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2003 ANNUAL REPORT

Regional euthanasia review committees

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Foreword

The results of the evaluation by Professors Van der Wal and Van der Maas of how medical decisions at the end of life are actually reached were published in mid-2003. One of the main purposes of the evaluation was to determine how the review procedure operates in practice.¹

The first findings were that most physicians have a positive attitude to the review procedure and that there is considerable uniformity in the committees' assessments. The evaluation also showed that the notification rate (as measured in 2001) has risen since the previous evaluation in 1996, especially among general practitioners.² This is important because euthanasia is mostly carried out by general practitioners. The increase in willingness to notify has largely taken place since the Euthanasia in the Netherlands Support and Assessment project (SCEN) was introduced. This suggests that the project should be extended to specialists and to physicians working in nursing homes.

However, the committees' previous annual reports pointed to a declining trend in the number of notifications, a trend that resumed this year. In 2003 there were 1,815 notifications of euthanasia and assisted suicide. In eight cases the committees found that the attending physician had not acted in accordance with the statutory due care criteria. The evaluation does not indicate the exact reason for this declining trend. What is apparent is that the quality of palliative care for patients in the final stages of life has increased owing to physicians' greater knowledge and experience in this field.

The evaluation findings suggest that improved palliative care in the Netherlands has to some extent reduced the number of requests for and incidence of euthanasia. However, no firm conclusions can be drawn on the basis of the findings.³

It is important to gain a better understanding of the background to these issues, in the interests of a clearer social and political debate and the development of medicoethical and legal policy on specific issues, such as the boundary between euthanasia and what is known as terminal sedation.

Arnhem, May 2004

R.P. de Valk-van Marwijk Kooy

Coordinating chair of the regional euthanasia review committees

¹ The results of the evaluation appeared in the report *Medische besluitvorming aan het einde van het leven: de praktijk en de toetsingsprocedure euthanasie*, G. van der Wal, A. van der Heide, B.D. Onwuteaka-Philipsen and P.J. van der Maas, Amsterdam/Rotterdam, 2003.

² The evaluation was confined to the 1998-2002 review procedure as set out in an order in council based on Section 10 of the Burial and Cremation Act. This procedure remained applicable until 1 April 2002, when the Termination of Life on Request and Assisted Suicide (Review Procedures) Act came into force.

³ See also the aforementioned evaluation report *Medische besluitvorming aan het einde van het leven: de praktijk en de toetsingsprocedure euthanasie*, Amsterdam/Rotterdam, 2003 pp. 197 and 198.

Introduction

The year under review was the first full calendar year in which the regional euthanasia review committees (referred to in the remainder of this report as ‘the committees’) reached decisions in accordance with the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (referred to in the remainder of this report as ‘the Act’), which came into force on 1 April 2002.

In essence, the statutory notification rules prescribe that physicians who terminate life on request or provide assistance with suicide are no longer deemed to have committed a crime, provided they have complied with the due care criteria set out in the Act and have notified the municipal pathologist of their action. Any other life-terminating procedure remains a criminal offence. The notification rules do not apply to life-terminating procedures that are not expressly requested. No separate arrangements have yet been made for the latter, and for the time being they are still governed by the 1994 notification rules, which require the municipal pathologist to refer to the public prosecutor all cases in which termination of life was not expressly requested.

In the year under review, the committees were again confronted with new issues and unusual circumstances in the cases submitted to them. There were also a number of matters that had come up in previous years but had not yet been clarified. As in previous years, the committees have used case histories to illustrate these points. Specific cases make clear how the committees work and what particular issues they had to deal with in 2003.

The committees emphasise that a number of the cases described in this report were unusual. However, the great majority of cases did not present any assessment problems. Three examples of these are given in the first section of Chapter III.

At the request of the Minister of Health, Welfare and Sport and the Minister of Justice, and in cooperation with the committees, the notification rules for euthanasia and assisted suicide were evaluated by Professors Van der Wal and Van der Maas, whose findings were published in May 2003 (see also foreword). They concluded that the 1998-2002 review procedure⁴ had achieved a number of its objectives, but not all of them. They made proposals to improve the review procedure, but saw no need for drastic changes. The committees have adopted the recommendations to make improvements by means of information, feedback to physicians about how they have complied with the due care criteria and openness about how cases are reviewed. At the same time, the committees point out that they have already paid attention to these aspects in the last few years, including in their annual reports.

⁴ The evaluation was confined to the period up to 1 April 2002, when the Termination of Life on Request and Assisted Suicide (Review Procedures) Act came into force.

Chapter I

Committee activities

The main task of the euthanasia review committees is to assess the cases that are submitted to them. In this chapter a diagram illustrates how the committees actually proceed. Their working procedures are laid down in Sections 8-13 of the Act.

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.⁵

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. In the year under review the committees drew up joint guidelines on their working procedures. These are reproduced in an annexe to this annual report (Annexe IV).

The committees assess whether the attending physician has or has not acted in accordance with the due care criteria set out in Section 2 of the Act. An exceptional ground for immunity from criminal liability is set out in Articles 293 and 294 of the Criminal Code. The physician's actions do not constitute a criminal offence 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. In other words, if a physician has complied with the due care criteria, the exceptional ground for immunity from criminal liability applies. In that case the committee's findings are final. Under the terms of Section 9, subsection 2a of the Act, the committee must forward its findings to the Board of Procurators General and the Health Care Inspectorate only if it finds that the attending physician has not complied with the due care criteria set out in Section 2 of the Act. In that case the Board of Procurators General considers whether or not to prosecute. The Health Care Inspectorate considers in the light of its own tasks and responsibilities whether any further action should be taken. This may range from interviewing the attending physician to lodging a complaint with a regional health care disciplinary board.

Diagram

- submits an immediate notification and report to

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

⁵ Since 1 January 2004 the offices of all the committees have been located on the premises of the Central Information Unit on Health Care Professions (CIBG). The offices previously based in Haarlem and Rijswijk have been located together in The Hague with effect from the same date.

- the secretary

enters relevant data in a database specially developed for the committee

prepares draft findings

sends copies of all dossiers and draft findings to the committee members

- the committee

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 municipal pathologist and if necessary to

invite the attending physician to an interview

the definitive findings are signed by the chair

the attending physician

the municipal pathologist

the regional euthanasia review committee

meets once every three to four weeks

committee's findings

due care criteria fulfilled

due care criteria not fulfilled

Board of Procurators General

attending physician

inspector

attending physician

decision not to prosecute

public prosecutor

interview

preliminary inquiry

regional disciplinary board

no further action

criminal court

Chapter II

Nationwide overview

Overview: 1 January to 31 December 2003

Notifications

In the year under review, 1,815 notifications were made to the committees.

Euthanasia/assisted suicide

There were 1,626 cases of euthanasia, 148 cases of assisted suicide and 41 cases involving a combination of the two.

Location

In 1,477 cases the life-terminating procedure took place at the patient's home, in 207 cases in a hospital, in 47 cases in a nursing home, in 41 cases in a residential care home and in 43 cases elsewhere (e.g. a hospice or at the home of relatives).

Competence and findings

In two instances the committees did not deem themselves competent to handle the case. In eight cases the committees found that the attending physician had not acted in accordance with the due care criteria.⁶

Length of assessment period

The average time that elapsed between the report being received and the committee's findings being forwarded was 29 days.⁷

Chapter III

1. Introduction to case histories

In the year under review the committees received 1,815 notifications of euthanasia or assisted suicide. In most cases the reports formed a satisfactory basis for 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 eight cases the committees found that the attending physician had not acted in accordance with the due care criteria. These cases were referred to the Board of Procurators General and the Health Care Inspectorate.⁸

⁶ It should be noted that the total number of notifications is based on notifications received in 2003. Since reported cases can be examined for a period of up to six weeks, which may be extended by a further six weeks cases reported in late 2003 were not assessed and disposed of until 2004. The committees' findings in these cases will therefore be taken into account in the next annual report. Final decisions on the eight cases referred to here (six of which were reported in 2002 and two in 2003) were reached in the course of 2003.

⁷ Under the terms of Section 9 of the Act, the committees must give the attending physician written notification of their findings not later than six weeks after the case is reported to them. This period can be extended by a further single period of six weeks. In most cases the committees manage to reach a decision within six weeks. It is only occasionally that this period has to be extended. If the committee asks the attending physician to supply further information, the period is automatically extended. The length of the assessment period will then depend to some extent on how quickly the physician responds.

⁸ Until 1 April 2002, when the Termination of Life on Request and Assisted Suicide (Review Procedures) Act came into force, a committee's findings merely constituted a strong recommendation to the Public Prosecution Service and therefore had to be

Although the due care criteria are clearly set out in the Act and the reports form a satisfactory basis for review, debatable situations do still arise in practice. The anonymous case histories in this report are intended to provide a picture of the issues the committees had to deal with during the year under review.

As already indicated, in most cases it was clear that the notifying physician had acted in accordance with the due care criteria. This is illustrated by the following three cases, which did not present any assessment problems.

Case 1

In 1996 a 56-year-old patient was diagnosed with a melanoma on his left arm. The tumour was removed by surgery. In 2003 metastases were found in the abdomen, and a gland dissection was performed. The patient was then given radiotherapy to treat vertebral metastases. Some time later, further metastases were found in his bones and liver and he was given chemotherapy. The patient became totally bedridden and dependent on care. Towards the end he was very weak and had a great deal of pain in his back and hip, despite the administration of large doses of morphine. The attending physician expected that he would die within several weeks. Some weeks before his death the patient made a request for euthanasia, and he repeated the request various times in the presence of the physician, several nurses and his relatives. He also signed an advance directive. A SCEN physician who was called in to give an independent assessment found that the pain had grown much worse in a short space of time. An increase in the morphine dosage had helped briefly, but the patient could now scarcely move. Such a situation, without any prospect of improvement, was intolerable to the patient. The independent physician discussed the possibility of further increasing the morphine dosage, but the patient wanted to remain lucid and refused. There were no alternatives left. The independent physician also found that the patient had made a voluntary, well-considered request and concluded on the basis of all this that the due care criteria had been fulfilled. The attending physician administered one gram of pentothal and twenty milligrams of Pavulon intravenously. The committee found that the attending physician had acted in accordance with the due care criteria.

Case 2

A 63-year-old patient had been suffering from multiple sclerosis (MS) for over twenty years. He was receiving medication and had been admitted to a nursing home some years previously. By now he could only move his mouth and eyes. He also had increasing difficulty in breathing and was afraid of death through suffocation. The patient had always tried to do as much as possible himself, but had eventually become totally dependent on the care of others. He perceived this physical deterioration as an intolerable loss of dignity. He had set himself a limit at an earlier stage, indicating that he did not wish to live any longer if he reached the point where he was completely dependent on others. That point had now been reached. Given the rapid progression of his condition, the attending physician felt that the patient was likely to die within a year. However, the physician could not rule out the possibility that the patient might remain alive for several more years.

forwarded in writing to the Board of Procurators General and the Health Care Inspectorate. Under the terms of the Act, however, a committee's findings are final and it can close the case on its own initiative. Only in cases where the committee finds that the attending physician has not acted in accordance with the due care criteria are its findings forwarded to the Board of Procurators General and the Health Care Inspectorate (Section 9, subsection 2 of the Act).

A year earlier the patient had discussed the possibility of euthanasia with his general practitioner, and the subject had since been raised repeatedly. His family were initially opposed to euthanasia, but eventually agreed that his wishes should be complied with. The independent physician stated in his report that the patient was completely paralysed and totally dependent on others. The patient also made it quite clear to the independent physician that the suffering caused by his total dependence on others was intolerable to him. The independent physician found that the patient was capable of giving informed consent, that there were no signs of depression and that the request had been voluntary and well-considered. The due care criteria had been fulfilled.

This was a case of assisted suicide. With the attending physician's assistance, the patient ingested a potion containing nine grams of pentobarbital in solution. His relatives were present. The committee found that the attending physician had acted in accordance with the due care criteria.

2. Powers of the committees

The committees have powers to act in cases where life has been terminated by a physician on request. They therefore only assess cases in which there has been an express request for termination of life or assisted suicide. In cases where such a request has not been made, they have no power to act and the rules governing unrequested termination of life must be followed, i.e. the municipal pathologist must refer the case directly to the public prosecutor.

The notification rules for termination of life on request do not apply to newborn babies or children under the age of twelve. Special provisions concerning consent by parents or guardians in the case of minors aged (a) twelve to fifteen and (b) sixteen or seventeen who request euthanasia or assisted suicide are laid down in Section 2, subsections 4 and 5 of the Act. In the year under review the committees did not in fact receive any notifications of this kind. Section 2, subsection 2 of the Act also prescribes that a physician may comply with a request for termination of life contained in an advance directive written 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. An advance directive 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

The Act does not cover what is known as 'normal medical procedure'. This refers to decisions to cease, or not to commence, treatment if it is medically futile or if the patient has expressly requested this. Normal medical procedure also includes intensive pain and symptom control measures whose unintended side effect may be the death of the patient.

Terminal sedation

Medication (usually in the form of benzodiazepines) can be used to reduce the patient's consciousness so that he is maintained in a deep sleep, as it were, and is no longer aware of his surroundings or his suffering. 'Terminal sedation' involves sedating the patient in conjunction with a decision not to administer fluids or food artificially. This type of sedation at the end of life, when it is clear that the patient will die in the near future, is currently the subject of much debate.

In his inaugural speech Professor J.J.M. van Delden⁹ called ‘terminal sedation’ a confusing term. On the one hand it is normal medical procedure, but on the other it has also been referred to as ‘crypto-euthanasia’. Van Delden distinguishes here between three different situations.

In the first situation, a patient who is expected to live a few days at most is sedated to counteract the extreme restlessness that can arise in that situation. As a result, the patient dies peacefully and the sedation probably has very little influence on the time of death. In the second situation, a patient who is suffering greatly but whose death is not imminent is sedated and the decision is taken not to administer fluids or food artificially. As a result, the terminal sedation may have a life-shortening effect. In this situation, however, it is not the physician’s intention to hasten or bring about death. In the third situation, terminal sedation is seen as a means of hastening death, whether or not at the patient’s request.

Both the first and second situations involve normal medical procedure. In the second situation, however, the decision to resort to terminal sedation must be in keeping with the gravity of the situation. In both cases either the patient or his representative must have given consent. According to Van Delden, the third situation actually involves termination of life rather than normal medical procedure.

A number of cases reported to the committees reveal that physicians sometimes see terminal sedation as an alternative to euthanasia or assisted suicide. One reason for this may be that death by terminal sedation seems more natural than death by euthanasia. However, even if the patient opts for terminal sedation (to bring about or hasten death), it is still a form of termination of life on request. Accordingly, any case in which terminal sedation is used by a physician with the intention of shortening life (at the patient’s request) must be reported to the review committee.¹⁰

Suffering that is primarily mental

In the year under review one committee received notification that the life of a patient with a psychiatric disorder had been terminated. In the past – under the previous legal arrangements – the committee would declare itself incompetent to act in such cases, since procedures to terminate the lives of patients whose suffering was primarily mental were not covered by the notification rules for termination of life on request or assisted suicide.¹¹ However, the Act no longer includes this restriction, and the committees therefore consider they are now competent to assess matters such as these, since further substantive investigations are needed to determine whether a patient is capable of giving informed consent. This means that a committee receiving notification that the life of a patient whose suffering as a result of a mental or psychiatric condition has been terminated on request will

⁹ J.J.M. van Delden in *Medicine-based ethics*, inaugural lecture on taking up his appointment as professor of medical ethics in the Medical Faculty of the University of Utrecht on September 2003, University of Utrecht, November 2003, pp. 15-17.

¹⁰ See also the aforementioned evaluation report *Medische besluitvorming aan het einde van het leven: de praktijk en de toetsingsprocedure euthanasie*, Amsterdam/Rotterdam, 2003, p. 197, which states that the statutory review procedure for termination of life on request is applicable in a number of cases, but that these represent a small proportion of the total. The Minister of Justice and the State Secretary for Health, Welfare and Sport have agreed to discuss the question of terminal sedation in their statement on the evaluation (Appendix to Proceedings, House of Representatives, 2002/2003, Nos. 1749 and 1572).

¹¹ The Explanatory Notes to the Regional Euthanasia Review Committees Order, which ceased to have effect on 1 April 2002, stated explicitly (with reference to Section 9 of the Order) that termination of the life of a patient whose suffering was primarily mental must be reported in accordance with the procedure governing unrequested termination of life. Under the terms of the repealed Order this also applied to patients who were suffering from a somatic condition but whose judgement could have been impaired as a result of, for example, depression or developing dementia.

declare itself competent to investigate whether the patient was capable of giving informed consent, in connection with the statutory due care criterion that the request must be voluntary and well-considered. If the investigation reveals that the patient was incapable or insufficiently capable of giving informed consent, the committee must conclude that the attending physician has failed to meet one of the criteria and hence has not acted in accordance with them. Accordingly, the committees still take the view that the incorrect first sentence of the note accompanying Question 11a of the standard report¹² – which in practice leads to misunderstandings – should be deleted.

Case 3

The notification concerned termination on request of the life of a patient with an evident psychiatric mood disorder and borderline personality disorder,¹³ which were confirmed by several consultants, so that the medical context was not in doubt.

In between periods of depression and panic attacks, the patient functioned only marginally. During those periods he forcefully and persistently expressed a wish to die. From the moment the attending physician became his general practitioner, the patient discussed with the physician the possibility of terminating his life. He had drawn up and signed an advance directive addressed to the attending physician, in which he described his situation in detail and requested that his life be terminated.

In the years that he had been the patient's general practitioner, the physician had come to accept and respect his wish and had eventually become convinced that the patient's suffering was intolerable. Talks with close friends of the patient's strengthened this conviction. He described this as a personal quest that he had undertaken with his patient, culminating in the provision of assistance in response to his patient's very insistent wish to be allowed to die. The independent physician – a psychiatrist – visited the patient several times. He concluded that the patient was capable of informed consent and that he was well aware and properly informed of his condition. Given the seriousness of the patient's psychiatric condition, his permanent invalidity and the likelihood of further deterioration, the independent physician could sympathise with the patient's perception that his suffering was intolerable. In the physician's opinion the due care criteria had been satisfied. In this case the committee found that the attending physician had acted in accordance with the due care criteria.

3. Due care criteria

Voluntary and well-considered request

Termination of life or assisted suicide must always have been expressly requested by the patient. The request for termination of life must have been voluntary and well-considered, otherwise the criterion that the attending physician must be satisfied that there was a voluntary, well-considered request (Section 2, subsection 1a of the Act) has not been fulfilled. The request must have been made by the patient personally and voluntarily. It must, for example, be clear that the request was not made under

¹² The sentence reads: 'A procedure to terminate the life of a patient whose suffering is mental and cannot be placed in a medical context, or whose ability to make a well-considered request may have been impaired as a result of, for example, depression or dementia must be reported in accordance with the rules governing life-terminating procedures that have not been expressly requested.'

¹³ A dysthymic mood disorder (DSM-IV classification 300.4) and a borderline personality disorder (DSM-IV classification 301.83).

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 relatives appears to have been a factor in the decision.

Case 4

In 2002 the patient, a 41-year-old woman, was found to have a large ulcerating carcinoma of the left breast with extensive skeletal and axillary metastases, for which she was treated with Zoladex, APD infusions and radiotherapy. A large brain metastasis was diagnosed about a year later. There was no longer any prospect of recovery. The patient became paraplegic, as a result of which she suffered from urine retention and had problems with defecation. She became totally bedridden and ADL-dependent. In March 2003 she made her first specific request to the attending physician that her life be terminated. A month later the physician performed euthanasia.

When this case was reviewed by the committee, various questions arose as to the procedure followed in connection with the termination of the patient's life. Since the notification details were not sufficiently clear on this point, the committee invited the attending physician to an interview. The physician had known the patient since early 2002, when her breast tumour was diagnosed. He noticed that the patient – who was very clear about what she wanted – displayed a particular pattern of response to his proposals for treatment. After the brain metastasis was discovered the physician visited the patient weekly to discuss the following week's treatment, which the patient sometimes agreed to but sometimes refused. The physician was frequently phoned the next day by the district nurse to say that the patient no longer wanted what she had told him earlier that week. The same thing happened shortly before her life was terminated. The physician visited her the day before leaving for a week's holiday. At that point the patient made no specific request for euthanasia, but over the weekend she asked the locum tenens to perform it. He felt cornered by the patient and her parents, and declined to terminate her life. He then notified the attending physician at his holiday address and, in consultation with the attending physician, called in an independent physician. When the latter visited the patient, she concluded that the patient's request had been voluntary and well-considered and that her suffering was intolerable, without prospect of improvement. When the attending physician returned from holiday, it became quite clear to him that the patient's suffering was intolerable. The main cause of her suffering was loss of control. She had spoken to the attending physician about euthanasia on several occasions and had made it clear during those conversations that losing control and autonomy was the end as far as she was concerned. During her illness she did not perceive her intense pain, dependence or countless disabilities as intolerable, but on various occasions she indicated that loss of autonomy was intolerable to her. According to the physician there had been some pressure from her parents, but in his opinion this did not interfere with the decision-making process. He sympathised with the parents, who had been on bad terms with their daughter for years but were now making every effort to have her wishes met, including her wish for euthanasia. The committee found that the attending physician had acted in accordance with the due care criteria.

In most cases an advance directive signed by the patient is evidence that the request is the patient's own. Although an advance directive is desirable, since it gives additional support to the patient's orally expressed wish for euthanasia, it is not mandatory. In some cases the attending physician or the independent physician has the patient sign such a directive just before the euthanasia is performed. 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 file. In general, physicians who are discussing euthanasia with their patients are advised to encourage them to draw up an advance directive in good time.

In some cases the existence of an advance directive is of decisive importance, for instance with Alzheimer patients. Under Section 2, subsection 2 of the Act, if a patient who is no longer capable of expressing his wishes drew up while he was still so capable a written directive requesting that his life be terminated, the attending physician may comply with that request (see Section 2 of this report). In determining whether the request was voluntary and well-considered, the committees assess whether the directive applies to the patient's present situation and whether the situation also satisfies the other due care criteria – none of which are easy matters. The more specific the advance directive, the firmer the basis for the attending physician's decision and the assessment by the committee. It is therefore important for attending physicians and patients to discuss the content and implications of such directives in good time.

The request must also be well-considered and the patient must be aware of its implications. Here the committees look at possible inhibiting factors such as depression or other disorders of the patient's cognitive or expressive faculties. The presence of such factors may make the request less valid, but need not necessarily do so. A request made in a moment of lucidity may be well-considered. A distinction must also 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 well-considered.

In order to reach a well-considered decision, the patient must also have a clear idea of his illness, the situation he is in, the prognosis and any alternatives. In assessing this, 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. In order to assess this properly, the physician must keep a good record of these conversations and attach the relevant documents to his report.

Intolerable 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's suffering is intolerable, with no prospect of improvement (Section 2, subsection 2b of the Act).

The fact that there is no prospect of improvement must be determined in the light of current medical knowledge. From a medical point of view, this can be determined fairly objectively. There is no prospect that things will get better. On the other hand, it is much more difficult to determine whether suffering is intolerable. This is one of the greatest dilemmas in the practice and assessment of euthanasia. Factors such as pain, nausea, exhaustion and shortness of breath greatly contribute to the intolerability of suffering. In the vast majority of cases that come before the committees, there is intolerable suffering due to untreatable, malignant processes. The concept of 'intolerable suffering' is also, in principle, assumed to be subjective. This means that the intolerability of the suffering is partly determined by the patient's outlook, personality and views on the matter. Terms such as 'increasing humiliation and dependency' or 'loss of dignity' are thus often used to describe the intolerability of suffering, yet perceptions of this differ from patient to patient. Although such subjective factors may play a part in the case of patients with incurable cancer, they are more frequent in the case of patients with diseases such as multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), Parkinson's disease, chronic obstructive pulmonary disease (COPD) and other ultimately fatal diseases that leave patients totally dependent and bedridden or at risk of death by suffocation. In patients with conditions that are not immediately fatal – such as paraplegia or cerebrovascular accident (CVA) – but can place the patient in a situation without prospect of improvement, these factors also play an important part in determining whether suffering is intolerable.

In general, the intolerability of suffering must be capable of being objectivised to the point where an attending physician with normal empathic ability – and hence the committee – can empathise with it.¹⁴ The following case history is one in which the committee found that the attending physician could not reasonably have concluded that there was intolerable suffering.

Case 5

After battling for years with cancer elsewhere in his body (from which he had recovered), the patient was diagnosed with an inoperable brain tumour. As a result of radiotherapy he developed a slowly progressing degenerative brain condition (post-radiation encephalopathy) which led to loss of hearing, epileptic seizures and paralysis of the left-hand side of his body. A fall during a seizure caused fractures of the vertebrae and ribs. He was also found to have motor function disorders in his right hand. The patient eventually became confined to a wheelchair and totally ADL-dependent. His care was very well organised. He resolutely refused admission to a nursing home. The attending physician indicated that he could not easily estimate how long the patient was likely to live, but that he thought it would be a matter of years rather than months. The physician had consulted the district nurse, who had at first found it hard to accept the patient's request but later was in complete sympathy with it. To determine whether the patient's request was the result of depression, and because he initially had doubts as to whether his suffering was intolerable, the physician first consulted an independent psychiatrist. The psychiatrist concluded that there was no clear evidence of depression or any other psychiatric disorder. However, the psychiatrist did report problems in the relationship between the patient and his partner which might be influencing the situation. The patient told the independent physician (a SCEN physician) that he was suffering from increasing tiredness and that he had to spend much of the afternoon in bed. Recently he had no longer been able to read, which he greatly missed. He also indicated that he was falling more and more often and needed more and more care. He was tired of struggling and constantly having to adapt to increasing disability. He could no longer see any prospects or scope for improvement and found this situation intolerable. The independent physician could empathise with this. After the independent physician had made a positive recommendation, the patient felt at peace. In the period that followed the patient made a number of arrangements for the funeral and for taking leave of friends and relatives, and he went on a holiday specially organised for people who were ill.

In view of the medical diagnosis and prognosis, the findings of the psychiatrist and the independent physician and the long period that had elapsed between the independent assessment and the performance of the euthanasia, the committee decided to ask the attending physician and the independent physician (a SCEN physician) to provide further particulars in an interview. When asked by the committee how long he thought the patient was likely to live, the attending physician said ten to twenty years, depending on possible infections and the progress of the epilepsy. The physician also said that at first he had had doubts about the patient's request and had felt that the patient was putting him under pressure. Eventually he had come to empathise with the patient's suffering in the light of his overall case history. According to the physician there was no prospect of improvement in treatment and care and the patient's suffering would become increasingly severe. He said that the problems in the relationship between the patient and his partner had had little influence on the decision. Since the situation had not changed in six months, the attending physician saw no need for the independent physician to visit the patient and speak to him personally a second time. When interviewed by the

¹⁴ See also G.A.M. Widdershoven "De werkwijze en de ervaringen van de toetsingscommissies", in J. Legemaate and R.J.M. Dillmann (eds), *Levensbeëindigend handelen door een arts op verzoek van de patiënt*, Houten/Antwerp, Bohn Stafleu Van Loghum, p. 55.

committee, the independent physician commented that with hindsight – in view of the long time that had elapsed since his first assessment – it would have been wiser and more thorough to carry out a second assessment by telephone. Instead, he had based his decision on what the attending physician had told him over the phone. The committee found that, in view of the medical diagnosis and prognosis, the attending physician’s estimate of how long the patient was likely to live and that fact that there had been no significant deterioration in the patient’s medical situation in the six months following the independent assessment, the attending physician could not reasonably have concluded that the patient was suffering intolerably, without prospect of improvement. With regard to the independent assessment, the committee found that, in view of the long period that had elapsed since the first assessment and the patient’s unusual circumstances, a second assessment based on a visit to the patient by the independent physician would have been necessary in order to determine whether the statutory due care criteria had been fulfilled. The committee concluded that the attending physician had not acted in accordance with the due care criteria. Both the Board of Procurators-General and the Health Care Inspectorate held investigations. After an interview with the attending physician the Health Care Inspectorate ended its investigation. The Board of Procurators-General initiated a preliminary inquiry.

Comatose patients

In the year under review the committees again had to deal with several notifications of termination of life at the request of patients who were no longer able to communicate by the time the life-terminating procedure took place. The patients had – often abruptly – lost consciousness just beforehand, for example after a heart attack or an increased dose of medication (morphine).

Although physicians in general are of the opinion that deeply comatose or comatose patients cannot suffer intolerably, if at all, 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. This is the case when a patient is in a near-coma and displays outward signs of suffering, such as groaning, fluttering eyelids or – as in the following case – acute shortness of breath. At the same time, there is still considerable medicoethical debate as to whether complete humiliation and loss of dignity are relevant factors in assessing whether a comatose patient’s suffering is intolerable.

In general, however, the committees feel that physicians should exercise extreme restraint in such situations, even if they have already promised the patient to cooperate in performing euthanasia and the change in the situation was unexpected. It is therefore advisable for physicians to avoid making unqualified promises, as it is often possible to wait and let nature take its course. Providing the patient and his relatives with timely information and reaching clear agreements may prevent stalemate situations from arising.¹⁵

In the following case the patient had already indicated orally and in writing, before becoming comatose, that she wanted euthanasia if ever she went into a coma. Although in such a situation the patient’s wishes play an important part in the decision whether or not to perform euthanasia, the Act also stipulates that the patient must be suffering intolerably.

Case 6

¹⁵ See also E. Hendriksen “Euthanasie bij comapatiënten. Consensus over hoe te handelen ontbreekt nog”, in *Medisch Contact*, 26 December 2003, No. 52, p. 2050.

A 71-year-old patient had suffered numerous cerebrovascular accidents in the past, and had been suffering for years from the lung condition known as chronic obstructive pulmonary disease (COPD). She had indicated on several occasions that this was the end as far as she was concerned. She had therefore requested euthanasia, and had had her request recorded in a notarised written statement. The patient eventually had a major heart attack and went into a coma. She was no longer conscious when euthanasia was performed. In this case the committee wondered if the patient could be deemed to be suffering intolerably now that she was no longer conscious. The question of whether she had made an express, well-considered request also came up. The documentation also indicated that, although the attending physician had consulted another physician, the latter had not visited the patient because she was comatose. The question arose whether the attending physician could not have consulted an independent physician at an earlier stage. The committee asked the attending physician to provide a written explanation.

The attending physician replied that the patient's situation had suddenly deteriorated. She had already been dying for some days. Her irregular breathing changed from Cheyne-Stokes respiration to gasping respiration which left her seriously short of breath. With regard to the request, the patient had asked the physician before becoming comatose to perform euthanasia if ever she contracted a serious disease or went into a coma. At first the physician and the patient's relatives thought that, given her condition, she would rapidly die a natural death. However, when after a few days she was still alive and visibly short of breath, the physician decided in consultation with her relatives to perform euthanasia after all. When asked whether the independent physician could not have been called in earlier, the attending physician replied that this had not been necessary until after the patient had gone into a coma. Before that there had been no need to respond to her request.

One of the things the committee took into account in this case was the general assumption that comatose patients cannot suffer intolerably. This patient, however, was seriously short of breath despite her comatose state and was clearly suffering as a result. In view of this the committee found that the attending physician could well have concluded that the patient was suffering intolerably, without prospect of improvement. A contributing factor was the patient's indication to the physician in a written statement (in this case a notarised document) as well as orally that she would perceive herself to be suffering intolerably if she went into a coma. With regard to the independent assessment, the committee concluded that, in these highly unusual circumstances, a personal visit by the independent physician would no longer have served any purpose and that, despite the absence of such a visit, the independent assessment criterion had been satisfied. The committee found that the attending physician had acted in accordance with the due care criteria.

(c) Informing the patient

The committees also examine the way in which the attending physician informed the patient about his illness and prospects. Unlike in the previous legislation, this is specifically included as a due care criterion in the Act (Section 2, subsection 1c). In order to make a well-considered request, the patient must have a clear picture of his illness, the diagnoses and prognoses and possible forms of treatment. The attending physician must ensure that the patient is sufficiently informed regarding these matters. If there is any uncertainty on this point, the committees ask questions about it.

(d) No reasonable alternatives

The attending physician must also discuss with the patient what alternative forms of treatment are still available to relieve his suffering (Section 2, subsection 1d of the Act). This due care criterion reflects (a) the notion that the decision is a matter for the physician and the patient jointly and (b) the fact that the patient must clearly have no alternative and that euthanasia is the only solution left.¹⁶

An important factor here is good palliative care, since care and treatment of the patient and limiting and, if possible, eliminating suffering have priority. However, this does not mean that palliative treatment must always be attempted. There may be good reasons to refrain from treatment. Some forms of palliative treatment may have distressing side effects. For example, a patient may refuse an increased dose of morphine because this may cause drowsiness or even 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.¹⁷ However, patients sometimes refuse palliative treatment that at first sight does not seem particularly distressing and hence may 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 attending physician should explain clearly in his report why any other alternatives were unreasonable from the patient's point of view.

(e) Independent assessment

Not only the attending physician but also a second, independent physician must see the patient and provide a written assessment of whether the statutory due care criteria have been complied with (Section 2, subsection 1e of the Act). The independent physician must therefore give an independent expert opinion on whether the patient's suffering is intolerable, with no prospect of improvement, including whether there are any alternative ways of relieving the suffering, and whether the request for termination of life or assisted suicide is voluntary and well-considered. This means that the independent physician must be independent of the patient, which in turn means that he must not be helping to treat the patient or be in a family relationship to him, and also in principle that he must not know the patient as a locum tenens. 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. In Section 9 of the Guidelines the committees have indicated how doubts about the independent physician's independence are dealt with. This procedure was adopted in the following case.

Case 7

A 77-year-old patient had metastasised cancer of the colon, for which he underwent surgery and was given chemotherapy. He later developed carcinomatous pleuritis, for which he underwent pleurodesis. There was no longer any prospect of recovery. The patient found his increasing pain (despite

¹⁶ See also the explanatory memorandum to the Termination of Life on Request and Assisted Suicide (Review Procedures) Bill, Parliamentary Papers, House of Representatives 1998-1999, 26 691, No. 3. Although the decision is a matter for the attending physician and the patient jointly, the performance of euthanasia or provision of assistance with suicide is the physician's own decision and sole responsibility.

¹⁷ See also G.A.M. Widdershoven "De werkwijze en de ervaringen van de toetsingscommissies", in J. Legemaate and R.J.M. Dillmann (eds), *Levensbeëindigend handelen door een arts op verzoek van de patiënt*, Houten/Antwerp, Bohn Stafleu Van Loghum, pp. 51-52.

appropriate medication) and shortness of breath so intolerable that he requested his attending physician to perform euthanasia on several occasions.

A physician who subsequently turned out to know the patient was asked to act as independent physician. He had been the patient's general practitioner ten years earlier, when they had both been living in a different locality. The committee obtained further information about this from the attending physician and the independent physician, to determine whether the latter was sufficiently independent with regard to the patient. When it became clear that the independent physician had not seen or been in contact with the patient and his family in the intervening ten years, the committee concluded that there had been an independent assessment in accordance with the statutory due care criteria. The committee found that the attending physician had acted in accordance with the criteria.

Reporting by the independent physician

The Act prescribes that the independent physician must see the patient personally and record his findings in writing. In the absence of an independent assessment, the physician performing euthanasia is deemed not to have complied with the due care criteria. Physicians who perform euthanasia are therefore advised to make sure that the independent assessment is correctly carried out and recorded in writing. 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 independent assessment requirement had not been complied with and the review committee therefore found that the attending physician had not acted in accordance with the due care criteria. An example is provided in the following case history.

Case 8

The patient, an 81-year-old woman, was diagnosed with ovarian cancer during a stay in hospital. In view of her age and poor physical condition, surgery or chemotherapy were no longer reasonable options. The patient was suffering as a result of her rapid deterioration and intense pain. She had lost two daughters to breast cancer and felt they had both died horrible deaths. She indicated that she did not want to die in the same unpleasant manner. In early April 2003 she made her first specific request to her attending physician to perform euthanasia, and he did so five days later. The documents submitted to the committee included an undated written report by the independent physician. In his standard report the attending physician stated that he did not know when the independent physician had seen the patient. In order to obtain a clear picture of how the life-terminating procedure had been carried out, the committee invited the attending physician to an interview. He said that, on admission to hospital, the patient was found to have a large tumorous mass in her abdomen, with no prospect of recovery. According to the physician, the patient was suffering as a result of her rapid deterioration, and there were no longer any alternative ways of relieving her suffering. On the Thursday the attending physician spoke to the patient and her husband at length about euthanasia, and during that conversation the patient specifically asked the physician to terminate her life. The physician visited her once more at the hospital during the weekend, and during that visit she confirmed her wish to have her life terminated. When the physician saw her again after the weekend, her condition had greatly deteriorated. She was in great pain despite being given morphine by pump, and again asked the physician to perform euthanasia. He told her that the rules required her to be seen by a second physician. He then got in touch with a fellow internist by telephone and asked him if he could agree to euthanasia. The attending physician reviewed the medical details with the independent physician to the extent necessary. The independent physician had never treated the patient but was familiar with

her file, as she had consulted colleagues in his department. According to the attending physician, the independent physician agreed to euthanasia while they were still on the phone. The attending physician said he had asked the independent physician to go and see the patient. When the attending physician visited the patient at 3 p.m. to perform euthanasia, it turned out that the independent physician had not yet seen her. Despite this, the attending physician proceeded with euthanasia. When asked by the committee whether the patient's situation at the time euthanasia was performed had been so acute that he could no longer wait, he replied that he could theoretically have waited another day. He did not feel pressured by her or her relatives. Over the weekend he decided for himself that he would consent to her request. When she persisted with her request for euthanasia after the weekend, he had considered this so realistic and understandable that he wanted to carry it out.

The committee found that the independent assessment criterion had not been complied with and hence that the attending physician had failed to act in accordance with the due care criteria. Both the Board of Procurators-General and the Health Care Inspectorate investigated the case. The Inspectorate interviewed the physician and took steps to prevent any future recurrence. The Board of Procurators-General decided not to prosecute unless the physician again failed to act in accordance with good medical practice in any future case of termination of life on request.

No independent assessment

It is only in highly exceptional circumstances – namely an acute emergency – that independent assessment can be omitted. To prevent this happening, it is important to ensure that the independent assessment is carried out in good time, especially in cases where complications such as brain metastases or side effects due to increased analgesic dosage may occur. These may impede communication with the patient so that it is no longer indisputably clear what his wishes are.

However, an assessment carried out in good time may make a second visit by the independent physician necessary, particularly if the patient's suffering was not yet intolerable at the time of the first assessment. In that case the independent physician draws up two reports. Here it is important to evaluate the intolerability of the patient's suffering during the second visit, i.e. to determine whether the circumstances which were foreseeable at the time of the first visit have now actually arisen. There are also cases in which the patient makes a request regarding a situation that has not yet arisen at the time of the independent physician's visit. In such cases the independent assessment is still carried out, because the patient wants to know whether his request can be granted in the (often near) future. A second assessment is also required in such cases.

Capacity of the independent physician

In practically all the cases submitted to the committees, the independent physician was a fellow medical practitioner. General practitioners almost always asked another general practitioner – often a SCEN physician – to perform this service, and specialists usually asked one or more fellow specialists working at the same hospital. In some cases a psychiatrist or psychologist was also called in to determine whether the patient was capable of informed consent or was possibly suffering from a mental or psychiatric disorder. In one or two cases a psychiatrist was the only person asked to make an independent assessment. In general, the committees do not consider this such a desirable option, since the independent physician must assess not only whether the request was voluntary and well-considered but also whether the patient is suffering intolerably, without prospect of improvement.

(f) Performance of euthanasia in accordance with good medical practice

In general, the requirement that the termination of life on request or assisted suicide must be performed in accordance with good medical practice 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, in most cases intravenously. Usually 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.¹⁸ Although the physician does not actually administer the euthanatics, but only supplies them, he must remain present while they are ingested. He must not leave the patient alone with the euthanatics. As the following case makes clear, some physicians are not sufficiently aware that in cases of assisted suicide the physician must remain in the patient's immediate vicinity while the potion is being ingested. This is because the patient occasionally vomits up the potion and the physician must then intervene actively after all. Furthermore, leaving such dangerous substances without medical supervision may pose a hazard to people other than the patient.

Case 9

A 78-year-old patient was diagnosed with a melanoma in his left eye, and three years later was also found to have lung, bone and brain metastases. There was no longer any prospect of recovery. The patient, a retired internist, refused chemotherapy in the light of his own professional knowledge and experience, but was given palliative radiotherapy as well as morphine and Dexamethasone. Despite this, he continued to suffer pain and nausea (with vomiting) and became increasingly bedridden and dependent. There was also a serious risk of paraplegia. The patient had repeatedly asked his attending physician to help him commit suicide. The independent physician who visited the patient concluded that all the due care criteria had been complied with.

The day before the patient died, the attending physician supplied the euthanatic to him and it was agreed that the patient would ingest it in the late afternoon or early evening of the next day. The physician would pay a visit late the next evening either to determine that the patient had died or to terminate the patient's life by intravenous administration of a euthanatic. The physician was available on his mobile phone the whole of that day and evening. The municipal pathologist was notified in advance of the patient's likely death. The committee found that the way in which the assisted suicide had taken place did not comply with the requirements laid down by the medical profession, and concluded that the life-terminating procedure had not been carried out in accordance with good medical practice. The committee concluded that the physician had not complied with the due care criteria, and forwarded this finding to the Board of Procurators-General and the Health Care Inspectorate. The Board of Procurators-General decided not to prosecute, and the Health Care Inspectorate interviewed the physician about what had taken place.

4. Reporting

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 an assessment report by the independent

¹⁸ Usually a 100-millilitre potion containing 9 grams of pentobarbital sodium or secobarbital sodium.

physician are sufficient, and no further written or oral information needs to be obtained from the attending physician, the independent physician or any other care provider.

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

The committees observed that reporting by attending physicians once again generally improved in the year under review. Information and feedback from the committees have ensured that physicians are increasingly well 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. In some cases the committees come across outdated forms in which the questions have not been adapted to take account of the new Act, so that essential information is missing. In such cases the attending physician is again often asked 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 be personally satisfied that the request was voluntary and well-considered and that the patient is suffering intolerably, without prospect of improvement. He must also indicate his relationship to the patient and the notifying physician. The committees have observed that some assessment reports are still extremely brief, especially ones from hospitals. In such cases the independent physician was asked to submit a more detailed report, either on the occasion in question or in future.

5. SCEN project

The Euthanasia in the Netherlands Support and Assessment project (SCEN), which now operates nationwide, trains physicians to make independent assessments in cases of euthanasia. So far practically all the trainees have been general practitioners. The course covers every aspect of independent assessment (medical, ethical and legal) in detail. 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 again noted improvements in the quality of both independent assessment and reporting as a result of this project.

The committees regret the fact that in late 2003 the continuation of the project was threatened by a deadlock between the Ministry of Health, Welfare and Sport and the Royal Dutch Medical Association concerning the provision of a grant for the project and the amount of SCEN physicians' fees.¹⁹

The committees have observed that the quality of independent assessment reports has greatly increased since the introduction and extension of the SCEN project. However, reporting by medical specialists is still in need of improvement. The committees are therefore very much in favour of the project being continued and extended to hospitals, since it greatly contributes to the quality of due care in cases of euthanasia and assisted suicide.

¹⁹ As this annual report went to press it was announced that the SCEN project will be continued and extended to hospitals and nursing homes.