Regional euthanasia review committees

2002 annual report

Contents

Introduction

Structure of the annual report

Chapter I begins by describing how the review committees deal with notifications of termination of life on request or assisted suicide. The entry into force of the new act on 1 April 2002 has entailed changes in the review procedure, which are discussed in detail in this report. Chapter 1 also describes the various forms of consultation conducted by the review committees and looks at other action taken by them to improve the quality of the medical interventions surrounding euthanasia and assisted suicide.

Chapter II discusses some specific cases of termination of life on request and assisted suicide in the light of the due care criteria.

CHAPTER I

Work of the review committees

The main task of the euthanasia review committees is to assess the cases that are submitted to them. This chapter uses diagrams to explain how they do their work. The first diagram shows the situation in the first three months of 2002, under the old regulations. Since 1 April 2002, the tasks, powers and working procedures of the committees have been laid down in Sections 8 to 13 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. The second diagram shows the new situation. The changes to the review procedure as a result of the new legislation are discussed in a separate section.

1. Working procedures

The regional euthanasia review committees were set up on 1 November 1998. There are five such committees, based in Groningen, Arnhem, Haarlem, Rijswijk and ‘s-Hertogenbosch. Their offices are on the premises of the regional health care inspectorates. The Arnhem and ‘s-Hertogenbosch committees both have their offices in Arnhem.

Each committee consists of three members: a lawyer (the chair), a physician and an expert on ethical or moral issues. Each member also has an alternate appointed from the same discipline. Each committee has a secretary, who is a lawyer and attends the meetings in an advisory capacity.

Working procedures of the committees under the Regional Euthanasia Review Committees Order (before 1 April 2002)

Under the terms of Article 10, paragraph 1 of the Order, the committee submitted its findings in the form of an authoritative opinion to the National Office of the Public Prosecution Service and the Health Care Inspectorate. The Public Prosecution Service then decided at its own discretion whether or not to prosecute. This meant that the findings of the committee were used to determine in each individual case whether the physician had acted in accordance with the due care criteria. The Health Care Inspectorate also had independent powers to investigate the attending physician’s actions. Any further action taken by the two authorities fell outside the purview of the committee. This is indicated in the diagram by the use of dotted lines.

[Diagram 1]

Diagram I

the attending physician

• submits an immediate notification and report to

the municipal pathologist

• sends all documents:

- his own report
- report by the independent physician
- advance directive
- form under Section 10 of the Burial and Cremation Act
- plus any annexes to

the regional euthanasia review committee

• the secretary

- enters relevant data in a database specially developed for the committee
- prepares draft findings
- sends copies of all documents and draft findings to the committee members

• the committee

meets once every three or four weeks

discusses all the cases and issues its findings within six weeks

- this deadline may be extended once by a further six weeks in order to obtain further information from the attending physician, the independent physician or the pathologist and if necessary to invite the attending physician to an interview
- the definitive findings are signed by the chairperson

FINDINGS

AGAINST PHYSICIAN

Board of PGs

attending physician

inspector

decision not to prosecute

public prosecutor

interview

preliminary inquiry

regional disciplinary board

no further action

criminal court

IN FAVOUR OF PHYSICIAN
attending physician
Board of PGs
inspector
sends final or interim notification within three weeks to
attending physician

Working procedures of the committees under the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (since 1 April 2002)

Under the new legislation, the phrasing of the committees' findings is different. Under the previous order they had to assess whether the physician had or had not acted *with due care*, but under the new legislation they assess whether the physician has or has not acted *in accordance with the due care criteria*. The changes that this entails for the review procedure will be discussed later in this chapter.

Under the terms of Section 9, subsection 2a of the Act, the committees are required to submit their findings to the National Office of the Public Prosecution Service and the Health Care Inspectorate only if in their opinion the physician has not acted in accordance with the due care criteria set out in Section 2 of the Act. The Public Prosecution Service then decides whether to prosecute. The Health Care Inspectorate decides whether the physician's action should lead to disciplinary or other measures, and if so what those measures should be.

[Diagram 2]

Diagram II

FINDINGS
NOT IN ACCORDANCE WITH DUE CARE CRITERIA
Board of PGs
attending physician
inspector
decision not to prosecute
public prosecutor
interview
preliminary inquiry
regional disciplinary board
no further action
criminal court
IN ACCORDANCE WITH DUE CARE CRITERIA
attending physician

Changes in review procedure

As the above diagrams show, the new legislation that entered into force on 1 April 2002 has implications for the committees' review procedure.

Before the Act came into force - i.e. under the terms of the Order - the committees assessed whether the attending physician had acted with due care. In the vast majority of cases they found in the physician's favour. They submitted all their findings - including those in the physician's favour - to the National Office of the Public Prosecution Service, giving an authoritative opinion on whether to institute a criminal investigation or criminal proceedings. Euthanasia and assisted suicide were deemed to be 'serious offences' (Articles 293 and 294 of the Criminal Code), but physicians who had acted with due care could claim impunity on the grounds that they had acted out of necessity. The procedure involving the Health Care Inspectorate will not be discussed in this section, since there are no changes in the committees' review procedure other than that the findings are no longer forwarded to the Inspectorate if the physician has acted in accordance with the due care criteria.

Exceptional grounds for immunity from criminal liability have been incorporated into articles 293 and 294 of the Criminal Code. The physician's action is not criminal if he has acted in accordance with the statutory due care criteria and has notified the municipal pathologist of the euthanasia or assisted suicide in the prescribed manner. As a result, the committees no longer assess whether physicians have acted with due care, but whether they have acted in accordance with the due care criteria. This has implications for the review procedure. If a physician has complied with the due care criteria, the exceptional ground for immunity from criminal liability applies and his action is not a criminal offence. In such cases the committee's findings are final. Findings in favour of the physician are no longer forwarded to the Public Prosecution Service, and the case is deemed closed. If, on the other hand, the committee finds that the physician has not complied with the due care criteria, the case is referred to the Public Prosecution Service.

As a result of this change, the committees now bear a greater responsibility. In making their assessments they now have only two options: they can find that the physician (a) has or (b) has not complied with the statutory due care criteria. There are no other alternatives. The situation under the previous legislation was different. When assessing whether a physician had acted with due care, the committees could - in cases where the physician had not acted entirely in accordance with the rules - mention the errors made and still find in the physician's favour. The phrasing 'with due care, except...' was often used.

The committees must now find against the physician if the due care criteria are not complied with for any reason whatsoever (on procedural grounds, for example). In most cases this involves an error at the consultation stage or when carrying out the termination or assisted suicide. As a result, there have been more findings against physicians in the last year than in previous years under the old legislation.

However, experience has shown that the committees do have some latitude in interpreting the due care criteria. The question of how the criteria are to be applied in specific cases is left up to them.

The case histories included in this annual report (from which all identifying details have been removed) are intended to give a picture of the kind of considerations that arise during the review procedure.

CHAPTER II

1. Introduction to case histories

In the year under review the committees received 1,882 notifications of euthanasia or assisted suicide. In most cases the reports formed a satisfactory basis for the review and there was no need to ask additional questions. In cases where such questions did arise, the attending physician or the independent physician was requested to provide information in an interview or in writing. In five cases the committees found that the attending physician had not acted in accordance with the due care criteria. These cases were referred to the National Office of the Public Prosecution Service and the Health Care Inspectorate.

Although the due care criteria are clearly formulated in the Act and the reports form a satisfactory basis for reviews, debatable situations do arise in practice. The case histories set out below are intended to provide a picture of the issues the committees have dealt with during the year under review. Each of the cases was assessed after 1 April 2002, under the new legislation, which thus forms the basis for the discussion in this chapter.

As already indicated, in the vast majority of cases it was clear that the notifying physician had acted in accordance with the due care criteria. This situation is illustrated by the following two ‘standard’ case histories.

Case 1

In early 2002 the patient, a 79-year-old man, was found to have lung cancer which had spread into the spinal column. He was given radiotherapy followed by one course of chemotherapy. The curative radiotherapy had no effect. There was no prospect of recovery.

The patient was in pain. He had been bedridden for a considerable time and had inevitably developed bedsores. Despite the administration of laxatives and enemas, he suffered serious constipation and had difficulty in urinating. Efforts by a specialised team to control his pain were ultimately of no avail. His suffering was aggravated by the realisation that there was no prospect of improvement and that the symptoms were getting worse. Towards the end he developed a urinary infection which caused fever, slight delirium and pain throughout his body. He refused treatment for the infection. The delirium was effectively treated with medication. If the patient’s life was not terminated, his family physician expected him to die within one or two weeks.

It was clear from the documents that the family physician and the hospital specialist had given the patient sufficient information about his situation and prospects. The patient had often spoken to specialists at the hospital about terminating his life. After being discharged he repeatedly told his family physician that he wanted euthanasia, and he signed a written directive to that effect. He made the same request in the presence of his children and a home carer, as well as a specialised home care team. Consultations took place with them. They all backed the patient's request. According to the family physician there was no outside pressure and the patient was aware of the implications of his request and his physical situation.

After the patient had made his request, the family physician discussed his medical situation with the attending lung specialist by telephone. The specialist confirmed that no further treatment was possible.

The family physician then got in touch with an independent SCEN physician (see Section 6 below) who was also a family physician but was not attending the patient. The independent physician had an interview with the patient. In his report on the interview he confirmed that the patient was suffering, with no prospect of improvement, and found his suffering unbearable. There were no palliative options left. During the interview the patient was lucid and capable of informed consent. His request had been sustained, carefully considered and voluntary. In the independent physician's opinion the due care criteria had been complied with.

A month after the request was made, the family physician administered Nesdonal and Pavulon to the patient intravenously, in the presence of his children and the home carer. The patient then died.

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

Case 2

In 1998 the patient, a 54-year-old man, was diagnosed as having amyotrophic lateral sclerosis (ALS), an incurable disease. The treatment consisted of rehabilitation, physiotherapy and occupational therapy. The patient's suffering was caused by pain, loss of speech and respiratory problems. He was at risk of choking and suffocating. The symptoms

were progressive. Morphine was administered to control his pain, but there were no other ways left to alleviate his suffering. If his life was not terminated, the attending physician expected him to die within several weeks. However, the physician indicated that this period was difficult to estimate, as the patient's condition might suddenly deteriorate.

The patient had already indicated in 2000 that he wanted euthanasia if ever he found his suffering unbearable. A few weeks before he died, in the presence of the attending physician and his partner, he expressly asked for his life to be terminated. His partner backed the request. The patient had made several written declarations over a period of time. He expressly indicated that he did not want artificial respiration. In the attending physician's opinion his request was voluntary and carefully considered.

An independent SCEN physician visited the patient twice. It was deliberately decided to hold the consultations at an early stage, before the patient's speech deteriorated too badly. In his report on the first consultation, the independent physician confirmed that the patient was suffering from an incurable, progressive disease. On his second visit he confirmed that the disease had progressed further. The patient's speech was no longer intelligible and he could no longer eat without choking. The painkillers were ineffective, and the patient was short of breath. As a result of all these factors, he found his suffering unbearable. In the independent physician's opinion the request had been voluntary and carefully considered. He concluded that the due care criteria had been complied with. The attending physician then administered 2 grams of pentothal and 20 milligrams of Pavulon to the patient intravenously, in the presence of his loved ones. The committee found that the attending physician had acted in accordance with the due care criteria.

The notifying physician is the person who has actually performed the termination

The basis for the notification procedure is that the physician who has actually terminated life on request or provided assistance with suicide subsequently reports this to the municipal pathologist, using the standard report form (Section 7, subsection 2 of the Burial and Cremation Act). The pathologist performs an external examination of the body and verifies how and with what substances the patient's life has been terminated. He then takes delivery of the attending physician's report, checks whether it has been completed fully and clearly and whether any annexes referred to are indeed attached, and (where available) adds the deceased person's written euthanasia directive and the statement by the independent physician to the file. He then notifies the competent committee by completing and submitting

a form intended for that purpose, together with the aforementioned documents (Section 10, subsection 2 of the Burial and Cremation Act).

A matter of importance to the committees is whether the notifying physician (the physician that has signed the notification form) is the person who has actually performed the termination or provided assistance with the suicide. If the committee discovers that this is not the case, it normally sends the notification back through the municipal pathologist with a request that the right person - i.e. the physician who has actually performed the euthanasia or provided assistance with the suicide - report the termination of life by completing and signing the standard report form.

It is not always immediately clear that the notifying physician has not performed the termination or provided assistance with the suicide. In that case the committee asks additional questions in writing. Occasionally a notification is submitted by two physicians. If another physician was involved in the procedure, he receives copies of the reports sent to the notifying physician. Only in the exceptional event that the two physicians state that they have performed the termination jointly are both physicians deemed to be notifying physicians.

Case 3

A 60-year-old patient was suffering from prostate cancer, with metastases. The personal particulars of two physicians appeared on the notification form, which was signed by both of them. The report indicated that the patient had expressed his wish for euthanasia in the presence of both physicians. The entire euthanasia procedure had also been supervised by both of them. However, the actual termination had been performed by one of them, whom the committee deemed to be the notifying physician. Both physicians were informed of this. The physician not deemed by the committee to be the notifying physician was sent a copy of its findings.

2. Powers of the committees

The power of the committees to assess the action taken by the attending physician to terminate life in a specific case is derived from the procedures set out in the Act, and in particular the due care criteria referred to in Section 2 of the Act.

With euthanasia and assisted suicide, life is terminated by a physician on request. The review committees therefore only examine cases in which an individual has expressly requested termination of life or assistance with suicide. If no such request has been made, the committees have no power to act and the procedure governing termination of life in the absence of an express request must be followed, i.e. the municipal pathologist must refer the case directly to the public prosecutor.

The notification procedure for termination of life on request is not applicable to newborn babies or children under the age of twelve. Special provisions concerning the consent of parents or guardians in the case of minors aged (a) twelve to fifteen and (b) sixteen or seventeen are laid down in Section 2, subsections 4 and 5 of the Act.

Section 2, subsection 2 of the Act also specifies that a physician may comply with a request for termination of life contained in a written euthanasia directive by a patient aged sixteen or older who is incapable of informed consent, provided that the directive was drawn up at a time when the patient was still able to make a reasonable assessment of his interests. The committees also have powers to act in such cases. A written declaration by a patient who is no longer capable of informed consent is then deemed to be an express request for termination of life and replaces the specific oral request that the patient is no longer capable of making.

'Normal medical procedure' is likewise not covered by the legislation governing termination of life on request. This refers to decisions to cease, or not to commence, treatment at the explicit request of the patient or if it serves no medical purpose. Nor is the notification procedure applicable to pain control measures whose unintended side effect is the death of the patient. As the following case history shows, the boundaries in such situations are not always clear.

Case 4

A 50-year-old patient had been suffering from breast cancer since 1999. She had been given radiotherapy, chemotherapy and hormone therapy, but there was no prospect of recovery. The patient was short of breath, had difficulty swallowing and vomited frequently. She was not expected to live more than a few weeks. There were no ways left to alleviate her suffering.

For the past three years she had said that she wanted euthanasia if ever her suffering became unbearable. In November 2002 she signed a written directive to this effect. Some days earlier she had indicated that she wanted to die. The attending physician then called in an independent SCEN physician who came and interviewed the patient. Partly at the recommendation of the independent physician, a specialised pain control team inserted a drip for the administration of Dormicum and morphine to control the patient's pain, before any decision was taken about whether to perform euthanasia. As a result of this 'sedation' the patient died without the attending physician being present.

The patient having died before euthanasia could be performed - as a result of the prior sedation - the committee concluded that her life had not been terminated on request within the meaning of the Act. The notification procedure was not applicable, and the notification was therefore sent back to the municipal pathologist. The patient had simply died of natural causes.

3. Clinical relationship between the notifying physician and the patient

The statutory procedure governing termination of life on request and assisted suicide is based on the assumption that the action to terminate life is taken by the *attending* physician. Indeed, this was the phrasing used during the parliamentary debate on the Bill.[1] The due care criteria likewise presuppose some kind of clinical relationship with the patient. How else can the physician be satisfied that the patient has made a voluntary, carefully considered request and that the patient's suffering is unbearable, with no prospect of improvement? Furthermore, the attending physician and the patient must together be satisfied that there are no reasonable alternatives left, and the physician must inform the patient about his situation and prospects.

Another pointer is the reference (in Section 1e of the Act) to Article 446 (Book 7) of the Civil Code on medical treatment contracts. A medical treatment contract is deemed to exist if, in the pursuance of a medical occupation or enterprise, a natural or legal person undertakes to carry out medical interventions that directly affect the patient. Section 1e of the Act thus presupposes that there is a medical treatment contract between the attending physician and the patient when the request for termination of life is made. That is not the case if the relationship is confined to the performance of euthanasia, as in the following case history.

[1] The response to questions from parliament on the Bill states: 'In Section 1c the term 'attending physician' is defined. It refers to the physician who has performed the euthanasia' (*Parliamentary Papers I*, 2000-2001, 26 691 No. 137b).

Case 5

A patient had been suffering from lung cancer, with vertebral metastases, since 1996. She had been given radiotherapy and chemotherapy, and efforts had been made to alleviate her pain. There was no longer any prospect of recovery. The patient suffered unbearably from the agonising, uncontrollable pain. She could not tolerate morphine. She was also short of breath and suffered from bedsores. She was expected to live a few days at most. From mid-October 2001 onwards the patient discussed her wish for euthanasia with her family physician. A few weeks before she died she requested euthanasia on a number of occasions, in the presence of the family physician and her children.

The day before the patient died, the notifying physician was summoned to her bedside while on evening duty - clearly not in his capacity as a SCEN physician - because she was in terrible pain. He found her in what he described as degrading circumstances - in severe, uncontrollable pain, restless, cachectic and short of breath. She was taking oxygen. That same evening the notifying physician discussed the possibility of euthanasia at length with the patient and her family. During this consultation it became clear to the notifying physician that the patient had mentioned euthanasia to her own family physician only indirectly. She felt extremely uncertain about the situation she was now in. It was unclear why she had not specifically discussed euthanasia with her family physician more often. The next day the notifying physician got in touch with the family physician to discuss what to do about the patient's situation, which was unbearable. Only then did it become clear to him that the family physician did not want to perform euthanasia for reasons of principle. His colleague in the group practice, who was not opposed to performing euthanasia, was away on holiday. The notifying physician went back to see the patient the same day and administered Haldol to her, but the pain continued unabated. The patient begged the physician to put her out of her misery. He perceived her suffering to be so intense and the situation to be so acute that he decided to perform the euthanasia. He briefly considered consulting another physician, but eventually decided that the patient's suffering was so evident that further consultation was no longer relevant.

The committee found that the notifying physician had not acted in accordance with the due care criteria. He had not complied with the consultation criterion, which prescribes that the attending physician must consult at least one other physician who has seen the patient and has given a written opinion that the due care criteria have been complied with. In this case the physician - who was initially summoned to the patient's bedside while on evening duty

because she was in severe pain - was eventually the person who performed the euthanasia (the notifying physician). He only consulted the patient's own family physician, who was treating her and hence was not independent. The notifying physician drew up and signed his own consultation report. Even after interviewing the physician, the committee - while in no way disputing his good intentions and integrity - was unable to conclude that the situation had been so acute that an independent physician could not be consulted. It found that consultation within the meaning of the Act had not taken place. The fact that the notifying physician had only known the patient for one day added to the weight of this argument. In a case such as this, consultation was essential in order to verify compliance with the due care criteria.

This case was referred to the Board of Procurators-General, because the file revealed that the clinical relationship between the physician and the patient had only been very brief and that no consultation with an independent physician had taken place. The Board shared the committee's view that the notifying physician had not acted in accordance with the due care criteria. However, it concluded that prosecution would be disproportionately harsh in this particular case, and no further action was taken.

4. Due care criteria

I. Request

Termination of life on request or assisted suicide can only take place if the patient has made an express request to that effect. Such a request must be voluntary and carefully considered. Only then can the due care criterion requiring the physician to be satisfied that the request was voluntary and carefully considered (Section 2, subsection 1a of the Act) be deemed to have been complied with.

Was the request voluntary and carefully considered?

The first question the committees ask in connection with this criterion is whether and how the patient made the request. It need not necessarily have been made in writing, although this is preferable for purposes of evidence.

In almost all cases, there was in fact a written advance directive. The committees can well imagine that physicians would prefer to have such a directive, but - with the patient so close to death - it can be replaced by an accurate rendering of an orally expressed wish for

euthanasia, for example in the patient's medical files. In general, physicians who are discussing euthanasia with their patients are advised to encourage them to draw up a written directive in good time.

In some cases the existence of a written euthanasia directive is of crucial importance. A patient may no longer be capable of informed consent but if, while he was still capable, he drew up a written directive requesting that his life be terminated, the attending physician may comply with that request. The committees must then examine whether the request was voluntary and carefully considered, whether it applied to the patient's present situation and whether the situation also satisfied the other due care criteria - none of which are easy matters. The more specific the euthanasia directive, the firmer the basis for the attending physician's decision and the committee's assessment. It is therefore important for physicians and patients to discuss the content and implications of such directives in good time.

In many cases patients raise the question of euthanasia with their physicians at an early stage, for example after hearing that they have an incurable disease. They also frequently indicate a wish for euthanasia as the disease progresses. Such conversations are an indication that the request is carefully considered, but must be distinguished from the situation in which the patient specifically asks for his life to be terminated.

The question on the notification form about when the patient first made the request can be a source of confusion. Some physicians indicate the point when the subject of euthanasia was first discussed, others the point when the patient first made a conditional advance request for euthanasia, and still others the point when the patient first made a specific request.

The time that elapses between the first specific request and the actual euthanasia is occasionally very short - sometimes less than a day. The committees feel that this is only justified in exceptional circumstances of unforeseen acute distress. In such cases it is important that the information provided by the attending physician and the independent physician should demonstrate the existence of such an acute situation. In other cases there may be a considerable time lag between the specific request and the actual euthanasia, for example a number of weeks. If this time lag is not mentioned in the notification, committees often ask the attending physician to account for it.

The next question concerns the nature of the request. In order to comply with the statutory due care criterion, the attending physician must be satisfied that the patient's request for euthanasia was completely voluntary and was entirely the patient's wish. It must, for

example, be clear that the request was not made under pressure from others or pressure of circumstances. Patients sometimes say that they no longer wish to be a burden upon their families. Physicians must then ascertain what value should be attached to this statement. In one or two cases pressure from the family appears to have been a factor in the decision.

The request must also be carefully considered and made repeatedly. Here, the committees look at possible inhibiting factors such as depression or other disorders of the patient's cognitive or expressive faculties. Such factors may make the request less valid, but need not necessarily do so. A request made in a moment of lucidity may be carefully considered. A distinction must be made here between clinical depression and gloominess or dejection due to the patient's grave illness. In such cases an assessment by an independent psychiatrist may help to confirm that the request was voluntary and carefully considered.

In some cases the data in the notification make the committees decide to seek additional information on the extent to which depression may have affected the patient's capacity for informed consent and his ability to make a voluntary, carefully considered request.

Case 6

A 65-year-old patient had had metastases from a melanoma in his chest and armpit since 2001. Early in 2002 metastases were also found in the liver and lungs, and within a few months the cancer had spread to the pelvis and vertebrae. The patient's suffering was due to pain, nausea, conspicuous skin cancer, double vision and the fact that he was totally dependent on others. The physician also reported that the patient was depressed and anxious that the pain might get worse. He was given Ritalin in an attempt to influence his mood, but the effects were disappointing. The patient refused other antidepressants. In April 2002 he asked the attending physician to terminate his life, and he repeated the request several times thereafter. There was a written euthanasia directive, originally drawn up in 1998 and updated in May and June 2002.

In May and June 2002 the patient was visited by two different independent physicians, the second of whom concluded in June 2002 that the due care criteria had been complied with. In his opinion the request was voluntary and carefully considered. During the interview the patient had been lucid and clear in his request for euthanasia. At the end of June 2002 his life was terminated by intravenous administration of Nesdonal and Pavulon.

From the data in the notification it was not completely clear to the committee whether, and if so to what extent, depression had affected the patient's capacity for informed consent and his ability to make a voluntary, carefully considered request for euthanasia. The committee asked the attending physician to submit a written report on the subject.

In his report the physician stated that, before becoming depressed, the patient had repeatedly indicated that he wanted euthanasia if ever he found his suffering unbearable. In the physician's opinion there were no indications that depression had affected the patient's capacity for informed consent at the point when he had requested that his life be terminated. The depression, which took the form of dejection and gloominess, was mainly due to the patient's grave illness and the fact that he had always been extremely independent. In the light of the additional information provided by the attending physician, the committee concluded that he had acted in accordance with the statutory due care criteria.

In order to make a carefully considered decision, the patient must also have a clear idea of his illness, the situation he is in, the prognosis and any alternatives. The attending physician is advised to discuss the patient's request on a number of different occasions, so that they both have a clear idea of where they stand on the matter. To enable the committee to assess properly whether the decision was carefully considered, the physician must keep a good record of these conversations and attach the relevant documents to his report.

II. Unbearable suffering with no prospect of improvement

The second due care criterion, which is of crucial importance in cases of termination of life on request or assisted suicide, is that the attending physician must be satisfied that the patient is suffering unbearably with no prospect of improvement (Section 2, subsection 2 (b) of the Act).

From a medical point of view, the fact that there is no prospect of improvement can be determined fairly objectively. There is no likelihood that things will get better, and the prospect is that they will get steadily worse. This must be determined in the light of current medical knowledge. The question of whether suffering is unbearable, on the other hand, is largely subjective. It all depends on the patient's outlook, personality and views on the matter. Furthermore, perceptions of suffering differ from patient to patient. Some patients find it unbearable to be completely dependent on others, while others find their increasingly undignified situation unbearable. In fact, even this is not entirely subjective. Factors such as

pain, nausea, exhaustion and shortness of breath contribute significantly to the conclusion that suffering is unbearable.

Nevertheless, the question of whether suffering is unbearable is one of the greatest dilemmas in the practice and assessment of euthanasia. To what extent should it be possible to objectivise it? Is it sufficient that the patient himself finds his suffering unbearable - assuming his condition is incurable? Is suffering all in the mind, even if there is also a somatic complaint? In general, when assessing this criterion, it is felt that it must be possible to objectivise how unbearable suffering is, at least to the point where the attending physician can empathise with it.

In some cases fear of future suffering is an important factor. This fear may be based on the patient's own experience or on his experience of someone else's illness. In the committee's opinion such fear of future suffering must be realistic, e.g. fear of suffocation, acute haemorrhaging or further loss of dignity.

The vast majority of cases that come before the committees involve untreatable, malignant processes that are often accompanied by uncontrollable pain, severe nausea and vomiting. There are also diseases such as multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), Parkinson's disease, chronic obstructive pulmonary disease (COPD) and other fatal diseases that leave patients totally dependent and bedridden or at risk of death by suffocation. In other cases, such as paraplegia or cerebrovascular accident (CVA), it may be harder to determine whether patients' suffering is unbearable. What *is* certain is that there is no prospect of improvement.

In the year under review the committees also had to deal with cases involving an accumulation of geriatric complaints. Here they look very closely at the physician-patient process, the factors that made the patient's suffering unbearable and the way in which the attending physician became satisfied that the patient's suffering was unbearable, with no prospect of improvement. This is illustrated by the following case.

Case 7

An 82-year-old patient was suffering from an accumulation of geriatric complaints. He had had glaucoma since 1982. Despite several operations, his vision had continued to deteriorate. He had also had diabetes and hypertension since the 1980s. In 1997 he developed multi-infarct dementia, with moderate to severe memory loss. About a month

before he died he suffered a CVA, which left him paralysed for several days and totally and permanently blind.

The committee asked the attending physician to provide additional written information, and then interviewed him. The physician emphasised that, apart from blindness, the patient had suffered from various serious complaints, including severe vascular disorders in several parts of the body (the brain, the heart and the legs, with concomitant ulceration) and repeated cerebral infarction leading on three occasions to paralysis and memory disorders. A further handicap was extreme difficulty in walking due to numbness of the feet, possibly caused by the diabetes and balance disorders. As a result of his blindness and memory loss, coupled with the loss of his wife and son, the patient felt his life was pointless and unbearable. He was also well aware that another CVA could occur at any moment, causing further invalidity. According to the physician this fear was realistic. After years of suffering owing to his impaired vision, he could not accept being totally blind. The prospect of even more suffering was unbearable to him. The physician stated that there were no alternative treatments left. He had offered the patient antidepressants and psychological help, but the patient had refused them, since they would do nothing to alleviate his physical disabilities. The physician stated in the interview and in writing that in the course of time he had become satisfied that the patient's suffering was unbearable, with no prospect of improvement.

In the last week of his life the patient refused all food and drink, and his diabetes became unregulated as a result. If his life was not terminated, the attending physician expected him to die within a week from dehydration and unregulated diabetes. The independent physician concluded that the request for euthanasia satisfied the statutory due care criteria. All things considered, and on the basis of the additional information provided by the attending physician, the committee concluded that, in the light of current medical knowledge, the patient's suffering was unbearable, with no prospect of improvement. The committee found that the attending physician had acted in accordance with the due care criteria.

Informing the patient: are there no reasonable alternatives?

The committees also examine the way in which the attending physician informed the patient about his illness and prospects (Section 2 subsection 1c of the Act). Was the patient sufficiently informed of the diagnosis and prognosis? Particular attention is paid to opportunities for palliative care. If there is any uncertainty about this, the committees inquire whether treatment options were discussed with the patient, what palliative care was provided and what effect it had. The attending physician and the patient must together be satisfied that

there were no reasonable alternatives, given the patient's situation (Section 2, subsection 1(d) of the Act). This does not mean that every palliative treatment must be attempted. There may be good reasons to refrain from certain treatments. Some forms of palliative treatment may have distressing side effects. For example, a patient may refuse a higher dose of morphine because of side effects such as loss of consciousness. Similarly, palliative radiotherapy may have side effects so serious as to outweigh the benefits of the treatment. In other cases the discomfort of being transported to the place of treatment may be more than the patient can bear. A patient's refusal of palliative treatment on such grounds may be reasonable, and hence need not be an impediment to complying with a request for euthanasia. However, patients sometimes refuse palliative treatment that at first sight does not seem particularly intrusive and may therefore be deemed a 'reasonable alternative'. In such cases the attending physician is expected to discuss the matter with the patient. The committees consider it important that the report should indicate how the attending physician has handled this situation.

Case 8

In May 2002 an 81-year-old patient was found to have cancer of the colon, with metastases. There was no longer any prospect of recovery. The patient asked the attending physician to perform euthanasia, and refused all palliative treatment. The committee felt that the information on the notification form did not make clear whether there were any alternative forms of treatment and, if so, what they were. The attending physician was therefore asked to provide additional information. In a written statement he indicated that the tumour had already spread to the abdominal wall, and that metastases in the liver and cancerous peritonitis had been discovered. The prognosis was that the patient would die very shortly. Surgery revealed that the intestine had been perforated for more than twenty-four hours, with faecal peritonitis, making it likely that complications would arise during post-operative recovery. Palliative chemotherapy would only be possible once the patient had recovered from the surgery, and its chances of success were estimated at twenty-five per cent. The physician indicated that he had discussed the situation with the patient several times. The patient had refused the treatment because of the complications that would arise during post-operative recovery and the slim chances of success. The physician considered this an acceptable decision. In the light of this additional information, the committee was also satisfied that the adverse effects of the treatment would have outweighed the benefits. There were no realistic alternatives. The committee found that the attending physician had acted in accordance with the due care criteria.

In the year under review the committees had to deal with several notifications of euthanasia requested by patients who were no longer able to communicate by the time the procedure took place. The patients had lost consciousness just beforehand, for example after an increased dose of medication (morphine). Although physicians in general are of the opinion that comatose patients cannot suffer unbearably, if at all, the special facts and circumstances of the case may lead the committees to conclude nevertheless that the attending physician acted in accordance with the due care criteria when performing the euthanasia. An important factor here may be whether the coma was reversible. The patient's circumstances before he became unconscious may have been such that it would have been inhumane to let him come round (or bring him round) again. Other factors, such as the patient's express wishes in the event of a possible coma, are also taken into account. In general, however, the committees feel that physicians should exercise extreme restraint in such situations. It is often possible to wait and let nature take its course. However, it is the specific facts and circumstances of a given case that will determine the committee's decision as to whether the attending physician acted in accordance with the due care criteria.

Case 9

A 96-year-old patient was suffering from various complaints. In 1992 she had undergone surgery for cancer of the colon, and from 1999 onwards she had had repeated urinary infections. She also suffered from anaemia, hypertension and hypothyroidism, and had had several cerebral infarctions since 2002. Further examination for possible intestinal cancer was considered, but the patient refused this. A week before she died she also suffered from pump failure. She was short of breath after minor exertion and when resting, and had occasional double incontinence. She was receiving various forms of medication. There was no prospect of recovery.

The patient's physical condition had deteriorated rapidly over the previous few months. Her suffering was due to extreme fatigue and shortness of breath. She had always been active and independent, and found her increasing dependence on others unbearable. She perceived her incontinence as a loss of dignity. The patient was living on her own in a service flat. In the previous few days she had been looked after by her children, very much against her wishes. Apart from the medication there were no alternative ways left to alleviate her suffering. Her attending physician had given her sufficient information about her situation and prospects. On the day the euthanasia was performed, the patient was no longer able to communicate. In view of this, the committee asked the physician to provide additional written information. The physician stated that a few days before the patient's death - in consultation

with the patient and in the presence of her sons - he had begun to administer morphine in view of her increasing pain and shortness of breath and pending the SCEN report. The patient was afraid that the medication would make her lose consciousness. It was agreed with her and her sons that unless she died within a few days her life would be terminated on an agreed date, even if she was no longer conscious. Her condition then deteriorated. She grew breathless and extremely restless and was no longer able to communicate. That evening she became extremely anxious, confused and short of breath. In addition to the morphine he had already given her, the physician now administered Haldol and Dormicum. The patient did not recover consciousness again.

She was now in the very situation she had indicated earlier she did not want to end up in. Her sons respected her previously expressed wish not to be washed any longer. She lay in her own bodily effluvia and developed bedsores. Despite the attending physician's explanation that in her present circumstances the patient was not actually suffering and would not notice being cleaned and washed, the sons insisted on respecting their mother's wishes.

From 1993 onwards the patient had regularly requested that her life be terminated, but had changed her mind when her situation improved. In 1993 she had signed a Dutch Voluntary Euthanasia Society declaration, with an additional provision concerning euthanasia in the event of coma. From July 2001 onwards she had regularly discussed termination of life with the attending physician. In March 2002 she indicated that she wanted to die. In a last written directive, which she had signed, she had indicated that she wanted her life to be terminated by euthanasia. Finally she had agreed with the attending physician that the euthanasia would be performed unless she had died of natural causes by the agreed date.

The independent SCEN physician was of the opinion that the due care criteria had been complied with. The attending physician administered 10 milligrams of Pavulon to the patient intravenously, in the presence of her children (since the patient was already in a coma, there was no need to administer medication to induce one).

The committee's considerations in this case were as follows. It is generally accepted that a comatose patient does not suffer. The question here was whether active intervention was necessary or desirable in this specific case, in which the patient was expected to die of natural causes very soon. In the light of the physician's statement that the patient's situation was partly due to the medication, the committee concluded that she had been in a potentially reversible coma. However, it would have been inhumane and hence inappropriate to bring

her round again under these circumstances. The committee did find that the attending physician might have been expected to exercise more restraint in agreeing to carry out euthanasia under these circumstances. However, in view of the patient's 1993 directive, which was confirmed in writing in 2002 and repeated orally just before she ceased to be able to communicate, as well as the suffering described by the physician, which left him satisfied that the due care criteria had been complied with, the committee found that the physician had acted in accordance with the due care criteria.

III. Consultation

One of the due care criteria concerns consultation with a second, independent physician who has seen the patient and has given a written opinion as to whether the due care criteria have been complied with (Section 2 subsection 1e of the Act). The independent physician must therefore give an expert, independent opinion on whether the patient's suffering is unbearable, with no prospect of improvement, whether there are alternative ways to alleviate the suffering, and whether the request for termination of life or assisted suicide is voluntary and carefully considered. This means that he must be independent of the patient, which in turn means that he must not be treating the patient or be in a family relationship to him, and also in principle that he must not have come into contact with the patient in the capacity of locum. He must also be independent of the physician who performs the euthanasia or provides assistance with the suicide, which in principle means that they must not be in a family or hierarchical relationship to one another and must not be members of the same group practice.

The requirement that the independent physician must have seen the patient and given a written opinion on whether the due care criteria have been complied with applied before 1 April 2002 but it has now been explicitly specified in the Act. If this requirement is not met, the attending physician is deemed not to have complied with the due care criteria. Physicians are advised to make very sure that the consultation is carried out and recorded correctly. Moreover, a detailed, well-documented report by the independent physician will substantiate the notification of euthanasia and will help the committee in reaching its decision.

In the year under review the committees had to deal with several notifications in which the consultation requirement had not been complied with. In the following case the committee found that the attending physician had not acted in accordance with the due care criteria.

Case 10

In April 2001 a 47-year-old patient was found to have stomach cancer, which in February 2002 was discovered to have spread to the liver. There was no longer any prospect of recovery. The voluntary, carefully considered nature of the request and the unbearable nature of the patient's suffering, with no prospect of improvement, were not in question. On the standard form the attending physician stated that the independent physician was a medical specialist, and he attached a letter from the specialist by way of a consultation report. The letter made no mention of the patient's request for euthanasia. The patient's case history, which was also attached to the notification, indicated that the attending physician had consulted the specialist by telephone on two other occasions: once on the day before the euthanasia was performed, and once on the day it was performed. Since there was no consultation report attached to the notification and the remaining documentation likewise failed to make clear whether the specialist had personally assessed whether the due care criteria had been complied with, the committee invited the attending physician for an interview on his report.

The attending physician told the committee that both the patient's visit to the specialist and his own two telephone conversations with the specialist were intended by him as consultations within the meaning of the Act. He also indicated that on several occasions when he had performed euthanasia in the past he had consulted the independent physician by telephone only. He added that the Public Prosecution Service had never made any comment to him about this.

The committee then obtained written information from the specialist and asked him whether he had considered the consultations with the attending physician to be consultations within the meaning of the Act. The specialist explicitly stated to the committee that this was not the case. He had seen the patient once as an outpatient, and could not remember euthanasia having been mentioned on that occasion. Nor had he been specifically asked during the two telephone conversations to give his opinion on whether to terminate the patient's life. He did talk about the fact that there were no alternative curative treatments left and that nothing could be done but treat the symptoms.

In the light of the report, the interview with the attending physician and the additional information supplied by the specialist, the committee found that the physician had not complied with the independent consultation requirement and that he had not acted in accordance with the due care criteria when terminating the patient's life on request.

After investigating the case, the Board of Procurators-General informed the committee that it shared this view but would refrain from prosecution. However, the case was referred to the Health Care Inspectorate, and an interview with the physician followed.

In almost all cases the person consulted was a fellow physician. Family physicians almost always consulted a fellow family physician, often a SCEN physician, and specialists usually consulted one or more fellow specialists at the same hospital. In some cases a psychiatrist or a psychologist was also consulted to determine to what extent the patient was capable of informed consent or whether he might be suffering from a mental or psychiatric disorder. In one or two cases the only person consulted was a psychiatrist. In general, the committees feel this is less desirable, since the person consulted must determine not only whether the request is voluntary, carefully considered and sustained, but also whether the patient's suffering is unbearable, with no prospect of improvement.

IV. Performance of euthanasia

In general, the requirement that the termination of life on request or assisted suicide must be performed with due medical care presents few problems. In most cases the method and substances used are based on the 1998 advisory report by the Royal Dutch Society for the Advancement of Pharmacy, entitled *Toepassing en bereiding van euthanatica* ('Application and preparation of euthanatics'). The attending physician actively terminates the patient's life by administering the euthanatics to the patient, usually by drip. Thiopental is administered intravenously to induce a coma; this is followed by a muscle relaxant such as pancuronium, atracurium, rocuronium or vecuronium. In some cases patients choose to take the euthanatics themselves. Legally speaking this is assisted suicide rather than termination of life. In that case the patient drinks a barbiturate potion. Although the physician does not actually administer the euthanatics, but only supplies them, he is normally expected to remain present while they are taken. He must not leave the patient alone with the euthanatics. Occasionally the patient vomits up the potion, and the physician must then intervene actively after all.

5. Reporting

A well-documented notification is of great importance in making a careful assessment, since the committees' review of the attending physician's action is primarily based on the written notification. In many cases a detailed standard report by the physician and a consultation report by the independent physician are sufficient, and no further written or oral information

needs to be obtained from the attending physician, the independent physician or other health care or welfare workers.

A standard form has been drawn up for physicians to use when making written reports on termination of life on request or assisted suicide. Its use is not compulsory. A report drawn up personally by the physician will also be accepted by the committee, provided it deals with each of the due care criteria. In practice, however, the standard form is used in almost all cases.

The standard form has been adapted to take account of the new legislation. The Ministry of Justice and the Ministry of Health, Welfare and Sport have set up a working group to examine all the forms used for the various reports and the notification procedure and to determine how they can be improved so that they are as clear and as easy to use as possible. The committees are represented on the working group.

The committees have noticed that in general reporting by attending physicians has again improved in the year under review. Information and feedback from the committees have ensured that physicians are better informed about how to make their reports. Occasionally, however, the answers to the questions on the form are extremely brief. In such cases the committees feel obliged to ask the notifying physician to provide additional information.

The independent physician also sets out his findings in a report, in which he must give a substantiated personal opinion regarding all the due care criteria. He must also indicate his relationship to the patient and the notifying physician. The committees have noticed that forms with ‘yes-or-no’ questions are being used a lot less. In most cases a personal report by the independent physician was attached to the notification. The committees have noticed that some consultation reports are still extremely brief, especially ones from hospitals. The independent physician is then often asked to submit a more detailed report, either on the occasion in question or in future.

6. SCEN project

The Support and Consultation for Euthanasia in the Netherlands (SCEN) project, which now operates nationwide, trains physicians to act as independent physicians in cases of euthanasia. So far practically all the trainees have been family physicians. The course looks closely at every facet of consultation (medical, ethical and legal). A physician who is a member of the committee and the secretary both give lectures during the course. In the year

under review the committees have again noted improvements in both consultation and reporting as a result of this project.

However, reporting by medical specialists is still in need of improvement. The quality of consultations in hospitals is currently under review, and the committees have indicated that they are willing to assist with this. The SCEN project has plans to offer the course to medical specialists as well if funding becomes available. The committees are very much in favour of the project being continued and extended, since it greatly contributes to the quality of the interventions surrounding euthanasia. They have made their views known to the ministry concerned.