvement".

[4] Van der Wal et al, 2003, page 83

Chapter 2 Overview of notifications

1 January 2004 to 31 December 2004

Notifications

The committees received 1,886 notifications in the year under review.

Euthanasia/assisted suicide

There were1,714 cases of euthanasia, 141 cases of assisted suicide and 31 cases involving a combination of the two.

Physicians

In 1,646 cases, the notifying physician was a general practitioner, in 188 cases a medical specialist working in a hospital, and in 52 cases a physician working in a nursing home.

Illnesses

The illnesses were as follows:

Cancer	1,647
Cardiovascular disease	24
Neurological disorders	63
Pulmonary disorders, other than cancer	34
AIDS	4
Other	73
Combination	41

Location

In 1,530 cases, patients died at home, in 177 cases in hospital, in 65 cases in a nursing home, in 62 cases in a care home, in five cases in another institution, and in 47 cases elsewhere (e.g. in a hospice or at the home of a relative).

Competence and findings

The committees deemed themselves competent to handle all the cases submitted to them. In four cases in this review year they found that the attending physician had not acted in accordance with the due care criteria.[5]

[5] The overview is of all notifications received in 2004. Notifications received at the end of the year are dealt with in 2005, given the time needed to review them. The committee's findings on these

Length of assessment period

The average time that elapsed between the notification being received and the committee's findings being returned to the physician was 30 days.

notifications are therefore included in next year's report. All four of the cases referred to here were received in 2004, and the committees' findings were issued in the same year.

Chapter 3 Due care criteria

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 and there is no prospect of improvement
c. inform the patient of his or her situation and further prognosis
d. discuss the situation with the patient and come to the joint conclusion that there is no other reasonable solution
e. consult at least one other physician with no connection to the case, who must then see the patient and state in writing that the attending physician has satisfied the due care criteria listed in a to d
f. exercise due medical care and attention in terminating the patient's life or assisting in his/her suicide.

The following two cases illustrate how the physicians' reports are examined for compliance with these criteria. In practically every case, the committees find that the physician has acted in accordance with them. That applies to these two cases too. The committees cite cases in order to give an idea of the problems they have dealt with in the year under review. This may give a distorted view, since reports seldom lead to discussion in the committee meetings.

Case 1

In 1990, a 55-year-old woman was diagnosed with a mammacarcinoma in the left breast. A lumpectomy was performed, followed by radiotherapy. In 1996, she underwent a mastectomy after a mammacarcinoma was discovered in her right breast. The patient was again given radiotherapy. She also underwent an ovariectomy and was prescribed Nolvadex. In August 2002, metastases were found in her bones, skin and lymph glands. The patient was given palliative hormonal and chemotherapeutic treatment. There was no longer any prospect of recovery. The pain increased, and morphine was administered intravenously, bringing it reasonably under control. The patient's suffering was caused by

physical deterioration and her dependence on care. Her condition could only deteriorate further. She no longer experienced any pleasure, and her life had lost all meaning. Her physical and mental suffering was unbearable. All possibilities to relieve her suffering had been exhausted. The documents show that the attending physician had informed the patient adequately of her situation and her prospects.

The physician expected the patient to die within several weeks if euthanasia was not performed. In early January 2004, the patient made a specific request for euthanasia. She repeated the request on several occasions and signed a euthanasia directive. The husband, mother and children of the patient were aware of her request, and respected her wishes. According to the physician no pressure was brought to bear on the patient, and she was aware of her physical condition and the implications of her request.

A SCEN physician was called in to give an independent assessment. He visited the patient, and his report shows that though intravenous administration of morphine kept the patient's pain under control, she found her situation unbearable, and without prospect of improvement. The patient frequently suffered from nausea and had to vomit. She could only manage sips of water. During the night, she suffered from hallucinations, and could not tolerate the medication to suppress them. The patient was continually aware of the fact that her liver had swollen to immense proportions, and that she was wholly dependent on others. During her talk with the independent physician, she was weak, but lucid. He felt that she could think rationally.

During the interview with the independent physician the patient and her husband became very emotional. This, he felt, was understandable. In his opinion, the patient's request was voluntary and well-considered, and her suffering unbearable with no prospect of improvement. He felt that the due care criteria had been fulfilled. The attending physician administered Pentothal and Pavulon intravenously. The patient died with her family at her bedside.

Case 2

In 2001, a 62-year-old man was found to have non-small-cell bronchial carcinoma in the right upper lobe with lymphogenic metastases. Recovery was no longer possible. Treatment comprised radiation therapy and first and second line chemotherapy. A brain metastasis was diagnosed two years later, for which he received palliative radiotherapy and dexamethasone. The symptoms became more serious as a result of the metastasis. The

patient suffered loss of memory, could not concentrate, was agitated and had mood swings, becoming aggressive, apathetic and remote in turn. He was bedridden. The patient's suffering became unbearable as a result of his agitation, his total dependence on others, his coughing fits, and the fact that he was finding it increasingly difficult to communicate. He had indicated in advance that he would find this situation unbearable. He rejected terminal sedation as an option, because it would only prolong a situation he regarded as unbearable. The documents show that the attending physician had informed the patient adequately of the situation he was in and his prospects.

The attending physician expected the man to die within one or two weeks, if euthanasia was not performed. The patient first made a specific request for euthanasia in late December 2003. He then repeated this request daily, in the presence of his wife and children, and of a colleague of the attending physician. The wife and children of the patient were consulted about the request for euthanasia. The patient had signed a euthanasia directive in 2002 which he had reconfirmed in 2003.

When it became clear to the patient that he could lose his powers of reasoning and of expressing himself as a result of the brain metastasis, he gave his wife powers of attorney. According to the attending physician, no pressure was brought to bear on him, and the patient was aware of his physical condition and of the implications of his request.

A SCEN physician was called in to give an independent assessment. She saw and spoke to the patient in early January 2004. In her report, she confirmed that the patient's suffering was unbearable and that he had no prospect of improvement. She also confirmed the attending physician's estimate of the patient's life expectancy. He was in the terminal stages of life. When the independent physician saw him, he was no longer capable of speech. He could only respond to her questions by moving his head. According to the independent physician, the patient's pain, helplessness and desperation were the reasons for his request for euthanasia and for invoking his euthanasia directive.

The patient was suffering from loss of control, anxiety, mood swings and helplessness, mainly as the result of the loss of brain function. His request was voluntary and well-considered, and the independent physician was of the opinion that the due care criteria had been fulfilled. The attending physician administered Pentothal and Pavulon intravenously, and the patient's wife and children were at his bedside.

Specific

Cases are cited below to illustrate how the committees assessed the reports on the basis of the due care criteria, and which elements were of importance to them in reaching their findings. These cases also illustrate the problems confronting the committees in 2004.

a. Voluntary and well-considered request

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

Patients must themselves request euthanasia, and their request must be voluntary. The physician must ascertain that the patient has not made the request under pressure from the people around him. In assessing the case, the committee investigates when and how the patient made this request.

It is important to be able to establish that the patient's wishes are well-considered. Though the family, and often the nursing and care staff are involved in discussing the patient's wishes, their agreement is not required. The patient's wishes are what matter.

In order to make a well-considered request, patients need to be fully informed on their illness, their situation, the prognosis, and possible alternatives that might improve their situation.

Advance directive

In the model report, the notifying physician is asked whether the patient has signed an advance directive. That may suggest that such a directive is obligatory. But that is not the case.

In order to fulfil the due care criteria as contained in the Act, the attending physician must be satisfied that the patient's request was voluntary and well-considered. The request is generally made in person, but physicians usually ask their patients to confirm it in writing.

Sometimes, due to the rapid progression of their illness, patients who were previously capable of making informed decisions are no longer able to express their wishes, and thus no longer able to make a request in person. If, however, on an earlier occasion – i.e. when they were capable of making an informed decision – they signed an advance directive requesting euthanasia, the physician may grant this request, provided the other due care

criteria have been fulfilled. In such situations, the advance directive stands, as it were, for the request in person.

In order to clear up any misunderstandings about the advance directive, its legal status is now enshrined in the provisions of the Act. An advance directive is of crucial importance when physicians have to decide whether to grant requests for euthanasia from patients who are no longer able to express their wishes at the point at which their request becomes relevant. It is therefore vital to update the directive at regular intervals, and to define as clearly as possible the circumstances in which euthanasia would be the preferred option. The clearer and more factual the advance directive, the more pointers it gives the physician in reaching a decision.

In many cases, patients' desire for euthanasia arises in the course of their illness. In many cases, they remain capable of making informed decisions. The attending physician must be satisfied that the request for euthanasia is indeed voluntary and well-considered. Being able to discuss the approach of death, the wishes of the patient in relation to it, and the opportunities to fulfil them, are all part of the interaction between doctors and their patients. What matters is that the wishes of the patient are clear. Even if they are quite capable of expressing their wishes and request euthanasia in person, an advance directive can help.

For the record, even though a patient may have drawn up an advance directive, a physician is never obliged to grant a request for euthanasia. In other words, physicians always have to make their own decision. After all, in the event of euthanasia or assisted suicide, they will be held to account for their actions.

The case of the patient suffering from Alzheimer's whose request for euthanasia was granted is presented below. In this case, there was a difference of opinion between the attending physician and the independent SCEN physician, as regards both the patient's ability to make informed decisions, and whether his suffering could be described as unbearable. After receiving the independent physician's assessment, the attending physician sought a second opinion. He consulted another three specialists.

With regard to the patient's wish for euthanasia, these specialists each concluded that he was capable of making an informed decision, that his desire for euthanasia was persistent and that he had considered the implications of his decision. The committee was of the

opinion that the attending physician, confronted with opposing views, and given his own opinion, was justified in attaching more significance to the opinion of the specialists.

Case 3 (Alzheimer's patient)

A 65-year-old man had been suffering from Alzheimer's disease for the past three years. The depression he suffered as a result of his illness could be treated successfully with medication. The patient also went to a nursing home for treatment during the day. The fact that he could no longer function independently in any way was a source of unbearable suffering. He also suffered from his understanding of what the future held for him, as the dementia progressed. When he was first diagnosed with Alzheimer's, he told his attending physician that he had no wish to see it through to the bitter end. In the year before euthanasia was performed, he repeatedly asked his doctor to help him commit suicide.

The attending physician consulted an independent physician, who agreed that the patient was suffering unbearably from his dependence on others, his awareness that he was deteriorating and losing all sense of decorum, his loss of independence and self-respect, and the knowledge that his situation could only get worse.

All the same, the independent physician could not entirely empathise with the patient. He also felt that since the patient's awareness of his shortcomings would decrease as his illness took its course, his suffering would become less unbearable over time.

According to the independent physician, though the patient had repeatedly requested euthanasia over a longer period of time, his ability to make an informed decision was debatable, given his inability to follow the physician's reasoning during their interview. The independent physician therefore concluded that the due care criteria had not been fulfilled.

After receiving the independent physician's assessment, the attending physician consulted three specialists: a psychologist, a nursing home doctor and a geriatric psychiatrist. From the examination that they each carried out independently, these specialists came to the conclusion that the patient was not suffering from depression, wanted to maintain control over his life and was aware that his illness would eventually deprive him of it. They each came separately to the conclusion that the patient was capable of making a voluntary, well-considered request for euthanasia, and that he was aware of the implications of his choice. Given the conclusion reached by these three specialists, the attending physician decided to grant the patient's request. The patient died as a result of assisted suicide.

In its assessment, the committee considered the fact that though the independent physician had questioned the ability of the patient to make an informed decision, each of the specialists consulted later came independently to the conclusion that he was most certainly able to do so, and was quite capable of deciding what he wanted and why. According to the committee, the attending physician had fulfilled the criteria of consulting at least one other physician. Confronted with the conflicting opinions of the independent physician and the three specialists consulted later, and given his own views in the matter, the attending physician rightly accorded more significance to the opinion of the three specialists. According to the committee, the attending physician could decide on that basis to assist the patient to commit suicide.

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 is satisfied that the patient is suffering unbearably and has no prospect of improvement.

This criteria has two components: suffering must be unbearable, and there must be no prospect of improvement.

Suffering is without prospect of improvement if that is the prevailing medical opinion, i.e. if the cause of the suffering cannot be removed. In the medical sense, therefore, this can be established fairly objectively.

It is more difficult to establish whether suffering is unbearable, because this is, in principle, person-related, since it is determined by the patient's outlook on life, their physical and mental pain threshold, and their personality. What one person regards as bearable is unbearable for another.

Unbearable suffering is often defined in reports in terms of pain, nausea, shortness of breath, exhaustion, increasing humiliation and dependence, and loss of dignity. Other forms of suffering can also be unbearable. The degree to which these symptoms and circumstances are experienced as suffering differs from patient to patient.

In order to assess whether suffering is unbearable, it has to be objectified to some extent. The committees therefore examine whether the physician found the patient's suffering palpably unbearable. The criterion "unbearable suffering" can lead to dilemmas in some specific situations, for instant where patients are comatose or suffering from Alzheimer's disease.

In 2004, a report was received – cited below as case 5 – of euthanasia at the request of a patient who was comatose at the point at which life was terminated.

It is generally accepted by the medical profession that a patient in a deep coma does not suffer unbearably. The committees therefore believe that doctors should adopt a very cautious approach to patients who are no longer able to communicate. Whenever they are notified of euthanasia performed on a comatose patient, they examine each specific circumstance and fact of the case in order to establish whether the physician acted in accordance with the due care criteria. If a patient is in subcoma and shows visible signs of distress, such as groaning, eye movement or shortness of breath, the physician may be satisfied that they are suffering unbearably.

Doctors may face a dilemma if they have promised the patient on an earlier occasion that they will perform euthanasia. If they have made such a promise, a sudden change in the situation may place them under moral pressure. It is therefore advisable for doctors to refrain from making unconditional promises to their patients.

Under the heading 'voluntary and well-considered request', this report has already looked at the issue of advance directives drafted on an earlier occasion by patients who are no longer capable of making an informed decision. A patient in coma may well have drafted such a directive. However, though the patient's wishes play an important role for the physician in deciding whether or not to perform euthanasia, the criterion that suffering must be unbearable with no prospect of improvement still applies.

A case is cited below in which the committee found that the physician could not have been satisfied that the suffering of a comatose patient was unbearable and without prospect of improvement (see case 5).

The criterion 'unbearable suffering' also presents difficulties in the case of patients with Alzheimer's disease. In deciding whether suffering is genuinely unbearable, it may be useful

to make the distinction generally accepted by the specialist community between suffering in the early stages of dementia (from the unacceptable prospect of further loss of dignity) and suffering at an advanced stage (from the dementia itself, which can be indirectly inferred from the patient's behaviour).

If a doctor believes that a patient in the early stages of Alzheimer's – when there are no relevant somatic complaints – is suffering unbearably, it is important to consult at least one specialist – a psychiatrist or geriatrician – in addition to an independent physician, and to request their assessment in writing. Patients who are aware of the progression of the disease may undergo appalling suffering, even though there is no physical suffering. Case 3 related to a patient in the early stages of Alzheimer's disease. This patient faced the prospect of the inevitable progression of the disease, and the deterioration that would accompany it. The independent physician could not empathise with the man's suffering, because in the future his situation would become more rather than less bearable to him. However it was precisely this prospect of losing control over his life as the disease progressed that was unbearable to the patient, and this was what he did not want to undergo. The attending physician, the specialists he consulted later, and the review committee were all of the opinion that this patient was suffering unbearably.

It sometimes occurs that the attending physician consults an independent physician who comes to the conclusion that a patient is not suffering unbearably. In many cases, however, the independent physician will point out that, as the patient's situation deteriorates, suffering is likely to become unbearable within a certain period of time. In such situations, the attending physician should consult the independent physician again to establish whether suffering has now indeed become unbearable. Depending on the circumstances, the independent physician may need to visit the patient again. In other cases, a phone call between the two physicians will suffice. In these situations, it is in any event advisable for the attending physician to record the phone call or visit in the report he submits to the committee. This matter will be dealt with in more detail under the heading 'Consultation'.

Case 4 (unbearable suffering with no prospect of improvement)

At the point at which the independent physician was consulted, the patient was not yet suffering unbearably. Euthanasia was performed six days later. What had changed in the patient's condition was not clear from the physician's report. The committee therefore asked questions about this.

Since December 2003, an 89-year-old woman had been suffering from symptoms that were probably caused by a carcinoma of the colon with metastases in the liver. Given her advanced years, the patient refused all tests and treatment, apart from a blood test and an ultrasound scan of the liver. Recovery was no longer possible. In the months that followed, the patient became increasingly dependent. She had periods of vomiting and diarrhoea, suffered bouts of pain and was at risk of developing a bowel obstruction. For the patient, the suffering ultimately became unbearable, a situation that could not be relieved. She refused further treatment. In early May 2004 she made repeated requests for euthanasia.

The independent physician visited the patient. According to his report, she had already been more or less bedridden for a week, and could only take fluids. She was compos mentis and had a clear understanding of her situation. She said she was reconciled to death and was not suffering from depression. She said that she did not want euthanasia immediately, but wished to have everything properly arranged should anything unforeseen happen. According to the independent physician, the patient was not suffering unbearably when he visited her. Her preference was for a natural death, but knowing that euthanasia was an option made her feel a lot calmer. The patient's request was voluntary and well-considered.

The independent physician came to the conclusion that the due care criteria had not all been fulfilled, but that as soon as the patient's suffering became unbearable, and her request for euthanasia relevant, her life could be terminated. He indicated that if euthanasia was not performed within six weeks, another consultation could be requested.

Six days after the independent physician had visited the patient, the attending physician performed euthanasia. Since it was evident from the independent physician's report that he was not of the opinion that the patient was suffering unbearably when he visited her, and given that the last notes written by the attending physician in the patient's file dated from three days before this visit, the committee wanted to know what had changed in the patient's condition between the independent physician's visit and the performance of euthanasia six days later.

The committee's doctor phoned the attending physician and was told that symptoms indicating the presence of a bowel obstruction had indeed arisen. The patient suffered from terrible nausea and had to vomit repeatedly. She became anorectic and cachectic and was suffering from extreme exhaustion. She had severe, unremitting abdominal cramps.

The attending physician had consulted the independent physician by phone. The latter indicated that in this situation he could well understand that the patient's suffering was unbearable.

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

Case 5 not included

c. Informing the patient

The physician has informed the patient of his or her situation and prognosis.

In assessing this criterion, the committees examine whether and how the physician has informed the patient of his or her illness and prognosis. For patients to make a well-considered request, they need to have a full understanding of their illness, the diagnosis, prognosis and possible treatment. It is the physician's responsibility to ensure that the patient is fully informed, and to verify that. This criterion gave rise to no problems in the cases reported.

d. No other reasonable solution

The attending physician and the patient have come to the joint conclusion that there is no other reasonable solution

It must be clear that there is no other alternative for the patient, and that euthanasia is the only remaining solution. This criterion shows that the decision-making process is also a matter involving both patient and doctor.

The main priority here is the care and treatment of the patient, limiting and where possible relieving suffering. Before euthanasia becomes an issue, good palliative care must first be provided.

That does not mean to say, however, that every possible type of palliative treatment must first be tried. Some forms of treatment have side effects which are difficult for patients to tolerate. Radiotherapy can have such serious side effects that the disadvantages of treatment outweigh the advantages. Some patients refuse further palliative treatment – in the form, for instance, of higher dosages of morphine – because they are afraid of becoming

drowsy or losing consciousness. There may therefore be good reason to desist from further treatment. If treatment is refused, the committees will decide on a case-by-case basis whether there was 'no other reasonable solution'. Because doctor and patient come to a joint decision, doctors are expected to indicate in their report why the patient's refusal of an alternative treatment was reasonable in that situation.

Cases 6,7,8 and 9 (not included)

e. Independent assessment

The attending physician has consulted at least one other, independent physician, who must then see the patient and state in writing that the attending physician has satisfied the due care criteria listed in a to d.

A second, independent physician is required to see the patient and state in writing whether the due care criteria have been fulfilled. Since this conclusion must be reached independently, this physician may have no connection to either the attending physician or the patient. That means that he or she may not be related to or work together with the attending physician, or work in the same practice. By the same token, he or she may not be related to the patient, have treated them, or have been consulted about them on an earlier occasion.

The independent physician's report is of major importance to the committees in making their assessment. [6] A report describing the patient's situation when they were visited by the independent physician, and how they expressed their wishes and view of the situation helps the committees in their understanding of the case. It is important for independent physicians to say how they established whether all the due care criteria had been met and – if applicable – to give the reasons why they had not all been met. They should also discuss their relationship with the attending physician and the patient. Though independent physicians are responsible for their own reports, the attending physician bears final responsibility for fulfilling all the due care criteria. Since the committees are assessing the actions of the attending physician, it is in the interests of the latter to ensure that independent physicians draft a report of their visit to the patient, and that the report is of sufficient quality.

[6] Guidelines for drafting this report can be found at www.toetsingscommissieseuthanasie.nl – formulieren – checklist consultatieverslag

It sometimes happens that, on visiting a patient, the independent physician concludes that one of the criteria has not yet been met (see also under the heading 'unbearable suffering with no prospect of improvement'). What exactly happened after the visit is not always clear to the committees. In these cases, they will ask the attending physician for further details. The basic principle is that the independent physician assesses whether the due care criteria have been met. If the visit takes place at an early stage in the process and the independent physician concludes that the patient is not suffering unbearably, a second visit will normally be needed. [7] But if this physician indicates that suffering is likely to become unbearable in the short term, describing the form it will take, it may suffice for the two physicians to discuss the matter over the phone should there be a change in the patient's condition.

It is important to point out in the report that there has been further contact between the attending physician and the independent physician.

The Euthanasia in the Netherlands Support and Assessment Project (SCEN) trains doctors to give second opinions in cases of euthanasia. Every aspect of the consultation – medical, ethical and legal – is dealt with during the course. Where a SCEN-trained doctor acts as an independent physician, the reports are usually of a high quality.

Case 10 (consultation)
The independent physician knew the patient and had treated him several times shortly before euthanasia was performed. The attending physician had therefore not fulfilled the criterion of consulting another physician with no connection to the case. In this case, the attending physician did not fulfil all the due care criteria.

A 67-year-old man was diagnosed as having an inoperable gastric carcinoma. The patient repeatedly asked his family doctor to perform euthanasia. Medication kept the pain reasonably under control, but the tumour was so large that the man could no longer eat and suffered from nausea and vomiting. He was also extremely tired. The patient found his suffering unbearable, and it could not be relieved. Because he no longer wanted to be a burden at home, the patient was admitted to hospital at his own request, and in consultation with the surgeon treating him.

[7] See H. van Delden*, Het juiste moment voor euthanasie*. (The right moment for euthanasia). In Adams et al. *Euthanasie – nieuwe knelpunten in een voortgezette discussie (*Euthanasia - new problems in an ongoing debate). Kampen, 2003 (In Dutch).

The surgeon started the euthanasia procedure. An anaesthetist, a colleague from the same hospital, was asked to act as the independent physician. In his report, he confirmed that the patient was suffering unbearably, from pain, nausea, vomiting and fatigue.

The surgeon had indicated that he expected the patient to die within two or three months unless euthanasia was performed. The patient died after Pavulon was administered to him.

The committee asked the surgeon and the independent physician for further information about the consultation procedure. It was clear to the committee that the independent physician had assessed compliance with the due care criteria. However, the committee was of the opinion that independence had not been safeguarded. The anaesthetist had known the patient for years, since they had worked at the same hospital. Moreover, he had examined and treated the patient on several occasions not long before euthanasia was performed. He had also been consulted by the attending physician on the most suitable euthanatic to administer. The committee was of the opinion that the anaesthetist could in fact be regarded as one of the patient's attending physicians, and that the consultation had not proceeded according to the due care criteria.

For this reason, the committee found that the attending physician had not acted in accordance with the due care criteria and notified the Board of Procurators General and the Health Inspectorate of its findings.

Cases 11, 12, 13 and 14 (not included)

f. **Due medical care**

The attending physician has exercised due medical care and attention in terminating the patient's life or assisting in his/her suicide

In terminating the patient's life or assisting in his/her suicide, the methods, drugs and dosages used are, in principle, chosen in accordance with the recommendations issued by the Royal Dutch Pharmaceutical Society (KNMP).[8] Euthanasia is active intervention on the part of the physician who administers the euthanatics, usually intravenously, to the patient. In some cases, patients decide to take the drugs themselves. From the legal viewpoint, this constitutes assisted suicide. In that case, the patient swallows a liquid containing a

[8] Application and preparation of euthanatics (1998)

barbiturate.[9] It is important for the attending physician to stay with the patient, since he or she may vomit. In that case, the physician may then proceed to perform euthanasia. Leaving such drugs unattended also constitutes a risk to others apart from the patient.

Case 15 not included.

[9] usually 100 millilitres of liquid with 9 grams of pentobarbital or secobarbital salts