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**Regional
euthanasia review
committees**
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Annual Report **2012**

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Foreword

This is the 2012 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 due care criteria laid down in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

The report provides details of the number of notifications received, which was again more than in the preceding year, the nature of the cases, the committees' findings and the considerations on which these were based.

In 2012 the Netherlands Organisation for Health Research and Development (ZonMw) published the second evaluation report on the functioning of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. In the report, various developments are discussed. In particular, the initial reluctance to consider requests for termination of life from certain groups of patients (such as those with mental illness or dementia) appears to be making way for a more liberal position. This shift can be seen in public and medical professional opinion as well as in the policy of the euthanasia review committees.

The evaluation report notes that *'this development does not imply an expansion of the legal requirements: it should be seen as further conceptualisation of the meaning and scope of the requirements, that are formulated rather "openly" in the Act.'* The report also underscores the value of the reviews conducted by the regional euthanasia review committees in further interpreting and developing the due care criteria, which are described in general terms in the Act.

Sometimes the committees' findings provoke a lively debate in the public domain or among professionals, such as the case involving a patient with advanced dementia (case 7 in the 2011 annual report). Broad debates like these can in turn lead to a discussion among committee members, which is considered invaluable for the committees' own deliberations.

In 2012 the committees organised a seminar for their legal experts (including the committees' secretaries), physicians and ethicists on 'the nature of unbearable suffering', with Joris Slaets, professor of geriatric medicine, as guest speaker. An important goal of such seminars, which are held on a regular basis, is to ensure the consistency of the committees' reviews of notifications. While taking account of the principle that every notification should be reviewed according to the specific circumstances of the case, the committees are always at pains to harmonise their findings.

It is crucial that the committees' findings – including the considerations on which they are based, the legislative history of the Act and the case law – create as much clarity as possible. A clear understanding of the scope of the Act benefits both physicians and patients.

Besides reviewing notified cases and publishing their findings, the regional euthanasia review committees provide extensive information on the euthanasia procedure with a view to contributing to the transparent and manageable development of euthanasia practices and to public debate.

The way the regional committees apply the Act is communicated to the notifying physician in a committee's findings on the notification and to third parties through publication of the findings on the website and in the annual report. To this end, the annual report has been

written in plain language, including the explanation of the committees' policy. Inevitably an annual report does not always present the most recent developments. These will be presented on the website, which is currently being renewed and updated.

Finally, in line with the recommendations of the second evaluation report (discussed in Chapter I), the regional committees are looking into ways of making their reviews of past (and recent) cases – which effectively function as ‘case law’ – more widely known, in addition to being published in annual reports, on the website and communicated to notifying physicians.

In 2012 the regional committees received 32 notifications from physicians associated with the End-of-Life Clinic (SLK), which started its work on 1 March of that year.

As the SLK is a new concept, the committees that received an SLK notification first presented their draft findings to the members of all the other regional committees. In this way, the committees found that the due care criteria had been complied with in all 32 cases notified by SLK physicians (see also Chapter I).

This year again, the committees often exceeded the statutory deadline for issuing their findings to the physicians concerned. This situation is both undesirable and unlawful. The committees greatly regret this state of affairs, which they have conveyed to the notifying physicians. Chapter I (Developments in 2012) describes the measures taken, including expanded secretariats and the appointment of 15 extra alternate members as per 1 December 2012, to resolve the substantial backlog accumulated in previous years. The committees expect to have caught up in the course of 2013.

All the committee members and the secretariats have worked hard to tackle these issues. I wish to express especial appreciation for the enormous amount of work done by our colleague Mr P. van Hasselt, who died suddenly this spring. He had been a physician member of the North Holland committee almost since the Termination of Life on Request and Assisted Suicide (Review Procedures) Act first came into force. We were inspired by his input, his insight into issues of life and death, his humanity and his sense of humour. We are indebted to him.

The committees are always pleased to receive feedback, which can be sent by email to the general secretary: n.visee@toetscie.nl, phone: 0031611797436.

W.J.C. Swildens-Rozendaal

Coordinating chair of the regional euthanasia review committees

The Hague, July 2013

Chapter I Developments in 2012

The following developments took place in 2012.

Notifications

In 2012 the regional euthanasia review committees ('the committees') received 4,188 notifications of termination of life on request (often referred to as 'euthanasia') or assisted suicide. More information about these notifications and a breakdown by region can be found in annexe 1. 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 section 2 (1) of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act ('the Act'). In 10 cases the committees found that the physician had not acted in accordance with the Act. The most relevant elements of these cases – as well as a number of complex cases in which the committees found that the physician had indeed acted in accordance with the due care criteria – are described in Chapter II (Due care criteria: specific) under the criterion concerned¹.

Increase in number of notifications continues

The number of notifications received by the committees in 2012 (4,188) showed an increase of 13% compared to 2011 (3,695). The number of notifications actually reviewed has not kept pace. This has been a matter of concern to the committees for some time. The period within which notifications were dealt with in 2012 was unacceptably long. The committees consider this a highly regrettable situation; dealing with notifications in good time and complying with the law is essential if they are to enjoy continuing confidence.

The committees and the secretariats worked hard in 2012 to clear the backlog and, thanks to a new working procedure implemented nationally in April 2012, are well on the way to succeeding in this. It currently looks as if the committees will be able to process notifications within the statutory time limit from the middle of 2013.

New working procedures

In the new procedure, an incoming notification is recorded and examined by an experienced member of the secretariat ('secretary') who estimates the likelihood that the review committee will have further questions regarding the notification ('straightforward' or not).

Notifications are considered straightforward if an experienced secretary, on receiving the papers (i.e. at the start of the review procedure), can establish with a high degree of certainty that the due care criteria have been complied with and that the information provided is so comprehensive that it raises no questions. To assess this, the secretary uses a checklist of criteria, which is based on the committees' long experience in reviewing notifications of euthanasia. Documentation concerning straightforward notifications is sent electronically to three members of the regional committee concerned (a lawyer, a physician and an ethicist) for assessment.

If all three members confirm that the notification is a straightforward case, which means they have no further questions and the due care criteria have been complied with, the findings on the notification can be finalised. However, even if just one committee member has questions with regard to the notification, the file will be sent to all committee members for plenary discussion at a monthly meeting.

The committees expect that some 80% of all notifications will be reviewed digitally. To underpin the new working procedure, a new registration and assessment system was also rolled out nationally in April 2012.

¹ The passages included as cases mainly concern the due care criterion that is being discussed at that point.

Regional euthanasia review committees expanded

After intensive discussions with the Ministry of Health, Welfare and Sport, three extra alternate members were appointed to each regional committee on 1 December 2012, bringing the membership to nine: three members (a physician, an ethicist and a lawyer) and six alternate members (two in each area of expertise). The Ministry also agreed to increase the staffing of the secretariats as of 2012.

The effects of the new working procedure and the expanded committees will probably start to become apparent around the middle of 2013.

Termination of Life on Request and Assisted Suicide (Review Procedures) Act applicable on Bonaire, St Eustatius and Saba

As of 10 October 2012, the Termination of Life on Request and Assisted Suicide (Review Procedures) Act is also applicable in the Caribbean Netherlands, i.e. Bonaire, St Eustatius and Saba. Notifications from physicians on these islands are assessed by the regional committee for Groningen, Friesland and Drenthe. In 2012 only one such notification was received; in this case, the committee found that the physician had acted in accordance with the statutory due care criteria.

Notifications from End-of-Life Clinic

The End-of-Life Clinic (SLK) started its activities on 1 March 2012². In this year, the regional committees received 32 notifications from the SLK's peripatetic euthanasia teams. Based on these notifications the committees have established that the SLK's procedure is as follows.

After receiving a request from or on behalf of a patient, the SLK asks the party who made the request to fill in a written questionnaire and asks the patient's permission to obtain medical data and other information. The patient's request for euthanasia and the medical data obtained are used to compile a medical record. The SLK then assesses whether it can handle the request. If so, it is passed on to one of the peripatetic teams, each made up of a doctor and a nurse who have been trained by the SLK. The peripatetic team talk extensively with the patient over several visits in order to

establish whether the patient's request is voluntary and well-considered, and whether his suffering is unbearable to him, with no prospect of improvement. In principle, the peripatetic team's physician will always try to contact the attending physician, unless the latter has indicated wanting to have no contact at all (which is rare). Next, the SLK physician contacts an independent SCEN physician. The SLK physician also presents the case to the SLK's own multidisciplinary consultation for a final review before performing euthanasia or providing assistance with suicide.

As the end-of-life clinic is a new concept, the competent committee in each case first presented its draft findings to the other regional committees in the Netherlands. In all 32 cases notified by the SLK, the committees found that the due care criteria had been complied with. Some of these cases are presented in Chapter II (e.g. case 2).

Dementia and mental illness or disorders

Patients' suffering was caused by dementia in 42 cases notified to the committees, and by mental illness in 14 cases. In 2011 these figures were 49 and 13, respectively. In two cases involving dementia, the committee found that the attending physician had not satisfied the due care criteria. In one of these cases, the attending physician had failed to consult an independent physician. The remaining notifications were found by the committees to have been handled with due care.

Second evaluation report on the Termination of Life on Request and Assisted Suicide (Review Procedures) Act

In 2011 and 2012, at the request of the Ministry of Health, Welfare and Sport, a second evaluation was conducted of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, covering the 2007-2011 period. The authors presented their findings in a report published in December 2012. The report's main conclusion is that the Act satisfies the aims of the legislation, providing a framework for public scrutiny, increasing transparency, ensuring medical decisions concerning the end of life are taken with due care, and giving physicians legal certainty. The authors observe that, thanks to the work of the committees, the due care criteria are becoming increasingly clear, which also results in a clearer delineation of the Act's scope in cases involving patients with dementia, mental illness, or multiple geriatric syndromes.

² End-of-Life Clinic (SLK): www.levenseindeklinik.nl.

The authors also made a number of recommendations. First, in order to give physicians and other interested parties a good, up-to-date overview of the committees' findings, the committees should improve access to their interpretation of key concepts in the due care criteria in the Act through other channels besides their annual reports. In particular, the committees are advised to publish their findings – which function as 'case law' – on their website as quickly as possible, for the benefit of physicians as well as members of the public. The committees should also make more use of the option of publishing their findings in scientific or professional journals.

The committees endorse these recommendations.

Website

In consultation with the Ministry of Health, Welfare and Sport, the committees have decided that in the future the website www.euthanasiecommissie.nl will focus on presenting the committees' integral assessments of non-straight-forward notifications of euthanasia with a view to promoting the development of general norms on euthanasia and the knowledge and expertise of physicians and other parties concerned. Cases where the committees found that the physician concerned did not satisfy all the due care criteria will always be published on the website, as well as cases where the due care criteria were satisfied but which initially raised questions, for instance cases involving conditions that are less prevalent in connection with euthanasia (dementia, psychiatric disorders and multiple geriatric syndromes). In other words, the type of notifications that the committees have always discussed extensively in their annual reports. In exceptional cases a finding may not be published, for instance when publication would compromise the patient's anonymity.

In 2012, due to work being done to improve the website's search function with a view to providing optimum accessibility, the committees were temporarily unable to publish relevant cases on the website.

New KNMG/KNMP guideline

In assessing compliance with the due medical care criterion, the committees carefully consider the current standard in medical and pharmaceutical research and practice. In 2012, in assessing the criterion of due medical care, the committees generally took the 2007 version of *Standaard Euthanatica* and the supplement published in 2010 as their guide. In *Standaard Euthanatica* the Royal Dutch Association for the

Advancement of Pharmacy (KNMP) recommends the method, substances and dosage to be used for termination of life on request or assisted suicide. In August 2012, the Royal Dutch Medical Association (KNMG) and the KNMP published their new guideline on performing euthanasia and assisting suicide (*KNMG/KNMP Richtlijn Uitvoering euthanasie en hulp bij zelfdoding*), referred to in the rest of this report as the KNMG/KNMP Guideline. The committees are pleased to note that most notifying physicians are complying with the new Guideline.

Experience has shown that notifications can be processed far more quickly if the notifying physician uses the new notification form and fills it in as completely as possible, digitally rather than by hand (with the exception of questions about how euthanasia/assisted suicide was performed). As the notification form for physicians is not entirely in line with the new KNMG/KNMP Guideline, the committees have submitted a proposal to the KNMG, the Ministry of Health, Welfare & Sport and the Ministry of Security & Justice to adapt question 22, which refers to the method used.

Chapter II Due care criteria

Due care criteria: general

The committee examines retrospectively whether the attending physician acted in accordance with the statutory due care criteria laid down in section 2 of the Act.

These criteria, as laid down in section 2 of the Act, are as follows. Physicians must:

- a. be satisfied that the patient has made a voluntary and carefully considered request;
- b. be satisfied that the patient's suffering is unbearable and that there is no prospect of improvement;
- c. have informed the patient of his or her situation and further prognosis;
- d. have come to the conclusion, together with the patient, that there is no other reasonable alternative;
- 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. have exercised due medical care and attention in terminating the patient's life or assisting in his or her suicide.

Procedures for termination of life on request and assisted suicide are almost always carried out by the attending physician; in practice, this is often the patient's general practitioner. In some cases the procedures are performed by a locum because the patient's situation rapidly deteriorates or because the attending physician is absent or does not wish to carry out the procedure himself, because of his religious or ethical views or for other reasons.

If the attending physician does not wish to carry out the procedure, it may be done by a physician affiliated with Right to Die-NL and the End-of-Life Clinic (SLK). See also Chapter I, Notifications from the End-of-Life Clinic, and case 2.

Where the procedure is performed by a Right to Die-NL and SLK physician, who is thus the notifying physician, he or she must first obtain reliable information about the patient's situation and be personally satisfied that the due care criteria have been satisfied.

The information provided by attending 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. The physician is expected to use the model notification form revised in 2009. The questions in it help attending physicians make it clear to the committee that they have complied with the due care criteria.

The committees sometimes require further information, which can often be provided by telephone or in writing. In some situations, however, the committees prefer to interview the physician in person in order to obtain a clearer picture of the physician's and patient's shared decision-making process at the end of the patient's life or details about how the procedure was performed.

The committees are aware that such an interview, besides taking up the physician's time, may be distressing to him. They wish to emphasise that the purpose of the interview is to give the physician an opportunity to provide further details regarding a notification which the committee still has its doubts about even after the physician has provided further information by telephone or in writing. In the absence of such details, the committee would be unable to find that the physician acted in accordance with the statutory due care criteria. The interview also gives the physician an opportunity to answer questions about his actions (which can of course be expected of him). In 2012 the great majority of notifications gave no grounds for further discussion or questions when they came before the committees. In those cases the committees could swiftly conclude that the physician had acted in accordance with the due care criteria. As of April 2012 straightforward notifications are processed digitally. Case 1 is included as an example of such a notification.

Case 1

Finding: criteria complied with

Summary: straightforward notification, processed digitally; all due care criteria complied with

In 2007 the patient, a man in his seventies, was diagnosed with a gastric tumour. In 2011 it had metastasised to his bones and abdomen. Just over a month before the patient died, further metastasisation resulted in ileus and his condition deteriorated. There was no prospect of recovery. Only palliative treatment could be given.

The patient's suffering was caused by increasing pain in the lower abdomen, inability to eat and great difficulty drinking, symptoms associated with ileus including nausea and vomiting, severe weight loss and his dependence on care by others. He also suffered from the loss of control over his life and the hopelessness of his situation.

The patient experienced his suffering as intolerable. The physician was satisfied that this suffering was unbearable to the patient and that there was no prospect of improvement according to prevailing medical opinion. Apart from the palliative measures that had already been taken, there were no other means acceptable to the patient to alleviate his suffering.

The documents make it clear that the attending physician and his specialists had informed the patient adequately about his situation and prognosis. The patient had discussed euthanasia with the physician before. Eleven days before he died, he specifically asked the physician to terminate his life.

The physician found that the request was voluntary and well-considered.

The physician consulted an independent physician who was also a SCEN physician. The independent physician saw the patient three days before the termination of life was performed, after he had been told about the patient's situation by the attending physician and had examined his medical records.

In his report the independent physician gave a summary of the patient's medical history and the nature of his suffering. The independent physician concluded, partly on the basis of his interview with the patient, that the due care criteria had been satisfied.

The attending physician performed the termination of life on request using the method, substances and dosage recommended in the KNMP/WINAP's *Standaard Euthanatica*.

The committee examines retrospectively whether the attending physician acted in accordance with the statutory due care criteria laid down in section 2 of the Act. The committee then decides whether, in the light of prevailing medical opinion and standards of medical ethics, the due care criteria were complied with.

In view of the above facts and circumstances, the committee found that the attending physician could be satisfied that the patient's request was voluntary and well-considered, and that his suffering was unbearable with no prospect of improvement. The physician gave the patient sufficient information about his situation and prognosis. Together, the physician and the patient could be satisfied that there was no reasonable alternative in the patient's situation. The physician consulted at least one other, independent physician, who saw the patient and gave a written opinion on whether the due care criteria had been complied with. The physician performed the euthanasia with due medical care.

The committee found that the physician had acted in accordance with the statutory due care criteria laid down in section 2 (1) of the Act.

The remaining cases included in this chapter are examples of cases that gave rise to in-depth, lengthy discussions within the committee and, usually, further questions. Discussion of these cases, below, will focus on those elements that pertain to a specific due care criterion.

Due care criteria: specific

a. Voluntary, well-considered request

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

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 who will perform the procedure.

Three elements are crucial here:

1. The request for termination of life or assisted suicide must have been made by the patient himself.
2. The request must be voluntary. There are two aspects to this.
 - The patient must be decisionally competent (internal voluntariness), that is he must have a clear understanding of relevant information about his situation and prognosis, be able to consider any possible alternatives and understand the consequences of his decision.
 - He must not have made his request under pressure or unacceptable influence from those around him (external voluntariness).
3. The request must be well-considered. In order to make a well-considered request, the patient must be fully informed and have a clear understanding of his disease.

Examples of situations where the committees examined these points more closely are case 4, which concerns decisional incompetence and dementia, case 8 concerning a patient with a mental illness, and case 15 concerning reduced consciousness.

Case 2 (abridged)

Finding: criteria complied with

Summary: The physician, affiliated with the SLK, was convinced that the patient had been able to make a voluntary and well-considered request after being informed about alternatives; the physician could be satisfied that the patient was suffering unbearably, there was no prospect of improvement.

Eighteen months before her death, the patient, a woman in her sixties, became hemiplegic after a haemorrhagic brainstem stroke. For some five years, she had suffered from peripheral arterial vascular disease and had multiple TIAs. There was no prospect of recovery. The TIAs and the brainstem stroke made the patient increasingly dependent on others. She developed severe problems with eyesight and speech. The patient did not want to go to a nursing home or a rehabilitation centre – she did not want to be in a situation of dependence. Some weeks before her death her condition deteriorated rapidly, as problems also developed in the opposite side of her body. The patient became completely bedridden and dependent on others for her personal care. She became doubly incontinent.

The patient's suffering consisted of increasing disability because of hemiplegia, increasing disability of the opposite side of her body, poor vision, and urinary and faecal incontinence. The patient was bedridden and dependent on others for her personal care. She also suffered from the rapid deterioration in her condition and the absence of any prospect of recovery.

The patient regarded her suffering as unbearable. The physician was satisfied that this suffering was unbearable with no prospect of improvement according to prevailing medical opinion. Apart from the palliative measures that had already been taken, there were no other means acceptable to the patient to alleviate her suffering.

The documents make it clear that the SLK physician, the general practitioner and the specialists had informed her adequately about her situation and prognosis.

The patient had discussed euthanasia with her general practitioner some months before her death. He supported the patient in her wish, but did not want to perform the end-of-life procedure himself because he had little experience with euthanasia and felt less sure of himself in this situation.

A month before she died, the patient contacted a nurse at the End-of-Life Clinic (SLK), which assessed her request.

Fifteen days before she died, the patient specifically asked the SLK physician to terminate her life. After that, they discussed euthanasia again several times. The SLK physician concluded that the request was voluntary and well-considered.

The independent physician concluded, in part on the basis of his interview with the patient, that the due care criteria had been satisfied.

The committee held as follows. The physician was affiliated with the SLK and had taken on the patient because her own GP did not want to perform the termination of life himself.

In the committee's opinion, if the attending physician cannot or does not want to comply with a request for euthanasia, the patient is free to seek another physician.

The physician who takes over the patient's treatment and becomes involved in the euthanasia procedure must take the time to become properly acquainted with the patient. Only in-depth, repeated consultations with the patient will enable the physician to assess whether the due care criteria are satisfied. It is impossible, however, to fix a minimum number of consultations required or a minimum time period in which these are to take place. This type of situation also calls for good communication between the physicians involved and a proper transfer of patient records.

In this case, the physician visited the patient twice prior to performing euthanasia. She also had several long conversations with the patient over the phone about the latter's request for termination of life. The physician contacted the patient's GP several times to exchange patient information, and also contacted the patient's family and carers. The patient's GP continued to be involved in the patient's treatment. The SLK physician contacted an independent physician following the usual procedure (by phoning the regional SCEN contact number) to discuss the case.

The committee found that, by following the procedure described above, the physician could be satisfied that the patient's request was voluntary and well-considered and that she was suffering unbearably with no prospect of improvement. The physician gave the patient sufficient information about her situation and prospects. Together, they could be satisfied that there was no reasonable alternative solution in the patient's situation. The other due care criteria were also fulfilled.

Mental illness or disorder

When a physician receives a request for termination of life or assisted suicide because of unbearable suffering arising from a mental illness or disorder, with no prospect of improvement, he or she must assess whether the request is voluntary and well-considered. A mental illness or disorder may make it impossible for the patient to determine his own wishes freely. The attending physician must then

ascertain 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 an independent physician but also one or more experts, including a psychiatrist. It is important that their findings are also made known to the committee.

In 2012 the committees received 14 notifications of euthanasia or assisted suicide involving patients with psychiatric problems. These were all found to have been handled with due care. Whether or not a patient suffering from a mental disorder lacks all prospect of improvement is something that must be considered especially carefully. For that reason we have included one such case in this report, case 8 below, under b. Unbearable suffering without prospect of improvement.

Depression

In addition to suffering from one or more somatic conditions, a patient can also have depression, which often exacerbates his suffering. The possibility that it will also adversely affect his decisional competence cannot be ruled out. If there is any doubt about whether the patient is depressed, a psychiatrist will in practice often be consulted in addition to the independent physician. If other medical practitioners have been consulted, it is important to make this known to the committee. 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 not in itself a sign of depression.

Written directive not a prerequisite

The Act requires the physician to be satisfied that the patient has made a voluntary and well-considered request. The request for termination of life is almost always made during a conversation between the physician and the patient, and hence is made orally.

Contrary to popular belief, the Act does not require an advance directive or living will to be drawn up. On the other hand, even if the patient is capable of expressing his wishes, a written directive can help eliminate any uncertainty and confirm the oral request. Although in practice the existence of such a directive makes it easier to subsequently assess the case, 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 difficult circumstances, in some cases only shortly before they die.

Advance directive and decisional incompetence

The Act makes specific provision for a physician to carry out a patient's request for euthanasia in cases where the patient is no longer capable of expressing his wishes, provided these wishes were written down in an advance directive at a time when the patient was still decisionally competent (section 2 (2) of the Act). In cases like these, an advance directive can

replace an oral request. The due care criteria likewise apply here.

Section 2 (2) of the Act may be applied in the following cases:

- the patient is in a state of reduced consciousness, but can still perceive his suffering as unbearable, or is in a state of reversible coma (see case 15);
- the patient is incapable of expressing his will or is decisionally incompetent as a result of, for instance, advanced dementia, Huntington's disease or aphasia. Unlike patients in a state of reduced consciousness or coma, these patients are usually still capable of some communication, either verbal or non-verbal, however poor.

In these cases, the attending physician and the independent physician – if he was unable to talk with the patient at an earlier stage of the disease – must establish what the patient's current wishes are from his behaviour and utterances. Both physicians will have to decide in the light of the situation described in the patient's advance directive and the current situation – and having regard to the entire process that the physician has gone through with the patient – whether the patient has made a voluntary and well-considered request, whether he is suffering unbearably and whether there is no prospect of improvement or reasonable alternative.

The independent physician will not be able to converse with the patient, as he normally would, and will have to determine whether the request is voluntary and well-considered based on information provided by the attending physician, the medical records, an advance directive, the patient's behaviour and expressions of his wishes since the directive was written, and statements by others, such as the patient's family³.

In these cases, the physician must be convinced that the patient still wishes his life to be terminated. If, when euthanasia is about to be performed, it is evident from the patient's behaviour that he no longer has this wish, the physician cannot go through with the procedure.

Although it is difficult to make any general statements as to the circumstances under which euthanasia may be performed in such situations, the possibility may not be excluded, bearing in mind the tenor of the Act. This will always have to be assessed based on the specific circumstances in each individual case.

³ The memorandum of 5 November 1999 on the legal status of advance directives in the healthcare sector (Parliamentary Papers, House of Representatives, 1999-2000 session, 26 885, no. 1) discussed the role of close family members in interpreting the patient's wishes as laid down in one or more directives.

In making a decision on a request for euthanasia laid down in an advance directive, the physician must consider the patient's current situation and compare it with his wishes as laid down in the directive and discussed previously with the physician. To avoid problems of interpretation, 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 patient is responsible for discussing the advance directive with the physician at the time it is drawn up and whenever it is updated. A handwritten directive drawn up by the patient in which he describes, in his own words, the circumstances in which he would want euthanasia to be carried out often provides additional personal confirmation, and is therefore more significant than a standard form, particularly one that is conditionally worded⁴.

The physician can help eliminate uncertainty by recording details of a patient's wish for euthanasia and the patient's and his decision-making process concerning the end of life in the patient's records. The physician is responsible for keeping a record.

The clearer and more specific the advance directive and the better the records kept, the firmer the basis they provide for everyone involved, such as the attending physician, the independent physician and observers, if any.

The role of an advance directive in cases involving patients in a state of reduced consciousness or coma is discussed in the section entitled Reduced consciousness, under **b**.

Unbearable suffering with no prospect of improvement.

Case 4 illustrates the important role fulfilled by the advance directive in a case concerning dementia; case 15 does likewise in a case concerning reduced consciousness.

Dementia

Of the 42 notifications dealt with in 2012 concerning termination of life on request or assisted suicide involving patients with demential syndrome, two were found by the committees not to have been handled with due care. In one case, the shortcoming concerned the independent assessment. In the majority of cases, the patients were in the early stages of dementia and still had insight into the condition and its symptoms (loss of bearings and personality changes). They were deemed decisionally competent because they could fully grasp the implications of their request.

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 entire course 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 disorder are less likely to be decisionally competent. In these cases, it is essential that there is a record of the patient expressing the wish for euthanasia in the past, namely a clear advance directive written by the patient when still decisionally competent, which incontrovertibly applies to the situation at hand.

If a patient is suffering from dementia, it is advisable to consult one or more experts, preferably including a geriatrician or a psychiatrist, 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, should be key elements in the physician's decision. Before agreeing to the patient's request, the physician must be convinced that the situation described in the patient's advance directive, in terms of the unbearable nature of his suffering and the absence of all prospect of improvement, is applicable to the patient's current situation.

Case 3 (not included here)

⁴ Govert den Hartogh, 'Wilsverklaring vergt onderhoud' (Advance directive needs maintenance), Medisch Contact no. 39, 25 September 2012

Case 4 (abridged)

Finding: criteria complied with

Summary: patient with advanced dementia. The physician established satisfactorily that the patient's suffering was unbearable to her and without prospect of improvement. There was no reasonable alternative in the patient's situation. The physician was satisfied that her request was voluntary and well-considered.

The patient, a woman in her eighties, was first diagnosed with dementia in spring 2010. The most prominent symptoms in her case were paranoid delusions and hallucinations. The patient had a long history of severe osteoporosis, which worsened in recent years, leading to vertebral collapse and multiple fractures and causing the patient severe pain. Just over a month before her death, the patient had a fall, breaking her hip and wrist, and required surgery. Her condition was incurable. She could only be treated palliatively. Despite the use of various types of analgesics the patient was not free from pain. Nor were the two types of antipsychotic drug that she was administered effective. In the last few weeks before her death, after she had been discharged from hospital, the patient suffered from severe paranoid delusions, anxiety and confusion. This also made her physically restless, so that she fell several times in the last week, even though she was receiving round-the-clock care. There was no prospect of improvement in her situation.

The patient, who had always set great store by her independence and self-reliance, was suffering primarily from the pain, which was difficult to manage, but also from her lack of mobility as a result of her deteriorating condition. She also suffered from the knowledge that she had progressive dementia. She was familiar with the process of cognitive decline, as she had cared full-time for her husband, who suffered from dementia, for a number of years. She was afraid that, like her husband at the time, she would eventually need to be admitted to a nursing home, an event she did not want to go through herself.

The patient also suffered enormously from the paranoid delusions which, especially in the final weeks of her life, made her very fearful. The patient found her suffering unbearable.

Apart from the palliative measures that had already been taken, there were no other means acceptable to the patient to alleviate her suffering. She did not want to be admitted to a nursing home which, in any case, would be unable to prevent her from falling. She was too restless and suspicious to be fitted with a morphine pump.

The patient's request

When the patient first registered with the physician's practice in 2004, they talked about euthanasia in general terms. At the beginning of 2011 she gave the physician an advance directive, which stated specifically that she wanted her life to be terminated should she ever be facing the same situation as her husband was in at that time.

About three months before her death, the patient told her physician that she wanted her life to be terminated when her suffering became unbearable to her, a stage she did not consider herself to have reached at that time. She again referred to her husband's situation and emphasised that she did not want anything like that to happen to her.

About two weeks before her death, the patient's children specifically requested that her life be terminated. The patient herself had indicated indirectly that she wanted to die, saying things like 'I don't want to live this way any longer' and 'I can't take it any more'. At some point she refused to take her medication because she 'wanted to die anyway'.

According to the physician, the voluntariness of the patient's request was evident from, in particular, the many occasions that the patient had discussed her wish for euthanasia with her. The physician did not believe the patient was influenced by or under pressure from others to make her request.

The physician also found the request to be well-considered because the patient had discussed her wish for euthanasia a number of times when she had still been lucid, and had been well aware at the time of the implications of her request and her physical condition.

In the final weeks before her death, an in-depth talk with the patient was no longer possible. However the day before the patient's death, the physician had used the word 'euthanasia' in a conversation with the patient and she had had the impression that the patient understood what she was talking about. The patient had then indicated she had lived long enough and had had a good life. The physician's decision was also based on the patient's behaviour and things she had said in the weeks before her death. This included thanking the physician profusely for everything she had done for her and saying goodbye to her loved ones. The physician also relied on the opinions of the SCEN physician and of the nurse who had cared for the patient in the last two days of the patient's life. The SCEN physician's impression from conversations with the patient was that the latter had a wish to die; the nurse believed the patient was suffering greatly.

The SCEN physician saw the patient twice. In his report he concluded unconditionally that all the due care criteria had been complied with.

Voluntary, well-considered request

In reviewing this notification, the committee observed that a request for termination of life from a patient suffering from progressive dementia must be responded to with even greater care than usual. In view of the nature of the condition, there may be doubts about whether the patient is decisionally competent, and whether the request is voluntary and well-considered.

Under section 2 (2) of the Act, a physician can carry out a patient's request for euthanasia in cases where the patient is no longer capable of expressing his wishes, provided the patient laid down these wishes in an advance directive when he was still competent to make a reasonable appraisal of his own interests. The due care criteria likewise apply here.

In this case, it could be established that the patient had discussed her wish for euthanasia several times in the years that her cognitive functioning was still unimpaired. She had also given her physician an advance directive in 2011, explaining that she wanted her life to be terminated when admission to a nursing home became unavoidable. Three months before her death, the patient had given the physician to understand that she wanted her life to be terminated if her suffering became unbearable. She also referred to the situation in which her husband eventually found himself: his psychogeriatric symptoms resulted in him being admitted to a nursing home. This was a situation she emphatically did not want to experience. In subsequent months, the patient and her physician no longer discussed euthanasia.

In the weeks before her death – after she had been discharged from hospital – the patient was no longer able to put her wish into words as such, but she did make it clear that she wanted to die. According to the doctor she had said she 'didn't want to live this way any longer' and 'couldn't take it any more'. She also refused to take her medication because she 'wanted to die anyway'. In the weeks before her death she had thanked the physician profusely and said goodbye to her loved ones. On the evening the procedure was carried out the

patient had been unusually calm. When the physician said she was going to give her a small injection, the patient had expressed her acquiescence.

On the question of whether the patient's request was *voluntary and well-considered*, the committee noted that, although the patient could not request euthanasia in so many words, her behaviour and things she had said until just before her death made it clear that she wanted to die because of her pain, her forgetfulness and because she did not want to be put in a nursing home. The physician established satisfactorily that she had become convinced that the patient's wish to die was in complete accordance with the patient's wish for euthanasia, as previously expressed both orally and in writing.

In view of the above facts and circumstances, the committee found that the attending physician could be satisfied that the patient was *decisionally competent* when she drew up her advance directive and that her request for euthanasia was *voluntary and well-considered*.

Unbearable suffering with no prospect of improvement

On the issues of unbearable suffering with no prospect of improvement, information provided to the patient and acceptable alternatives, the committee held as follows.

On the advice of an external expert, the physician administered Seroquel for a number of days in an attempt to relieve the patient's complaints, but she thought she should not wait any longer for beneficial effects to arise because of the sharp deterioration in the patient's condition. The patient was not only in great pain, she was also very anxious and had frequent panic attacks. She was very restless and at increased risk of falling. She had also lost control over her bowel movements.

The physician established satisfactorily that the patient's suffering was unbearable to her. The independent physician consulted had also concluded that the patient's suffering was palpably unbearable. Admission to a nursing home was not a reasonable alternative as, there too, the patient would be at increased risk of falling. Moreover, when the patient had still been able to communicate clearly, she had said several times that a nursing home represented unbearable suffering for her.

In view of these facts and circumstances, the committee found that the attending physician could be satisfied that the patient's suffering was *unbearable and without prospect of improvement*. The physician gave the patient sufficient information about her situation and prognosis. Together, the physician and the patient could be satisfied that there was no reasonable alternative in the patient's situation.

b. Unbearable suffering without 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 the symptoms cannot be alleviated to the extent that the suffering is no longer unbearable. 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, for which there are no realistic curative or palliative treatment options that may – from the patient's point of view – be considered reasonable.

Patients also use equivalent terminology to indicate that the absence of 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. What is still bearable to one patient may be unbearable to another.

Whether suffering is unbearable is determined not only by the patient's current situation, but also by his perception of the future, his physical and mental stamina, his personality and his life history.

Notifications often describe unbearable suffering in terms of physical symptoms such as pain, nausea and shortness of breath, and feelings of exhaustion, increasing humiliation and dependence, and loss of dignity. In practice, it is almost always a combination of aspects of suffering that determines whether suffering is unbearable. The degree of suffering cannot be determined merely by looking at the symptoms themselves; it is ultimately 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 it clear that he found the patient's suffering to be palpably unbearable.

Case 5 (not included here)

Suffering must have medical dimension

As the preparatory work on the Act makes clear, the expression 'finished with life' refers to the situation of people who, often at an advanced age and without it having been established by the medical profession that they have an untreatable disease or disorder that is accompanied by great suffering, have come to the conclusion that the value of their lives to them has decreased to the point where they would rather die than carry on living. Suffering within the meaning of the Act must therefore include a medical dimension. Suffering that arises in a non-medical context should not be assessed by physicians, for it lies beyond the medical field. The committee must therefore investigate whether the physician could be satisfied not only that the patient's suffering was unbearable with no prospect of improvement, but also that it was mainly due to a recognised disease or medical condition, i.e. that there was a medical dimension. However there is no requirement that the medical condition should be serious or life-threatening. Multiple geriatric syndromes can also cause unbearable suffering with no prospect of improvement (see, for example, case 7).

Case 6 (not included here)

Case 7 (abridged)

Finding: criteria complied with

Summary: unbearable suffering caused by multiple geriatric syndromes, thus having a medical dimension.

The patient, a woman in her eighties, suffered from multiple symptoms, including poor overall condition, low cardiopulmonary capacity and fatigue. These symptoms were the result of general age-related degeneration. The patient received medication for reduced cardiac function. She also had problems with her back and joints as a result of osteoporosis. The patient had already had a number of falls. She had a chronic tingling sensation in her hands, despite having undergone surgery and received injections to alleviate this condition. The patient's eyesight and hearing had deteriorated. She did not want further medical treatment. She indicated that she had had a good life, and did not want to get any older or more decrepit. She was afraid that something might happen that would make her lose control over her life, such as a stroke or a fall resulting in fractures. She had always been very active and done a lot to help other people. She was almost completely disabled as a result of her physical limitations. She did not want to become dependent on others and was absolutely opposed to going into a nursing home. The patient regarded her suffering as unbearable. She was not downcast or depressed, and had retained her sense of humour. She had initially made preparations to commit suicide, but she was afraid the attempt would fail. The physician believed that leaving the patient to carry out this course of action on her own would be inhumane.

In an advance directive, the patient described her daily activities and the trouble and effort it cost her to perform them. She was exhausted and wrote that she did not want to go on living in this way. Some months before she died, the patient specifically asked the physician to provide assistance in her suicide.

The regional committee wanted further information about the medical dimension of the patient's suffering and why the physician had found the unbearable nature of the patient's suffering palpable and her situation to be without prospect of improvement.

The physician informed the committee that the patient had talked about her suffering caused by multiple geriatric syndromes since 2009. She had seen her father become severely incapacitated in old age and did not want to suffer the same fate. Initially, she had tried to live with her symptoms as well as she could. She was not depressed or downcast and continued to try to do all sorts of things, but could do less and less due to her physical debilitation. She could not see or hear well and was extremely tired after the least bit of activity. She was afraid of falling, and as a result, of losing her autonomy. She had considered suicide and had already made preparations to carry it out. She had in her possession lethal medication whose effectiveness she had had tested. The physician knew of the patient's intentions. He believed that the patient's suffering was genuine but did not think that euthanasia was legally permitted in these circumstances. In 2011 the KNMG published its position paper on the role of physicians in termination of life at the patient's request. According to the KNMG, increasing debilitation caused by multiple geriatric syndromes, including functional disorders, can lead to unbearable suffering without prospect of improvement within the meaning of the Act. However the suffering must have a medical dimension, i.e. it must be caused by a recognised disease or a combination of diseases/symptoms. On reading this position paper it became clear to the physician that performing euthanasia on this patient fell within the scope of the Act. Naturally, the physician wanted reassurance that terminating this patient's life would be the right thing to do. He gradually came to understand that the suffering arising from the exacerbation of physical symptoms and limitations, connected with multiple geriatric syndromes, was unbearable to the patient. He had investigated whether any alternatives were available to make the patient's life bearable, but nothing could be done to relieve her fatigue and the impending loss of independence.

The committee concluded that the patient's suffering was caused by a combination of age-related conditions, which caused increasing debilitation. These geriatric syndromes, including severe fatigue due to poor cardiac function, loss of hearing and eyesight, and a realistic fear of fractures due to a fall, have a medical dimension. Due to her incapacitation and increasing dependence on others, and in view of her past life and personal values, the patient could no longer consider her current life meaningful. Living in this way was more than she could bear. The committee concluded that the physician had satisfactorily established that the patient's suffering was palpably unbearable. Suitable interventions or reasonable alternatives were no longer available in the patient's situation.

Dementia

As 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 perception of the deterioration that is already taking place in their personality, functions and skills, coupled with the realisation that this will only worsen and eventually lead to utter dependence and total loss of self. Being aware of their disease and its consequences may cause patients great and immediate suffering. A realistic assessment of how the illness is likely to progress may also lead to a fear of future suffering. The specific circumstances of the

case will determine whether the doctor is satisfied that the patient's suffering is unbearable.

In the case of dementia, there is a close connection between both aspects, i.e. assessing whether the request is voluntary and well-considered and assessing whether suffering is unbearable with no prospect of improvement. Case 4 has therefore been included as an example, above, under **a. Voluntary and well-considered request**, Dementia.

Mental illness or disorder

It has already been emphasised elsewhere in this report that a wish to die expressed by a patient suffering from a mental illness or disorder requires the attending physician to exercise particular caution. Apart from the question of decisional competence and whether the patient can be deemed capable of making a voluntary, well-considered request, a key question is whether the suffering considered unbearable by the patient is without prospect of improvement. Case 8, below, illustrates this point.

Case 8 (abridged)

Finding: criteria complied with

Summary: patient had been treated unsuccessfully for 30 years for severe, recurring depression. The physician established satisfactorily that the patient's suffering was unbearable with no prospect of improvement, and that there was no reasonable alternative.

The patient, a woman in her seventies, had had recurring periods of severe depression for more than 30 years. Over the years she had usually received outpatient care. She had also been admitted to hospital a number of times for extensive, including pharmacologic, treatment, but with very limited effect. None of the treatments cured her depressive episodes completely or for a long period of time. The patient rejected new treatments, such as electroconvulsive therapy (ECT). She did not want to be admitted to a psychiatric ward again due to previous traumatic experiences. She was afraid that changing her medication would have a negative effect on her depression. In the past, certain substances had induced psychosis. She had tried to end her life several times, the most recent attempt being a month before she died. Recently the patient's physical condition had deteriorated. Two weeks before her death, she had stopped eating and drinking in order to hasten death. On her physician's advice she had resumed eating and drinking in order to be clear-headed for her talk with her psychiatrist.

The patient's suffering was primarily mental, and was caused by chronic depression. She also suffered from reduced concentration, so that she could no longer enjoy books and music. The patient had lost touch with her physical and social environment. Her declining physical condition was characterised by limited mobility, severe fatigue, listlessness, lack of appetite, painful joints in her hands and loss of independence. She still had close ties with her family, but she could not and did not wish to live any more.

The patient regarded her suffering as unbearable. The physician was satisfied that this suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate her suffering that were acceptable to her. The patient had discussed euthanasia with the physician before. She had had a wish to die for many years. A month before she died, the patient had specifically asked the physician to terminate her life.

Two weeks before her death the physician asked an independent psychiatrist to examine the patient to determine the presence of a psychiatric disorder, possible treatment options, prognosis and whether the patient was decisionally competent with regard to her request. The psychiatrist concluded that the patient had a depressive disorder which did not respond to treatment. The psychiatrist was not convinced that the remaining treatment options would produce results that would be acceptable to the patient or that committal to hospital

would have added value. The psychiatrist could not rule out the possibility that the patient's request for euthanasia was motivated by her depression. Nevertheless, the patient understood the implications of her actions and decisions. The psychiatrist concluded that the patient had a realistic perception and understanding of her disease, and that she was decisionally competent with regard to her request.

The physician consulted an independent physician who was also a SCEN physician, who visited the patient some days before she died. In her report the independent physician gave a summary of the patient's medical history and the nature of her suffering.

The patient's request was voluntary and well-considered. She had a clear wish to die. She had thought well about her situation and her wish. She had a realistic picture of her options, or lack of options, in terms of psychiatric treatment. The independent physician deemed her to be decisionally competent and was satisfied that her suffering was unbearable with no prospect of improvement. The independent physician concluded, partly on the basis of her interview with the patient, that the due care criteria had been satisfied.

With regard to the question of whether the physician could be satisfied that the patient's suffering was *without prospect of improvement* and that there was *no reasonable alternative*, the committee found as follows. The patient was examined by a psychiatrist two weeks before her death, who established that she had been using antidepressants in adequate doses for many years, but that depression nevertheless recurred time and again. The psychiatrist noted that the patient would object to any change in medication and that she would not even discuss the possibility of ECT. He also noted that, in view of her psychiatric history and her declining physical condition, he did not believe that remaining treatment options, including committal to hospital, would lead to acceptable results for the patient. The committee could be satisfied that the patient's suffering was without prospect of improvement and that the physician and the patient together could reasonably have concluded that there was no reasonable alternative in the patient's situation.

The committee also considered the nature of the patient's suffering. The patient had been treated (usually on an outpatient basis) for recurring depressions for more than thirty years, without the desired result. Her chronic depression caused her mental suffering. In addition, the patient's physical condition was declining, so that she suffered from limited mobility, severe fatigue, listlessness, lack of appetite, painful joints in her hands and loss of independence. She had no more social ties and could no longer enjoy the activities that previously gave her pleasure.

In view of all this, the committee found that the physician could be satisfied that this particular patient's suffering was unbearable to her.

Case 9 (not included here)

Coma and reduced consciousness (non-comatose)

Suffering assumes a conscious state. Since a patient in a coma is in a state of complete unconsciousness, he cannot be said to be suffering. In this situation, euthanasia cannot be performed.

One exception can be made to this principle: unlike in cases where coma has occurred spontaneously as the result of illness or complications associated with illness, euthanasia

may be justified in the case of medically induced coma, resulting from the administration of medication to alleviate pain and symptoms and therefore in principle reversible. In this case, it is considered inhuman to wake the patient simply so that he can confirm that he is again, or still, suffering unbearably.

If a patient is in a state of reduced consciousness (but not in a coma) – either spontaneously or as a result of medication to reduce pain or symptoms – the physician may, in the light of the patient's responses, reach the conclusion that

the patient is indeed suffering unbearably. The Glasgow Coma Scale can be a valuable tool to assess the level of consciousness or depth of coma (and therefore the possibility of suffering)

Guideline on euthanasia for patients in a state of reduced consciousness

The KNMG Guideline ‘Euthanasia for patients in a state of reduced consciousness’ deal specifically with the situation where, after the attending physician has consulted an independent physician and is ready to carry out euthanasia, the patient – spontaneously or unintentionally, as a result of medication to reduce pain or dyspnea – falls into a state of reduced consciousness. According to the Guideline, the physician may proceed with the euthanasia if the patient is still suffering unbearably. This is determined using the Glasgow Coma Scale (GCS). The Guideline also allows the physician to proceed if the patient unintentionally falls into a coma resulting from the administration of medication to alleviate pain or dyspnea. While such a coma is in principle reversible, it is not necessary to wake the patient simply so that he can confirm that he is again, or still, suffering unbearably. In these situations set out in the Guideline, the physician may proceed with the euthanasia without again consulting an independent physician. Although the patient is no longer able to express his wishes immediately prior to euthanasia, an advance directive is not required.

Guideline does not apply

Euthanasia based on an advance directive

In cases where the Guideline does not apply, a physician may – on the basis of section 2 (2) of the Act – carry out a patient’s request for euthanasia, which the patient can no longer express because he is in a state of reduced consciousness or reversible coma, but which is stated in an advance directive.

For instance, the patient’s condition may suddenly deteriorate to the extent that he spontaneously enters a state of reduced consciousness before an independent physician has been consulted. Or a patient’s condition may suddenly decline so sharply that the attending physician has to administer medication to alleviate the pain and/or other symptoms, causing the patient to enter a state of reduced consciousness or a reversible coma before an independent physician has been consulted. The Guideline does not apply to these types of situation. In both situations described above, the independent physician can conclude that the patient’s request for euthanasia was voluntary and well-considered, based on the advance directive. Whether the patient’s suffering was unbearable with no prospect of improvement must be assessed through observation (seeing the patient), information and medical records provided by the attending physician, and (if available) information from

the patient’s immediate family. Here, too, the Glasgow Coma Scale can be a valuable tool to assess the level of consciousness or depth of coma (and therefore the possibility of suffering).

In the case of a reversible coma, it is considered inhuman to wake the patient simply so that he can confirm to the independent physician that he considers his suffering unbearable.

Cases involving semi-conscious 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 (see case 15).

Palliative sedation

The Act does not apply to palliative sedation, which is a normal medical procedure. Palliative sedation means deliberately reducing 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 within two weeks. There are patients who expressly refuse palliative sedation and indicate that they wish to remain conscious to the very end. The physician and patient may together conclude that palliative sedation is not a reasonable alternative if the patient in question wishes euthanasia. In other words, the possibility of palliative sedation does not always rule out euthanasia.

Sometimes a patient may make a conditional request for euthanasia. In this case, the patient is initially palliatively sedated, but the physician and the patient agree that euthanasia will be carried out should certain circumstances arise, for instance it may take longer for the patient to die than he wishes and/or the patient may still show symptoms of suffering despite being in a state of reduced consciousness. The patient may wish to avoid putting his loved ones through such an ordeal or his wish to die with dignity may be put at risk.

The committees emphasise that it is essential that the patient inform the attending physician of the specific situations in which he wants his request for euthanasia to be carried out.

c. Informing the patient

Physicians must inform the patient about his situation and prognosis.

In assessing compliance with this criterion, the committees determine whether, and how, the physician, or other attending physicians, 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 in 2012.

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, for instance because he considers that the positive effects of treatment do not outweigh the negative effects, e.g. side effects which he finds unacceptable or hard to tolerate. For instance, there are 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.

Refusal of palliative treatment or other care is an important subject for discussion between physicians and patients. The physician is expected to indicate in his report to the committee why the patient did not consider other alternatives reasonable or acceptable.

Case 10 (not included here)

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 sees the patient to determine whether the physician who intends to perform the procedure has not overlooked anything regarding the due care criteria under (a) to (d); the same applies to any other independent physicians who are consulted. The independent physician gives an independent expert opinion, and draws 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 the due care criteria, and reflect on matters before granting the request.

If an independent physician who has been consulted earlier is consulted again, this consultation may, depending on the circumstances described below, take place by telephone.

The 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 requirement to consult an independent physician does not imply that the attending physician needs the independent physician's 'permission' to carry out euthanasia. Naturally, the attending physician should take the independent physician's opinion very seriously, but if there is a difference of opinion between the two, the attending physician must reach his own decision, for it is his actions that the committees will be assessing.

Independent physician

The independent physician must be independent of the attending physician and the patient. The KNMG's 2003 Position Paper on Euthanasia explicitly states (p. 15) that the physician's independence must be guaranteed.

According to the KNMG, this implies that a member of the same group practice, a registrar, a relative or a physician who is otherwise in a position of dependence in relation to the physician who has called him in cannot normally be

deemed independent. It is important to avoid anything that might suggest the physician is not independent.

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.

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 may appear that the physician is not independent. Whether the fact that they know each other as members of a peer supervision group – a professional activity – rules out an independent assessment will depend on how the group is organised. What matters is that the attending physician and independent physician should be aware of this and make their opinion on the matter clear to the committee.

In the interests of an independent assessment, attending physicians are advised to – and usually do – consult a SCEN physician as independent physician, via the regional division of the Euthanasia in the Netherlands Support and Assessment Programme (SCEN) (see below).

Finally, there must, among other things, be no family relationship or friendship between the independent physician and the patient, 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.

When must an independent physician be consulted for a second time?

Questions are sometimes asked about the period that an independent physician's opinion is valid, i.e. at the most, how much time may there be between the independent physician seeing the patient and the euthanasia procedure? There is no simple answer to this question, although it is more likely to be weeks than months. Much depends on the independent physician's findings, expected and unexpected developments in the patient's situation, and other factors.

Sometimes an independent physician concludes on seeing the patient that one or more of the due care criteria have 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 the independent physician 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 or a second consultation by telephone or in any other manner will not normally be necessary if the patient's suffering does indeed become unbearable very soon.
- If the unbearable nature of the patient's suffering is already 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 relatives, for example – a second visit or a second consultation by telephone or in any other manner will not normally be necessary.

If the independent physician has concluded that the due care criteria have been complied with, but the patient's condition turns out to be less predictable and/or a long period of time is involved, the independent physician will in principle have to see 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 is mentioned in the notification.

The committees also receive notifications in which the independent physician was consulted, saw the patient and made his report very shortly before the patient died, or even on the day of death. In such cases it is advisable for the attending physician to make clear when and how he received the independent physician's report.

Assessing a decisionally incompetent patient

The attending physician must consult an independent physician who must give his opinion on a decisionally incompetent patient's request for euthanasia. In accordance with section 2 (1) (e) of the Act, the independent physician must see the patient. The regional committees consider that, normally, the independent physician will see the patient as well as speak with the patient.

However there may be circumstances in which the patient is no longer capable of expressing his wishes. Section 2 (2) of the Act, which establishes the legal status of the advance directive, provides for the attending physician to carry out euthanasia in this situation.

If the independent physician has not visited the patient at an earlier stage in the physician's and patient's joint decision-making process, he will find himself facing a patient with whom he is unable to communicate, or only with great difficulty. The independent physician's position in this type of situation has been discussed in other parts of this report, namely the paragraphs entitled '**Advance directive and decisional incompetence**', '**Coma and reduced consciousness**' and '**Dementia**'.

The euthanasia procedure may be carried out in cases where a patient can only communicate non-verbally, provided the due care criteria are satisfied.

The independent physician will in that case no longer be able to speak with a patient in such a situation, but he will be able to establish that the request for euthanasia is voluntary and well-considered on the basis of the patient's advance directive. Whether the patient's suffering is unbearable with no prospect of improvement must be assessed on the basis of the advance directive and the patient's current condition, the relationship between the two, information and medical records of the attending physician, and (if available) information from the patient's immediate family.

Independent physician's report

The independent physician's written 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 – in so far as possible – 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. In order to establish his independence, he should specifically mention what his relationship is to the attending physician and the patient.

The independent physician is responsible for his own report. However, the attending physician bears final respon-

sibility 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.

SCEN

The Euthanasia in the Netherlands Support and Assessment Programme (SCEN) trains physicians to make independent assessments in such cases. In most cases, physicians consult a SCEN physician as an independent physician, by calling the regional SCEN telephone number. The committees are pleased to note that specialists these days almost always call in a SCEN physician when euthanasia is performed in a hospital. Increasingly, they are themselves trained SCEN physicians.

SCEN physicians also have a part to play in providing support, for example by giving advice. In some cases, however, this may conflict with the role of independent physician.

The committees note that by no means all physicians consult the SCEN physician about how the euthanasia or assisted suicide procedure is to be performed.

Although section 2 (1) (e) of the Act only requires the independent physician to give an opinion on compliance with criteria (a) to (d), there is no reason why the attending physician should not discuss with the independent physician (who is usually a SCEN physician) how he intends to perform the procedure.

The committees note that some SCEN physicians offer to advise the attending physician on the performance of the procedure – an excellent example of the support component of the SCEN programme.

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

Case 15 (abridged)

Finding: criteria complied with

Summary: The independent physician saw but did not speak with the patient, who was drowsy and unresponsive due to the administration of analgesics. The independent physician saw that the patient was in pain. Information obtained from the patient's attending physician and family members revealed that the patient had specifically requested euthanasia the day before. The advance directive played an important role in this case. The Guidelines on euthanasia for patients in a state of reduced consciousness did not apply.

The patient, a man in his seventies, had very extensive orthopedic problems. In the summer of 1997 he had had a total left-hip replacement without complications. Eight years later, in 2005, he underwent a total right-hip replacement. A month after surgery, a deep infection of the implant was diagnosed. The patient was hospitalised for five months, during which time he had around eight operations. The infection was ultimately cured, but the patient effectively no longer had a hip joint. His right leg had become much shorter and could bear only very little weight. His disability was severe, not only due to his right leg and hip but also because of cardiac and pulmonary problems, hemiparesis on the right side of his body, and kidney failure. Sepsis was a major factor in the onset of cardiac dysrhythmia. In a short space of time he underwent surgery twice in connection with growing, persistent abscesses. Despite receiving maximum treatment, the patient remained septic and the infection spread to his joints and lungs. The patient would have to be operated on again, but on the day of the scheduled operation he told nursing staff that he wanted no further treatment, including another operation.

The patient was in extreme pain, even when touched superficially. The pain was difficult to treat, as the patient had on an earlier occasion suffered respiratory depression after being given morphine. The patient had never been one to give up easily, but he experienced his present suffering as unbearable. The physician was satisfied that this suffering was unbearable to the patient and that there was no prospect of improvement according to prevailing medical opinion.

Apart from the palliative measures that had already been taken, there were no other means acceptable to the patient to alleviate his suffering. The physician and the patient together reached the conclusion that there was no reasonable alternative in the patient's situation.

The documents make it clear that the attending physician and other specialists gave the patient sufficient information about his situation and prognosis.

Two days before he died the patient told nursing staff and another physician (who was the colleague of the attending physician) that he wanted no more treatment and that he wanted euthanasia. Later that day he discussed euthanasia with his attending physician and specifically requested the latter to terminate his life. After this, he repeated his request several times.

The patient had discussed his wish for euthanasia several times with his family and his GP. He had signed an advance directive some years before, and drawn up and signed a refusal of treatment directive because, in the words of his GP, he did not want to live like a vegetable. The patient had emphasised that he did not want a prolonged deathbed.

According to the attending physician the patient was under no pressure from those around him and was well aware of the implications of his request and his physical situation. There was no doubt that the patient was decisionally competent when he made his repeated requests.

The physician consulted an independent physician who was also a SCEN physician. The independent physician saw the patient a day before the termination of life, after she had been told about his situation by the attending physician and had examined his medical records.

In her report the independent physician gave a summary of the patient's medical history and the nature of his suffering. The independent physician declared that she had seen the patient but had been unable to speak with him. A day before her visit he had been very responsive and alert and had been able to clearly explain his wishes. However at the time of the independent physician's visit the patient had been drowsy due to his condition and the pain

medication, and did not respond to her questions. He moaned when touched. The independent physician observed that the patient was clearly in pain, despite receiving good pain medication.

She talked extensively with the patient's family, who told her how much he had suffered in the last few days and that he had said 'I can't take it any more. I don't want to go on.' The patient had said this several times, to family members and everyone who came to provide care. In her report, the independent physician concluded that the patient's suffering was unbearable and without prospect of improvement. Although she had not been able to talk to the patient herself, she concluded from his advance directive, the medical records, her talks with the physicians and the patient's family that his desire for euthanasia had been genuine and there had been a voluntary and well-considered request. It was palpable to the independent physician why the patient, who had been informed about his poor prognosis and treatment options, rejected further treatment. Based on her visit to the patient, the medical records, her talks with the patient's physicians and family and his advance directive, the independent physician reached the unqualified conclusion that all the due care criteria had been satisfied in this case.

The patient was no longer conscious on the day the procedure was carried out. He had been administered a high dose of morphine, so that it was impossible to ask him to confirm his request and the unbearable nature of his suffering. Based on the patient's previous repeated, specific requests and his advance directive, the physician carried out the termination of life on request.

With regard to due care criteria a and b the committee considered as follows. Under section 2 (2) of the Act, a physician may carry out a request for termination of life from a patient who is no longer able to express his wishes, provided the patient laid down the request in an advance directive drawn up when he was still decisionally competent.

In this case the patient – when he was decisionally competent – had drawn up both an advance directive and a refusal of treatment directive some years before, and discussed these with his GP and with his family. He clearly described the circumstances in which he would want his life to be terminated.

Having received information from several physicians, the patient had a clear picture of his situation and prognosis. The physician to whom the patient had several times put his request for termination of life, came to the conclusion together with the patient that there was no reasonable alternative in the patient's situation. The physician could be convinced that the patient's request was voluntary and well-considered.

In general, the committees find that a patient's request for euthanasia can be carried out even if the patient is in a state of reduced consciousness, if it can be satisfactorily established that the patient's suffering is unbearable to him.

In this connection, the committee notes that administering medication to relieve pain or other symptoms can result in reduced consciousness or coma. The committee considers it inhuman to wake a patient in this state only so that he can confirm that he is again, or still, suffering unbearably. In this case the physician reached the conclusion that the patient was suffering unbearably without waking him from his state of reduced consciousness.

With regard to the requirement to consult at least one other, independent physician, the committee considers that it is generally preferable if the independent physician can speak

with the patient privately in order to reach a conclusion on whether the due care criteria have been fulfilled.

If the independent physician is unable to speak with the patient, for instance because the patient is in a state of reduced consciousness, he should still see the patient and reach a conclusion based on the patient's circumstances and information obtained from other sources.

In this case the independent physician visited the patient and saw him, but was no longer able to communicate with him. However, she could establish that he was in pain despite receiving good pain medication. The independent physician met with the patient's physicians and spoke extensively with his family. Based on her visit to the patient, the medical records, her talks with the patient's physicians and family members, and his advance directive, the independent physician reached the unqualified conclusion that all the due care criteria had been satisfied in this case.

The committee found that these conversations and the other information obtained by the physician compensated for the fact that she could not converse with the patient himself, so that she was still able to reach a conclusion on whether the patient's wish was voluntary and well-considered, and his suffering unbearable and without prospect of improvement.

In view of the above facts and circumstances, the committee found that the due care criteria were satisfied in this case.

f. Due medical care

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

In the case of euthanasia, i.e. termination of life on request, the physician actively terminates the patient's life by administering the euthanatics to the patient intravenously.

In the case of assisted suicide, the physician gives the euthanatic to the patient, who ingests it himself. The physician must remain with the patient or in his immediate vicinity until the patient is dead. This is because there may be complications; for example, the patient may vomit the potion back up or death may not ensue as quickly as expected. In that case the physician may perform euthanasia. The physician must discuss these possible events with the patient and his family beforehand.

The physician may not let some one else administer or give the euthanatic to the patient, nor may he leave the patient alone with the euthanatic. This may be hazardous, to other people as well as to the patient. The physician must obtain the euthanatic directly from the pharmacist, in person.

In assessing the criterion of due medical care, the committees generally took as their guide the method, substances

and dosage recommended in the 2007 version of *Standaard Euthanatica*⁶ of the Royal Dutch Association for the Advancement of Pharmacy (KNMP). In cases of termination of life on request, *Standaard Euthanatica 2007* recommends intravenous administration of a coma-inducing substance, followed by intravenous administration of a muscle relaxant. In the guideline, the KNMP indicates which substances should be used to terminate life on request.

If a physician does not use a first-choice substance and fails to give grounds for having used the other substance, the committees will ask him further questions.

The use of non-recommended substances may have negative consequences for the patient. This can be avoided by using the appropriate substances. There must be a guarantee that a patient is in a deep coma when the muscle relaxant is administered.

A substance such as midazolam may be used as pre-medication before a recommended coma-inducing substance is administered.

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 2007*, it

is important to fulfil patients' personal wishes as far as possible.

Standaard Euthanatica 2007 also states, for each substance, which dosage 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 2007*. There must be a guarantee that a patient is in a deep coma when the muscle relaxant is administered. The use of a coma-inducing substance recommended in *Standaard Euthanatica 2007*, as well as the correct dosage, is crucial in order to ensure that the patient cannot perceive the effects of the muscle relaxant. In case 17, the physician used a lower dosage than recommended in *Standaard Euthanatica 2007*.

In case 18, the physician followed the hospital's protocol, in which the coma-inducing substance and the muscle relaxant are combined in a single drip bag and administered together. The committee noted that it is the physician, not the pharmacist, who bears responsibility for performing the life-terminating procedure with due care, and hence for the choice, dosage and administration of the substances used. In this case, and in cases 16 and 17, the committees found that the physician concerned had not complied with the criterion concerning due medical care as he was unable to guarantee that the patient was in a deep coma when the muscle relaxant was administered. The physician must check the depth of the coma in an appropriate manner before administering the muscle relaxant.

In August 2012 the KNMG and the KNMP published their new guideline on performing euthanasia and assisted suicide.

Cases 16, 17 and 18 were assessed on the basis of *Standaard Euthanatica 2007* and have therefore not been included in this report.

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 (Articles 293 (2) and 294 (2)) identify compliance with these conditions 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 Termination of Life on Request and Assisted Suicide (Review Procedures) 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.

As of 10 October 2012 the Termination of Life on Request and Assisted Suicide (Review Procedures) Act is also applicable in the Caribbean Netherlands, i.e. Bonaire, St Eustatius and Saba. Notifications from physicians on these islands are assessed by the regional committee for Groningen, Friesland and Drenthe.

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. A

standard report form is available as an aid in drawing up the report. The physician should preferably fill it in by computer (in the interests of legibility). The form can be downloaded on www.euthanasicommissie.nl.

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.

The committees decide whether, in the light of prevailing medical opinion and the standards of medical ethics, the physician has acted in accordance with the statutory due care criteria.

It is the physician's responsibility to convince the committee that this is the case.

If a committee has any questions following a notification, the physician will be informed. Physicians, sometimes including the independent physician, may be asked to respond in writing to additional questions. The committees sometimes contact physicians by telephone if they need extra information. If the information provided by the physician and/or the independent physician is insufficient, one or both may be invited to provide further information in person. Physicians are less likely to be called on to provide further information if their reports are sufficiently clear. A physician will usually be invited to an interview if the committee reviewing his case is inclined to find that he did not act in accordance with the due care criteria. This gives him an opportunity to explain in more detail what took place in this particular case.

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

For a number of years capacity at the committee secretariats had not kept pace with the increase in the number of notifications. In 2012 the committees made every effort to reduce the backlog, and they expect to be able to process all notifications within the statutory time limit in the course of 2013. The committees issue 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 attending 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 the members and alternate members of its own and other committees for their advice and comments. This helps ensure harmonisation and consistency of assessment. The ultimate decision is reached by the competent committee.

In 2012 10 physicians were found not to have acted in accordance with the criteria. In such cases, the findings are not only sent to the attending physician but are also, in accordance with the Act, referred to the Board of Procurators General and the Healthcare Inspectorate. The Board decides whether or not the physician in question should be prosecuted⁷. 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 (see annexe II to the full report (in Dutch)).

The coordinating chair and the alternate coordinating chair of 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. As of 1 December 2012 each member has two alternates. 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; it should be noted here that, in cases where physicians are found to have acted

with due care, their findings are final. 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 implementing 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 KNMG's Euthanasia in the Netherlands Support and Assessment Programme (SCEN) to train physicians to perform independent assessments. The members of a regional committee are sometimes invited to visit a peer supervision group of SCEN physicians in their region.

The committees see all the reports drawn up by the independent physicians consulted by the attending physicians, and thus have an overall picture of the quality of these reports. The quality of reporting needs to be constantly monitored, but the committees are very pleased to have noted a definite improvement in this regard.

The committees' general findings are forwarded to SCEN each year. Committee members also give presentations to municipal health services, associations of general practitioners, hospitals, community organisations, foreign delegations and so on, using examples from practice to provide information on applicable procedures and the due care criteria.

⁷ Instructions on prosecution decisions in the matter of termination of life on request and assisted suicide, Government Gazette, 6 March 2007, no. 46, p. 14

Annexe I

Overview of notifications

1 January 2012 to 31 December 2012

Overview of notifications, total

1 January 2012 to 31 December 2012

Notifications

In the course of the reporting year, the committees received 4,188 notifications.

Euthanasia and assisted suicide

There were 3,965 cases of euthanasia (i.e. active termination of life at the patient's request), 185 cases of assisted suicide and 38 cases involving a combination of the two.

Physicians

In 3,777 cases the attending physician was a general practitioner, in 171 cases a specialist working in a hospital, in 166 cases a geriatrician, in 21 cases a registrar and in 53 cases another physician (e.g. a junior doctor, non-practising physician or hospice physician).

Conditions involved

The conditions involved were as follows:

Cancer	3,251
Cardiovascular disease	156
Neurological disorders	257
Pulmonary disorders	152
Dementia	42
Mental illness	14
Other conditions	144
Combination of conditions	172

Settings

In 3,335 cases patients died at home, in 194 cases in hospital, in 139 cases in a nursing home, in 206 cases in a care home, in 250 cases in a hospice and in 64 cases elsewhere (e.g. at a family member's home).

End-of-Life Clinic

In the course of the reporting year, the committees received 32 notifications from the End-of-Life Clinic (SLK).

Bonaire, St Eustatius and Saba

In the course of the reporting year, the committees received 1 notification from the Caribbean Netherlands.

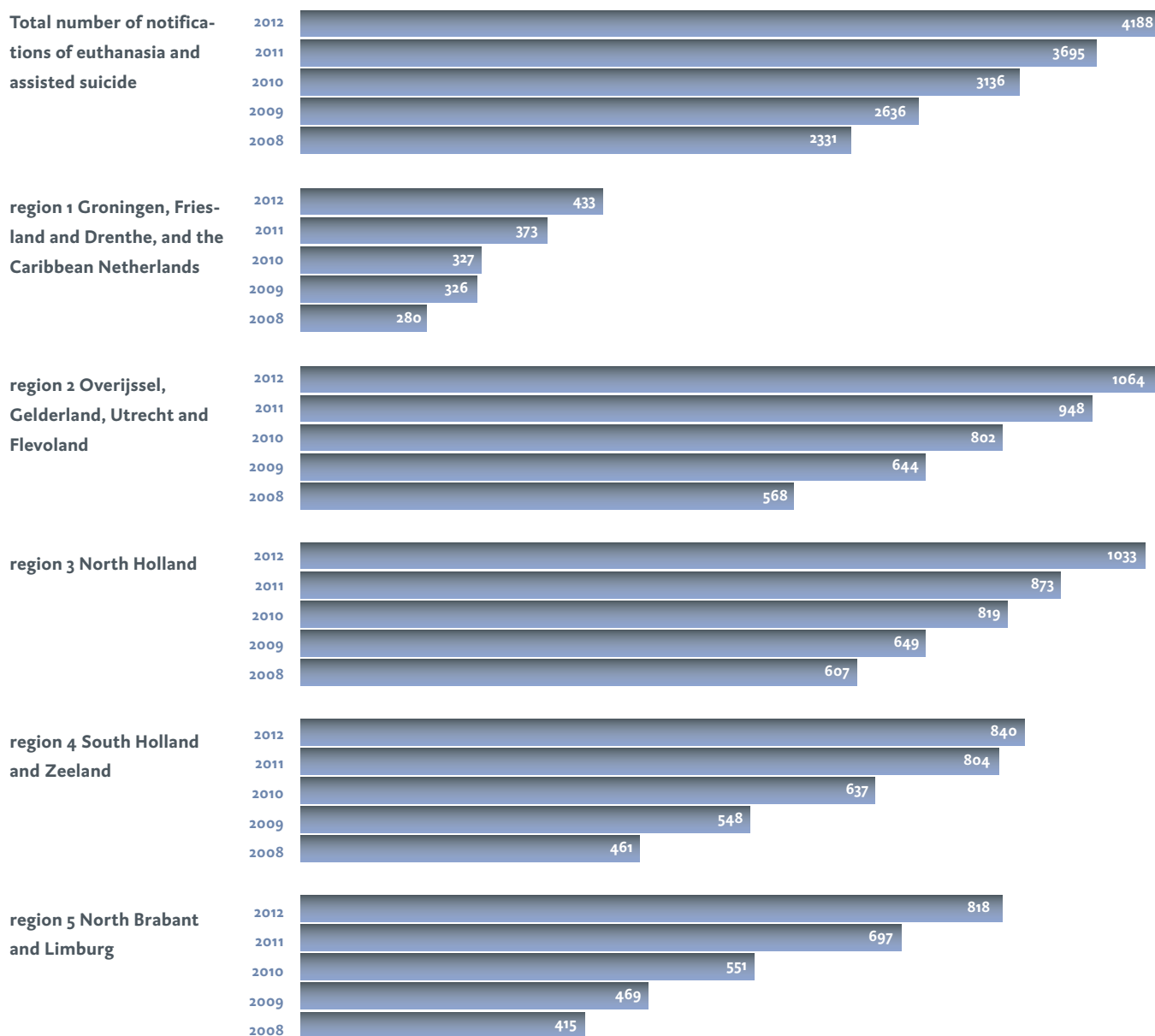
Competence and findings

In all cases the committee deemed itself competent to deal with the notification. In the year under review there were 10 cases in which the physician was found not to have acted in accordance with the due care criteria.

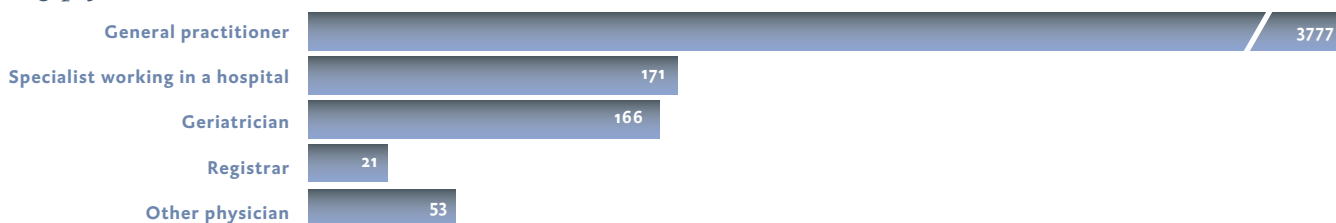
Length of assessment period

The average time that elapsed between the notification being received and the committee's findings being sent to the physician was 127 days.

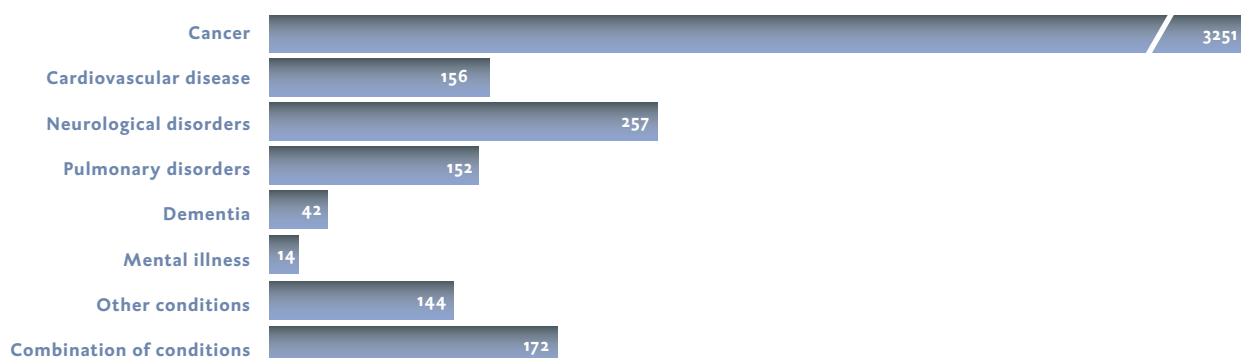
Number of notifications of euthanasia and assisted suicide 2012, 2011, 2010, 2009 en 2008



Notifying physicians in 2012



Conditions involved in 2012



Annexe II

Termination of Life on Request and Assisted Suicide (Review Procedures) Act

Act of 12 April 2001, containing review procedures for the termination of life on request and assisted suicide and amendment of the Criminal Code and the Burial and Cremation Act (Termination of Life on Request and Assisted Suicide (Review Procedures) Act)

We, Beatrix, by the grace of God Queen of the Netherlands, Princess of Orange-Nassau, etc., etc., etc.

Greetings to all who shall see or hear these presents! Be it known:

Whereas We have considered that it is desirable to include in the Criminal Code grounds for granting immunity to a physician who, acting in accordance with the statutory due care criteria laid down in this Act, terminates life on request or provides assistance with suicide, and also that it is desirable to create a statutory notification and review procedure;

We, therefore, having heard the Council of State, and in consultation with the States General, have approved and decreed as We hereby approve and decree:

Chapter I *Definitions*

Section 1

For the purposes of this Act:

- a. Our Ministers: the Minister of Justice and the Minister of Health, Welfare and Sport;
- b. assisted suicide: intentionally helping another person to commit suicide or providing him with the means to do so as referred to in article 294, paragraph 2, second sentence, of the Criminal Code;
- c. the attending physician: the physician who, according to the notification, has terminated life on request or has provided assistance with suicide;
- d. the independent physician: the physician who has been consulted about the attending physician's intention to terminate life on request or to provide assistance with suicide;
- e. the care providers: the natural persons referred to in article 446, paragraph 1, of Book 7 of the Civil Code;
- f. the committee: a regional review committee as referred to in section 3;
- g. regional inspector: a regional inspector employed by the Healthcare Inspectorate of the Public Health Supervisory Service.

Chapter II *Due care criteria*

Section 2

1. In order to comply with the due care criteria referred to in article 293, paragraph 2, of the Criminal Code, the attending physician must:
 - a. be satisfied that the patient has made a voluntary and carefully considered request;
 - b. be satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement;
 - c. have informed the patient about his situation and his prospects;
 - d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;
 - e. have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to in a. to d. above; and
 - f. have terminated the patient's life or provided assistance with suicide with due medical care and attention.

2. If a patient aged sixteen or over who is no longer capable of expressing his will, but before reaching this state was deemed capable of making a reasonable appraisal of his own interests, has made a written declaration requesting that his life be terminated, the attending physician may comply with this request. The due care criteria referred to in subsection 1 apply *mutatis mutandis*.
3. If the patient is a minor aged between sixteen and eighteen and is deemed to be capable of making a reasonable appraisal of his own interests, the attending physician may comply with a request made by the patient to terminate his life or provide assistance with suicide, after the parent or parents who has/have responsibility for him, or his guardian, has or have been consulted.
4. If the patient is a minor aged between twelve and sixteen and is deemed to be capable of making a reasonable appraisal of his own interests, the attending physician may comply with the patient's request if the parent or parents who has/have responsibility for him, or his guardian, is/are able to agree to the termination of life or to assisted suicide. Subsection 2 applies *mutatis mutandis*.

Chapter III *Regional review committees for the termination of life on request and assisted suicide*

Division 1: Establishment, composition and appointment

Section 3

1. Regional committees will be established to review reported cases of the termination of life on request or assisted suicide as referred to in article 293, paragraph 2, and article 294, paragraph 2, second sentence, of the Criminal Code.
2. A committee consists of an odd number of members, including in any event one legal expert who also chairs the committee, one physician and one expert on ethical or moral issues. A committee also comprises alternate members from each of the categories mentioned in the first sentence.

Section 4

1. The chair, the members and the alternate members are appointed by Our Ministers for a period of six years. They may be reappointed once for a period of six years.
2. A committee has a secretary and one or more deputy secretaries, all of whom must be legal experts appointed by Our Ministers. The secretary attends the committee's meetings in an advisory capacity.
3. The secretary is accountable to the committee alone in respect of his work for the committee.

Division 2: Resignation and dismissal

Section 5

The chair, the members and the alternate members may tender their resignation to Our Ministers at any time.

Section 6

The chair, the members and the alternate members may be dismissed by Our Ministers on the grounds of unsuitability or incompetence or other compelling reasons.

Division 3: Remuneration

Section 7

The chair, the members and the alternate members are paid an attendance fee and a travel and subsistence allowance in accordance with current government regulations, insofar as these expenses are not covered in any other way from the public purse.

Division 4: Duties and responsibilities

Section 8

1. The committee assesses, on the basis of the report referred to in section 7, subsection 2 of the Burial and Cremation Act, whether an attending physician, in terminating life on request or in assisting with suicide, acted in accordance with the due care criteria set out in section 2.
2. The committee may request the attending physician to supplement his report either orally or in writing, if this is necessary for a proper assessment of the attending physician's actions.
3. The committee may obtain information from the municipal pathologist, the independent physician or the relevant care providers, if this is necessary for a proper assessment of the attending physician's actions.

Section 9

1. The committee notifies the attending physician of its findings within six weeks of receiving the report referred to in section 8, subsection 1, giving reasons.
2. The committee notifies the Board of Procurators General of the Public Prosecution Service and the regional health care inspector of its findings:
 - a. if the attending physician, in the committee's opinion, did not act in accordance with the due care criteria set out in section 2; or
 - b. if a situation occurs as referred to in section 12, last sentence, of the Burial and Cremation Act.

The committee notifies the attending physician accordingly.
3. The time limit defined in the first subsection may be extended once for a maximum of six weeks. The committee notifies the attending physician accordingly.
4. The committee is empowered to explain its findings to the attending physician orally. This oral explanation may be provided at the request of the committee or the attending physician.

Section 10

The committee is obliged to provide the public prosecutor with all the information that he may require:

- 1° for the purpose of assessing the attending physician's conduct in a case as referred to in section 9, subsection 2; or
- 2° for the purposes of a criminal investigation.

The committee notifies the attending physician that it has supplied information to the public prosecutor.

Division 6: Procedures

Section 11

The committee is responsible for making a record of all reported cases of termination of life on request or assisted suicide. Our Ministers may lay down further rules on this point by ministerial order.

Section 12

1. The committee adopts its findings by a simple majority of votes.
2. The committee may adopt findings only if all its members have taken part in the vote.

Section 13

The chairs of the regional review committees meet at least twice a year in order to discuss the methods and operation of the committees. A representative of the Board of Procurators General and a representative of the Health Care Inspectorate of the Public Health Supervisory Service will be invited to attend these meetings.

*Division 7: Confidentiality and disqualification***Section 14**

The members and alternate members of the committee are obliged to maintain confidentiality with regard to all the information that comes to their attention in the course of their duties, unless they are required by a statutory regulation to disclose the information in question or unless the need to disclose the information in question is a logical consequence of their responsibilities.

Section 15

A member of the committee sitting to review a particular case must disqualify himself and may be challenged if there are any facts or circumstances which could jeopardise the impartiality of his judgment.

Section 16

Members or alternate members or the secretary of the committee must refrain from giving any opinion on an intention expressed by an attending physician to terminate life on request or to provide assistance with suicide.

*Division 8: Reporting requirements***Section 17**

1. By 1 April of each year, the committees submit to Our Ministers a joint report on their activities during the preceding calendar year. Our Ministers lay down the format of such a report by ministerial order.
2. The report referred to in subsection 1 must state in any event:
 - a. the number of cases of termination of life on request and assisted suicide of which the committee has been notified and which the committee has assessed;
 - b. the nature of these cases;
 - c. the committee's findings and its reasons.

Section 18

Each year, when they present their budgets to the States General, Our Ministers report on the operation of the committees on the basis of the report referred to in section 17, subsection 1.

Section 19

1. On the recommendation of Our Ministers, rules will be laid down by order in council on:
 - a. the number of committees and their territorial jurisdiction;
 - b. their locations.
2. Further rules may be laid down by Our Ministers by or pursuant to order in council with regard to:
 - a. the size and composition of the committees;
 - b. their working methods and reporting procedures.

Chapter IIIa *Bonaire, St Eustatius and Saba*

[Entry into force: 10/10/2012]

Section 19a [Entry into force: 10/10/2012]

This Act also applies in the territories of the public bodies Bonaire, St Eustatius and Saba in accordance with the provisions of this chapter.

Section 19b [Entry into force: 10/10/2012]

1. For the purposes of:
 - section 1 (b), ‘article 294, paragraph 2, second sentence, of the Criminal Code’ is replaced by: ‘article 307, paragraph 2, second sentence, of the Criminal Code of Bonaire, St Eustatius and Saba’.
 - section 1 (f), ‘a regional review committee as referred to in section 3’ is replaced by: ‘a committee as referred to in section 19c’.
 - section 2, subsection 1, opening words, ‘article 293, paragraph 2, second sentence’ is replaced by: ‘article 306, paragraph 2, second sentence’, of the Criminal Code of Bonaire, St Eustatius and Saba’.
 - section 8, subsection 1, ‘section 7, subsection 2 of the Burial and Cremation Act’ is replaced by: ‘section 1, subsection 3 of the Death Certificates (Bonaire, St Eustatius and Saba) Act’.
 - section 8, subsection 3, ‘or the relevant care providers’ lapses.
 - section 9, subsection 2, opening words, ‘the Board of Procurators General of the Public Prosecution Service’ is replaced by ‘the Procurator General’.
2. Section 1 (e) does not apply.

Section 19c [Entry into force: 10/10/2012]

Notwithstanding section 3, paragraph 1, a committee will be appointed by Our Ministers that is competent to review reported cases of termination of life on request or assisted suicide as referred to in article 306, paragraph 2, and article 307, paragraph 2, second sentence, of the Criminal Code of Bonaire, St Eustatius and Saba.

Section 19d [Entry into force: 10/10/2012]

The chair of the committee referred to in section 19c takes part in the meetings referred to in section 13. The Procurator General or a representative appointed by him and a representative of the Health Care Inspectorate also take part.

Chapter IV *Amendments to other legislation*

Section 20

[Amends the Criminal Code.]

Section 21

[Amends the Burial and Cremation Act.]

Section 22

[Amends the General Administrative Law Act.]

Chapter V *Concluding provisions*

Section 23

This Act enters into force on a date to be determined by Royal Decree.

Section 24

This Act may be cited as: the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

We order and command that this Act be published in the Bulletin of Acts and Decrees and that all ministries, authorities, bodies and officials whom it may concern diligently implement it.

Done at The Hague, 12 April 2001

Beatrix

Minister of Justice,
A. H. Korthals

Minister of Health, Welfare and Sport,
E. Borst-Eilers