**Regional euthanasia review committees: 2009 annual report**

**Contents**

**Foreword**

This is the 2009 annual report of the five regional euthanasia review committees. In our annual reports we account for the way in which we review cases on the basis of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

The number of notifications received under the Act has risen sharply again, from 2,331 in 2008 to 2,636 in 2009, an increase of just over 13%. Since 2006 the number of notifications has risen by a steady 10% or more a year. This trend has a number of implications.

Firstly, the five regional review committees and their secretariats have now reached the limits of their capacity. The secretaries are overburdened and, despite working at maximum efficiency, are now forced to focus on their core task – supporting the committees in reviewing notified cases of termination of life – with the result that other tasks are not performed. The online anonymised publication of our findings on www.euthanasiecommissie.nl has for example fallen behind schedule. This is a regrettable situation. The Act cannot properly serve its purpose if the manner of review is not as widely known as possible, first and foremost to physicians and health lawyers, but also to all other stakeholders. The committees are therefore very keen to account publicly for their work. We do this mainly through our annual report, by publishing (in principle) all findings on the website and by giving lectures, participating in debates or attending meetings organised for SCEN doctors and other members of the medical profession.

Senior management at the Ministry of Health, Welfare and Sport have acknowledged that this problem can be addressed only by taking on more staff, the go-ahead for which was given in March 2010. Aware that any increase in the number of ‘civil servants’ is far from popular in this day and age, we appreciate the Ministry’s gesture all the more.

Every year, the question of why the number of notifications is on the increase arises. It is not possible to pinpoint exact causes. I considered the matter in the preface to the 2008 annual report. We had commissioned a quick scan of the possible causes, which found that though likely explanations can be suggested (such as a growing willingness to

notify), more in-depth research would be needed to determine precisely what is happening.

We are therefore pleased that former State Secretary Jet Bussemaker has decided to commission a thorough evaluation of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act in 2010, similar to that commissioned in 2005. The evaluation will include research into the number of cases of termination of life on request or assisted suicide, and the causes of the increase. The caretaker status of the government has fortunately had no impact on the study, although any policy implications cannot of course be dealt with until a new government has taken office.

In nine cases (out of the 2,636) the committee found that the physician had not acted with due care. Anonymised versions of the relevant passages from the assessments have been reproduced in this report. As in previous annual reports, we also consider euthanasia in special cases, such as dementia. We also focus more attention on how physicians actually perform the procedure of terminating a patient's life.

The committees are always pleased to receive feedback.

J.J.H. Suyver
Coordinating chair of the regional euthanasia review committees

The Hague
May 2010

## Chapter I Developments in 2009

**The following developments took place in 2009.**

*Notifications*

In 2009, the regional euthanasia review committees ('the committees') received 2,636 notifications of termination of life on request or assisted suicide. The 2008 figure had been 2,331; there was thus a 13.1% increase. The Termination of Life on Request and Assisted Suicide (Review Procedures) Act ('the Act') will be evaluated again in 2010; the evaluation will investigate the sharp rise in notifications. In each case the committees examined whether the physician who had performed the procedure had acted in accordance with the due care criteria set out in the Act. In nine cases the committees found that the physician had not acted in accordance with the Act. The most relevant elements of these findings are described in Chapter II (Due care criteria: specific) as cases under the criterion concerned. The actual findings (as well as all the findings in which the committees concluded that the physician had acted in accordance with the due care criteria) are published in full on the committees' website www.euthanasiecommissie.nl. Only findings whose publication might jeopardise the patient's anonymity are withheld. Unfortunately, since the increase in the number of notifications over the past few years has not been matched by a similar increase in the number of staff working for the committees, they have been unable to process any findings for publication. Consequently, none have been published.

*Due medical care*

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

The Pharmacy Research Institute (WINAp), which is linked to the KNMP, confirms that the Association makes a distinction between first-choice and second-choice coma-inducing substances. The second-choice substances are listed in the *Standaard*

*Euthanatica* under ‘Emergency solutions’. These are substances with which physicians have less experience (on which there is less evidence), but which can be used as alternatives to first-choice substances if necessary. The guidelines also list substances that are not alternatives to first-choice substances and substances that the Association specifically advises against.

If a physician does not use a first-choice substance, the committees will ask further questions. When assessing whether the due medical care criterion has been complied with, the basic principle is that emergency solutions (second-choice substances) are permitted if the physician provides sufficient grounds for having used them. The committees will therefore ask further questions if the physician fails to cite such grounds or uses substances that are not listed as alternatives or should not be used at all. If the dosage is not specified, the committees will also ask about it. If the dosage is not in accordance with the recommendations, the physician will be asked to explain why. If the method of administration is not indicated, the committees will also enquire about this.

In 2009, the committees again came across the use of substances that are not listed as first-choice substances, and notifications in which the dosage was not specified or was not in accordance with the KNMP’s recommendations. However, overall the committees concluded that in 2009 use in compliance with the *Standaard Euthanatica* had increased considerably among the notifying physicians. This appears to be partly the result of an article on the matter published in the journal *Medisch Contact*, November 2008, no. 4. Nevertheless, the committees again concluded in four cases in the year under review, on the basis of the dosage of euthanatics administered, that the physician had not complied with the due medical care criterion.

In 2009, notification was also received of a case of assisted suicide by a physician who was not with the patient when he actually took his life (case 18). The committee concluded that the physician had not acted in accordance with the due medical care criterion laid down in section 2, subsection 1f of the Act.

The committees have noted that physicians do not consult a SCEN physician concerning the method of termination of life on request and assisted suicide as a matter of course. Although, under section 2, subsection 1e of the Act, the independent physician is asked

only for an opinion on parts a. to d., there is nothing to stop the notifying physician from discussing the intended method with the independent physician, who will generally also be a SCEN physician. The committees have noted that a number of SCEN physicians have offered on their own initiative to advise the notifying physician on the method of implementation, if required, thus discharging their duty to provide support, as reflected in the title of their organisation.

*Psychiatric problems*

The committees received no notifications of assisted suicide involving patients with psychiatric problems. In general, requests for termination of life or assisted suicide made by patients who are suffering because of a psychiatric illness or disorder should be treated with great caution. In such cases, it is more difficult to decide whether the patient is suffering unbearably with no prospect of improvement and has made a voluntary and well-considered request. The physician must therefore be even more alert than usual.

*Dementia*

The committees have taken note of the State Secretary for Health, Welfare and Sport's undertaking to the House of Representatives to clearly state the number of cases of dementia reported under the Act in the committees' annual report. In 2009 the committees assessed 12 notifications of termination of life on request involving patients in the early stages of dementia. In all cases, the committee concluded that the physician had acted in accordance with the due care criterion. A number of cases are described in this report by way of illustration (cases 4, 5 and 6).

*Combination of factors determines suffering*

In responding to the above-mentioned questions from the House of Representatives, the State Secretary also undertook to ensure that the committees' annual report 2009 would focus specifically on notifications of euthanasia involving a combination of conditions, in which several factors determine the extent of suffering and, above all, the extent to which it is unbearable.

As described below in Chapter II, section b, in cases of termination of life on request or assisted suicide, suffering is almost always determined by a combination of elements/factors that overwhelm the patient to such an extent that the suffering is

perceived to be unbearable. The unbearable nature of the suffering must also be palpable to the physician.

*Notifying physician*

Procedures for termination of life on request and assisted suicide are almost always carried out by the attending physician; in practice, this is often their general practitioner. A physician other than the attending physician may perform the procedure if the patient's condition has deteriorated and the regular physician is absent, for example, or if the latter does not wish to perform the procedure because of his or her beliefs. It is important that the physician actually performing the procedure thoroughly apprises himself of the patient's situation, and personally checks that the due care criteria have been complied with.

In case 14, in which it only became clear at the very last moment who was to perform the procedure, in the chaos of the moment the physician terminating the patient's life (the general practitioner) failed to comply with the statutory requirement to seek an independent assessment. Although, given the circumstances, he had exercised due care from a medical and ethical point of view, the committee was forced to conclude that the physician had not acted in accordance with the due care criteria in section 2 of the Act.

During the year under review, one notification of termination of life on request performed by a company doctor was received. Further information from the physician concerning his professional relationship with the patient led the committee to conclude that he had complied with the due care criteria.

Occasionally, physicians are unclear as to their role in the termination of life. If, for example, a case of euthanasia is reported by a physician who did not actually perform the procedure himself, the physician who actually performed the procedure will still have to sign the notification, and will be regarded by the committee as the notifying physician.

*Appearing before the committee*

The committees sometimes encounter notifying physicians who refuse to provide more information in person when invited to do so by the committee. The committees are aware that appearing before the committee is quite an imposition in terms of time,

arranging cover, etc. Nevertheless, there are situations where the committees prefer to meet the physician in person to discuss the circumstances surrounding issues such as the decision to terminate life, or the actual procedure. Physicians may be expected to make themselves available for assessment.

The committees wish to underline the fact that an interview with the committee gives the physician an opportunity to further explain the notification if things still remain unclear to the committee even after further written information has been provided. This is necessary in situations where the committee is unable to arrive at a conclusion as to whether the physician has acted in accordance with the statutory due care criteria without further explanation.

Cases 13 and 17 are examples of such situations.

## Chapter II Due care criteria

*Due care criteria: general*

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

Physicians must:

a. be satisfied that the patient's request is voluntary and well-considered;

b. be satisfied that the patient's suffering is unbearable, with no prospect of improvement;

c. inform the patient about his situation and prognosis;

d. have come to the conclusion together with the patient that there is no reasonable alternative in the patient's situation;

e. consult at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled;

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

The information provided by notifying physicians is of crucial importance to the committees' reviews. If the physician gives an account of the entire decision-making process in his notification, he may not be required to answer further questions at a later stage. Over the past year a new standard report form has been produced which, thanks to the wording of the questions, provides notifying physicians with a better guide as to how to make it clear to the committee that they have complied with the due care criteria.

In 2009, most notifications again gave no grounds for further discussion or questions when they came before the committees. In almost every case the committees concluded that the physician had acted in accordance with the due care criteria. In some cases a notification led to in-depth and lengthy discussion within the committee. Where necessary, the physician was asked to provide further information in writing or in person. This chapter includes examples of cases that led to further discussion and questions.

*Due care criteria: specific*

**(a) Voluntary and well-considered request**

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

Key elements in the contact between the physician and the patient include willingness to discuss the (possibly imminent) end of the patient's life, the patient's wishes, and ways in which they can or cannot be fulfilled. The patient's request must be specific and made to the physician.

A number of elements are crucial here. First, the request for termination of life or assisted suicide must have been made by the patient himself. Second, it must be voluntary. There are two aspects to this. The request must be *internally* voluntary, i.e. the patient must have the mental capacity to determine his own wishes freely, and

*externally* voluntary, i.e. he must not have made his request under pressure or unacceptable influence from those around him. Third, in order to make a well-considered request, the patient must be fully informed and have a clear understanding of his disease. The patient is considered decisionally competent if he is capable of making an internally voluntary, well-considered request.

*Psychiatric illness or disorders*

In general, requests for termination of life or assisted suicide based on suffering arising from a psychiatric illness or disorder should be treated with great caution. If such a request is made by a psychiatric patient, even greater consideration must be given to the question of whether the request is voluntary and well-considered. A psychiatric illness or disorder may make it impossible for the patient to determine his own wishes freely. The physician must then determine whether the patient is decisionally competent. Among other things, he must look at whether the patient appears capable of grasping relevant information, understanding his condition and advancing consistent arguments. In such cases it is important to consult not only the independent physician but also one or more experts, including a psychiatrist, who can give an expert opinion on the matter. If other medical practitioners have been consulted, it is important to make this known to the committee.

*Depression*

As we have already stated, no notifications of euthanasia involving only psychiatric problems were received in 2009. Nevertheless, there were notifications in which the patient was also suffering from depression. Depression often adds to the patient's suffering but the possibility that it will also adversely affect his decisional competence cannot be ruled out. If there is any doubt, a psychiatrist will often be consulted in addition to the independent physician. The attending physician must thus ascertain, or obtain confirmation, that the patient is capable of making an informed decision. If other medical practitioners have been consulted, it is important to make this known to the committee. In some cases, after weighing everything up, a physician may decide neither to consult an additional medical practitioner, nor to call in for a second time one who has been consulted previously. Such information is also of relevance to the committee's assessment (see case 8, for example).

It should also be noted that it is normal for patients to be in low spirits in the circumstances in which they make a request for euthanasia, and that this is therefore not generally a sign of depression.

*Dementia*

All twelve notifications concerning termination of life on request or assisted suicide involving patients suffering from dementia dealt with in 2009 were found by the committees to have been handled with due care. The patients were in the initial stages of the disease and still had insight into the condition and its symptoms (loss of bearings and personality changes). They were deemed capable of making an informed decision because they could fully grasp the implications of their request. Cases 4, 5 and 6 serve as illustrations.

The committees adhere to the principle that physicians should normally treat requests for termination of life from patients suffering from dementia with additional caution. They must take the stage of the disease and the other specific circumstances of the case into account when reaching a decision. Patients at a more advanced stage of the disease will rarely be decisionally competent. If a physician believes that a patient is in the initial stages of dementia, it is advisable to consult one or more experts, preferably including a geriatrician, in addition to the independent physician. Apart from whether or not the request is voluntary and well-considered, the question of whether there is no prospect of improvement in the patient's suffering, and above all whether his suffering is unbearable, must be assessed by the physician with extreme care in all such cases. The committees' advice is that in such cases the physician must take additional care in reaching his decision and must make clear to the committee how it was reached.

*Advance directive*

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

The Act makes specific provision for a written directive. This replaces a verbal request in cases where a patient who used to be decisionally competent is no longer capable of

expressing his wishes when the time comes to consider ending his life. The due care criteria likewise apply here, which is why it is so important that the physician to whom the request is made in a specific situation should be in no doubt regarding the advance directive. It is therefore advisable to draw up the directive in good time and update it at regular intervals. It should describe as specifically as possible the circumstances in which the patient would wish his life to be terminated. The clearer and more specific the directive is, the firmer the basis it provides for the physician's decision. The latter, as well as the independent physician, will have to decide in the light of both the described and the current situation whether the patient has made a voluntary and well-considered request, whether he is suffering unbearably with no prospect of improvement and whether he has no reasonable alternative. In Case 3 the advance directive played a key role in determining whether a patient who was no longer able to express his wishes had made a voluntary and well-considered request.

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

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

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

***Case 1 (not included here)***

***Case 2***

**Voluntary and well-considered request**

*Despite limited capacity for verbal communication (aphasia), the patient was able to make his request clear; he was decisionally competent; no advance directive had been made*

Eighteen months prior to his death, a man in his 70s suffered a cerebral infarction in the left hemisphere, which left him with hemiparesis on the right side and motor aphasia, as well as difficulty swallowing. With a great deal of effort and enormous motivation, both mental and physical, the patient had managed to regain an acceptable quality of life in the nursing home.

A year later, he broke his hip. The patient's swallowing problems grew progressively worse, causing recurrent pneumonia. He was also suffering from urine retention, as a result of which he needed to use a suprapubic catheter. The patient was treated for various infections, and was receiving physiotherapy, ergotherapy and speech therapy.

A psychologist was brought in to counsel the patient through his illness. The patient received trial treatment with antidepressants, even though he had not been diagnosed with depression. Treatment commenced when his motivation declined as his situation failed to improve. The patient had attempted to fight back to an acceptable level, but was hampered by his shortage of breath resulting from pneumonia and other conditions. His condition continued to deteriorate, despite all his efforts. Eventually, he became bedridden. The patient refused any treatment to prolong his life and ate very little. He became a shadow of his former self. The fact that he could no longer communicate was particularly difficult to bear for a man who had previously been very sociable. His suffering became unbearable, and both the patient and his body were simply 'worn out'.

The patient specifically asked his physician to end his life a month and a half before his death, communicating through hand gestures. A few days later, he repeated his specific request in the presence of his daughter and others. As a result of his aphasia, he had

not made an advance directive. The physician stated that she had carefully considered whether the patient was decisionally competent. He was at all times able to indicate clearly what he did and did not want. The independent physician consulted by the notifying physician visited the patient three times three to four weeks prior to the termination of his life. The independent physician gave a comprehensive summary of the patient's illness, and stated that he had spoken to the patient's children. It had become clear in these discussions that the patient had deteriorated dramatically over the previous year, and that for three months he had been indicating that he no longer wished to live. The patient had intended to draw up an advance directive, but was unable to do so due to his aphasia. The independent physician visited the patient three times. Little verbal communication was possible, though he could respond 'yes' or 'no' when asked a question. Otherwise, the patient spoke in an incomprehensible manner. He was however able to convey his emotions to the independent physician by non-verbal means, clearly indicating that he wished to put an end to his life. The independent physician did not believe that he was suffering from depression. He was decisionally competent, and had not been put under pressure by his family. The independent physician came to the conclusion that the due care criteria had been observed, despite the difficulties of verbal communication, which were compensated for by the well-considered remarks of those who had cared for him day to day. The committee found that the physician could be satisfied that the patient had made a voluntary and well-considered request.

***Case 3***

**Voluntary and well-considered request**

*Patient with aphasia unable to communicate; importance of advance directive*

The patient, a man in his 70s, had had several forms of cancer during the nine years prior to his death, for which he had received a variety of treatments. Several months before his death the patient suffered a cerebral infarction in the left hemisphere, which left him paralysed down his right side. He was also left entirely dependent and unable to speak. He was entirely incapable of communication. The patient underwent thrombolysis, which caused severe bleeding. To alleviate his symptoms, the patient received physiotherapy and speech therapy. These treatments did not, however, produce any progress, and were discontinued after a time. The patient had no prospect

whatsoever of recovery. He had already indicated at various stages of his illness that he did not wish to be forced to continue living in a humiliating and degrading condition such as that in which he now found himself. There was no prospect of improvement, and this contributed towards making the patient's suffering unbearable, which was palpable to the physician. After the first carcinoma had been diagnosed, the patient and physician had had several conversations about euthanasia. On each occasion the patient had sought reassurance that the physician would agree to any specific request on his part to terminate his life. When the other carcinomas were found, roughly six and three years prior to his death, the patient again repeatedly discussed the question of termination of life with his physician. He had made an advance directive some two and a half years before his death. After the patient had a cerebral infarction, his wife and sons asked the physician to initiate the procedure for terminating his life. On the basis of his previous conversations with the patient and the information he had obtained, the physician decided to regard the advance directive signed by the patient as a request for termination of life as referred to in section 2, subsection 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. A specialist in geriatric medicine – who is also a SCEN physician – was consulted as an independent physician. He visited the patient approximately a week and a half before his death, having first consulted the physician on several occasions and held discussions with the specialists who had treated the patient when he was admitted to hospital, as well as with the physicians treating him at the time. The independent physician also consulted the patient's medical records. When the independent physician introduced himself, the patient tried to talk to him, but was unable to do anything more than utter a few incomprehensible sounds. The patient became visibly frustrated, repeating the sounds louder and louder, and eventually bursting into tears. This process recurred several times during the independent physician's subsequent discussion with the patient's wife and sons. They felt that the patient was trapped in his body, totally incapable of expressing himself. They were aware of his constant suffering. This once active individual, who loved playing sports and cherished his independence, was now bedridden and entirely dependent on the help of others. He was not even capable of expressing his need to use the lavatory, which had led to incontinence. He was now in precisely the condition that he had on many occasions described as degrading. The medical specialists treating him had underlined the fact that there was no prospect of

improvement. In his report, the independent physician confirmed that the patient's suffering was unbearable, with no prospect of improvement.

There were no alternative ways to relieve the patient's suffering. During the independent physician's visit, he was unable to express his wishes verbally. He had however signed an advance directive at an earlier point in time, when he was fully competent. The independent physician believed that the request had been voluntary and well-considered. In his opinion, the due care criteria had been met.

At the committee's request for further information on the entire decision-making process and on the actual performance of the procedure, the physician stated that he had known the patient for many years. He had survived a carcinoma three times in the past. Every time the situation arose, the patient would discuss the possibility of euthanasia with the physician, and update his advance directive. The physician remarked that he had had more conversations about the possibility of euthanasia in the future with this patient than with any other. During these conversations, they had discussed at length the circumstances in which the patient would want to have euthanasia. He had also recorded this in a written directive. Some three and a half months prior to his death, the patient's condition had altered dramatically. He had become aphasic and had severe paresis down the right side. Neurologists and close relatives of the patient hoped, and expected, that he would die soon. This did not, however, occur. In the subsequent period there was little improvement. The physician had considered whether he could proceed with euthanasia. In this case, the patient was entirely incapable of communicating. He was unable to respond to questions by raising an eyelid, nor could he squeeze a finger to confirm his request when asked to do so. Given his earlier discussions with the patient, however, the physician was well aware of his desire for euthanasia. On questioning, the physician explained that, on visiting the patient, he always found him in bed, and that the patient would look at him. He had asked the patient all kinds of questions in order to ascertain his wishes. Each time, in response, the patient made incomprehensible noises. He would repeat the noises and look increasingly desperate. Eventually, he would burst into tears and appear highly frustrated. The physician explained that he had interpreted the patient's behaviour as indicating that he was in extreme distress. His demeanour and look suggested he was desperate. The physician explained that he had considered whether the frustration exhibited by the patient could

be interpreted as a desire for euthanasia or as an indication that he did not in fact want euthanasia. In his decision to proceed with euthanasia he had been guided by the many conversations he had had with the patient about euthanasia, during which the patient had always described the circumstances in which he would want his life to be terminated. On the day of the procedure, the physician spoke to the patient's family again. The patient submitted in a calm and resigned manner to the preparatory procedure and the actual administration of the euthanatics. He had certainly not put up any resistance. The decision-making process concerning termination of life had taken several months in this case. During that period, the patient's condition had not improved at all. He could have remained in this condition for some time, and there was absolutely no prospect of improvement.

The committee noted the following with regard to the criterion that a voluntary and well-considered request be made. Under section 2, subsection 2 of the Termination of Life and Assisted Suicide (Review Procedures) Act, a signed written directive constituting a request for termination of life may replace a verbal request in the case of patients who were previously decisionally competent but are no longer able to express their wishes when the time comes for their life to be terminated. In the present case, during the nine years prior to his death the patient had discussed termination of life with his family and his physician on many occasions, in response to several successive periods of illness. Each time, the patient had indicated the circumstances in which he would regard his suffering as unbearable and would want his life to be terminated. The patient had recorded his views in a request for euthanasia in the form of an advance directive which he had signed and regularly updated while he was decisionally competent. In the opinion of the committee, the physician had convincingly argued that the request made by the patient in the advance directive was voluntary and well-considered.

As regards the absence of any prospect of improvement, the committee notes that in the months prior to his death there had been absolutely no improvement in the patient's condition. As confirmed by the specialists treating him, this situation could have persisted for some time, and could therefore be regarded as suffering with no prospect of improvement. The committee noted the fact that, in the many conversations he had had with his physician about his desire for euthanasia, the patient had discussed in detail what he considered to be unbearable suffering. His greatest fear was to become

completely dependent, a position which he regarded as degrading. Since the patient was now in precisely the situation he feared and, as indicated in his advance directive, he expressly did not wish for any such situation to persist, the physician was satisfied that the patient was suffering unbearably, an impression reinforced by the patient's desperation in the face of his inability to communicate.

Although, shortly before the termination of his life, the patient could no longer express the unbearable nature of his suffering in words, the physician gained the strong impression from his demeanour and responses that the patient perceived his current condition as precisely the kind of unbearable suffering he had described. The physician believed his conclusions were reinforced by the fact that the patient did not resist in any way either during the preparations for euthanasia or during the procedure itself. In contrast to his previous extreme manifestations of frustration at his failed attempts to communicate, the patient underwent the procedure in a calm and resigned manner. Given the fact that the physician had been able to gain a very good impression of what the patient regarded as unbearable suffering during many conversations with him in the past, and this was confirmed in his advance directive, the committee found that the physician could be satisfied that the patient was suffering unbearably at the time the procedure was performed. Despite the fact that it was impossible for the physician to obtain confirmation immediately prior to the procedure, due to the patient's inability to communicate, he was satisfied on the basis of the patient's advance directive, his past conversations with him and his calmness during the preparations for euthanasia and the actual procedure, that he was acting in accordance with the patient's wishes. He had taken the following considerations into account. By not granting the patient's wish and allowing a situation to persist which the patient had expressly indicated he wished to avoid, both in the advance directive and in conversations, he would furthermore have created the risk of prolonging the patient's suffering even further, contrary to his express wishes. The committee found that the physician had adequately demonstrated that he had made a correct assessment. In conclusion, the committee found that the physician had convincingly argued that he was satisfied that the patient had made a voluntary and well-considered request and that his suffering was unbearable, with no prospect of improvement.

***Case 4***

*Dementia: the physician consulted several experts in order to establish whether the patient was decisionally competent, and the request for termination of life voluntary and well-considered*

The patient, a man in his 70s, had been diagnosed with Alzheimer's disease. Repeated neurological and neuropsychological examinations had revealed that, since 2004, he had been suffering from a slow and progressive dementia syndrome with clinical symptoms of Alzheimer's. The patient was suffering unbearably due to the fact that he had begun to lose his grasp of matters and his grip on life, and to the realisation that he was in a process of decline. He found the lack of prospects for the future and the loss of dignity and control unbearable. Four and a half months prior to his death the patient had made his first specific request for euthanasia to his physician. Since that time, he had repeated the request on many occasions. He had previously discussed the possibility of euthanasia when it had become clear he was suffering from dementia, and had often discussed his desire for euthanasia with his wife and children. He had been thinking seriously about euthanasia for about a year, and had made an advance directive. Prior to the legally required independent assessment, the physician had approached the neurologist treating the patient and a psychiatrist as experts. An independent general practitioner, who is also a SCEN physician, was consulted as an independent physician. The psychiatrist first visited the patient five months before his death, and had had contact with him several times after that.

The neurologist wrote in his report that the patient was suffering unbearably from his mental deterioration, with no prospect of improvement. He was battling against the loss of his grasp of matters, but it was clear to him that his efforts were to no avail. The patient wanted to retain his dignity. He no longer had the will to live. He was able to do less and less and 'knew less and less'. As a younger man, the patient had already stated that he would not wish to experience any process of mental deterioration. According to his doctor, this was typical of his down-to-earth, rational character. Previously in the course of his illness, the patient had indicated that he would want to have euthanasia if his suffering became unbearable. He had made an advance directive in 2008. Eventually, he made a specific request for euthanasia. In his visits to the patient, it had

become clear to the psychiatrist that the patient was aware of his cognitive decline. The patient was afraid of what the future would bring, and did not want to suffer a complete loss of dignity. He had always had great aspirations, both in his work and in his associations with others. He was suffering greatly from the fact that there was something wrong with him, that he kept failing, and that he no longer had control. He was afraid that if he could no longer express his desire for euthanasia he would not receive any help to end his life. He was gradually losing his capacities. Sometimes he lost his way. He was afraid of the progressive nature of the illness and of not knowing how he would end up. He was in low spirits, but indicated that he understood that this was a symptom of Alzheimer's. He was withdrawing more and more from social activities and beginning to lose interest in what was going on around him. He had lost his energy.

The patient felt his life was empty and could find no inner peace. He preferred to stay at home. He felt his situation was hopeless and that things were getting worse. He was aware that his memory was failing and that he was being treated more and more as a person with a cognitive disorder, something which he found very uncomfortable. He had no future. He did not want to lose his dignity, nor did he wish to experience an irreversible loss of control over his life. He wanted to die before he was no longer able to recognise his family, and did not wish to become entirely dependent on the help of others. His wish to die and to escape the humiliation of dementia was greater than his desire to see his grandchildren grow up. The patient wanted to die as soon as possible, and his desire for euthanasia remained equally strong every time the psychiatrist discussed the matter with him.

The psychiatrist concluded that the patient was decisionally competent and had an abiding wish to end his life in a dignified way before dementia made it impossible for him to recognise his family, who would have to watch him suffer a humiliating decline. The psychiatrist did not believe that the patient would change his mind on the matter. According to the psychiatrist, he had an above-average awareness and understanding of his progressive cognitive disorder and decline in function. Because of his personality, he suffered more than the average in the face of these facts. The psychiatrist noted that the patient's mood disorder stemmed from the fact that he had a progressively more demeaning condition which he could not escape. The patient was increasingly afraid that there would come a point where he could no longer express his desire for euthanasia,

and that it would not therefore be granted. He had already made it clear that he would not wish to experience the entire process of dementia before he became ill, and had remained steadfast in this opinion. The patient had made his request for euthanasia independently, under no pressure from others. The independent physician was of the opinion that the notifying physician had conducted the euthanasia process with due care. The physician had known the patient for a long time. He had consulted a psychiatrist to assess his decisional competence, and asked the psychiatrist and the neurologist to explore whether any other treatment options were available, including counselling, antidepressants and the like. A number of antidepressants had been tried, but none had had any clear effect. The independent physician concluded that the patient had made a voluntary and well-considered request for euthanasia. The psychiatrist had found him to be decisionally competent. The independent physician was of the opinion that the due care criteria had been complied with. The committee found in its assessment of this case that, in patients suffering from dementia, greater caution must be exercised in responding to any request for termination of life. The nature of their condition can after all give rise to doubts as to whether dementia patients are decisionally competent, and whether their request is voluntary and well-considered. The question of whether their suffering is unbearable is also relevant. The committee was of the opinion that the physician had at any rate proceeded with great caution, not only consulting an independent physician, but also seeking the expert opinion of the neurologist treating his patient and a psychiatrist, who had based their opinion of his request for euthanasia and the nature of his suffering on their own expertise. The committee found that the physician had acted in accordance with the due care criteria.

***Case 5 (not included here)***

***Case 6 (not included here)***

**b. Unbearable suffering with no prospect of improvement**

*The physician must be satisfied that the patient's suffering is unbearable, with no prospect of improvement*

There is *no prospect of improvement* if the disease or condition that is causing the patient's suffering is incurable and even partial 'recovery', in which the symptoms are alleviated to such an extent that the suffering is no longer unbearable, is also impossible. It is up to the physician to decide whether this is the case, in the light of the diagnosis and the prognosis. In answering the question of whether there is any realistic prospect of alleviating the symptoms, account must be taken both of the improvement that can be achieved by palliative care or other treatment and of the burden such care or treatment places on the patient. In this sense, 'no prospect of improvement' refers to the disease or condition and its symptoms. Patients use equivalent terminology to indicate that the fact that there is no longer any prospect of improvement is unacceptable to them, and that they want their suffering to end. In that sense, this perception of the situation by the patient is part of what makes suffering unbearable.

It is harder to decide whether suffering is *unbearable*, for this is essentially an individual notion. Whether suffering is unbearable is determined by the patient's perception of the future, his physical and mental stamina, and his own personality. What is still bearable to one patient may be unbearable to another.

Notifications often describe unbearable suffering in terms of physical symptoms such as pain, nausea and shortness of breath – all based on the patient's own statements – and feelings of exhaustion, increasing humiliation and dependence, and loss of dignity. In practice, a combination of aspects of suffering almost always determine whether it is unbearable. The degree of suffering cannot be determined merely by looking at the symptoms themselves; it is also a matter of what they mean to the patient, in the context of his life history and values.

The physician must find the patient's suffering to be palpably unbearable. The question here is not whether people in general or the physician himself would find suffering such as the patient's unbearable, but whether it is unbearable to this specific patient. The physician must therefore be able to empathise not only with the patient's situation, but also with the patient's point of view.

A crucial factor when the committees make their assessments is whether the physician is able to make clear that he found the patient's suffering to be palpably unbearable.

***Case 7***

*The unbearable nature of the suffering is caused by a combination of factors*

A woman in her 80s had been suffering severe lumbar arthrosis since 2004, including repeated compression fractures. She had undergone various courses of treatment, and there was no prospect of a cure. The opiates administered for pain relief and their side effects had caused the patient's condition to deteriorate rapidly in recent weeks. She soon became bedbound, and continued to suffer pain despite an increase in the dosage of painkiller (morphine). She was also experiencing side effects from the medication, including drowsiness, reduced appetite and difficulty finding words. The patient's suffering had become unbearable to her because of the fact that she was completely confined to bed and dependent on others for her care, that she could no longer stand, had a great deal of back pain, constipation, difficulty sleeping, a dry mouth, reduced appetite and difficulty finding words. She was also suffering unbearably in the knowledge that there was no prospect of any improvement in her condition, and because of her complete dependence, immobility and her fear of humiliation and loss of dignity. There were no other options for alleviating her suffering besides the palliative treatment already administered. The physician was satisfied that her suffering was determined above all by her complete immobility and dependence, and the lack of prospects for any improvement in the future. This was also palpable to the independent physician. The committee found that the due care criteria had been complied with.

***Case 8 (not included here)***

***Case 9 (not included here)***

**Unbearable suffering in special cases**

*Dementia*

As already indicated in the section on voluntary and well-considered requests, requests for euthanasia made by patients suffering from dementia should normally be treated with great caution. The question of decisional competence has already been discussed.

Another key issue is whether dementia patients can be said to be suffering unbearably. What makes their suffering unbearable is often their awareness of the deterioration in their personality, functions and skills that is already taking place, coupled with the realisation that this will get worse and worse and will eventually lead to utter dependence and total loss of self. Already being aware of their disease and the prognosis may cause patients great and immediate suffering. In that sense, 'fear of future suffering' is a realistic assessment of the prospect of further deterioration. Here again, the specific circumstances of the case will determine whether the physician feels the patient's suffering to be palpably unbearable. (Cases 4, 5 and 6 serve as examples.)

*Coma*

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

Unlike in cases where coma has occurred spontaneously as the result of illness or complications associated with illness, euthanasia may be justified if the coma is the result of medical treatment (the administration of medication to alleviate symptoms) and is therefore in principle reversible.

If a patient is in a reduced state of consciousness rather than a full coma and still displays outward symptoms of suffering, the physician may indeed reach the conclusion that the patient is suffering unbearably. To assist physicians in determining the level of consciousness – and thus also in answering the question of whether the patient is indeed comatose – and to minimise interpretation problems, at the request of the Board of Procurators General the Royal Dutch Medical Association (KNMG) is drawing up a set of guidelines on euthanasia for patients in a state of reduced consciousness, which is due to be published in mid-June 2010.

Cases involving comatose patients usually lead the committees to ask further questions. The committees then examine the specific facts and circumstances. In the light of these, a committee may find in such cases that the physician has acted in accordance with the due care criteria.

Physicians sometimes perform euthanasia in the case of patients who can no longer communicate because they feel obliged to keep a promise to the patient that was made without allowing for the possibility that the latter might go into a coma. Physicians must however be fully aware of the fact that such unforeseen situations can arise. There are 'get-out' clauses to every promise, in situations where the promise cannot and need not be kept. This applies to any promise to perform euthanasia, which is always contingent on the patient not ending up in a situation where they cannot be said to be suffering unbearably, in which case euthanasia may not be performed.

Both the committees and the KNMG therefore advise physicians not to make unconditional promises to patients and their families which they are unable to keep.

*Palliative sedation*

Palliative sedation means deliberate reduction of the patient's consciousness in order to eliminate untreatable suffering in the final stage of his life. Palliative sedation can only be considered if the patient is expected to die soon.[1] The possibility of palliative sedation does not always rule out euthanasia. There are patients who expressly refuse palliative sedation and indicate that they wish to remain conscious to the very end. In such situations, the physician and patient may conclude that there is no reasonable alternative.

**c. Informing the patient**

*Physicians must inform the patient about his situation and prognosis.*

In assessing fulfilment of this criterion, the committees determine whether, and how, the physician has informed the patient about his disease and prognosis. In order to make a well-considered request, the patient must have a full understanding of his disease, the diagnosis, the prognosis and the possible forms of treatment. It is the physician's responsibility to ensure that the patient is fully informed and to verify that this is the case. This criterion did not lead the committees to comment on any of the reported cases.

[1] See the Royal Dutch Medical Association's guidelines on palliative sedation (revised in 2009).

**d. No reasonable alternative**

*The physician and the patient have together come to the conclusion that there is no reasonable alternative in the patient's situation.*

It must be clear that there is no realistic alternative way of alleviating the patient's suffering, and that termination of life on request or assisted suicide is the only way left to end that suffering. The focus is on treating and caring for the patient and on limiting and where possible eliminating the suffering, even if curative therapy is no longer possible or the patient no longer wants it. The emphasis in medical decisions at the end of life must be on providing satisfactory palliative care. However, this does not mean that the patient has to undergo every possible form of palliative care or other treatment. Even a patient who is suffering unbearably with no prospect of improvement can refuse palliative care or other treatment. Refusal of treatment is an important subject for discussion between physicians and patients.

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

There are also patients who refuse an increased dose of morphine because of a fear of becoming drowsy or losing consciousness. The physician must then ensure that the patient is properly informed and discuss with him whether this fear is justified, for such feelings of drowsiness and confusion often pass quickly. If the physician and the patient then reach a joint decision, the physician will be expected to indicate in his report to the committee why other alternatives were not deemed reasonable or acceptable in this specific case.

In the year under review the committee found in one case that the physician had not come to the conclusion together with the patient that there was no reasonable alternative in the patient's situation (case 10).

***Case 10***

**No reasonable alternative**

*The physician had not come to the conclusion together with the patient that there was no reasonable alternative*
*Findings: the physician had not acted in accordance with the due care criteria*

The patient, a man in his 70s, was diagnosed with metastasised non-small cell lung carcinoma. There was metastasis in the pericardial fat and a peritonitis carcinomatosa. There was no prospect of a cure, and the patient refused palliative chemotherapy. He was suffering as a consequence of pain, dyspnoea, fatigue, nausea and vomiting. He found this suffering unbearable. According to the physician, nothing further could be done to alleviate his suffering, other than the measures already taken. The physician consulted an independent nursing home physician and SCEN physician for an independent assessment, who concluded that the patient's suffering was unbearable, with no prospect of improvement. She indicated that the suffering could be eased a little, on a temporary basis, by changing the patient's medication, but warned that the pleural fluid, and therefore the shortness of breath, would soon increase again.

The physician had drafted a very brief report, which did not make clear how the patient's condition had developed in the last two months prior to his death, what the physician had done during that time, and what he had discussed with his patient. The physician gave a detailed verbal summary of the patient's illness from December 2008, stating that the patient had first been informed of his diagnosis and prognosis by the pulmonary specialist. The physician had later discussed these matters with the patient in the presence of his son and daughter. The patient did not wish to receive any further treatment, and raised the subject of euthanasia several times. He had asked the physician: 'When I can't go on any longer, will you help me …?'. According to the physician, the patient was fully aware of his situation and made a well-considered request. A week before his death, the patient made a specific request for euthanasia. In response to the committee's questions, the physician said that he had read the independent physician's report and the remark that his medication could be altered. The physician had not discussed this with the patient, as he was very short of breath, and lived alone. The physician was of the opinion that the patient did not wish to receive any

informal, night or home care, and did not therefore discuss these options with him. Like most people living in the area, the patient assumed that ‘the doctor knows best’. The physician could have given the patient a morphine pump, but the patient indicated that he did not wish to go on like this. The physician could also have given him more medication but could not have guaranteed that it would improve matters. The patient was very short of breath and nauseous, and had bouts of vomiting. The physician said that if pain had been the main problem, he could have done something about it. Since the patient was having great difficulty breathing, however, he could do nothing for him. The only other option would have been to induce coma. The physician did not wish to experiment with medication, and did not want to raise any expectations he could not fulfil.

With respect to the question of whether the physician and patient had together come to the conclusion that there was no reasonable alternative in the patient’s situation, the committee noted the following. The independent physician’s report indicated that she felt there were (temporary) alternatives for alleviating the patient’s suffering, by changing his medication. During the interview, the physician indicated that he had not discussed this option with his patient; nor had he discussed possibilities such as informal, night or home care. The physician had assumed, on the basis of his own estimation of the situation, that the patient did not want any further care. The decision concerning termination of life on request or assisted suicide is a matter for the physician and patient together. It must be clear that there is no realistic prospect of ending the patient’s suffering, and that termination of life on request or assisted suicide is the only remaining solution. The physician must investigate all available palliative care options and discuss them with the patient. The committee felt that the physician should have discussed with the patient the alternatives available for alleviating his suffering. Only after the patient had refused these options could the physician come to the conclusion, together with the patient, that there was no alternative to alleviate his suffering. The committee therefore concluded that the physician had failed to explore, together with the patient, whether there was any reasonable alternative in his situation, and found that the physician had not acted in accordance with the statutory due care criteria.

**e. Independent assessment**

*Physicians must consult at least one other independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in a. to d. have been fulfilled.*

The physician is legally required to consult a second, independent physician who will give an independent expert opinion on whether the due care criteria set out under a. to d. have been fulfilled before the termination of life on request or the assisted suicide takes place, and draw up a written report. The purpose of this is to ensure that the physician's decision is reached as carefully as possible. The independent assessment helps the physician confirm that he has complied with all the due care criteria, and to reflect on matters before fulfilling the request. The independent physician sees the patient to determine whether the physician who intends to perform the procedure has not overlooked anything regarding the due care criteria. This consultation must be formal, and specific questions must be answered. The committee interprets the term 'consult' to mean considering the independent physician's findings and taking account of them when deciding whether to grant the patient's request for termination of life.

The second physician must be independent of the attending physician and the patient. In the case of the physician this means, for example, that there is no family or working relationship between the two physicians. Nor may they be members of the same group practice. In reality, the committees are confronted with a number of different arrangements in which general practitioners work under the same roof. They are not members of a group practice who care for patients jointly, but they do share facilities; for example, they may rent the same premises, share computer systems or share electronic patient files. It is not easy to decide beforehand which particular arrangements will jeopardise a physician's independence, for such information is not usually available in advance. In cases of doubt, the committees will therefore always ask further questions when the attending physician and the independent physician are involved in the same such working arrangement. The physician's independence may also appear open to question if the same two medical practitioners very often act as independent physicians on each other's behalf, thus effectively acting in tandem. This may create an undesirable situation, for their independence may then – rightly – be called into question. The

committees feel that, if a physician always consults the same independent physician, the latter's independence can easily be jeopardised. It is vital to avoid anything that may suggest the physician is not independent.

A notifying physician and an independent physician may also know each other privately, or as members of a peer supervision group. The fact that they know each other privately does not automatically rule out an independent assessment, but it does call the physician's independence into question. The fact that they know each other as members of a peer supervision group – a professional activity – need not call the physician's independence into question; whether it rules out an independent assessment will depend on how the group is organised. What matters is that the notifying physician and independent physician should be aware of this and make it clear to the committee how they reached an opinion on the matter.

The independence of the physician conducting the assessment must be guaranteed. This implies, for example, that a member of the same group practice, a business partner, trainee doctor, relative or doctor who is in some other way in a dependent relationship with the physician who calls in the independent physician is not in principle eligible to act as a formal independent physician. The appearance of dependence must also be avoided. In the case of the patient there must, among other things, be no family relationship or friendship between them, the physician must not be helping to treat him (and must not have done so in the past) and he must not have come into contact with him in the capacity of locum (in case 11 the palliative specialist did not act as such, which meant that he was able to act as independent physician in the context of the euthanasia procedure).

The independent physician's report is of great importance when assessing notifications. A report describing the patient's situation when seen by the physician and the way in which the patient talks about his situation and his wishes will give the committee a clearer picture.

The independent physician must give his opinion on whether the due care criteria set out in a. to d. have been fulfilled. He should also specifically mention his relationship to the attending physician and the patient. The independent physician is responsible for his

own report. However, the attending physician bears final responsibility for performing the life-terminating procedure and for complying with all the due care criteria. He must therefore determine whether the independent physician's report is of sufficient quality and whether the independent physician has given his opinion as to whether the due care criteria set out in a. to d. have been fulfilled. If necessary, he must ask the independent physician further questions.

Sometimes an independent physician concludes on seeing the patient that one of the due care criteria has not yet been fulfilled. In such cases, it is not always clear to the committees what exactly happened subsequently, so that further questions have to be put to the notifying physician. This might, for example, occur in the following situations.

If the independent physician is called in at an early stage and finds that the patient is not yet suffering unbearably or that a specific request for euthanasia has not yet been made, he will usually have to see the patient a second time. If he has indicated that the patient's suffering will very soon become unbearable and has specified what he believes that suffering will entail, a second visit will not normally be necessary, but it may still be advisable for the two physicians to consult by telephone or in some other manner.

If the unbearable nature of the patient's suffering is already clearly palpable to the independent physician, but the patient has not yet made a specific request for euthanasia to be performed – in order to say goodbye to family, for example – a second visit will not normally be necessary. If a longer period of time is involved or if the prognosis is less predictable, the independent physician will normally have to visit the patient a second time. If there has been further consultation between the attending physician and the independent physician, or if the independent physician has seen the patient a second time, it is important that this be mentioned in the notification. The physician should take the opinion of the independent physician very seriously, but if there is a difference of opinion between the two physicians, the attending physician must ultimately reach his own decision, for it is his own actions that the committees will be assessing.

The Euthanasia in the Netherlands Support and Assessment Project (SCEN) trains physicians to make independent assessments in such cases. In most cases it is 'SCEN

physicians' who are called in as independent physicians. SCEN physicians also have a part to play in providing support, for example by giving advice.

***Case 11***

**Independent assessment**

*The physician initially approached as a palliative specialist cannot in this case be regarded as being involved in the patient's treatment; he acted immediately afterwards as independent physician in connection with the euthanasia request.*

The patient, a man in his 70s, was suffering from overwhelming fatigue, uncontrollable pain, nausea and vomiting. He felt exhausted and found his suffering unbearable. No alternatives were available to relieve his suffering besides the measures already taken. An independent general practitioner and SCEN physician was approached for an independent assessment. The attending physician initially approached him for advice on intractable nausea in a patient who was seriously ill and wished to be given euthanasia. Since the problem sounded complex, the independent physician offered to visit the patient at home, and explained that he also worked as a SCEN physician. If necessary, his visit to the patient could therefore also serve to initiate a SCEN independent assessment. The physician accepted the offer of visiting the patient with the independent physician to discuss the remaining options for palliative treatment. The visit was made a number of days before the patient's death. Since it became clear to the independent physician during the visit that the patient had a clear desire for euthanasia, and that advice on treating the nausea was therefore no longer necessary, he decided together with the attending physician that he would act not as a palliative specialist but as an independent physician as part of the euthanasia procedure. The independent physician held a private consultation with the patient. The attending physician then faxed him detailed medical records on the patient. In his report, the independent physician confirmed the patient's medical history on the basis of his conversation with the patient, the information he had received from the physician and the medical records the latter had provided. In the report, he described how he had encountered a slightly dyspnoeic man sitting on a couch. He appeared tired and desperate. It turned out that he had not eaten for days, and had been drinking only small amounts of water. The patient said that he had managed to keep going until now, but that he did not wish to continue and

wished to be given euthanasia. According to the independent physician, the man was 'worn out'. In his report, the independent physician confirmed that there was no prospect of improvement in the patient's unbearable suffering, caused by physical and mental exhaustion resulting from a combination of conditions. There were no alternatives for relieving his suffering. His request was voluntary and well-considered. The independent physician was of the opinion that the due care criteria had been met. The committee took the following considerations into account concerning the due care criterion relating to independent assessment. By performing an independent SCEN assessment as part of the euthanasia procedure as soon as it became clear that the patient had made a specific request for euthanasia, the palliative specialist had acted properly and in the interests of the patient. The committee found that the physician had acted in accordance with the due care criteria.

***Case 12 (not included here)***

***Case 13 (not included here)***

***Case 14***

*No independent assessment could be made for lack of time. From an ethical point of view, the physician acted with great care.*
*Findings: not compliant with the due care criteria*

The patient, a woman in her 70s, developed diabetes mellitus in 1989. Angioplasty performed on both the left and right side in 2002 was partially successful. In the years that followed, she developed heart failure due to coronary ischaemia. She again received angioplasty, and a stent was inserted. During the previous year, she had had mild mitral insufficiency, renal insufficiency and severe heart failure. Over the previous two years she had suffered increasing pain in her legs due to severe intermittent claudication. The pain became unbearable when she lay down. During the previous two weeks the number of necrotic spots on her left leg had increased to such an extent that she was admitted to hospital. There was no prospect of a cure, nor of any alleviation of her suffering. It was decided to withdraw treatment. She was no longer administered medication for her heart condition and diabetes. The patient's suffering was caused by

severe pain in both her left and right legs, despite the administration of very high doses of morphine via a pump; she was also given Dormicum. Even in semicoma, the patient continued to groan loudly, her face distorted by pain, and she suffered repeated attacks of sharp pain. This suffering was unbearable for the patient. From the moment treatment was withdrawn at the hospital the patient had said to the attending surgeon, in the presence of the physician – her general practitioner, who was visiting her in the hospital – that she assumed she would die within a few hours or days. The day before her death, when the patient realised this was not the case and she was still in pain – and had even experienced hours of unbearable pain – she made a specific request for her life to be terminated. She repeated her request in the presence of her physician, family and nursing staff. She had made an advance directive. The physician explained that, given the lack of time, it was no longer possible to approach an independent physician for an assessment. All the specialists treating the patient and the hospital management had been consulted on the issue of whether her life could be terminated, and all concurred with the plan to perform euthanasia.

At the request of the committee, the physician gave the following additional information, both verbally and in writing, concerning the progress of the entire euthanasia procedure. The patient had been 'in a trap' for the past two years. Her intermittent claudication was such that she could only sleep seated in a chair. Two years prior to her death she had already asked the physician to perform euthanasia if her pain should become constant. The pain had increased significantly in the previous few weeks. Against his better judgment, the physician had consulted a cardiologist to ascertain whether she could be given angioplasty again, given the fact that she had terminal heart failure. When the patient was admitted to hospital because of her excruciating and constant pain, it soon became clear that angioplasty was technically no longer possible, and that indeed no other treatment could be given. The patient was offered pain relief and the withdrawal of other medication, and was told that she would die in a few days. The physician said that the patient had been receiving 80 mg of morphine a day prior to her admission to hospital. In the hospital, however, she was initially given only 20 mg a day. Although the dosage was then gradually increased to 120 mg an hour, the patient continued to suffer severe pain. It was subsequently found that the intravenous drip used to administer the morphine was defective and had been working subcutaneously. A few days after her admission the patient's husband telephoned the physician to report that the hospital was

going to arrange for his wife to be transferred to the hospice the following day (Saturday), so that her life could be terminated there, by the physician. As a result of poor communication by the hospital, the physician was the last person to hear that he was expected to terminate the life of a patient who had urgently requested euthanasia. The physician explained that the hospital was reluctant to grant requests for termination of life. According to the hospital's protocol, patients must have made repeated requests for termination of life over the course of a week before the euthanasia procedure can commence. Since the attending specialists at the hospital were under the impression that the patient's condition was so bad that she would soon die naturally, the procedure had not been set in motion. When it became clear that the patient could no longer bear her suffering, mainly because of the pain, it was too late to start the procedure. After being informed that he was expected to terminate the patient's life, the physician had spoken to almost everyone involved in her treatment, consulting nursing staff, the trainee doctor on duty, and the attending specialists. It became clear to him that her pain had in fact increased, despite the fact that her morphine dosage had been raised to a very high level. The nursing staff said they could no longer bear to see her suffering and were only too happy to witness her written directive, as a way of expressing their powerlessness to help in any other way. The trainee doctor could not understand why there was no one in the hospital who was prepared to take the responsibility for doing the right thing.

The patient's relatives felt 'conned', as they had been promised that she would be given good pain relief, on the assumption that she would not live much longer. However, the pain seemed only to have grown worse, and when it became clear that she was surviving longer than expected, the hospital offered to transfer her to a hospice.

The physician went to the hospital a total of five times on the Saturday. The patient was in semicoma, but was still groaning, her face distorted with pain. When a further increase in her dose of morphine and Dormicum failed to improve the situation, he came to the conclusion that she met the criteria for euthanasia, which she had already requested. Her repeatedly expressed desire for euthanasia was very palpable to the physician. He felt it was his responsibility to terminate her life, as he believed it would be inhumane to first move her to a hospice. The hospital board agreed that her life should be terminated at the hospital, provided the physician would take full responsibility. According to the physician, lack of time prevented him from consulting an independent physician. He

assumed that the requirement for an independent assessment was not paramount in such an extreme situation. The physician believed that his actions were fully open to scrutiny, and that an independent physician could not but have concluded that he had complied with the due care criteria.

The committee noted that the requirement in the hospital's protocol that patients must repeat their request for euthanasia over the course of a week cannot be regarded as compliant with section 2, subsection 1a of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. As regards the independent assessment, the committee commented as follows. The physician had explained that, besides consulting a number of nursing staff, he had also spoken with all the specialists involved in the patient's treatment. They could not however be regarded as independent physicians as referred to in section 2, subsection 1e of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. The committee was of the opinion that the physician had more than met the requirements of careful practice from an ethical point of view by 'sticking his neck out' for his patient in a serious situation that was not of his own making. However, since he had failed to consult an independent physician who would see the patient and give a written opinion on the situation, the committee was forced to find that the physician had not acted in accordance with the due care criteria in section 2, subsection 1e of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

**f. Due medical care**

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

Termination of life on request or assisted suicide is normally carried out using the method, substances and dosage recommended in the *Standaard Euthanatica* (2007), the guidelines drawn up by the KNMP. In cases of termination of life on request, the report recommends intravenous administration of a coma-inducing substance, followed by intravenous administration of a muscle relaxant. In the guidelines, the KNMP indicates which substances should be used to terminate life on request. It makes a distinction here between 'first-choice' and 'second-choice' substances. Physicians have

less experience with the latter category of substances, which are also less discriminating. The KNMP also lists substances that are not alternatives to first-choice substances and substances that should not be used at all.

If a physician does not use a first-choice substance, the committees will ask him further questions. When assessing whether the due medical care criterion has been complied with, the committees act on the principle that emergency solutions (second-choice substances) are permitted, provided that the physician gives sufficient grounds for having used them. The committees will therefore ask further questions if the physician fails to give sufficient grounds for using emergency solutions, or uses substances that are not listed as alternatives or are advised against.

The use of non-recommended substances may have negative consequences for the patient. This can be avoided by using the appropriate substances.

The committees note that Dormicum is sometimes used as pre-medication before euthanasia is performed. The prescribed coma-inducing substances are also administered in such cases. There is then no objection to the use of Dormicum or similar substances as pre-medication. Before performing euthanasia, physicians are advised to discuss with the patient and his relatives what effect the substances will have. Subject to the constraints imposed by the KNMP's recommendations in *Standaard Euthanatica*, it is important to fulfil patients' personal wishes.

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

There must be a guarantee that a patient is in a deep coma when the muscle relaxant is administered. The dosage of the coma-inducing substance is crucial in order to ensure that the patient cannot perceive the effects of the muscle relaxant. In cases 15 and 16 the physicians used a lower dosage than recommended in *Standaard Euthanatica*. In both cases they had taken advice from a pharmacist. The committee noted that it is the

physician who bears responsibility for performing the life-terminating procedure with due care. In both cases it was found that the physician had not acted in accordance with the due care criteria, for owing to the low dosage used there was no guarantee that the patients were in a deep coma when the muscle relaxant was administered.

In the case of euthanasia, i.e. termination of life on request, the physician actively terminates the patient's life by administering the euthanatic to the patient intravenously. In the case of assisted suicide, the physician gives the euthanatics to the patient, who ingests it himself. The physician must remain with the patient until the patient is dead. This is because there may be complications; for example, the patient may vomit the potion back up. In that case the physician may perform euthanasia. Nor may the physician leave the patient alone with the euthanatics. This may be hazardous, including to people other than the patient. Case 18 is an example of such a situation.

***Case 15***

*Dosage of coma-inducing substance differed from KNMP-recommended dose; depth of coma not adequately verified*
*Findings: not compliant with the due care criteria*

The patient, a woman in her 70s, was diagnosed with diabetes mellitus in 1993. The disease caused macrovascular damage. She received vascular surgery on her lower left leg on several occasions from 1995; eight years later the leg was amputated. The patient's subsequent rehabilitation went well, and for a long time she was able to walk using a prosthesis. The stump of the amputated left lower leg became so swollen and inflamed after a time, however, that no prosthesis could be worn. In early 2009 she developed nonhealing wounds on her right foot, and necrosis was identified. After a discussion with the attending specialist the patient decided she wanted no further surgical treatment. There was no prospect of the wounds healing. The woman had become a complete invalid, entirely dependent on her wheelchair – which she could not get out of without assistance – and on the care of others. She barely ate, and drank only water. She had difficulty sleeping, and as a result had become very fatigued. The patient was in severe decline due to her total dependence and the progressive reduction in her radius of action. Having always been independent, the patient was distressed at her loss

of control. She felt she no longer had any quality of life. Her suffering was unbearable due largely to the deterioration in her condition, her awareness that there was no prospect of improvement and the knowledge that things could only get worse. The physician terminated her life on request by intravenous administration of 1000 mg of Pentothal (coma-inducer) and 20 mg of Pavulon (muscle relaxant). The committee noted that the dosage used by the physician to induce coma was not the dosage recommended in *Standaard Euthanatica* (2007). The committee asked the physician to explain why this was the case. The physician stated that this dosage had been recommended by the patient's pharmacist, on the basis of the patient's height and weight. The physician said he had assumed that the pharmacist's advice was correct and had therefore followed it. She stated that it had since become clear to her that the dosage (1000 mg of Pentothal) she had used had been too low. She could not understand why the pharmacist had not pointed this out to her. She had sought contact with the patient's regular pharmacist because he was aware of all the medication prescribed to the patient in the months prior to her death. The physician also pointed out that the only interests she wished to serve were those of her patient. She had realised that she should keep more up-to-date on the relevant literature. She was receptive to the advice of others and said that she would discuss her experiences in connection with the present notification with her colleagues. When asked how she had determined the depth of the patient's coma, the doctor replied that she had not administered a pain stimulus, but that she had examined her carefully. In discussions with colleagues, she had discovered that not all of them verify the depth of coma before administering the muscle relaxant. The committee took the following considerations into account with regard to the life-terminating procedure. In assessing the question of whether the patient's life was terminated in accordance with prevailing medical opinion, the committee in principle takes *Standaard Euthanatica* (2007) as its guide. This advises the use of 2000 mg of thiopental to induce coma; this dosage has been changed since the previous edition (2008) of the KNMP guidelines, since the dosage of 1500 mg recommended then was found in some cases to be too low. The committee endorses the principle that there must be a guarantee that patients will not wake from their coma and that they should not be able to experience the effects of the subsequently administered muscle relaxant, and therefore regards the dosage of the coma-inducing substance as vital.

The committee underlined the fact that the physician was responsible for ensuring that the patient's life was terminated with due care, even though she believed she was acting on the advice of an expert (a pharmacist, in this case). The details in the notification revealed that the physician had administered the muscle relaxant two minutes after administering the coma-inducing substance. She pronounced the patient dead 13 minutes later. The administration of Pavulon had paralysed the patient's muscles, so she was incapable of any action. If the patient had not been completely comatose at that point, she would have been unable to make this clear because of the paralysis in her muscles. Given the low dosage of Pentothal, there was a risk that the patient would not actually have been in a deep coma throughout the entire procedure. This was an even more distinct possibility, since the physician had stated that she had ascertained that the patient was in coma only by examining her, rather than by administering a pain stimulus or checking whether she still had an eyelash reflex. The committee found that the physician had not terminated the patient's life with due medical care, and had thus failed to act in accordance with the due care criteria.

***Case 16 (not included here)***

***Case 17***

*The physician refused to explain the dosage of euthanatics administered*
*Findings: not compliant with the due care criteria*

The patient, a woman in her 60s, had been diagnosed with a lung carcinoma in autumn 2006. In the final months before her death her condition deteriorated rapidly. She was suffering from severe attacks of pain that could barely be alleviated, and from severe shortness of breath. The patient found this suffering unbearable, and there was no prospect of improvement. Nor was there any prospect of a cure, and the patient was not expected to live much longer. The physician terminated the patient's life at her request by administering Nesdonal (to induce coma) and Pavulon (a muscle relaxant).

Upon receipt of the notification, the committee immediately asked the physician for information as to what dosages of Nesdonal and Pavulon he had used in terminating the patient's life. Since the committee had received no response from the physician by the

time the notification was discussed, the secretary telephoned the physician after the meeting to ask him about the dosages. During this telephone conversation the physician stated that the dosages had been high enough and that he did not intend to state the exact dosage. The physician member of the committee then telephoned the notifying physician and attempted to explain the reasons for the question and the possible implications of not providing the information requested. During this telephone conversation, too, the physician remained unclear regarding the dosages of euthanatics he had used in terminating the patient's life. A month later the physician informed the committee in a letter that he would not provide information on the exact dosages, as he believed this matter was beyond the committee's remit. The committee replied by return of post explaining its tasks and responsibilities under the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, and inviting the physician to a meeting. The committee gave the physician another opportunity to respond in writing if he preferred. In response, the physician sent a letter stating his view that the quantity of medication used is irrelevant given the fact that the response depends on the patient's clinical condition and weight. In his opinion, without any insight into this situation, no conclusions could be drawn as to whether due care was taken. Assuming that this written response would suffice, he informed the committee that he would not be availing himself of the opportunity of meeting with the committee. In response, the committee sent a letter urging the physician to inform it as soon as possible of the dosages he had used and, if necessary, his reasons for deviating from the KNMP recommendations in *Standaard Euthanatica* (2007), so that the committee could assess the notification. The physician did not appear before the committee to offer an explanation as invited, and no written response had been received from the physician by the time of the next meeting. With regard to the question of whether the physician had terminated the patient's life with due medical care, the committee noted the following. The physician informed the committee that he had used Nesdonal and Pavulon in terminating the patient's life. Despite repeated requests from the committee, he failed to state what dosages he had used. The physician did not therefore furnish the committee with all the necessary information and did not allow the committee to make a well-founded assessment of whether the patient's life had been terminated with due medical care. Due in part to this fact, the committee was unable to establish whether the physician had terminated the patient's life with due medical care, and found that the physician had not acted in accordance with the due care criteria.

***Case 18***

**Assisted suicide**

*The patient ingested the euthanatics which the physician had left with him when the physician was not present*
*Findings: not compliant with the due care criteria*

In its assessment of a notification of assisted suicide, the committee found that the physician had left the euthanatics with the patient and, contrary to his agreement with the physician, the patient had ingested them when the physician was not present. The committee invited the physician to appear in person to provide further information. The physician informed the committee that he had discussed the procedure for assisted suicide with the patient on several occasions. The patient knew that the physician had to be present when he ingested the drink, in view of possible complications in the form of vomiting etc. He knew that, if complications occurred, his life could then be terminated by the intravenous administration of euthanatics by the physician. On the day of his death, the physician had visited the patient in the morning, and had inserted a venflon to use if problems should arise with the ingestion of the euthanatics. It had been agreed that termination of life would take place that afternoon. At the time appointed, the physician returned to the patient to prepare and hand over the drink containing the euthanatics. At the time, the patient's children had come to say goodbye to him. The patient then indicated that he wished to postpone the procedure, and would inform the physician when he was ready to ingest the drink. The physician left, after first discussing the entire procedure with the patient again, leaving the euthanatics with the patient in good faith. He had expressly pointed out to the patient that he must be present during the life-terminating procedure. The physician spoke to the patient on the telephone in the early evening, and the patient indicated that he wished to postpone termination of life a little longer. This phone call put the physician's mind at ease. The next morning the patient's partner called the physician's practice to inform him of his death. The physician was very surprised by the news. He had always had good contact with the patient and they had a good relationship. They had made clear arrangements, and the physician had no inkling that this might occur. The patient's partner told the physician that the patient had already ingested part of the drink containing the euthanatics around midnight. He

had ingested the rest in the presence of his partner and sister. According to the patient's partner, he had died some three hours later. She did not call the physician at that point. The physician assured the committee that he would never again act as he had in this case. He would never leave euthanatics with a patient, realising that in doing so he had given this patient the opportunity to ingest it when he was not present. He stated that he had left the euthanatics with the patient in the context of their specific relationship. He had been treating the patient for this illness for several years, and they had discussed so many matters that the physician had had every confidence that they understood each other. He was of the opinion that in this case the physician/patient relationship justified his confidence that the patient would call him when he wished to actually terminate his life. The physician had learnt that he should never leave euthanatics with a patient, no matter how much confidence he had in them.

The committee noted that, in the event of assisted suicide, according to the standards of the medical profession, the physician should hand the euthanatics to the patient, be present while the patient ingests it, and remain with the patient until he is pronounced dead. This allows the physician to take immediate action if the euthanatics fail to work in any way as expected, and also to prevent the euthanatics from being used at the wrong time, or by someone for whom they are not intended. The physician and patient must discuss the procedure for assisted suicide and the options in the event of complications beforehand. Though the physician had thoroughly discussed these matters with the patient, he had nevertheless left the euthanatics with him. The patient had ingested them by himself, contrary to his agreement with the physician, without first informing him, and at a time when the physician was not present. By leaving the euthanatics with the patient the physician had created a situation in which he no longer had any control over proceedings, and in which the patient had the opportunity to take the euthanatics without the physician being present, with all the attendant risks. Given this fact, the committee found that the physician had not acted with due medical care in assisting the patient's suicide. It did however note that it did not doubt the physician's integrity in any way. The committee found that the physician had not acted in accordance with the due care criteria.

***Case 19 (not included here)***

## Chapter III Committee activities

*Statutory framework*

Termination of life on request and assisted suicide are criminal offences in the Netherlands (under Articles 293 and 294 of the Criminal Code). The only exception is when the procedure is performed by a physician who has fulfilled the statutory due care criteria and has notified the municipal pathologist. If the physician satisfies both conditions, the procedure he has performed is not treated as a criminal offence. The aforementioned articles of the Criminal Code identify them as specific grounds for exemption from criminal liability.

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

Termination of life on request means that the physician administers the euthanatics to the patient. Assisted suicide means that the physician supplies the euthanatics to the patient, who ingests them himself.

*Role of the committees*

When a physician has terminated the life of a patient on request, or assisted in his suicide, he notifies the municipal pathologist. When doing so, he submits a detailed report showing that he has complied with the due care criteria.[2] The pathologist performs an external examination and ascertains how the patient died and what substances were used to terminate his life. He then establishes whether the physician's report is complete. The report by the independent physician and, if applicable, an advance directive drawn up by the deceased are added to the file.

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

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

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

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

In view of the fact that the capacity at the committee secretariats has not kept pace with the increase in the number of notifications, in the period under review it was unfortunately not possible to meet the six week deadline in all cases.

The committees issue their findings on the notifications they assess. In almost every case they conclude that the physician has acted in accordance with the statutory due care criteria. In such cases, only the notifying physician is informed.

If the committee is of the opinion that the physician has not acted in accordance with the due care criteria, it will send its proposed findings to all members and deputy members of its own and other committees for their advice and comments. This helps ensure harmonisation and consistency of assessment.

In 2009, nine physicians were found not to have acted in accordance with the criteria. In such cases, the findings are not only sent to the notifying physician, but are also referred to the Board of Procurators General and the Healthcare Inspectorate. The Board decides whether or not the physician in question should be prosecuted. The Inspectorate decides in the light of its own tasks and responsibilities whether any further action should be taken. This may range from interviewing the physician to disciplinary action. The committees hold consultations with the Board and the Inspectorate every year.

There are five regional euthanasia review committees. The place of death determines which committee is competent to review the case in question. Each committee

comprises three members: a lawyer, who is also the chair, a physician and an ethicist. They each have an alternate. Each committee also has a secretary, who is also a lawyer, with an advisory vote at committee meetings. The committees act as committees of experts. The secretariats are responsible for assisting the committees in their work. For organisational purposes the secretariats form part of the Central Information Unit on Healthcare Professions (CIBG) in The Hague, which is an executive organisation of the Ministry of Health, Welfare and Sport. The secretariats have offices in Groningen, Arnhem and The Hague, and the committees meet there every month.

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

The committees see all the reports by the independent physicians consulted by the notifying physicians, and they alone have an overall picture of the quality of these reports. The quality of reporting needs to be constantly monitored. The committees' general findings are forwarded to SCEN each year.

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

**Annexe I**

**Overview of notifications: total**

*1 January 2009 to 31 December 2009*

**Notifications**

The committee received 2,636 notifications in the year under review.

**Euthanasia and assisted suicide**

There were 2,443 cases of euthanasia, 156 cases of assisted suicide and 37 cases involving a combination of the two.

**Physicians**

In 2,356 cases the notifying physician was a general practitioner, in 184 cases a medical specialist working in a hospital, in 87 cases a geriatrician and in ten cases a physician being trained as a specialist.* (One notification was submitted by two physicians.)

**Conditions involved**

The conditions involved were as follows:

| | |
|---|---|
| Cancer | 2,153 |
| Cardiovascular disease | 54 |
| Neurological disorders | 131 |
| Other conditions | 168 |
| Combination of conditions | 130 |

**Location**

In 2,117 cases patients died at home, in 170 cases in hospital, in 77 cases in a nursing home, in 111 cases in a care home, in 124 cases in a hospice and in 37 cases elsewhere (e.g. at the home of a relative).

**Competence and findings**

In all cases the committee deemed itself competent to deal with the notification. In the year under review there were nine cases in which the physician was found not to have acted in accordance with the due care criteria.

**Length of assessment period**

The average time that elapsed between the notification being received and the committee's findings being sent to the physician was 37 days.