REGIONAL
EUTHANASIA
REVIEW COMMITTEES

RTE

ANNUAL REPORT 2019

REGIONAL
EUTHANASIA
REVIEW COMMITTEES

RTE

ANNUAL REPORT 2019

CONTENTS

CHAPTER II CASES

FOREWORD

Legal issues relating to euthanasia based on a written euthanasia request from patients with advanced dementia

For the first time since the introduction of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act ('the Act') in 2002, a physician was called before a criminal court to account for her actions. The physician was an elderly-care specialist who had performed euthanasia on the basis of an advance directive from a patient who was by then in an advanced stage of dementia. The Regional Euthanasia Review Committee (RTE) found in 2016 that the physician in question had not acted in accordance with the due care criteria.

Both the Central Healthcare Disciplinary Board and The Hague District Court issued rulings in this case. The Procurator General at the Supreme Court has filed an appeal in cassation against both rulings in the interests of the uniform application of the law. Partly because of this, much attention has been focused over the past year on the complex dilemmas that confronted the physician in this case and the associated legal issues that need to be addressed.

There can be no doubt that lawmakers have enabled physicians in certain circumstances, on the basis of an advance directive, to carry out a request for euthanasia from a patient who has developed advanced dementia. The Supreme Court will now however have to answer the following salient questions:

- If the advance directive is not entirely clear, may a physician to seek to ascertain the exact intentions of the patient by making enquiries among, for example, the patient's family members, others close to the patient, or carers?
- May a physician administer premedication (midazolam) if the physician believes this to be necessary as part of good medical practice to prevent startle responses which could cause complications when carrying out the request to terminate life?
- Is a physician required under the Medical Treatment Contracts Act (WGBO) to ask a decisionally incompetent patient whether a request for euthanasia set out in an advance directive is still valid before performing euthanasia?

The last of these three questions, which stems from the WGBO, is one which it would not be logical for the RTEs to answer since it is clear from the parliamentary history of the Act that the termination of life on request is not a normal medical procedure to which

the WGBO applies.[1] The other two questions have been considered in the past by the RTEs and answered in the affirmative. In case 2018/29 for example the committee found that the patient in question did not have an unequivocal advance directive, but it concluded on the basis of information from close family and friends, the general practitioner and the SCEN physician (an independent physician contacted through the Euthanasia in the Netherlands Support and Assessment Programme (SCEN)) that the patient's circumstances were 'plainly' those in which he had indicated he would wish euthanasia to be performed. The committee therefore found that the physician could be satisfied that the patient's request was voluntary and well considered. And in case 2018/41 the committee concluded that 'by administering premedication the physician acted in accordance with good medical practice in these specific circumstances'. Similarly, the Euthanasia Code 2018[2] states that giving premedication can be part of good medical practice. The two judgments to be given by the Supreme Court are expected to remove the existing uncertainty for physicians about how they should proceed in the case of a request to terminate life on the basis of an advance directive from a patient who has since developed advanced dementia. The Royal Dutch Medical Association (KNMG) has meanwhile taken steps to frame a position on how physicians could or should act in situations of this kind from a medical and professional perspective.

Once the Supreme Court has handed down its judgments, the RTEs will adapt their review of notifications of the termination of life on the basis of a written euthanasia request in cases of patients with advanced dementia accordingly, since it is our task to examine notifications of euthanasia for compatibility with both legislation and case law. In addition, we will examine whether there are grounds to reformulate parts of the Euthanasia Code 2018.

Improved and modified working methods

We are happy to note that it has proved possible to reduce yet further the time between notifications being received and findings being sent from an average of 37 days in 2018 to 29 days in 2019 without in any way compromising the care with which the RTEs' review process is performed. We feel it is very important to ensure that physicians are not left in a position of uncertainty for any longer than is strictly necessary as to the RTE's findings on a case of euthanasia.

1 Parliamentary Papers, Senate, 2000/01, 26 691, no. 137b. p. 18 and Parliamentary Papers, Senate, 2000/01, 26 691, no. 137e, p. 22

2 Euthanasia Code 2018, page 40

One of the recommendations of the third evaluation of the Act concerned improving and clarifying the formulation of findings in non-straightforward cases. The format of these findings has therefore been amended with effect from 1 November 2019 so that they only address that specific part of the notification that was the subject of discussion within the committee. This is followed by the committee's considerations. Unlike before, the due care criteria about which the committee entertains no doubts as to the physician's compliance are not addressed in the findings. This new format will be evaluated in mid-2020 and the scope for making further improvements will be assessed.

Organisation

Preparations continued in the year under review for the relocation to Utrecht in 2020 of the three secretariats which in 2019 were still based in Groningen, Arnhem and The Hague. Merging the secretariats is expected to provide significant impetus for the improved and more effective operation of the RTEs.

Discussions were held this year with the Ministry of Health, Welfare and Sport on the allocation of roles in the working relationship with the RTEs. The RTEs' independence from the Ministry of Health, Welfare and Sport is not in question as regards the review of individual notifications of euthanasia. In that respect the RTEs do not fall under ministerial responsibility. With regard to the functioning of the RTEs, the ministers of Health, Wealth & Sport and Justice & Security appoint a General Secretary whose tasks include coordinating the functional and administrative work of the secretaries.

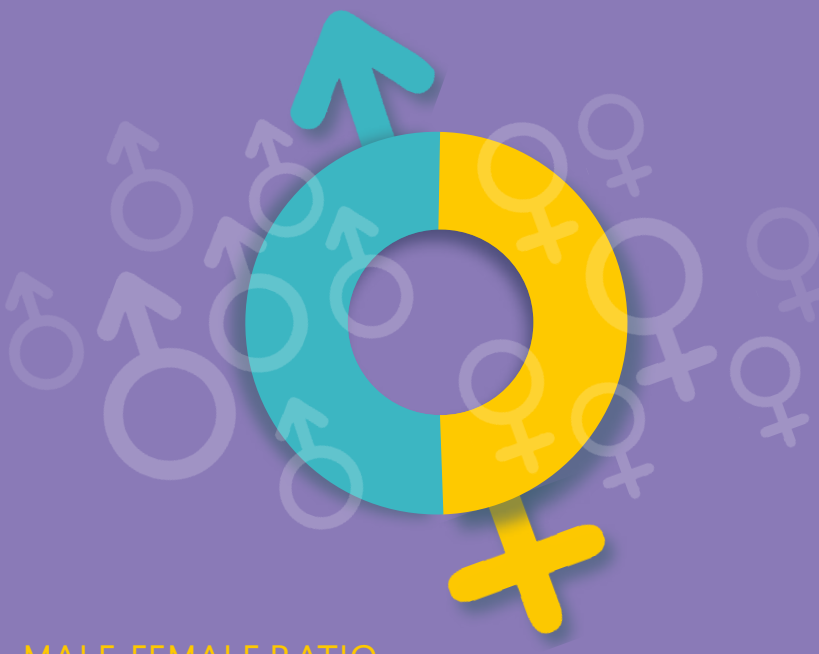
The Ministry of Health, Welfare and Sport is responsible for appointing the RTEs' secretaries and administrative staff. How does the RTEs' independence in terms of performing reviews relate to the responsibility borne by the Ministry of Health, Welfare and Sport for assigning a General Secretary and secretarial staff and providing the administrative support, office space, IT facilities and budget that the RTEs need to operate? How can greater clarity be obtained concerning the matrix structure – a complex form of governance – in which the RTEs interact with the ministry? In autumn 2019 constructive consultations were held between the Ministry of Health, Welfare and Sport and the RTEs about cooperation in the matrix. One of the outcomes was the decision to combine, in 2020, the positions of General Secretary and Deputy Director of the Disciplinary Boards and Review Committees (Secretariats) Unit (ESTT).

Summary

Looking at 2019 as a whole, relevant steps have been taken towards further improving and professionalising the way the RTEs work and are organised. Even more important is that, as in previous years, the review of notifications in 2019 delivers the incontrovertible message that due care is exercised in the practice of euthanasia in the Netherlands: in only four of a total of 6,361 notified terminations of life on request in the past year did the RTE find a failure to satisfy one or more of the due care criteria laid down in the Act. Finally, the judgments soon to be given by the Supreme Court will offer greater legal certainty on how physicians should proceed in the case of a euthanasia request on the basis of an advance directive from a patient who has since developed advanced dementia. Although in past years it has been possible to count requests of this kind on the fingers of one hand (2017: three; 2018: two; 2019: two), the Supreme Court's rulings are eagerly anticipated by many, including the RTEs.

Jacob Kohnstamm,
Coordinating chair of the Regional Euthanasia Review Committees

March 2020



MALE-FEMALE RATIO

male	3,309
female	2,935

CHAPTER I
DEVELOPMENTS IN 2019

1. ANNUAL REPORT

For more information on the outline of the Act, the committees' procedures, etc., see the Euthanasia Code 2018 and https://english.

In this annual report the Regional Euthanasia Review Committees ('RTEs') report on their work over the past calendar year. They thus account – to society, government and parliament – for the way in which they fulfil their statutory task of reviewing notified cases of termination of life on request and assisted suicide on the basis of the due care criteria laid down in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act ('the Act'). This report uses the term 'euthanasia' to refer to both forms of termination of life. The distinction between termination of life on request and assisted suicide is made only where necessary.

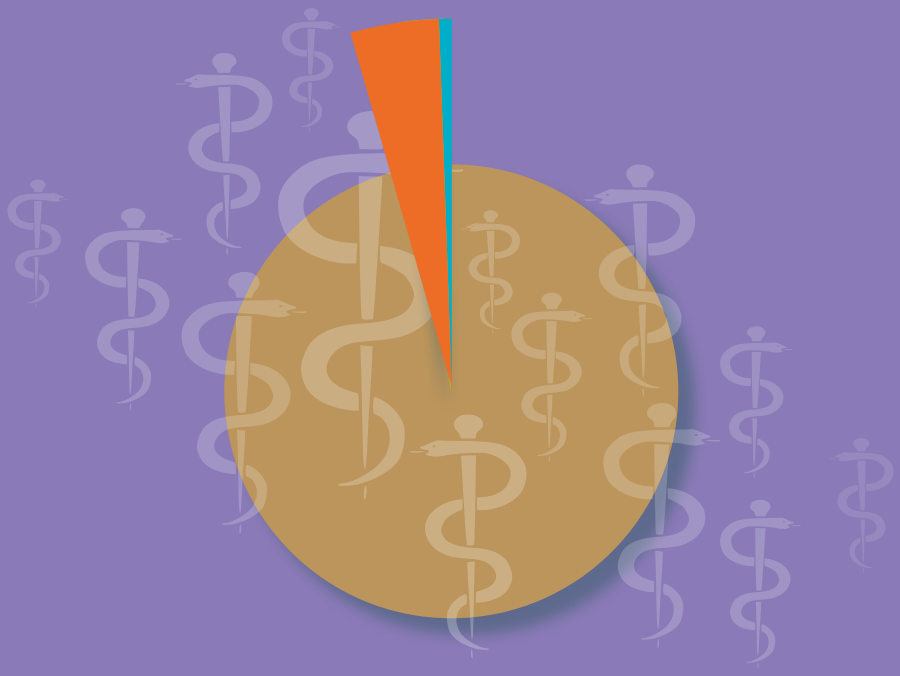
Another aim of the annual report is to give physicians and other interested parties insight into the way in which the committees have reviewed and assessed specific notifications. Chapter II therefore gives an extensive account of common and less common review findings. We have aimed to make the annual report accessible to a wide readership by avoiding the use of legal and medical terms as much as possible, or by explaining them where necessary.

2. NOTIFICATIONS

Number of notifications

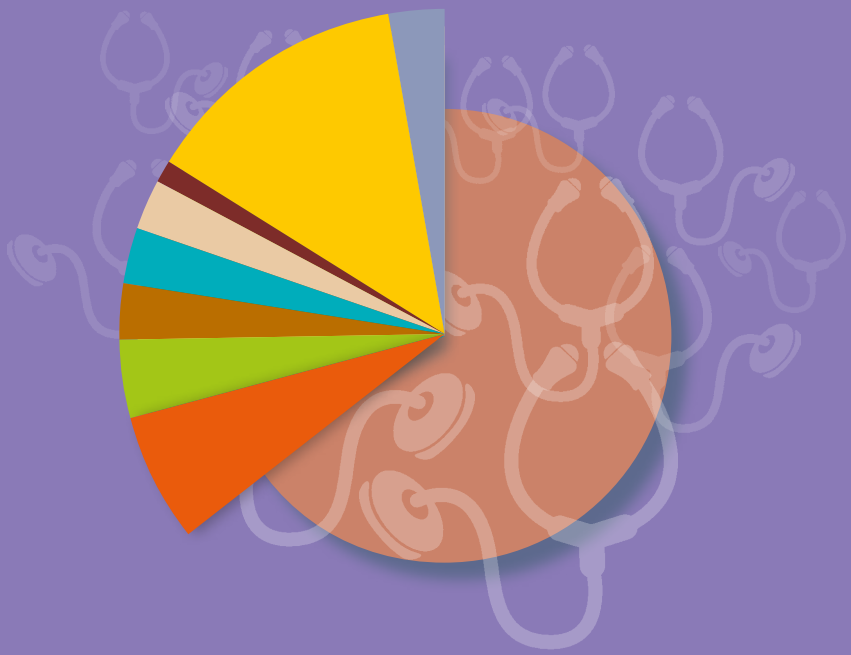
The breakdown of the number of notifications of euthanasia in the five separate regions can be found on the website (www.euthanasiecommissie.nl/uitspraken-en-uitleg (in Dutch)). euthanasiecommissie.nl.

In 2019 the RTEs received 6,361 notifications of euthanasia. This is 4.2% of the total number of people who died in the Netherlands in that year (151,793). This represents a 3.8% rise in the number of notifications compared with 2018 (6,126 notifications) but a decline of 4.4% compared with 2017 (6,585 notifications). Notifications as a percentage of total deaths were 0.2 percentage points higher than in 2018 but 0.2 percentage points lower than in 2017. In 2018 the first fall in a long while was recorded in the number of euthanasia notifications. A study commissioned by the Minister of Health, Welfare and Sport in 2019 did not provide a clear answer as to why it had occurred. It suggested that the fall could have been caused by the influenza epidemic at the beginning of that year and the announcement by the Public Prosecution Service that a notification of euthanasia that was found by the RTEs not to fulfil the due care criteria would be the subject of a criminal investigation.



RATIO BETWEEN CASES OF TERMINATION OF LIFE ON REQUEST AND CASES OF ASSISTED SUICIDE

termination of life on request	6,092
assisted suicide	245
combination of the two	24



NATURE OF CONDITIONS

cancer	4,100
neurological disorders	408
cardiovascular disease	251
pulmonary disorders	187
multiple geriatric syndromes	172
dementia	162
early-stage dementia: 160	
(very) advanced stage of dementia: 2	
psychiatric disorders	68
combination of disorders	846
other conditions	167

Male/female ratio

The numbers of male and female patients were again almost the same: 3,309 men (52%) and 2,935 women (48%).

Ratio between cases of termination of life on request and cases of assisted suicide

For points to consider regarding due medical care, see page 34 ff of the Euthanasia Code 2018.

There were 6,092 notifications of termination of life on request (95.8% of the total), 245 notifications of assisted suicide (3.9%) and 24 notifications involving a combination of the two (0.4%). A combination of the two occurs if, in a case of assisted suicide, the patient ingests the potion handed to them by the physician, but does not die within the time agreed by the physician and the patient. The physician then performs the termination of life on request by intravenously administering a coma-inducing substance, followed by a muscle relaxant.

Conditions

Most common conditions

91.1% of the notifications (5,792) involved patients with:

- incurable cancer (4,100)
- neurological disorders such as Parkinson's disease, multiple sclerosis and motor neurone disease (408);
- cardiovascular disease (251);
- pulmonary disorders (187);

or a combination of conditions (846).

Dementia

For points to consider regarding patients with dementia, see page 44 ff of the Euthanasia Code 2018.

Two notifications in 2019 involved patients in an advanced or very advanced stage of dementia who were no longer able to communicate regarding their request and in whose cases the advance directive was decisive in establishing whether the request was voluntary and well considered. These cases are described in Chapter II and have been published (numbered 2019-79 and 2019-119) on www.euthanasiecommissie.nl.

In 160 cases the patient's suffering was caused by early-stage dementia. These patients still had insight into their condition and its symptoms, such as loss of bearings and personality changes. They were deemed decisionally competent with regard to their request for euthanasia because they could still grasp its implications. Case 2019-90, described in Chapter II, is an example.

AGE

30 years or younger	15
30-40 years	45
40-50 years	163
50-60 years	587
60-70 years	1336
70-80 years	2083
80-90 years	1628
90 years or older	504

Psychiatric disorders

For points to consider regarding patients with a psychiatric disorder, see page 42 ff of the Euthanasia Code 2018.

In 68 notified cases of euthanasia the patient's suffering was caused by one or more psychiatric disorders. In 42 of these cases the notifying physician was a psychiatrist, in 11 cases a general practitioner, in two cases an elderly-care specialist and in 13 cases another physician. In 52 cases of euthanasia involving patients with psychiatric disorders, the physician performing euthanasia was affiliated with the Euthanasia Expertise Centre (EE), formerly the End-of-Life Clinic (SLK). In these cases, the physician must exercise particular caution, as was done in case 2019-121 (described in Chapter II).

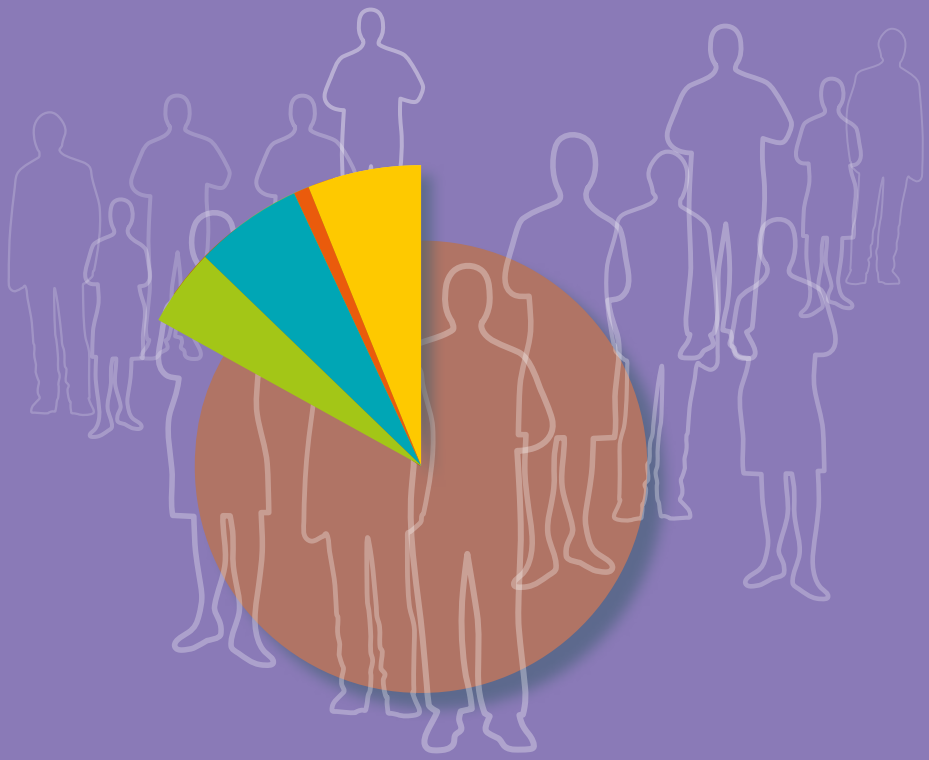
Multiple geriatric syndromes

For points to consider regarding multiple geriatric syndromes, see page 22 ff of the Euthanasia Code 2018.

Multiple geriatric syndromes – such as sight impairment, hearing impairment, osteoporosis, osteoarthritis, balance problems or cognitive deterioration – may cause unbearable suffering without prospect of improvement. These syndromes, which are often degenerative in nature, generally occur in elderly patients, and are the sum of one of more disorders and related symptoms. In conjunction with the patient's medical history, life history, personality, values and stamina, they may give rise to suffering that the patient experiences as unbearable and without prospect of improvement. In 2019 the RTEs received 172 notifications of euthanasia that fell into this category. Two notifications reviewed by the RTEs relating to multiple geriatric syndromes are included in Chapter II (2019-67 and 2019-127).

Other conditions

Lastly, the RTEs register cases involving conditions that do not fall into any of the above categories, such as chronic pain syndrome, as 'other conditions'. There were 167 such cases in 2019.



NOTIFYING PHYSICIANS

general practitioner	5,290
elderly-care specialist	269
specialist working in a hospital	361
registrar	61
other physician (e.g. doctors affiliated with the End-of-Life Clinic)	380

Age

The highest number of notifications of euthanasia involved people in their seventies (2,083 cases, 32.7%), followed by people in their eighties (1628 cases, 25.6%) and people in their sixties (1,363 cases, 21.4%). In 2019 the RTEs reviewed no notifications of euthanasia involving a minor between the ages of 12 and 17.

For points to consider regarding minors, see pages 41 and 42 of the Euthanasia Code.

There were 60 notifications concerning people aged between 18 and 40. In 38 of these cases, the patient's suffering was caused by cancer and in 10 cases it was caused by a psychiatric disorder. In the category 'dementia', the highest number of notifications involved people in their eighties (71 cases). In the category 'psychiatric disorders', in 2019 there were 20 notifications involving people in their fifties and the same number involving people in their sixties. In the category 'multiple geriatric syndromes' most of the notifications concerned people aged 90 or older (123 cases).

Locations

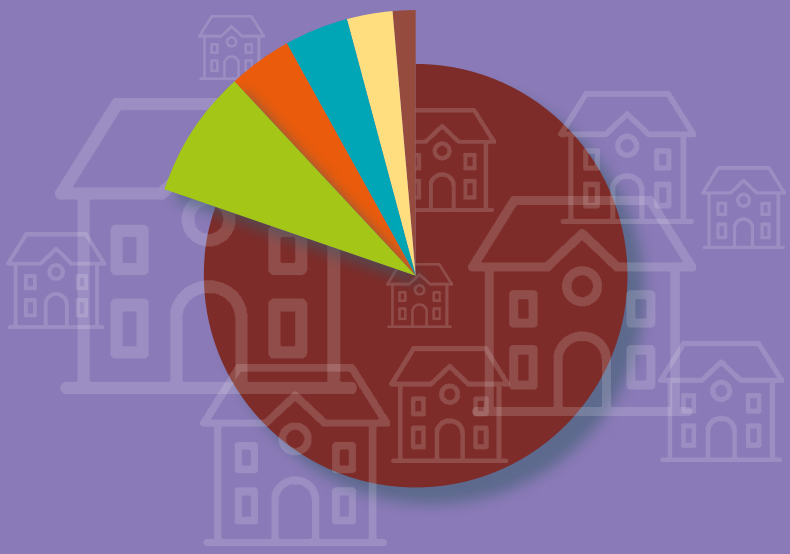
As in previous years, in the vast majority of cases the patient died at home (5,098 cases, 80.1%). Other locations were a hospice (480 cases, 7.6%), a care home (273 cases, 4.3%), a nursing home (231 cases, 3.6%), a hospital (178 cases, 2.8%) or elsewhere, for instance at the home of a family member, in a sheltered accommodation centre or a convalescent home (101 cases, 1.6%).

Notifying physicians

The vast majority of cases (5,290) were notified by a general practitioner (83.1% of the total number). The other notifying physicians were elderly-care specialists (269), other specialists (361) and registrars (61). There was also a group of notifying physicians with other backgrounds (380), most of them affiliated with the EE.

The number of notifications by physicians affiliated with the EE (904) rose by 25% in comparison with 2018, when there were 726 notifications by this group.

EE physicians are often called upon if the attending physician considers a request for euthanasia to be too complicated. Physicians who do not perform euthanasia for reasons of principle or who will only perform euthanasia if the patient has a terminal condition also often refer patients to the EE. In some cases, rather than being referred by an attending physician, the patients themselves contact the EE or ask their families to do so. Many of the notifications involving patients with a psychiatric disorder came from EE physicians: 52 out of 68 notifications (over 76%). Of the 162 notifications of cases in which the



LOCATIONS

home	5,098
hospice	480
care home	231
nursing home	273
hospital	178
elsewhere	101

(for instance at the home of a family member, in a sheltered accommodation centre or a convalescent home)

patient's suffering was caused by a form of dementia, 84 (51.9%) came from EE physicians. Of the 172 notifications involving patients with multiple geriatric syndromes, 88 (51.1%) came from EE physicians.

Euthanasia and organ and tissue donation

Termination of life by means of euthanasia does not preclude organ and tissue donation. The *Richtlijn Orgaandonatie na euthanasie* (Guidelines on organ donation after euthanasia) published by the Dutch Foundation for Transplants provides a step-by-step procedure for such cases. In 2019 the RTEs received 12 notifications indicating that organ donation had taken place after euthanasia.

Couples

In 34 cases, euthanasia was performed simultaneously on both members of a couple (17 couples). Cases 2019-08 and 2019-09 on the website are examples. Of course, the due care criteria set out in the Act must be satisfied in both cases separately. Each partner must be visited by a different independent physician in order to safeguard the independence of the assessment.

Due care criteria not complied with

In four of the notified cases in 2019, the RTEs found that the physician who performed euthanasia did not comply with all the due care criteria set out in section 2 (1) of the Act: that is less than 0.1% of all notifications. These four cases are discussed in Chapter II.

Grey areas in the review procedure

Limiting this report to an account of how often the RTEs found that the physician had not complied with one or more of the statutory due care criteria would not do justice to the complexity of the review procedure. In practice, there are grey areas. In 29 cases (including the four mentioned above where the committee found that the due care criteria had not been satisfied), the committee asked the notifying physician for further information in writing, and in one case the independent physician was asked to provide more information. In 19 cases the committee invited the notifying physician (and in one case the independent physician) to answer the committee's questions in person, sometimes after having first put written questions to the physician. Generally these oral and written explanations by the notifying and independent physicians provided sufficient clarification, allowing the committee to reach the conclusion that the physician in question had complied with the due care criteria. Nevertheless, the committees also regularly advised physicians on how they could improve their working methods and their notifications in the future.

3 COMMITTEE PROCEDURES – DEVELOPMENTS

Non-straightforward cases, straightforward cases and findings letters

Since 2012, notifications received by the RTEs have been processed as follows. Upon receipt, a notification is categorised by the secretary of the committee, who is an experienced lawyer, as a non-straightforward case (VO) or a straightforward case (NVO). Notifications are categorised as straightforward if the secretary of the committee considers that the information provided is comprehensive and the physician has complied with the statutory due care criteria. After the initial selection by the secretary of the committee, the committee reviews the notifications. This is done digitally for the straightforward cases. The committee then decides whether it agrees with the secretary's provisional view that the notification is straightforward or whether on the contrary it considers it to be non-straightforward. In the latter case the committee categorises the notification as non-straightforward and discusses it at a meeting. In 2019 it did so in 26 cases (less than 1% of notifications).

In response to a recommendation to the RTEs in the third evaluation of the Act to better explain the reasons for their findings, they decided to amend their procedures from November 2019. If a notification is completely straightforward, the physician nearly always receives a findings letter (ODB). This is a letter outlining the facts of the case and informing the physician of the committee's finding, based on those facts, that the physician has complied with the due care criteria. The practice of sending findings letters was introduced in 2018 for completely straightforward cases where the patient's suffering was caused by cancer, motor neurone disease, chronic obstructive pulmonary disease or heart failure or a combination of two or more of these disorders. An example of a findings letter is shown on the next page.

Full findings are issued in non-straightforward cases. In such findings the committee has started setting out more clearly than before which aspects of a notification were not straightforward and what its reasons were for deciding that the due care criteria were, or were not, complied with in regard to those aspects.

Occasionally a straightforward notification will be discussed at a committee meeting and full written findings will be issued. This happens in cases where the committee takes the view that it needs to explain its findings in more detail because of one or more aspects of the notification. By providing a more complete description of certain aspects of their findings concerning non-straight-

FINDINGS LETTER

Dear Mr/Ms [name],

On [date] the Regional Euthanasia Review Committee ('the committee') received your report and the accompanying documents concerning your notification of termination of life on request for Mr/Ms [name], born on [date], deceased on [date]. The committee has studied all the documents carefully.

In view of the facts and circumstances described in the documents, the committee has found that you could be satisfied that the patient's request was voluntary and well considered, and that the patient's suffering was unbearable, with no prospect of improvement. You informed the patient sufficiently about their situation and prognosis. Together, you and the patient could be satisfied that there was no reasonable alternative in the patient's situation. You 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. Lastly, you performed the euthanasia procedure with due medical care.

On the grounds of the above, the committee finds that you acted in accordance with the statutory due care criteria laid down in section 2 (1) of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

The committee consisted of the following persons:
[name], chair, lawyer
[name], member, physician
[name], member, ethicist

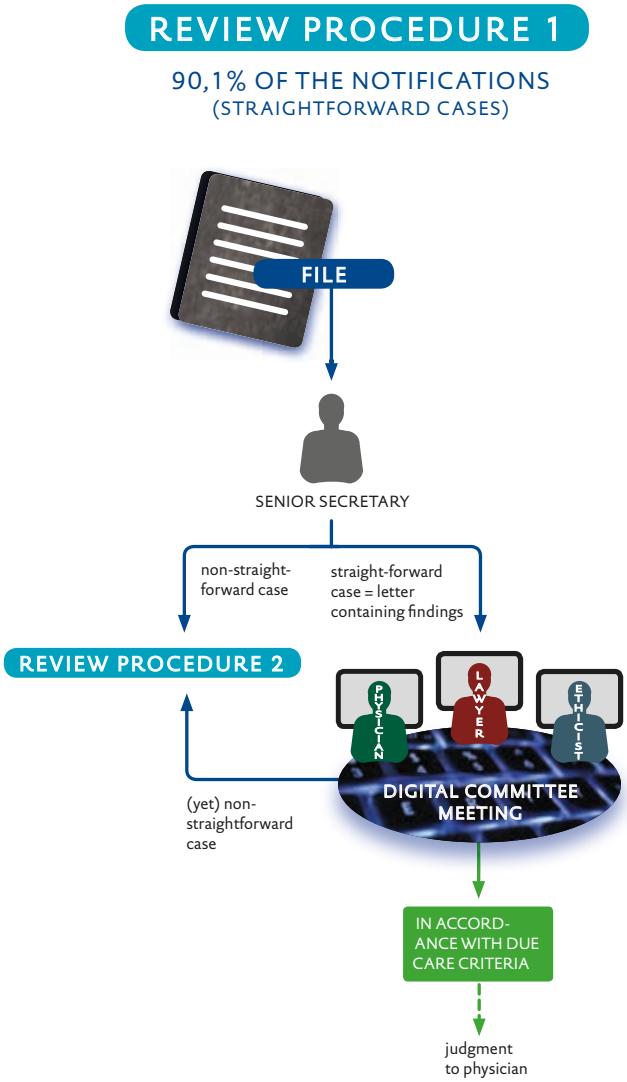
Yours sincerely,

[signature]
chair

[signature]
secretary

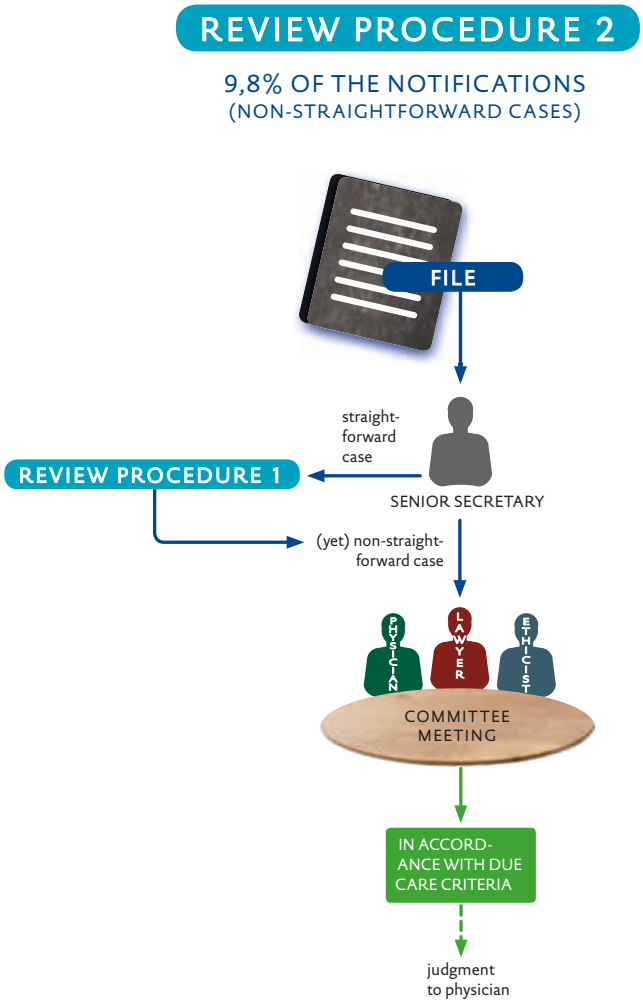
forward notifications and unusual notifications, the RTEs expect to give physicians and other stakeholders a clearer picture of the way the RTEs reach their findings and the decisive arguments underlying them.

Cases 2019-128, 2019-129, 2019-130 and 2019-131 have been included in Chapter II as examples of cases that were dealt with by means of a findings letter. It should be noted that, given this fact, these are summaries of the case histories in question and not the findings sent to the doctor.



In 2019, 90.1% of the notifications received were categorised as straightforward by the secretary of the committees, a higher percentage than in 2018 (85%). This rise can partly be explained by amended criteria for the compulsory categorisation of cases by the secretary of the committee as non-straightforward, and partly by increasingly comprehensive reporting by physicians. In 69.2% of the cases, the notifications were dealt with by means of a findings letter to the physician.

Of all the notifications received, 9.8% (623) were immediately categorised as non-straightforward because, for example, they involved patients with a psychiatric disorder, there were questions about how euthanasia had been performed, or because the case file submitted by the notifying physician was not detailed enough.



In 2019 the average time that elapsed between the notification being received and the findings being sent to the physician was 29 days. This is within the time limit of six weeks laid down in section 9 of the Act and quicker than the average in 2018 of 37 days.

Complex notifications

Some cases are considered to be so complex that all the RTE members should be able to have a say in the matter. This leads to intensive consultations between the committees. The standard practice is that when a committee believes a particular notification does not meet the due care criteria, it makes the case file and its draft findings available to the members of all the committees on the RTE intranet site. It reaches a final conclusion after studying the comments from other committee members.

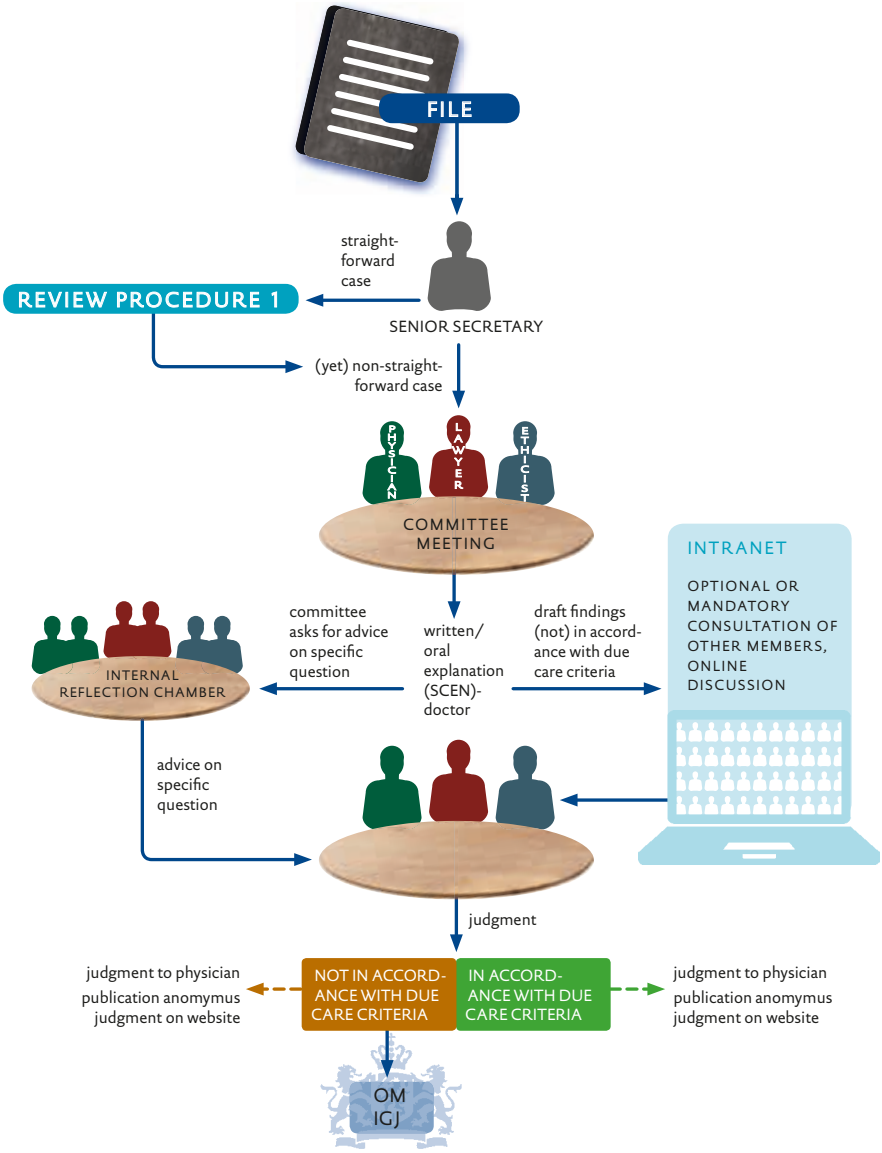
The same is done in other cases where the committee feels it would benefit from an internal debate. The aim is to ensure the quality of the review is as high as possible and to achieve maximum uniformity in the findings. Nineteen cases were discussed in this way in 2019, including the cases in which the committee found that the due care criteria had not been fulfilled.

Reflection chamber

In 2016 the RTEs decided to establish an internal reflection chamber to further a number of aims, including enhanced coordination and harmonisation. The reflection chamber consists of two lawyers, two physicians and two experts on ethical or moral issues, all of whom have been a member of an RTE for at least three years and are expected to remain a member for at least another two. They are assisted by a secretary. A committee can consult the chamber if it is faced with a complex issue. The chamber does not review the entire notification, but instead looks at one or more specific questions formulated by the committee. Given the time that is needed for the reflection chamber to do its work, the notifying physician is informed that there will be a delay in dealing with the notification. The committees did not seek the opinion of the reflection chamber in 2019. An ongoing evaluation of the reflection chamber is due to be completed in the first quarter of 2020.

REVIEW PROCEDURE 3

<1% OF THE NOTIFICATIONS (NON-STRAIGHTFORWARD CASES)



Organisation

There is one RTE in each of five regions. Each region has three lawyers (who also act as chair), three physicians and three experts on ethical or moral issues (ethicists). This brings the total number of committee members to 45.

The committee members are publicly recruited and appointed for a term of four years by the Minister of Health, Welfare and Sport and the Minister of Justice and Security, on the recommendation of the committees. They may be reappointed once.

The committees are independent: they review the euthanasia notifications for compliance with the statutory due care criteria and reach their conclusions without any interference from ministers, politicians or other parties. In other words, although the members and the coordinating chair are appointed by the ministers, the latter are not empowered to give 'directions' regarding the substance of the findings.

The coordinating chair of the RTEs presides over the policy meetings of the committee chairs, at which the physicians and ethicists are also represented. The coordinating chair also chairs one of the five regional committees.

The committees are assisted by a secretariat consisting of approximately 25 staff members: the general secretary, secretaries (who are also lawyers) and administrative assistants (who provide process support). The secretaries attend committee meetings in an advisory capacity

and are supervised by the general secretary. All the staff members are civil servants formally employed by the Ministry of Health, Welfare and Sport and part of the Disciplinary Boards and Review Committees (Secretariats) Unit (ESTT). In organisational and operational terms, the secretariats therefore fall under the director of the ESTT.

Over 70 staff members are employed in this unit, including the support unit (10 staff) and management (director and deputy director).

The administrative assistants of the RTEs are responsible for all administrative processes, from registering the details of received notifications to sending the committee's findings to the notifying physician and/or the Public Prosecution Service and the Health and Youth Care Inspectorate.

The secretariat of the committees is currently based at two locations in the Netherlands: Arnhem and The Hague. The Groningen location was closed in the autumn of 2019 in anticipation of the reorganisation discussed below. The ESTT support unit and management are located in The Hague.

Changes are in the pipeline that will reduce the vulnerability of these small, decentralised units and enhance the ongoing professionalisation of the secretariat of the RTEs. The Senior Management Board of the Ministry of Health, Welfare and Sport decided at the end of 2018 to conduct a reorganisation that will locate the entire secretariat in Utrecht. After the Works Council had issued a positive opinion on the proposed reorganisation on 21 November, the Deputy Secretary-General of the Ministry of Health, Welfare and Sport officially took the reorganisation decision on 9 December 2019. This marked the formal start of the reorganisation process. The aim is to complete the move to the new location by the end of summer, 2020.

The number of staff and the types of jobs they do will not change as a consequence of this reorganisation. It only involves moving their place of work from Arnhem and The Hague to Utrecht. In addition, the aim is to hold all RTE meetings in Utrecht.

Lastly, a few words on costs. In 2019, the costs of the RTEs amounted to over €4 million. Of that total, committee members' fees and allowances amounted to €769,000, while costs relating to materials, hiring external staff, IT and office accommodation were €857,000. €2,448,000 was spent on staff (management, support unit and secretariat).

CHAPTER II
CASES

II

1. INTRODUCTION

This chapter describes various findings by the RTEs. The essence of the RTEs' work consists of reviewing physicians' notifications concerning termination of life on request and assisted suicide (euthanasia).

A physician who has performed euthanasia has a statutory duty to report this to the municipal pathologist. The municipal pathologist then sends the notification and the various accompanying documents to the RTE. The main documents in the notification file submitted by physicians are the report by the notifying physician, the report by the independent physician consulted, excerpts from the patient's medical records such as letters from specialists, the patient's advance directive if there is one and a declaration by the municipal pathologist. The independent physician is almost always contacted through the Euthanasia in the Netherlands Support and Assessment Programme (SCEN), which falls under the Royal Dutch Medical Association (KNMG).

The committee examines whether the notifying physician has acted in accordance with the six due care criteria set out in section 2 (1) of the Act.

The due care criteria say that the physician must:

a. be satisfied that the patient's request is voluntary and well considered;
b. be satisfied that the patient's suffering is unbearable, with no prospect of improvement;
c. have informed the patient about his situation and his prognosis;
d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation;
e. have consulted 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 suicide.

The RTEs review notifications in the context of the Act, its legislative history, the relevant case law and the Euthanasia Code 2018, which was drawn up on the basis of earlier findings of the RTEs. They also take the decisions of the Public Prosecution Service and the Health and Youth Care Inspectorate into account.

The RTEs decide whether it *has been established* that the criteria of (c) informing the patient, (e) consulting an independent physician, and (f) due medical care have been fulfilled. These are matters that can be established on the basis of the facts. The other three due care criteria prescribe that the physician *must be satisfied that / have come to the conclusion* that (a) the patient's request was voluntary and well considered, that (b) the patient's suffering was unbearable, with no prospect of improvement, and that (d) there was no reasonable alternative. Given the phrasing of the due care criteria ('be satisfied that / have come to the conclusion that'), the physician has a certain amount of discretion in making the assessment. When reviewing the physician's actions with regard to these three criteria, the RTEs therefore look at the way in which the physician assessed the facts and at the explanation the physician gives for their decisions. The RTEs thus review whether, within the room for discretion allowed by the Act, the physician was able to decide that these three due care criteria had been met. In so doing they also look at the way in which the physician substantiates this conclusion. The independent physician's report often contributes to that substantiation.

The cases described in this chapter fall into two categories: cases in which the RTEs found that the due care criteria had been complied with (section 2) and cases in which the RTEs found that the due care criteria had not been complied with (section 3). The latter means that in the view of the committee in question, the physician failed to comply fully with one or more of the due care criteria.

Section 2 is divided into three subsections. In subsection 2.1 we present seven cases that are representative of the vast majority of notifications received by the RTEs. These are cases involving incurable conditions, such as cancer, neurological disorders, cardiovascular disease, pulmonary disease or a combination of conditions, where the findings were not always set out in detail but the physician generally received a findings letter. This is a letter stating that the physician has complied with the due care criteria and briefly explaining the reasons for this conclusion.

In subsection 2.2 we examine the various due care criteria, with a particular focus on (a) a voluntary and well-considered request, (b) unbearable suffering without prospect of improvement, (d) the joint conclusion that there is no reasonable alternative, (e) consultation of an independent physician and (f) due medical care. This subsection presents cases that are more complex. This complexity is conveyed, for example, by means of additional information about the patient, the patient's request and the nature of their suffering, as well as more details on the committee's considerations. There is no explicit reference here to one of the due care criteria: (c) informing the patient

about his prognosis. This criterion is generally closely connected with other due care criteria, including the criterion that the request must be voluntary and well considered. This can only be the case if the patient is well aware of their health situation and prognosis. Since the requirements of unbearable suffering without prospect of improvement and the lack of a reasonable alternative are also closely related, they are addressed together in a single cited case.

In subsection 2.3 we describe a number of cases of euthanasia or assisted suicide involving patients in a special category: patients with a psychiatric disorder, patients with dementia and patients with multiple geriatric syndromes. The majority of these cases were reported by the Euthanasia Expertise Centre (EE), formerly the End-of-Life Clinic (SLK). However, except for two notifications of euthanasia based on a written euthanasia request, in the selected cases in section 2.3 euthanasia was performed by an attending physician.

Finally, this year a number of notifications concerned patients who were subject to an order restricting their liberty during the euthanasia process. Of those discussed in this report, one concerned a patient subject to a hospital order, one concerned a patient who underwent euthanasia one day after completing a prison sentence, and one concerned a patient committed to a psychiatric hospital under the Psychiatric Hospitals (Committals) Act (section 2.4).

In all the cases described in section 2, the committee found that the physician had complied with the due care criteria laid down in the Act.

Section 3 describes the four cases in which the committee found that the due care criteria had not been met. In three of these cases the committee found that the physician had not fulfilled the requirements regarding consulting at least one independent physician and in one case that the procedure to terminate the patient's life had not been carried out with due medical care.

Some cases are numbered. These numbers can be used to find the full text of the findings (in Dutch) on the RTEs' website (www.euthanasiecommissie.nl). In cases where the physician received a findings letter, a full report of findings was not drawn up. Instead, the facts included in the notification are summarised for the purpose of the annual report. These summaries are also available on the website.

2. PHYSICIAN ACTED IN ACCORDANCE WITH THE DUE CARE CRITERIA

2.1 Seven examples of the most common notifications

As stated in Chapter 1, the vast majority of euthanasia cases involve patients with cancer (4,100), neurological disorders (408), cardiovascular disease (251), pulmonary disease (187) or a combination of conditions (846). The seven examples discussed below are illustrative. They give an impression of the issues that the RTEs encounter most frequently.

Two cases are presented of patients with cancer. The first concerns a very short illness, the second a period of illness lasting several years. Two cases involving neurological disorders are also described in brief. In one, several members of one family suffered from the same disease, while the other concerned a very lengthy illness with symptoms that became increasingly severe.

The findings are set out in most detail for the first case discussed, to show that the committee examines all the due care criteria. Detailed findings are omitted from the discussion of the other cases included in this report: the focus is on the suffering of the patients.

CANCER

KEY POINTS: straightforward notification; findings letter; short illness; decision not to undergo treatment; summarised under number 2019-131

The patient, a man in his seventies, was diagnosed with pancreatic cancer with metastases to several organs three months before his death. His condition was incurable. He could only be treated palliatively. The patient had witnessed several examples of suffering at the end of life in his immediate circle. Because of this, he was clear in his own mind long before he fell ill that he did not want to go through suffering of this kind and that he wanted to take control of his own fate. He did not wish to become reliant on others to perform activities of daily living such as getting out of bed, washing and eating.

At the time of his diagnosis, the patient still felt relatively well. He therefore made a considered decision not to undergo chemotherapy because what he might be expected to gain in terms of a longer life did not, in his view, offset the loss in terms of quality of life resulting from that treatment. In the weeks before his death, the patient's condition deteriorated sharply. He was no longer able to eat and could only drink a little, and if he did so he immediately became nauseous. The patient quickly became weak and was almost completely bedridden. His loss of independence and dignity left him, in his opinion, with 'no life'. Lying in bed waiting for complications (high intestinal obstruction) or until he became emaciated was not in keeping with his character.

The patient suffered from his increasing dependency. He was accustomed to being in charge of his own life and was aware that this was becoming increasingly difficult. He did not wish to wait for the illness to take its course and wanted a dignified end to his life. The patient experienced his suffering as unbearable.

The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate his suffering that were acceptable to the patient.
The documents made it clear that the physician and the specialists had given him sufficient information about his situation and prognosis.

The patient had discussed his wish for euthanasia with the physician shortly after his diagnosis. He did not change his mind in subsequent discussions. His experience of long-term illness in other people had given the patient clear ideas about what kind of death he viewed as lack-

ing dignity and how things could be done differently. These considerations lay behind his decision to request euthanasia. He had also discussed his decision with his partner, children and grandchildren. They were all reconciled to his decision. Six days before his death, the patient asked the physician to actually perform the procedure to terminate his life. The physician concluded that the request was voluntary and well considered.

The physician consulted an independent SCEN physician who concluded that the due care criteria had been complied with. The physician performed the euthanasia using the method, substances and dosage recommended in the KNMG/KNMP's 'Guidelines for the Practice of Euthanasia and Physician-assisted Suicide' of August 2012.

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

CANCER

KEY POINTS: straightforward notification; findings letter; illness lasting several years involving many treatments; independent physician finds in the first instance that the due care criteria not yet complied with; summarised under number 2019-129

The patient, a woman in her thirties, was diagnosed with breast cancer four years before her death. In spite of surgery, extensive chemotherapy and radiotherapy, metastases were found in her brain and lungs two years prior to her death. The patient underwent several operations, some palliative in nature, to remove the metastases in her brain. However, when it became apparent that another operation would soon be needed, she decided she no longer wanted to go through with it. The patient's condition was incurable. She could only be treated palliatively.

The patient's suffering consisted of blindness due to the metastases in her brain. Her eyes could still see, but her brain could no longer process this information. She walked into doors and could no longer eat with cutlery. As a result, she was dependent on others, and was painfully aware of this. The patient felt she could not go on, she was very tired. After developing hemiplegia, she considered that she no longer had any quality of life. The patient had already indicated, after a similar period following brain surgery, that what she had to endure amounted in her view to unbearable suffering. She was aware that there was no prospect of improvement and that her situation would only get worse.

The physician was satisfied that this suffering was unbearable to her and without prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate the patient's suffering that were acceptable to her.

The patient had discussed euthanasia with the physician before. She wished to decide for herself when it had become too much. In those circumstances, she wanted euthanasia to avoid having to suffer in the way she had seen her parents suffer. Close family and friends were aware of her decision and supported her. There was no doubt she was decisionally competent. One day before her death, the patient asked the physician to actually perform the procedure to terminate her life. The physician concluded 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 nine days before she died. The independent physician concluded that due care criteria not yet been fulfilled because the patient had not yet made a request. The day before the patient's death, the physician telephoned the independent physician, stating that the patient was now asking for euthanasia to be performed. The independent physician then supplemented the earlier report, indicating that the due care criteria had been fulfilled.

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

NEUROLOGICAL DISORDER HUNTINGTON'S DISEASE

KEY POINTS: straightforward notification; full report of findings; patient with experience of the disease because it caused death of family members; published as number 2019-123

The patient, a woman in her sixties, heard that she had Huntington's disease about 10 years before euthanasia was performed. Her condition was incurable. She could only be treated palliatively. She often experienced involuntary movements and was constantly tired. The patient was also restless and lived in a state of constant anxiety. She was afraid of developing dementia and incontinence and, as the dementia progressed, of no longer being able to communicate.

She suffered from the loss of independence, the prospect of having to be admitted to a care institution and the lack of any prospect of improvement. She was aware of how the disease would progress because a number of deceased relatives of hers had suffered from it and she did not wish to experience the same process of decline. She experienced 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 the patient's suffering that were acceptable to her.

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

NEUROLOGICAL DISORDER (MULTIPLE SCLEROSIS)

KEY POINTS: straightforward notification; full report of findings; progressive condition; very protracted illness; published as number 2019-124

The patient, a woman in her sixties, had been suffering for decades from multiple sclerosis (MS, a disease of the central nervous system). The symptoms gradually became more severe. Her condition was incurable. She could only be treated palliatively.

The patient's suffering consisted of a loss of bodily functions. She found it virtually impossible to operate her electric wheelchair and hardly ever went outdoors any more. She had a low cardiopulmonary capacity (capacity to carry out actions) and increasing difficulty speaking. She could no longer feed herself. She suffered from her dependence on others and the lack of any prospect of improvement in her situation. She had lost the capacity to bear her suffering and wished to die in a dignified manner. She experienced 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 the patient's suffering that were acceptable to her.

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

PULMONARY DISEASE

KEY POINTS: straightforward notification; findings letter; decision not to undergo treatment; summarised under number 2019-128

The patient, a woman in her sixties, was diagnosed nine years before her death with chronic obstructive pulmonary disease (COPD). Two years before her death, she had reached stage four of the disease (GOLD IV). She derived no benefit from extra oxygen. She also obtained insufficient relief from strong painkillers. After being admitted to hospital, the patient received round-the-clock care. She initially felt better as a result. Eventually she decided to forego treatment because it would only prolong the suffering. Her condition was incurable. She could only be treated palliatively.

The patient's suffering consisted of extreme fatigue and shortness of breath. She had severe coughing fits during which she was afraid of suffocating. Everything drained her energy, energy which she no longer had. Essentially there was nothing the patient was capable of doing, while she had always been somebody who wanted to do everything herself. She suffered from her state of dependency and the fact that her condition could only deteriorate further. She did not wish to experience that deterioration. She experienced 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 the patient's suffering that were acceptable to her.

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

CARDIOVASCULAR DISEASE

KEY POINTS: straightforward notification; findings letter; summarised as no. 2019/-130

The patient, a man in his 80s, had suffered for many years from a condition affecting his heart muscle, inhibiting its ability to pump blood (ischaemic cardiomyopathy). The ultimate diagnosis was terminal heart failure. His condition was incurable. He could only be treated palliatively.

The patient's symptoms consisted of chest pain, severe shortness of breath, extreme fatigue after minor exertion and general malaise. He could no longer go to the toilet by himself and even moving in bed caused additional shortness of breath. He could only sip water and was no longer able to eat. Oxygen provided no relief and morphine helped to only a limited extent.
It was difficult for him to accept that he was no longer able to pursue a hobby in which he had won many prizes. The patient experienced his suffering as unbearable.

The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate his suffering that were acceptable to the patient.

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

COMBINATION OF CONDITIONS

KEY POINTS: straightforward notification; full report of findings; published as number 2019-122

The patient, a man in his eighties, had suffered for some considerable time from prostate cancer, rectal cancer, atrial fibrillation (abnormal heart rhythm), sudden deafness and idiopathic axonal sensorimotor polyneuropathy (a condition affecting the nerves resulting in reduced or altered sensation and muscles ceasing to function properly or at all). Recovery from any of these conditions was no longer possible. He could only be treated palliatively.

The patient's suffering consisted of loss of mobility, hearing loss, shortness of breath and incontinence. He could only walk a few steps and was in continual fear of falling. Because of difficulty walking, he regularly failed to reach the toilet in time. He experienced this situation as degrading. There was virtually nothing the patient, who had been an enterprising person, was still capable of doing, due to his conditions. He was suffering from his increasing dependency on care and was afraid that he would become bedridden. The patient knew there was no prospect of improvement in his situation and had no wish to experience further loss of dignity. He experienced his suffering as unbearable.

The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate his suffering that were acceptable to the patient.

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

2.2. Five cases illustrating one of the due care criteria in the Act

This subsection describes five cases involving five of the due care criteria: the physician must be able to conclude that (a) the patient's request voluntary and well considered, that (b) the patient's suffering is unbearable, with no prospect of improvement, and that (d) there is no reasonable alternative; the physician must also (e) consult an independent physician and (f) exercise due medical care and attention in terminating the patient's life.

These notifications too were designated as straightforward. The notifying physicians were given a full report of findings.

VOLUNTARY AND WELL-CONSIDERED REQUEST

The Act states that the physician must be satisfied that the patient's request is voluntary and well considered. A written request is not required by law; an oral request is sufficient. It follows from the Act that the patient must make the request himself. Most patients are capable of conducting a normal (i.e. oral) conversation until the moment that euthanasia is performed. In some cases the patient's ability to speak is severely impaired or hampered by their illness. Sometimes the patient is able to express his request in other ways, e.g. hand gestures, by nodding or by squeezing the physician's hand in response to 'yes or no' questions, or using a speech-generating device (Euthanasia Code 2018, p 18). The first case described below concerns just such a situation.

The second relates to a patient with dementia. In cases involving patients with dementia, there is reason to exercise particular caution when considering whether the statutory due care criteria have been met, especially with regard to the criteria relating to decisional competence and unbearable suffering. In the early stages of dementia, the patient generally has sufficient understanding of his disease and is decisionally competent in relation to his request for euthanasia. (Euthanasia Code 2018 p. 44).

CASE INVOLVING VOLUNTARY AND WELL-CONSIDERED REQUEST (SPEECH DISORDER)

KEY POINTS: straightforward notification; full report of findings; request; aphasia; SLK; published as number 2019-04

The patient, a man in his sixties, suffered a major cerebrovascular accident (CVA), a severe stroke, nine months before his death. He followed an intensive course of rehabilitation, but was left with paralysis on one side of his body (hemiparesis) and a serious speech disorder (aphasia). Following his course of rehabilitation, patient was admitted to a nursing home. He gradually deteriorated. His condition was incurable. He could only be treated palliatively. The patient's suffering consisted of serious and permanent physical disabilities as a result of the stroke. He was dependent on round-the-clock care and completely confined to his wheelchair. He had pain in his arm, hand and leg. His ability to communicate verbally was virtually non-existent and he felt trapped in his body. The patient was suffering from the loss of his quality of life. He knew there was no prospect of improvement in his situation and that it would only deteriorate. He did not wish to experience further decline. The patient experienced his suffering as unbearable. The physician was satisfied that this suffering was unbearable to him and that there was no prospect of improvement.

The patient had already discussed euthanasia with his general practitioner and the attending elderly-care specialist. His general practitioner sympathised with the patient's request but considered it too complex to carry out himself. The attending elderly-care specialist did not wish to perform euthanasia either. For that reason, with the help of someone close to him, the patient contacted the End-of-Life Clinic (SLK) about a month before his death. The burden of suffering on the patient was so great that a rapid procedure was necessary.

The physician saw the patient on three occasions. Because of his speech disorder, the patient could only produce a single sound. In this way he responded verbally to the physician's questions. The patient was also able to answer the physician's questions non-verbally by clenching his fist, squeezing the physician's hand and by nodding or shaking his head. The patient was also supported by his wife during these conversations.

The physician's first conversation with the patient took place a week and a half before the latter's death. During this conversation, the patient immediately asked the physician to actually perform the procedure to terminate his life. The patient repeated his request to the physician during the two subsequent conversations. The physician did not doubt the patient's decisional competence. The physician concluded that the

request was voluntary and well considered. (A psychological examination had shown that the man was not suffering from depression.)

The physician consulted an independent physician who was also a SCEN physician. The independent physician saw the patient five days before he died. In spite of his inability to speak, the patient was able to communicate effectively with the independent physician by means of gestures. The independent physician also considered the patient to be entirely decisionally competent regarding his request for euthanasia. The independent physician concluded, partly on the basis of her interview with the patient, that the due care criteria had been complied with.

The committee found that the physician could be satisfied that the patient's request was voluntary and well-considered. The committee reached this conclusion because the patient, despite being unable to express his wishes verbally, was able to convey them in other ways. For the physician and the independent physician, it was sufficiently plausible on the basis of the patient's expression of his wishes and on the basis of his behaviour that his request was voluntary and well considered.

In view of the above facts and circumstances, the committee found that the physician could be satisfied that the patient's request was voluntary and well considered.

The other due care criteria had also been fulfilled, in the committee's view.

CASE INVOLVING VOLUNTARY AND WELL-CONSIDERED REQUEST (EARLY-STAGE DEMENTIA)

KEY POINTS: straightforward notification; full report of findings; request; dementia; doubt about decisional competence; SLK; published as number 2019-90

The patient, a man in his 80s, had suffered from a variety of conditions for many years including visual impairment, diabetes mellitus, osteoporosis, osteoarthritis and complete incontinence. About two years before his death, the patient was diagnosed with Alzheimer's disease. The patient's condition was incurable. He could only be treated palliatively. Because of his care requirements, the patient was admitted to a nursing home about nine months before his death.

The patient's suffering consisted of increasing weakness, loss of strength, balance problems and incontinence, as well as his general decline. He could no longer stand or walk and needed to be lifted out of bed using a hoist. He could not get out and about, which made him deeply unhappy. He understood that he needed to live apart from his wife because of his care requirements, but it caused him considerable distress. He had always been an active man, a real doer. He was suffering due to chronic pain throughout his body, his near-inability to function, his complete dependence and the lack of any prospect of improvement in his situation. The fact that he sometimes became disoriented and had difficulty remembering things and finding the right words also caused him suffering. Essentially, however, his suffering stemmed from his physical decline and loss of independence. The patient experienced his suffering as unbearable. The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion.

The patient had discussed euthanasia with his general practitioner before. Because his general practitioner considered the patient's situation to be too complex, he referred him to the End-of-Life Clinic. More than two months before his death, the patient asked the physician to actually perform the procedure to terminate his life. The patient repeated his request to the physician during the four subsequent conversations. The physician concluded that the request was voluntary and well considered.

The physician asked the patient's attending psychiatrist for medical information. The latter concluded that the patient's cognitive impairments due to dementia were so far advanced that he should be considered decisionally incompetent with regard to his request. The attending

psychiatrist provided no further reasons in support of her position. The physician, an elderly-care specialist, did not share this conclusion. She asked the independent physician she consulted, who was also an elderly-care specialist, to devote extra attention to the patient's decisional competence with regard to his request for euthanasia. The independent physician saw the patient about two months before his death. He took the view that the patient was well able to appreciate the consequences of requesting the termination of his life and to give the reasons for his decision. The independent physician considered the patient to be decisionally competent regarding his request. Nevertheless, he advised the physician to have an independent psychiatrist assess the patient's decisional competence, in light of the opinion given by the attending psychiatrist.

Following an examination, the independent psychiatrist concluded that the patient was not suffering from depression. With regard to the question of whether the patient was decisionally competent to make his request, the independent psychiatrist concurred with the findings and conclusions of the independent physician and the physician. He considered that, despite suffering from Alzheimer's disease, the patient was quite capable of conveying his point of view and considerations concerning his request for euthanasia. He considered him to be decisionally competent regarding his request.

The committee noted that in the case of a patient with early-stage dementia the physician is called upon to exercise particular caution in ascertaining whether the statutory due care criteria have been satisfied, especially the criteria that the request should be voluntary and well considered and that the patient's suffering must be unbearable.

On the basis of information submitted by the physician, the committee found that the physician had indeed exercised particular caution. The physician – an elderly-care specialist – had no doubt as to the decisional competence of this patient with early-stage dementia. When the attending psychiatrist concluded that the patient was not decisionally competent with regard to his request, the physician reflected on her own conclusions and how she had intended to proceed. She both asked the independent physician to pay extra attention to the patient's decisional competence and consulted an additional independent expert to assess that competence. Both considered him to be decisionally competent regarding his request for euthanasia. By acting as she did, the physician exercised particular caution.

In reaching its opinion, the committee took account of the fact that the physician enjoys a certain degree of discretion. The attending psychiatrist failed to provide reasons in support of her opinion that the patient

was not decisionally competent. The physician, the SCEN physician and the independent psychiatrist found that the patient was decisionally competent and provided arguments and observations in support of their conclusions. In light of this the committee found that the physician, using the discretion accorded to her, could be satisfied that the patient's request was voluntary and well considered.

The other due care criteria had also been fulfilled, in the committee's view.

UNBEARABLE SUFFERING WITHOUT PROSPECT OF IMPROVEMENT AND ABSENCE OF A REASONABLE ALTERNATIVE

The physician must be satisfied that the patient is suffering unbearably and that there is no prospect of improvement. Suffering is a broad concept. It can result from pain and shortness of breath, extreme exhaustion and fatigue, physical decline, or the fact that there is no prospect of improvement, but it can also be caused by growing dependence, or feelings of humiliation and loss of dignity (Euthanasia Code 2018 p. 21).

It is sometimes hard to establish whether suffering is unbearable, for this is a subjective notion. What is bearable for one patient may be unbearable for another. This depends on the individual patient's perception of his situation, his life history and medical history, personality, values and physical and mental stamina. It must be palpable to the physician, also in light of what has happened so far, that this particular patient's suffering is unbearable. The physician must therefore not only be able to empathise with the patient's situation, but also see it from the patient's point of view (Euthanasia Code 2018 p. 24).

The physician and the patient must together come to the conclusion that there is no reasonable alternative in the patient's situation. This due care criterion, which must be seen in relation to suffering with no prospect of improvement, is necessary in view of the profound and irrevocable nature of euthanasia. If there are less drastic ways of ending or considerably reducing the unbearable suffering, these must be given preference. The physician and the patient must together arrive at the conclusion that no reasonable alternatives are available to the patient. This means that the perception and wishes of the patient are important. There is an alternative to euthanasia if there is a realistic way of alleviating or ending the suffering which may – from the patient's point of view – be considered reasonable. An invasive or lengthy intervention with a limited chance of a positive result will not generally be regarded as a 'reasonable alternative'. Generally, 'a reasonable alternative' intervention or treatment can end or considerably alleviate the patient's suffering over a longer period (Euthanasia Code 2018 p. 26 and 27).

CASE INVOLVING UNBEARABLE SUFFERING WITHOUT PROSPECT OF IMPROVEMENT AND ABSENCE OF A REASONABLE ALTERNATIVE

KEY POINTS: straightforward notification; full report of findings; unbearable suffering; absence of a reasonable alternative; SLK; published as number 2019-125

The patient, a man in his fifties, had a congenital disorder of the iris (aniridia) as a result of which he gradually became blind. His condition was incurable. His medical history also included diabetes mellitus, tinnitus and recurring episodes of kidney stones which regularly caused him severe pain.

The patient's suffering consisted of deteriorating sight and increasing lack of self-reliance. The knowledge that he would eventually become completely blind and hence dependent on other people and various aids distressed him. He did not want that. He was adamant on this point. On the advice of his physician, the patient had tried to learn to use aids for the visually impaired. But he had come to the conclusion that this did not suit his personality at all. His physician understood his feelings in this regard. The patient could not countenance the idea that he had to adapt his former active lifestyle to his disability. The idea that people in his social circle would feel pity was repugnant to him. The patient had therefore sharply scaled back his social life and had gradually stopped visiting, and receiving visits from, his friends. Shortly before the patient's death he was diagnosed by his ophthalmologist as legally blind.

The patient experienced his suffering as unbearable. The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion.

Six weeks before his death, the patient was examined by an independent psychiatrist on the advice of the first independent physician consulted by the physician. The independent psychiatrist was asked to examine whether the fact that the patient found it so difficult to accept his disability was due to a psychiatric disorder. The psychiatrist characterised the patient as a jovial person with a 'no-nonsense' mentality and the associated 'all or nothing' mindset. She concluded that he was not suffering from a psychiatric disorder.

The first independent physician consulted by the physician was a SCEN physician. This independent physician saw the patient about four months before his death. In her report, the independent physician concluded that the due care criteria had not been complied with. She advised the physician to arrange for an examination of the patient by a

psychiatrist, the outcome of which is described above. After the patient had been examined by the psychiatrist, the physician consulted a second independent physician who was also a SCEN physician and a psychiatrist. The second independent physician was satisfied that the due care criteria had been complied with, emphasising that this patient found his suffering unbearable.

The committee paid particular attention to the requirement that the physician be satisfied that the patient's suffering is unbearable and to the question of whether the physician together with the patient could be satisfied that there was no reasonable alternative, especially in the light of the patient's condition.

The committee found that the physician had put forward adequate reasons for his conclusion that this patient's blindness was unbearable to him. The physician could view the finding of the independent psychiatrist as confirming his conclusion. This was also confirmed by the second independent physician. Given the physician's clear description of the patient's personality, the committee had no reason to form a different opinion.

With regard to the requirement that physician must come to the conclusion together with the patient that there is no reasonable alternative, the committee found that the physician could be satisfied that this was the case. The physician prevailed upon the patient to contact an institute for the visually impaired and to seek their advice. The physician could be satisfied, again in light of the patient's personality, that the solutions offered did not suit the patient because they were too far removed from his independent lifestyle.

The other due care criteria had also been fulfilled, in the committee's view.

CONSULTING AN INDEPENDENT PHYSICIAN

Before performing euthanasia, the physician must consult at least one other, independent physician who must see the patient and assess whether the statutory due care criteria concerning the request, the suffering, the absence of a reasonable alternative and informing the patient have been complied with.

According to the Act, the independent physician must see the patient. 'Seeing' the patient will normally mean 'visiting' the patient. In the Caribbean part of the Netherlands, this requirement can give rise to practical problems. In that case the independent physician and the patient may speak to each other via an online video link (Euthanasia Code 2018 p. 31). A situation of this kind arose in the year under review.

CASE INVOLVING THE QUESTION OF CONSULTATION IN THE CARIBBEAN PART OF THE NETHERLANDS

KEY POINTS: straightforward notification; full report of findings; the independent physician must see the patient; island in the Caribbean part of the Netherlands; published as number 2019-66

The patient, a woman in her sixties, was diagnosed about six weeks before her death with a neurodegenerative disorder (a disease of the nervous system in which nerve cells die over a number of years). Her condition was incurable. She could only be treated palliatively. The patient's suffering consisted of the loss of personal autonomy. In a short period of time she became fully dependent on care and found it increasingly difficult to communicate. She lost strength throughout her body. She was also suffering from the lack of any prospect of improvement in her situation and the knowledge that she would deteriorate further . She could no longer do the things that gave meaning to her life. She experienced 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.

The physician consulted an independent physician who was a SCEN physician from the Netherlands. The independent physician conducted a video call with the patient. In his report, the physician explained his decision to consult an independent physician in the Netherlands. General practitioners on the islands in the Caribbean part of the Netherlands are few in number and know each other well. This means it is hard to avoid the appearance of a lack of independence. In the physician's view, ensuring his independence from the independent physician, and the fact that

this was the only way to have the patient assessed by a SCEN physician outweighed the desirability of the independent physician visiting the patient.

The independent physician concluded, partly on the basis of her video call with the patient, that the due care criteria had been met.

In respect of the deviation from the standard procedure as regards consulting an independent physician, the committee observed that it was aware of the difficulty that could be encountered in the Caribbean part of the Netherlands in consulting an independent physician who was also a SCEN physician. It also noted that it can be difficult to avoid the appearance of dependence. The physician presented well-founded arguments for his decision to consult an independent physician in the Netherlands. The committee referred in this regard to the passage in the Euthanasia Code 2018 which expressly provides for the option of a discussion via an online video link between the independent physician and patient as an alternative to visiting the patient. The committee found that the physician had complied with the requirements of consulting at least one independent physician, who had seen and spoken to the patient via a video link.

The other due care criteria had also been fulfilled, in the committee's view.

PERFORMANCE OF EUTHANASIA

The physician must exercise due medical care in performing euthanasia. Two aspects of this are the substances and doses administered, and appropriate checks to determine the depth of the induced coma. In assessing compliance with this due care criterion, the committees refer to the KNMG/KNMP 'Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide' of 2012 (Euthanasia Code 2018, p. 34). The Royal Dutch Medical Association (KNMG) and the Royal Dutch Association for the Advancement of Pharmacy (KNMP) are currently revising these Guidelines. The revised version is expected to be published in the course of 2020.

The physician bears final responsibility for exercising due medical care. The physician's actions are assessed by the committees. If the pharmacist prepares the syringe or potion beforehand, they have an individual responsibility for its preparation and labelling. The physician must check whether he has received the correct substances in the correct doses (Euthanasia Code 2018 p. 36).

CASE INVOLVING THE QUESTION OF DUE MEDICAL CARE IN PERFORMING EUTHANASIA

KEY POINTS: straightforward notification; full report of findings; intravenous infusion not flowing properly; emergency set past expiry date; published as number 2019-64

The patient, a woman in her seventies, was diagnosed with lung and pancreatic cancer six months before her death. A few months later she was found to have metastases in the liver. Her condition deteriorated rapidly in the final weeks before her death. The patient's condition was incurable. She could only be treated palliatively. The patient had discussed euthanasia with her own general practitioner before. The latter was absent from the practice for some time, and the physician was acting as locum.

The physician started the euthanasia procedure by intravenously administering 2000 mg of thiopental (a substance that induces a coma). After having administered approximately 1300 mg, the physician observed that the IV cannula was no longer properly in place. The physician then halted the procedure and contacted the independent physician. The latter advised restarting the entire procedure from the beginning.

The physician had a new IV cannula inserted by a specialist team. When the physician proceeded to prepare the substances from the emergency set, it transpired that the expiry date of the substance to be used to

induce a coma had passed. The physician contacted the pharmacist, who brought new ampoules. The physician then carried out the termination of life on request.

The committee noted the complicated course of the procedure. It found that, in the circumstances, the physician had carried out the termination of life with due medical care. The committee took account of the fact that after observing that the IV cannula was no longer properly in place, the physician had a specialist team insert a new IV cannula. When it became apparent that the expiry date of the coma-inducing substance in the emergency set had passed, she arranged for new substances to be brought. She subsequently carried out the termination of life in accordance with the KNMG/KNMP 'Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide' of August 2012.

The other due care criteria had also been fulfilled, in the committee's view.

2.3 Five findings concerning patients with a psychiatric disorder, dementia or multiple geriatric syndromes

PSYCHIATRIC DISORDER

Termination of life on request and assisted suicide are not restricted to patients in the terminal phase of their life. People with a longer life expectancy, such as psychiatric patients, may also be eligible. However, physicians must exercise particular caution in such cases. This means that they must consult an independent psychiatrist, mainly in order to obtain an opinion on the patient's decisional competence regarding their request for euthanasia, the lack of prospect of improvement and whether there is any reasonable alternative.

CASE INVOLVING PSYCHIATRIC DISORDER

KEY POINTS: non-straightforward notification; full report of findings; patient with psychiatric problems; published as number 2019-121

The patient, a man in his sixties, suffered from recurring depressions and narcissistic and antisocial personality disorders. (A narcissistic personality disorder has two aspects. It is characterised on the one hand by an inflated sense of self-importance and a deep need for admiration, on the other by an extreme sense of inferiority and insecurity. People with an antisocial personality disorder find it difficult to adhere to rules and take account of other people. It can be accompanied by irritability, aggression, impulsiveness and indifference.) The patient also suffered from a serious alcohol use disorder. The patient was treated over many years with both medication and psychotherapy. He was admitted to an institution on several occasions. In spite of this, his condition continued to deteriorate. He had lived since 2010 in sheltered housing. In 2016 he began Function Assertive Community Treatment – Mentalisation-Based Treatment (FACT-MBT), which focuses on making a person aware of their actions, feelings and behaviour, especially in terms of how they interact with other people. The patient stopped this treatment about six months before his death because it was not yielding sufficient results in terms of changing his wellbeing.

At the physician's request, an independent geriatric psychiatrist assessed the scope for any other realistic treatment options for the patient. The geriatric psychiatrist spoke to the patient on three occasions. He confirmed the earlier diagnoses, but also found that the patient exhibited autistic tendencies (autism is a disorder characterised by impairments in the area of social interaction and verbal and non-verbal communication, and by restricted behaviour patterns with a great deal of repetition or

fixed habits). The geriatric psychiatrist therefore took the view that change-oriented treatment of the patient's personality disorders would not lead to further improvement but was likely to ask too much of him. The patient recognised his impairments but clearly indicated that he lacked the motivation and saw no possibilities to change and adapt. The geriatric psychiatrist therefore saw no further realistic alternative treatment options.

The patient's suffering consisted of deep mistrust of other people. This meant that he could not establish any meaningful contact with others. Although he could establish superficial contact, as soon as he was alone he was assailed by doubt as to the sincerity of the other person. Then he felt a great void within himself. He also felt sorrow at the harm that his behaviour had caused in his personal relations. This gave rise to a feeling of existential loneliness which he could not escape and could only suppress through alcohol. People shunned him when he was under the influence of alcohol, which in turn confirmed his suspicions and his self-image. He repeatedly reverted to behaviour that made people turn their backs on him. As a result he was despondent. The patient experienced his suffering as unbearable. The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate his suffering that were acceptable to the patient.

The patient first spoke with the physician about euthanasia in August 2018 and they subsequently talked at length on about 20 occasions. During each conversation the patient asked the physician to actually perform the procedure to terminate his life. He also regularly repeated his request for euthanasia to other practitioners who were treating him.

The geriatric psychiatrist referred to above also examined the patient's decisional competence. He established that the patient was capable of fully grasping the implications of his request. Although his alcohol disorder was serious, the patient was capable of abstaining when he had appointments with health professionals. The geriatric psychiatrist considered the patient to be decisionally competent regarding his request for euthanasia.

The physician found that the patient's request was persistent and consistent. She considered him fully decisionally incompetent. The physician concluded that the request was voluntary and well considered.

The physician consulted an independent physician who was also a SCEN physician and a psychiatrist. The independent physician saw the patient about six weeks before the termination of life was performed, after he

had been informed of the patient's situation by the physician and had examined his medical records. The independent physician found that there was no prospect of improvement in the patient's psychiatric problems. He reached this conclusion on the basis of the chronic nature of the patient's condition and the lack of an effective treatment. The independent physician also considered the patient to be decisionally competent regarding his request for euthanasia.

The committee noted that, in the event that a request for euthanasia is prompted by suffering resulting from a psychiatric disorder, the physician must exercise particular caution. Such caution must be exercised especially when assessing the voluntary and well-considered nature of the request, the absence of any prospect of improvement, and the lack of a reasonable alternative. If contact with both a psychiatrist and an independent physician places an unacceptable burden on the patient, an independent psychiatrist or a SCEN physician who is also psychiatrist will have to provide specific expertise.

On the basis of all the information submitted by the physician, the committee found that she had indeed exercised particular caution in the case in question. It took into account the fact that the physician had acted in accordance with the guidelines applicable to her profession. The committee was also mindful that the physician consulted an independent psychiatrist, who concluded that the patient was decisionally competent in relation to his request for euthanasia, that the patient's suffering was without prospect of improvement and that there were no reasonable treatment options left.

The independent physician confirmed the physician's opinion that, after a long period in which the patient had undergone treatment without any lasting improvement, it could be concluded that there were no longer any realistic alternatives for the patient, and that his unbearable suffering was therefore without prospect of improvement. In addition, the independent physician confirmed the physician's conclusion that the patient's wish was a longstanding one and that his request was voluntary and well-considered.

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

DEMENTIA

A distinction can be drawn between euthanasia involving patients with early-stage dementia and those with late-stage dementia. In the early stage of dementia, the patient generally has sufficient understanding of the disease and is decisionally competent in relation to the request for euthanasia (an example is described in 2.2). It is still possible to grant a request for euthanasia at the stage where dementia has progressed to such an extent that the patient is no longer decisionally competent and is no longer able to communicate (or is able to communicate only by simple utterances or gestures), provided the patient drew up an advance directive when still decisionally competent. The directive must be clear, and evidently applicable to the current situation. In such cases the review committees always invite the physician to give an oral explanation (Euthanasia Code 2018 p. 45).

Two cases are described below of euthanasia involving patients in a very advanced stage of dementia. Both patients had drawn up a written request for euthanasia when they were still decisionally competent. At the time this annual report was being written, the question of what precise requirements euthanasia on the basis of an advance directive should have to meet was being examined by the Supreme Court. Among the issues to be addressed are how clear the advance directive must be and whether a physician must check whether a patient still wishes euthanasia to be performed before carrying out the procedure. At the time the notifications below were reviewed, the foregoing could not of course be taken into account.

CASE INVOLVING DEMENTIA (DECISIONALLY INCOMPETENT PATIENT WITH A WRITTEN EUTHANASIA REQUEST)

KEY POINTS: non-straightforward notification; full report of findings; patient with advanced dementia; advance directive; in the event of a euthanasia request in this phase, the physician must also consult an independent expert physician; SLK; published as number 2019-79

The patient, a man in his eighties, was diagnosed with Alzheimer's disease two years before his death. Despite medication, his condition gradually deteriorated. He was initially cared for at home by his wife.

About a year before his death the patient fell and broke his hip. Following surgery he was disoriented and restless. When he returned home after a course of rehabilitation, his mental condition rapidly deteriorated. When the domestic situation became untenable, about four and a half months before the patient's death, he was admitted to a nursing home.

A year before the patient's death, his general practitioner discussed euthanasia with him on several occasions. At that time, the patient's request was not immediately relevant. During the discussions about euthanasia after the hip fracture, the patient no longer had any awareness of his illness according to the general practitioner, nor was there an immediately relevant request for euthanasia. The physician did not wish to perform the euthanasia procedure because he considered the request to be too complex. The patient was referred to the End-of-Life Clinic.

He had drawn up an advance directive in 2012 and in 2018. Nobody doubted his decisional competence at the time he drew up the two documents. The physician noticed that the second advance directive been signed when the patient was in hospital. The physician therefore contacted the civil-law notary in whose presence the advance directive had been drawn up to verify whether the patient had been decisionally competent at the time.
The civil-law notary confirmed that he had been.

In the first advance directive, the request was formulated as follows:
'I want every effort – I repeat every effort – to be made to ensure that my wish for euthanasia is complied with if, as a result of dementia (Alzheimer's):
- I can no longer communicate
- I need help with everyday tasks
- My character changes or I become a different person
- I no longer recognise close family and friends
- I lose my grip on my thoughts and actions

I also want euthanasia to be carried out if dementia (Alzheimer's) causes humiliation in the form of incontinence, difficult and aggressive behaviour and a loss of personal dignity that is not in keeping with my lifestyle. On no account do I wish to be admitted to a psychogeriatric nursing home.'

In his *levenstestament* (a legal document that generally combines a lasting power of attorney and an advance directive on medical issues), drawn up a year before his death by the civil-law notary, the request for euthanasia was worded as follows:

'If I find myself in a situation in which I am suffering without prospect of improvement; and/or in which there is no reasonable prospect of returning to what I would consider a dignified way of living; and/or in which progressive loss of dignity is to be expected, I expressly request my physician to administer or provide to me the substances that will end my life.' It also stated: 'I have given this request for euthanasia careful consid-

eration, I have informed myself about it properly and I have signed it in full possession of my mental capacities.'

The physician saw the patient on ten occasions. During the fourth visit it became apparent that the domestic situation was no longer tenable and that the patient would have to be admitted to a nursing home. According to the physician, it was a clear turning point when the patient was admitted to the nursing home. When he was taken there and it became apparent to him that he would have to stay behind, he became angry. In the nursing home he regularly called out 'I don't want this!'

When the patient had been at the nursing home for three weeks, the physician visited him there. His suffering was unclear to the physician during this visit. However, his family and care staff did see signs that the patient was suffering. He was said to be restless, especially in the evening. When the physician visited in evening, he saw a very agitated person who was angry and sad when his wife said goodbye. According to the care record, this was a recurring pattern. In addition, the reports of carers showed that the patient would walk around aimlessly all day long, often coming to a standstill in front of objects and walls. He was also very restless at night and began to wander about. He slept little and often vented his anger and frustration on fellow residents. His carers said the patient was often sad. Owing to his lack of communication skills, he could no longer say what he wanted and felt that people did not understand him. This angered him. The patient was given medication for his restlessness but it made him groggy and his compulsion to move increased. He fell down regularly. After a number of months at the nursing home, an acceptable equilibrium had not yet been reached. The patient could no longer communicate, his personality had changed, and he had lost his grip on his thoughts and actions. In addition he was incontinent and dependent on others for his everyday care needs.

Two months before his death, the physician asked the attending elderly-care specialist to report on the patient's condition and to assess whether there were still options to alleviate his suffering. The attending elderly-care specialist stated that, during the patient's stay at the nursing home, he had become entirely dependent on others for his everyday care needs and his incontinence had worsened. He also exhibited further cognitive decline.

The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion. In order to carry out the assessment, the physician had to rely upon non-verbal utterances because the patient could no longer articulate his suffering through speech. According to the physician, the

patient's desperation was visible, audible and palpable. An evaluation of the patient's suffering carried out by the physician using the framework devised by Kimsma reinforced his conviction that this patient, in the light of his life history and personality, experienced his suffering as unbearable. The physician noted that the situation in which the patient found himself corresponded to his description in his euthanasia directive of what would be unbearable to him. During his final visit, a day before euthanasia was performed, the physician asked the patient whether he wanted euthanasia, in accordance with his wishes, to go ahead. The patient did not respond to this question.

The physician twice consulted an independent physician who was also a SCEN physician. The first independent physician, who was also an elderly-care specialist, saw the patient over two months before his death. When the independent physician visited, verbal communication was not possible. According to the independent physician, the patient was decisionally incompetent due to the advanced dementia process. The independent physician spoke to the patient's wife about the course of his illness. The independent physician concluded that this decisionally incompetent person found himself in a situation which – as was apparent from the advance directive which he had frequently discussed with his general practitioner – he had never wanted. According to the independent physician, there were moments when the patient was visibly suffering. He was angry and sad when he was separated from his wife. According to the independent physician, there were no alternative treatments; the patient's situation was without prospect of improvement. Based on her own observations when she visited the patient, information from the physician and supplementary information from others, the independent physician reached the conclusion that the due care criteria had been satisfied.

The physician then consulted an elderly-care specialist with expertise in advanced dementia. The second independent physician visited the patient twice. During these visits, verbal communication was not possible. According to the independent physician, the patient had lost his grip on his surroundings, had become dependent on care and was increasingly isolated, as a result of which his restlessness had increased. In the opinion of the independent physician, the patient expressed his wish for euthanasia through his behaviour. According to the independent physician, the patient's world had been disrupted too much in the preceding months for it ever to be restored. There was no longer any way of helping him experience something positive or enabling him to find calm. The second independent physician also concluded that the due care criteria had been complied with.

In view of the patient's condition, it was not entirely possible to predict how he would react when the IV cannula was inserted. The physician was convinced that the patient wanted euthanasia and over the entire course of his contact with the patient, the latter had made no verbal utterances or given any physical signs that could be interpreted as going against his advance directives and the wishes he had expressed previously. The physician therefore concluded that any adverse reactions on the part of the patient could not be considered to be signs of an objection to euthanasia, but simply as reactions to the insertion of the IV cannula or other procedures. In anticipation of any such reactions, the physician had drawn up a plan for the euthanasia procedure.

The patient was taken home on the day euthanasia was performed. He allowed the IV cannula to be inserted without any problem. When a physician informed him that he was about to carry out the euthanasia procedure, the patient did not respond.

In the physician's opinion, everything had been done to make the situation more bearable for the patient. The physician observed that possibly different medication with a greater tranquillising effect could have been tried out and that the patient's daily routine could have been modified. The physician was convinced however that this would not have provided a solution for the unbearable suffering which the patient referred to in his advance directive and which was also clearly visible.

The committee noted that with regard to patients with dementia the physician is required to exercise particular caution, especially with regard to the statutory due care criteria concerning a voluntary and well-considered request, unbearable suffering without prospect of improvement and absence of reasonable alternatives.

It is still possible to comply with a request for euthanasia at the stage where dementia has progressed to such an extent that the patient is no longer decisionally competent and is no longer able to communicate (or is able to communicate only by simple utterances or gestures), provided the patient drew up an advance directive when he was still decisionally competent (Euthanasia Code 2018, pp. 44 and 45). Section 2 (2) of the Act states that an advance directive can replace an oral request and that the due care criteria mentioned in section 2 (1) of the Act apply *mutatis mutandis*. The directive must be clear, and evidently applicable to the current situation. The committee found that the physician had exercised the particular caution referred to above. On this point, the committee noted the following. It had been established that the patient was no longer decisionally competent when the physician became involved in his case. The committee found that, when the patient drew up his

advance directive and updated it, there was no reason to believe that he was already decisionally incompetent.

The committee was satisfied on the basis of all the information that when the termination of life was carried out, the circumstances described by the patient in his advance directive indeed existed.

The committee found that the physician could be satisfied that the performance of euthanasia was in line with the previous written advance directive and that there were no contraindications: the documents did not show that the patient indicated, in the nursing home or prior to the termination of life at his home, that he did not want the termination of life to go ahead.

During the phase in which the dementia process has advanced so far that the patient is no longer decisionally competent, it must also be plausible that a patient is at that moment suffering unbearably. The committee found that the physician could be satisfied that the patient's suffering was without prospect of improvement and unbearable to him. The committee noted the following in this respect. It was clear from the file that the physician had studied the patient's situation carefully. It was apparent from extensive and lengthy observation that, in the nursing home, the patient was constantly visibly anxious, confused, restless, angry and aggressive. Over time the physician saw the situation steadily deteriorate and the suffering increase. Despite attempts to do so in the nursing home, it proved impossible to improve the patient's situation, making the unbearable nature of the patient's suffering palpable to the physician. The physician could be satisfied that the patient was suffering unbearably.

With regard to the requirement that the physician must be satisfied that the patient's suffering, besides being unbearable, is also without prospect of improvement, and the requirement that the physician must come to the conclusion together with the patient that there is no reasonable alternative, the committee found that the physician could be satisfied that this was the case. The report by the attending elderly-care specialist listed options for improving the patient's situation. The list included, among other things, trying medication with a greater tranquillising effect, arranging for the patient to talk to a spiritual counsellor and further optimising the patient's daily routine. The committee endorsed the physician's conclusion that the administering of stronger tranquillising medication could not be considered a reasonable alternative (Euthanasia Code 2018, p. 26). The elderly-care specialist did not expand on how the patient's daily routine might be further optimised. The committee accepted the physician's view that discussions with a spiritual coun-

sellor would probably have had no impact on someone in an advanced stage of dementia. It also emerged clearly from the documents that staff made great efforts to make the patient's situation bearable, but this proved impossible. The physician also found support for his conclusion in the medical records of the attending elderly-care specialist and nursing staff and in statements from the patient's close family and friends.

As regards the due care criterion that there is no reasonable alternative, in principle this is a conclusion that the physician and the patient must arrive at together. According to the legislative history in respect of section 2 (1) of the Act, the due care criteria apply 'to the greatest extent possible in the given situation'. In other words, the physician must take account of the specific circumstances of the case; for instance, the patient may no longer be capable of communicating or responding to questions. It is therefore important that the physician carefully consider in cases such as this what the patient has written about this matter in his advance directive and what he said when he was still able to communicate.

At the time the physician became involved, the patient was already decisionally incompetent. On the basis of what the patient wrote in his advance directive concerning the circumstances in which he wanted euthanasia, and given the fact that – as described in the foregoing – there was no reasonable alternative which would end or considerably reduce these circumstances (which constituted the unbearable suffering), the committee found that the physician could be satisfied that this due care criterion, too, was complied with.

When euthanasia is to be performed in the late stages of dementia, the physician must consult both a regular independent physician and a physician specialised in dementia (Euthanasia Code 2018, p. 45).

The committee noted that the physician consulted two independent expert physicians, who saw the patient and gave a written opinion on whether the due care criteria had been complied with. They both concluded that the due care criteria in the Act had been complied with. The physician thus complied with the due care criterion referred in section 2 (1) (e) of the Act. The committee did observe that the reports drawn up by the two SCEN physicians did not substantiate the conclusion that there were no reasonable alternatives and did not address the alternative treatments suggested by the attending elderly-care specialist. As already indicated above however, the physician himself had already put forward satisfactory arguments that the patient's suffering was without prospect of improvement and that there were no reasonable alternatives.

The committee found that all the due care criteria had been complied with.

CASE INVOLVING DEMENTIA (DECISIONALLY INCOMPETENT PATIENT WITH A WRITTEN EUTHANASIA REQUEST)

KEY POINTS: non-straightforward notification; full report of findings; patient with advanced dementia; advance directive; in the event of a euthanasia request in this phase, in addition to consulting a regular independent physician, the physician must also consult another independent physician who is an expert in the field; SLK; published as number 2019-119

The patient, a man in his seventies, had been having increasing cognitive problems that started about six years before his death. Three years before his death, he had to be admitted to hospital with pneumonia. While in hospital, he experienced delirium, after which it became clear that he was no longer able to function at the same level as before. Shortly after, he was diagnosed with Alzheimer's disease.

Three years before his death, the patient had drawn up an advance directive. It included the following:

'- If, for any reason, I end up in a mental or physical state that offers no real prospect of returning to a reasonable and dignified life, I do not wish to continue living and wish to die quickly and peacefully.

- In the event that as a result of (further) treatment being withheld, I will not die quickly and peacefully, I urgently request that my attending physician fulfil my wish to die by administering to me the substances that will bring about a mild death or by having me ingest those substances under his/her supervision.

I consider at least the following to comprise the above-mentioned state:

- a state of long-term terminal suffering;
- unavoidable loss of dignity;
- any mental or physical state that I may later specify or that may befall me, with consequences that are clearly unacceptable to me;
- in the event that, in the above-mentioned state, I am clearly still able to express my wishes, I request that the attending physician ask me to confirm this directive. Should I not be able to do so, this directive must be considered to contain my express wishes.'

After he was diagnosed the patient had had several conversations with his general practitioner about euthanasia. He said, among other things, that he was afraid of losing his dignity and becoming aggressive. These conversations took place up to a year before his death. In that final year, the patient did not bring up the subject of his wish for euthanasia, nor did the general practitioner ask him about it.

About a year before his death the patient was admitted to a nursing home because his care needs were increasing and he was very argumentative. In the beginning all went well in the nursing home. However, because his illness was becoming more serious he began to lose control of his situation, and this caused feelings of frustration and fear. The patient's ability to communicate deteriorated and eventually he could hardly communicate at all. He was very agitated every day. In addition he was increasingly aggressive towards other residents and it was almost impossible to distract him. His outbursts of aggression increased. Attempts at improvement were hampered by his inability to speak (aphasia) and communication problems, and his behaviour remained the same. The use of medication to suppress his symptoms made him extremely lethargic, but any reduction in the medication caused his symptoms to flare up. Various other means besides medication were used to improve the situation. For instance, after several falls he slept in an enclosed safety bed, but even then he was sometimes agitated.

The patient's suffering consisted of loss of control over his situation and of the ability to communicate properly with other people, and the related consequences: anxiety and anger. There were periods when he hardly slept for nights on end due to agitation. As a result he became fatigued. He sometimes compulsively cleaned the floor and it was almost impossible to stop him from doing it. In his confusion he also showed distressing behaviour, such as soiling his room, crawling on the floor and aggression towards the care staff and other residents. When the patient was calm, he was regularly completely apathetic and withdrawn.

When the patient's situation in the nursing home continued to deteriorate and his condition worsened substantially, the members of his family discussed the advance directive. His wife spoke about the advance directive with the attending elderly care specialist, but the latter considered the request to be too complex. The patient's wife then contacted the general practitioner. The general practitioner brought in a euthanasia counsellor from the End-of-Life Clinic (SLK) and visited the patient in the nursing home. In the end the general practitioner also refused to carry out the request for euthanasia, because he considered it too complex. In consultation with the euthanasia counsellor, the general practitioner transferred the request to the SLK. The general practitioner remained closely involved in the SLK euthanasia process.

From the moment the SLK physician became involved, the patient was completely decisionally incompetent. The physician visited the patient four times over a period of five months. During each visit the physician tried to make contact with the patient. The patient responded to the attempts, but it was impossible to have a conversation. The physician

spoke to the patient's wife about the fact that although the advance directive was not particularly specific, it was very comprehensive. She said that her husband's parents had also suffered from Alzheimer's disease and their decline had been a terrible experience for him. He had always been adamant that he did not want that to happen to him.

An observation period was agreed with the family. During that period, all those involved saw loss of dignity on many occasions. This mainly consisted of agitation, incontinence, anxiety and aggression, whereby the patient could not be managed and interventions did not help. After the observation period it was clear to the physician that the patient was suffering unbearably in the way he had described and intended in his advance directive.

More than three months before the termination of life, the physician asked an independent psychiatrist to assess the patient's suffering. This psychiatrist visited the patient at the nursing home. During his visit the psychiatrist concluded that it was impossible to have a conversation with the patient. He therefore spoke with the patient's wife, children and children-in-law. The psychiatrist also spoke on the phone with the general practitioner. On the basis of his visit and the conversations with the patient's family and the general practitioner, the independent psychiatrist concluded that the anxiety and agitation were being treated correctly.

Taking into account the patient's personality, his medical history and the written records of his wishes, it was not necessary for the independent psychiatrist to hear an oral account from the patient of his suffering. In his opinion it could not be established objectively and convincingly that the patient's suffering was unbearable. On the other hand, when the patient was agitated, a state that defined a large part of his day, it could be said that his suffering was unbearable. At those times there was clearly an unavoidable loss of dignity. The psychiatrist did not doubt that the patient's situation completely matched what he had described as unbearable when he was still decisionally competent.

The physician consulted an independent physician who was also a SCEN physician and an elderly care specialist. The independent physician saw the patient about a month and a half before his death. During the visit the independent physician made several attempts to start a conversation with the patient. The patient looked at the independent physician, but did not respond to his questions. According to the independent physician, the patient was decisionally incompetent due to the advanced dementia process.

The independent physician found it difficult to gain an impression of the patient's mood and suffering without any communication. He was unable to establish any impression of positive affect on the part of the patient and also noted the lack of expressions of enjoyment or pleasure. According to the independent physician, the patient's situation evidently fell within the boundaries set in the advance directive. No improvement was to be expected; the loss of dignity would only continue.

In his report the independent physician concluded that the due care criteria had been complied with.

Given the patient's situation it was difficult to predict his reaction to various procedures necessary to carry out the termination of life on request. According to the physician, during the entire assessment process there were no verbal or physical signals that could be interpreted as being contrary to the patient's advance directive. The physician therefore concluded that any contrary reactions on the part of the patient could not be considered to be signs of objection to the termination of his life, but as reactions to the insertion of an IV cannula or to other procedures. To be prepared for all eventualities, the physician had drawn up a detailed plan for the euthanasia procedure. It stated, for instance, that the procedure would not be carried out if the patient were to expressly say or make it clear that he did not want euthanasia. It also stated that the patient would be given premedication to prevent him from reacting negatively to the sensation of the IV cannula being inserted. If the patient did not accept the premedication, the physician would make a second attempt some time later. And if the patient were to refuse it again, the physician would discontinue the procedure at that point.

The procedure was carried out at the nursing home. The SLK nurse explained to the patient that they were going to give him substances that would end his life and that he would first be given medication to calm him. The patient then ingested the medication. After he had calmly lain on the bed for some time, next to his wife, the patient wanted to get up. Attempts were made to keep him on the bed, which made him agitated. This behaviour was comparable to how he regularly behaved in the nursing home. The patient then briefly walked around his room, with assistance, after which he lay down again. Nonetheless the patient's agitation continued and it was decided to give him a sedative (Dormicum) and morphine. Shortly after, the patient fell asleep and the physician administered the euthanatics.

The committee noted that with regard to patients with dementia the physician is required to exercise particular caution, especially with regard to the statutory due care criteria concerning a voluntary and

well-considered request, unbearable suffering without prospect of improvement and absence of reasonable alternatives. When euthanasia is to be performed in the late stages of dementia, the physician must consult both a regular independent physician and a physician specialised in dementia (Euthanasia Code 2018, p. 45).

It is still possible to grant a request for euthanasia at the stage where dementia has progressed to such an extent that the patient is no longer decisionally competent and is no longer able to communicate (or is able to communicate only by simple utterances or gestures), provided the patient drew up an advance directive when he was still decisionally competent (Euthanasia Code 2018, pp. 44-45). Section 2 (2) of the Act states that an advance directive can replace an oral request and that the due care criteria mentioned in section 2 (1) of the Act apply *mutatis mutandis*. The directive must be clear, and evidently applicable to the current situation. The committee noted the following in this respect. It had been established that the patient was no longer decisionally competent when the physician became involved in his case. On the basis of the documents and the physician's oral explanation, the committee found that at the time when the patient wrote his advance directive there was no reason to believe he was already decisionally incompetent.

The committee considered the content of the advance directive at length. After all, the directive must be clear, and evidently applicable to the current situation. On the basis of all the information, the committee was satisfied that when the termination of life on request was carried out, the circumstances described by the patient in his advance directive of 2016 indeed existed, in particular the 'unavoidable loss of dignity'. From the information given by the patient's general practitioner, family and care staff the physician was able to deduce what the patient meant by 'unavoidable loss of dignity'. The committee took into consideration the fact that both the independent physician and the independent psychiatrist consulted were satisfied that the patient's existing situation was the situation that the patient had referred to in his advance directive.

According to the Euthanasia Code 2018 (p. 45), the physician must ascertain whether a decisionally incompetent patient shows any clear signs that he does not wish his life to be terminated. The physician made several – fruitless – attempts to make contact with the patient to ascertain whether he was able to indicate, verbally or non-verbally, that he no longer wanted euthanasia. It was clear from the file that there were no such indications.

In view of the above, the physician was able to conclude that carrying out the euthanasia procedure was in accordance with the patient's advance

directive and not contrary to his utterances. The committee found that the physician could be satisfied that the patient's request was voluntary and well considered and that the physician exercised the above-mentioned particular caution.

During the phase in which the dementia process has advanced so far that the patient is no longer decisionally competent, it must be plausible that the patient is at that moment suffering unbearably. In reaching its conclusion, the committee took account of the fact that it was clear from the file and the physician's oral explanation that the physician had studied the patient's situation carefully. The physician ascertained step by step whether the patient was currently suffering unbearably.

The committee found that the physician exercised particular caution and that the physician could be satisfied that the patient's suffering was unbearable and without prospect of improvement.

As regards the due care criterion that requires that there be no reasonable alternative, the committee considered that in principle this is a conclusion that the physician and the patient must arrive at together (Euthanasia Code 2018, p. 25). Furthermore, in view of the legislative history, the due care criterion applies 'to the greatest extent possible in the given situation'. The committee noted the following in this respect. In the present case it was important that the physician had carefully considered what the patient wrote about this matter in his advance directive and what he said when he was still able to communicate. When the physician became involved with the patient's case the patient was already decisionally incompetent and, as became clear to the committee on the basis of the documents and the oral explanation, communication with him on this matter was no longer possible, despite various attempts. The documents showed that the only way to treat the patient's suffering was to administer so much sedative medication that he became extremely lethargic. The committee found that administering more sedative medication could not be considered a reasonable alternative (Euthanasia Code 2018, p. 25). On the basis of what the patient wrote in his advance directive concerning the circumstances in which he wanted euthanasia, and given the fact that the physician could be satisfied that there was no reasonable alternative which would remove or considerably reduce these circumstances (which constituted his unbearable suffering), the committee found that the physician exercised particular caution and that he could be satisfied that this due care criterion, too, was complied with.

The committee found that all the due care criteria had been complied with.

MULTIPLE GERIATIC SYNDROMES

For a person's request for euthanasia to be considered, their suffering must have a medical dimension. However, it is not a requirement that there be a life-threatening medical condition. Multiple geriatric syndromes – such as sight impairment, hearing impairment, osteoporosis, osteoarthritis, balance problems or mental deterioration – may cause unbearable suffering without prospect of improvement.

These syndromes, which are often degenerative in nature, generally occur in elderly patients. It is the sum of these problems resulting from one or more conditions, in conjunction with the patient's medical history, life history, personality, values and stamina, that may give rise to suffering which that particular patient experiences as being unbearable and without prospect of improvement.

This is where the distinction lies between multiple, largely degenerative syndromes and the issue of 'completed life', insofar as the latter refers to suffering that has no medical dimension. Multiple geriatric syndromes, conversely, do have a medical dimension (Euthanasia Code 2018, pp. 22-23). Two cases involving this issue follow below.

CASE INVOLVING MULTIPLE GERIATRIC SYNDROMES (PATIENT HARD OF HEARING AND ALMOST BLIND)

KEY POINTS: non-straightforward notification; full report of findings; patient with multiple geriatric syndromes; published as number 2019-127

The patient, a woman in her eighties, suffered from two eye conditions (glaucoma and macular degeneration) and hearing loss (presbycusis). As a result she was virtually blind, and hard of hearing. The patient's condition was incurable. She could only be treated palliatively.

Her suffering consisted of the (socially) disabling consequences of the conditions. She suffered from loss of autonomy, the prospect of having to be admitted to a care institution and the absence of any prospect of improvement. She experienced 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 longer any acceptable ways to alleviate the patient's suffering.

The documents made it clear that the physician and the specialists gave her sufficient information about her situation and prognosis.

The patient had discussed euthanasia with her general practitioner before. At first the general practitioner was willing to consider the request for euthanasia. Around five months before the patient's death, a clinical psychiatrist was consulted. In the psychiatrist's opinion the patient was not suffering from mood-related disorders. However, the general practitioner could not sympathise with her wish for euthanasia. With the support of her general practitioner, the patient then turned to the End-of-Life Clinic (SLK).

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

CASE INVOLVING MULTIPLE GERIATRIC SYNDROMES (VARIOUS CONDITIONS)

KEY POINTS: non-straightforward notification; full report of findings; patient with multiple geriatric syndromes; published as number 2019-67

The patient, a woman over 90 years of age, had suffered from various conditions for a considerable time. Her suffering consisted of chronic pain caused by osteoarthritis (a specific form of arthritis), for which she took opiates. This led to untreatable abdominal problems. In addition her eyesight had seriously deteriorated, she was hard of hearing, she could not move around and suffered from fatigue and weight loss. Due to her disabilities, the patient sat at home in a chair all day with no daytime activities at all. For instance, she was no longer able to watch television, do needlework or read a book. She dreaded every single day and felt it was degrading that her condition was deteriorating with no prospect of improvement. The patient's condition was incurable. She could only be treated palliatively.

The patient experienced 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 the patient.

The patient had discussed euthanasia before with the physician and others who treated her. More than two months before her death, the patient

asked the physician to actually perform the procedure to terminate her life. She repeated her request several times. The physician concluded that the request was voluntary and well considered.

The committee noted that in cases involving a patient with multiple geriatric syndromes, these multiple syndromes may cause unbearable suffering without prospect of improvement. It is the sum of these problems, in conjunction with the patient's medical history, life history, personality, values and stamina, that may give rise to suffering which that particular patient experiences as being unbearable and without prospect of improvement. On the basis of the information provided by the physician, the committee found that the physician could be satisfied that there was a medical dimension to the patient's suffering and that the patient was suffering unbearably and without prospect of improvement as a result of the multiple geriatric syndromes.

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

2.4 Three requests for euthanasia from patients subject to an order restricting their liberty

In the period under review the RTEs received three notifications of cases in which the patient was subject to an order restricting their liberty during the assessment of their request for euthanasia. In such situations it is very important to assess whether the request may have been prompted by the patient's stay in the secure psychiatric institution, prison or mental health institution. This turned out not to be the case in all three notifications.

HOSPITAL ORDER

KEY POINTS: non-straightforward notification; patient in secure psychiatric institution; combination of somatic and psychiatric disorders; SLK; published as number 2019-22

The patient, a man in his seventies, was diagnosed with an autism spectrum disorder (a disorder characterised by impairments in the area of social interaction and verbal and non-verbal communication, and by a restricted behaviour pattern with a great deal of repetition or fixed habits) and with obsessive-compulsive disorder (intrusive anxious and unpleasant thoughts that are difficult to suppress). In addition he suffered from a lung disease (chronic obstructive pulmonary disease; COPD), intermittent claudication and diabetes mellitus. From his adolescence onwards, the patient had been treated extensively with medication and psychotherapy. Over the years he had attempted suicide on several occasions.

After severe dysregulation of his condition more than 20 years before his death, the patient had been placed in a long-stay ward in a secure psychiatric institution (a treatment clinic where people are admitted who have committed a serious crime for which they cannot be held – fully – responsible due to a personality disorder and/or a serious psychiatric disorder. Patients who cannot be cured and who continue to pose a danger remain in a long-stay ward for the rest of their lives.). The patient was no longer receiving active treatment; his condition was in fact now untreatable. Several years before the patient's death, the Centre for Consultation and Expertise strongly advised against transferring the patient to a specialised clinic for people with autism. There was nothing that he could realistically achieve there. Admitting him to a regular mental health institution was not seen as a genuine option either, because he required a high level of security. This was not because he was a flight risk but because he had little to no control over his natural urges, which could lead to serious consequences for other people.

At the physician's request, around four months before the patient's death an independent psychiatrist reviewed the diagnosis and any possible treatment options for the patient. The independent psychiatrist agreed with the diagnosis that was apparent from the documents. The patient was not suffering from a mood disorder, depression or mania (periods of elevated mood, such as elation, anger or hyperactivity). Nor were there any indications of dementia. The psychiatrist established that the patient was suffering from a long-term psychiatric disorder (an unchanging chronic defect state). He, too, thought that it was not a good idea to admit the patient to a specialised treatment clinic for autism. This would carry a large risk of dysregulation (upsetting the existing equilibrium). Impulsive suicide could then not be ruled out. The independent psychiatrist concluded that the patient could no longer be treated. His condition was incurable.

The patient was suffering from his inability to participate in society. He had always felt out of place in the world and had wanted euthanasia for years. He constantly had compulsive thoughts. The patient was unable to live among other people, as he quickly became overstimulated. As a result he lived in isolation in the clinic and did not take part in group activities. Due to exhaustion, he could also no longer carry out household tasks. The patient felt the world was too complicated for him. In addition, as he grew older various physical problems had developed. His legs hurt and he quickly became short of breath. As a result of these physical problems he was barely able to function. He could only take small, shuffling steps, was tired all the time and wanted to stay in bed every day. He felt completely off-balance, both physically and mentally.

The patient experienced his suffering as unbearable. The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate his suffering that were acceptable to the patient.

The patient had discussed euthanasia before with his attending psychiatrist in the clinic where he was staying. The attending psychiatrist supported the patient's request, but due to the clinic's protocol was not allowed to carry it out.

For this reason, the patient contacted the End-of-Life Clinic (SLK), over a year before his death. The physician spoke extensively on five occasions with the patient about his request. During their first conversation, the patient immediately asked the physician to actually perform the procedure to terminate his life. As they had to wait for a decision from the Ministry of Justice and Security as to whether the patient was permitted

to enter into a euthanasia process, the first conversation was around eight months before the patient's death. He repeated his request to the physician during many subsequent conversations.

The aforementioned independent psychiatrist considered the patient to be decisionally competent regarding his request. During the physician's conversations with the patient, it was clear that the patient was well aware of what his request entailed. The physician considered him to be decisionally competent regarding his request for euthanasia. He concluded that the request was voluntary and well considered.

The physician consulted an independent physician who was also a SCEN physician. The independent physician was satisfied that the patient was suffering unbearably as a result of multiple geriatric syndromes, in combination with an unchanging chronic defect state. The independent physician considered the patient to be decisionally competent.

The committee noted the following in this case.

The patient had been detained under criminal law in a custodial psychiatric clinic. The committee wished to determine whether his stay in a long-stay ward and the reason he remained there might in one way or another have influenced the voluntary and well-considered nature of the request.

The patient had a realistic perception and understanding of his illness and he felt the long-stay ward was the best place for him to be. With the help of his attending psychiatrist, the patient had turned to the End-of-Life Clinic (SLK). The committee concluded from this that the patient's wish was well considered and consistent. It was plausible that the patient's request was voluntary, as the physician, the attending psychiatrist and the independent psychiatrist considered him to be decisionally competent regarding his request. In view of the above facts and circumstances, the committee found that the physician could be satisfied that the patient's request was voluntary and well considered.

The other due care criteria had also been fulfilled in the committee's view.

EUTHANASIA ONE DAY AFTER DETENTION

KEY POINTS: non-straightforward notification; euthanasia one day after detention; SLK; personality disorder characterised by dependence and avoidance, PTSD and depression; published as number 2019-100

The patient, a woman in her fifties, had ended the life of a close relative several years before her own death. Assessment of her mental health after she had committed this offence showed that she was withdrawn and dependent, showed little initiative and was socially anxious. The physician and the experts she consulted later diagnosed this as a personality disorder. After killing her relative, and attempting suicide immediately after, the patient developed post-traumatic stress disorder (an anxiety disorder that involves being constantly alert to a danger that no longer exists) and chronic depression with suicidal tendencies and severe self-reproach. After her conviction the patient was placed in the psychiatric ward of a prison. There, too, she attempted suicide several times. During her detention, treatment with medication was started but this had no effect; the treatment caused only side-effects. In addition, the patient received psychotherapy, Eye Movement Desensitisation and Reprocessing (EMDR, a treatment method used with people who continue to have problems caused by a traumatic experience, such as an accident, sexual violence or other kinds of violent incident) and bereavement counselling. None of these treatments led to a substantial improvement in the situation, so the patient refused to continue with them. During the meeting the physician had with the committee, she explained that at her request another attempt at treatment was made. Anti-depressant medication was started again, to support EMDR therapy. The patient stopped taking the medication shortly after, as it was having too many side-effects. The EMDR stirred up emotions and caused the patient to relive events, and she was unable to cope.

The patient was suffering from her inability to give shape to the rest of her life due to her feelings of guilt, her personality disorder and her post-traumatic stress disorder. She felt her life was futile and meaningless; she saw no future prospects for herself. The relative in question had been the focal point of her life. The patient had no social contacts left and was unable to build new ones. The future held nothing for her and she regretted that her suicide attempts had failed.

The patient experienced her suffering as unbearable. The physician, a psychiatrist specialised in mood disorders, was satisfied that this suffering was unbearable to her and without prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate the patient's suffering that were acceptable to her.

After many conversations, the physician was satisfied the patient was suffering unbearably and without prospect of improvement and that she was so badly traumatised that no treatment whatsoever could change her situation. The physician talked to the patient about waiting several months after her release and then undergoing another course of treatment, but the patient said she could not summon the energy to do so. For her there was no life without her relative. The physician was of the opinion that any treatment would be doomed to fail, as treatment requires a will to change. As treatment in the psychiatric ward of the prison had failed, the physician was satisfied that treatment in a psychiatric institution (after committal) would not be successful either.

The physician consulted an independent psychiatrist, specialised in forensic psychiatry, and a second independent physician, who was also a psychiatrist. In their opinion too, the patient was suffering unbearably and without prospect of improvement, and there were no reasonable alternatives that would alleviate her suffering.

The physician was satisfied that the request for euthanasia was voluntary and well considered. This was confirmed by the independent psychiatrist and the independent physician. Continuing to live after her release was in no way whatsoever a reasonable alternative for the patient.

At the request of the physician, the aforementioned independent psychiatrist also assessed the patient's decisional competence. In the psychiatrist's opinion the patient had thought carefully and thoroughly about her request for euthanasia. She was consistent and clear in relation to her request. The request for euthanasia was related to psychiatric problems, but was not driven by those problems alone.

The independent psychiatrist concluded that the patient was decisionally competent in relation to her consistent and clearly expressed request for euthanasia. On the day when the patient was released from prison after serving her sentence, she went to a hospice. The procedure to terminate her life took place there that same day.

Before reviewing the case in terms of the due care criteria, the committee noted that this was a complex case that was dominated by the patient's psychiatric problems and in which existential feelings of guilt played an important role. In addition there the exceptional circumstance of the patient's imprisonment.

The committee noted that physicians must exercise particular caution when a euthanasia request results (largely) from suffering arising from a psychiatric disorder. Such cases often involve complex psychiatric prob-

lems, and require specific expertise. Particular caution must be exercised when assessing the voluntary and well-considered nature of the request, the unbearable nature of the suffering, the absence of any prospect of improvement, and the lack of a reasonable alternative. In such cases, the physician must always also consult an independent psychiatrist in addition to the regular independent physician (Euthanasia Code 2018, pp. 43-44).

It can be established that the physician complied with this requirement for particular caution by consulting both an independent physician, who was also a psychiatrist, and an independent psychiatrist, who was specialised in forensic psychiatry.

Voluntary and well-considered request

The committee found that in this case the physician could be satisfied that the patient's request was voluntary and well considered. On this point, the committee noted the following.

The possibility that the psychiatric disorder had impaired the patient's powers of judgment must be ruled out. The physician had to take particular note of whether the patient had shown she was able to grasp relevant information, understood her disease and was consistent in her deliberations.

The reports provided by the physician of the 12 conversations she had had with the patient showed that the patient's wish to die was consistent and motivated. From the very first conversation, the patient indicated that since the death of her relative she no longer wished to go on living. Her request was not influenced by anyone else (external voluntariness) and the physician was satisfied that the patient was able to grasp relevant information, was able to explain clearly why she wanted euthanasia and was consistent in relation to her request (internal voluntariness).

The physician was satisfied that her request was voluntary and well-considered and this was confirmed by the independent psychiatrist and independent physician consulted. The committee found that in the circumstances the physician could be satisfied that the patient's request was voluntary and well considered.

Unbearable suffering without prospect of improvement and absence of a reasonable alternative

In the committee's opinion, in this case the physician could be satisfied that the patient's suffering was unbearable and without prospect of improvement, and that the physician and the patient together could be satisfied that there was no reasonable alternative in the patient's situation. On this point, the committee noted the following.

The unbearable nature of the suffering depends on the individual patient's perception of their situation, their life history and medical history, personality, values and physical and mental stamina. It must be palpable to the physician, also in light of what has happened so far, that this particular patient's suffering is unbearable and with no prospect of improvement (Euthanasia Code 2018, pp. 23-24).

A patient is regarded as suffering with no prospect of improvement if the disease or disorder causing the suffering is incurable and there are no means of alleviating the symptoms so that the suffering is no longer unbearable. The diagnosis and the prognosis are central to the assessment of whether there is no prospect of improvement. This must be determined in the light of whether there are realistic options, other than euthanasia, that would end or alleviate the symptoms. 'No prospect of improvement' must be seen in relation to the patient's disease or disorder and its symptoms. There is no prospect of improvement if there are no realistic treatment options that may – from the patient's point of view – be considered reasonable. It is thus clear that the assessment of the prospect of improvement is closely linked to determining whether there is a reasonable alternative that would alleviate or end the suffering (Euthanasia Code 2018, p. 23). The physician and the patient must together arrive at the conclusion that no reasonable alternatives are available to the patient. The perception and wishes of the patient are important. There is an alternative to euthanasia if there is a realistic way of alleviating or ending the suffering which may – from the patient's point of view – be considered reasonable (Euthanasia Code 2018, p. 26). It is noted in the Euthanasia Code that the proposed alternative must have positive effects within a reasonable period of time and that the patient may always refuse treatment although such a refusal may have consequences for the euthanasia request (Euthanasia Code 2018, pp. 26-27).

In the committee's opinion it can be deduced from the reports of the 12 conversations between the patient and the physician that the physician made a thorough assessment of both the nature of and background to the patient's suffering and the question of whether there were any reasonable alternatives. In the committee's opinion, the independent psychiatrist and independent physician consulted confirmed the physician's conviction that the patient's suffering was unbearable and without prospect of improvement and the physician and the patient together could be satisfied that there was no reasonable alternative in the patient's situation.

In the committee's view, the other due care criteria were also fulfilled.

COMMITTAL UNDER THE PSYCHIATRIC HOSPITALS (COMMITTALS) ACT (BOPZ)

KEY POINTS: non-straightforward notification; full report of findings; Psychiatric Hospitals (Committals) Act; SLK; published as number 2019-126

The patient, a man in his twenties, had had behavioural problems and anger management issues since he was 12. For this reason he had been placed in various youth care institutions and foster families since he was 15. Eventually, in 2011, he was diagnosed with borderline personality disorder characterised by antisocial tendencies. (Borderline personality disorder is a mental disorder whereby the patient experiences severe mood swings, has difficulty forming stable relationships and is often afraid of being abandoned. Antisocial tendencies means that the patient finds it very difficult to adhere to rules and consider other people.) Other psychiatric disorders were also diagnosed, such as ADHD (a concentration disorder) with features of autism. (Autism is a disorder characterised by impairments in the areas of social interaction and verbal and non-verbal communication, and by restricted behaviour patterns with a great deal of repetition or fixed habits). He also suffered from obsessive compulsive disorder (intrusive anxious and unpleasant thoughts that are difficult to suppress), pyromania (an irresistible impulse to start fires) and problematic substance use. He was also thought to be suffering from acquired brain injury. From the age of 13, the patient attempted suicide on three occasions. He often inflicted serious self-harm.

From adolescence the patient was treated extensively with both medication and psychotherapy. He had spent a long period in a forensic ward under a court order for committal to a mental healthcare institution pursuant to the Psychiatric Hospitals (Committals) Act. Despite long-term treatment in the institution and some initial progress, in the past five years the patient's situation had deteriorated in comparison with the situation on admission. Social rehabilitation had also proved impossible.

The attending psychiatrist suspected psychological treatment would have no chance of success. Schema therapy (a type of psychotherapy that helps the patient to understand and change long-standing patterns of behaviour) had had no effect on the patient. The patient no longer wanted to receive any treatment. The attending psychiatrist thought that the suspected brain injury played a part in that respect. She thought the patient's chances of changing his behaviour were very slim.

Around two months before the patient's death the physician consulted an independent psychiatrist. She asked him to review the diagnosis and possible treatment options for the patient. The psychiatrist's findings

matched those of the others who had been treating the patient. As the patient had no desire whatsoever to receive treatment, there was no way of starting psychotherapy. In any case, given the patient's long treatment history and the very limited results achieved, it was unlikely that psychotherapy would have much effect in terms of behavioural change. The independent psychiatrist, too, thought that the patient's ability to change his behaviour was very limited. The independent psychiatrist concluded that there were no realistic treatment options left for the patient. The patient's condition was incurable.

The patient was suffering from an urge to carry out impulsive acts that could not be managed. These acts included starting fires, self-harm and acting out (when a person acts destructively and aggressively without taking account of the negative consequences). In this way he was trying to cope with mounting internal tensions. The thoughts about starting fires and self-harming occupied him all day long. He was barely able to suppress these thoughts, and as a result he self-harmed constantly. The patient knew that as a result of his disorders he would never be able to function normally in society. He therefore saw his future as unliveable. The patient experienced his suffering as unbearable. The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion. There were no alternative ways to alleviate his suffering that were acceptable to the patient.

Since 2015 the patient had spoken with several attending physicians about euthanasia. In that same year he registered with the End-of-Life Clinic (SLK) for the first time. Shortly after, he cancelled his registration due to personal circumstances. Shortly afterwards those personal circumstances changed, and from that moment his wish for euthanasia remained undiminished in the years that followed. He discussed it repeatedly with those treating him. The patient's attending psychiatrist refused to carry out his request, for reasons that were not disclosed. Moreover, she was not entirely convinced that the patient's suffering was without prospect of improvement. For that reason, the patient registered with the SLK again in April 2018.

Over a period of six months, the physician spoke extensively on four occasions with the patient about his request. During each of those conversations the patient asked the physician to actually perform the procedure to terminate his life.

On the basis of the conversations the physician had with the patient, she considered him decisionally competent in relation to his request. He was able to clearly explain the reasons for his decision and the consequences

of his request. The physician concluded that the request was voluntary and well considered. The aforementioned independent psychiatrist also considered the patient to be decisionally competent regarding his request.

The independent SCEN physician consulted by the physician was satisfied that the patient was suffering unbearably from his constant thoughts about starting fires and self-harming. As a result the patient would never be able to participate in society in a normal manner. He established that, in view of the patient's treatment history, the independent psychiatrist's report, the patient's character and his inability to make something of his life, there were no reasonable alternatives for the patient. The independent physician concluded that the patient had had a consistent wish for euthanasia for many years and he considered him decisionally competent in relation to his request.

The committee noted that, in the event that a request for euthanasia is prompted by suffering resulting from a psychiatric disorder, the physician must exercise particular caution. Particular caution must be exercised especially when assessing the voluntary and well-considered nature of the request, the absence of any prospect of improvement, and the lack of a reasonable alternative. The specific expertise of an independent psychiatrist is required in such cases (Euthanasia Code 2018, pp. 42-43).

On the basis of all the information provided by the physician, the committee found that in the present case the physician exercised particular caution, among other things because she consulted an independent psychiatrist, who concluded that the patient was decisionally competent in relation to his request for euthanasia, his suffering was without prospect of improvement and there were no reasonable treatment options left. The independent physician confirmed the physician's assessment that the due care criteria had been complied with.

The committee reflected on the fact that the patient had previously been confined under criminal law and at the time of his request for euthanasia had been placed in a secure ward subject to a temporary court order under the Psychiatric Hospitals (Committals) Act. The committee noted the following in this respect.

A stay in such a setting, in which the patient is deprived of his liberty by the state and is subject to legal status rules relating to (involuntary) treatment can, in the committee's opinion, have an influence on external voluntariness, whether the suffering is unbearable and/or without prospect of improvement, and/or the absence of reasonable alternatives.

It became clear to the committee from the documents that the temporary order was intended to provide the patient with a safe place to stay. This patient, for whom social rehabilitation had proved impossible, could only function in an involuntary setting. It was also clear to the committee that extension of the temporary order would mean the patient had a place to stay if he changed his mind about euthanasia. The committee therefore considered it plausible that the involuntary setting in which the patient was staying did not require further review.

The other due care criteria were also fulfilled in the committee's view.

3. PHYSICIAN DID *NOT* ACT IN ACCORDANCE WITH THE DUE CARE CRITERIA

Cases in which the RTEs find that the physician has not acted in accordance with the due care criteria always lead to lengthier findings than other cases. This is because a conclusion cannot be reached in such cases without giving the physician the opportunity to give an oral explanation.

In the year under review, the RTEs found in four cases that the physician had not acted in accordance with the due care criteria in performing euthanasia. In three of the cases this concerned the requirement to consult an independent physician and in one case it concerned the way the euthanasia procedure was carried out.

NON-COMPLIANCE WITH THE CRITERION OF CONSULTING AT LEAST ONE OTHER, INDEPENDENT PHYSICIAN

Section 2 (1) (e) of the Act states that the physician must have consulted 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 purpose of the consultation is to ensure that the physician's decision is reached as carefully as possible. It helps the physician establish whether all the due care criteria have been met.

The committees believe it is important for the physician performing euthanasia to request a consultation. If this is not the case, the committee will expect the physician to explain the reasons for this in his report. For instance, the patient may be being treated by several physicians working together and it may be the case that one physician requests the consultation and another actually performs euthanasia. In such cases the independent physician will also have to affirm his independence in relation to the physician performing euthanasia (Euthanasia Code 2018, p. 28).

The physician is expected to take note of the independent physician's findings before making a final decision on the request for euthanasia. The physician must take the independent physician's opinion very seriously (Euthanasia Code 2018, p. 29).

According to the Act, the independent physician must see the patient, which for the committee means that in principle the independent physician must see and speak with the patient. It is possible that the patient is no longer capable of conversation by the time he is visited by the independent physician, in which case the independent physician must base his assessment on all other available and relevant facts and circumstances. The Act therefore does not require that the independent physician is always able to communicate with the patient (either verbally or non-verbally) (Euthanasia Code 2018, p. 31).

The first notification discussed below (2019-12) was a case in which the independent physician did not visit the patient. In the second case (2019-03) a different physician requested the consultation with the independent physician, and the physician who performed euthanasia did not personally take note of the independent physician's report. In the third case (2019-15) the physician did not contact a physician who gave his opinion on *all* the due care criteria.

THE INDEPENDENT PHYSICIAN MUST SEE THE PATIENT

KEY POINTS: non-straightforward notification; full report of findings; requirement for consultation of an independent physician; the independent physician must see the patient; published as number 2019-12

The patient, a woman in her seventies, suffered a severe cerebrovascular accident (stroke) around a month before her death. She immediately lost the use of the right side of her body and had problems with swallowing. She also suffered from global aphasia (a speech disorder). She could no longer speak and appeared to have severe cognitive deficits. As a result no communication was possible. The attending neurologist established that the chance of the patient recovering to the extent that she could lead what she would consider a dignified life was virtually non-existent. The patient's condition was incurable. She was now in a situation she had previously said that she really did not want to arise.

She had had an advance directive for years, which included a passage on euthanasia in the event of dementia. She had also written a refusal of treatment directive, and had discussed both documents with her general practitioner. In her advance directive she stated that she wanted euthanasia in the event that she was suffering unbearably without prospect of improvement or if she was in a situation in which progressive loss of dignity was to be expected. She also requested euthanasia if her situation was one in which there was no reasonable prospect of a return to what she would consider a dignified life. In addition, in the passage on euthanasia in the event of dementia she stated that she wanted euthanasia if she came to be in a situation in which there was progressive loss of dignity, and in which she was unable to communicate, needed help with day-to-day activities and no longer recognised her family.

The patient's husband and children asked the physician (the locum for the patient's general practitioner) to assess the patient's situation. They discussed her advance directive with the physician and asked him if he would carry out the request she had expressed in it. The physician visited the patient in hospital and tried to make contact with her. At times, the physician observed some response from the patient; she appeared to be able to perform a simple task but shortly after, she could no longer manage to do so. She was unable to communicate directly. After the physician had established what the patient's situation was, and after further consultation with her family, he said he was willing to assess whether euthanasia was possible on the basis of advance directive.

The physician consulted an independent physician who was also a SCEN physician. The SCEN physician was informed about the patient by the

physician and given insight into the relevant medical information. The independent physician then contacted the ward where the patient had been admitted to make an appointment to visit her. A nurse told him that communication with the patient was not possible. This was confirmed during telephone conversations with the ward doctor and the attending neurologist. On the basis of this and the information he had received from the physician, the independent physician decided not to visit the patient. No useful response was to be expected from her. Instead, the independent physician visited the patient's husband and children, around a week and a half before the patient's death. The independent physician wanted to hear from them what the patient's assessment of her situation would be if she were still able to express it. The patient's husband and children were convinced that the patient was suffering unbearably due to her current situation and that she would want euthanasia.

The committee asked both the physician and the independent physician to explain the fact that the independent physician had not visited the patient. The physician explained that the independent physician's decision not to visit the patient had not been made in consultation with him. He had understood previously that it was not strictly necessary for the independent physician to visit the patient. Afterwards it occurred to the physician that he should have told the independent physician to visit the patient.

The independent physician said that he had understood that the patient was no longer able to communicate, but did have a clear advance directive. He said that he was aware that in principle he should visit the patient. However, the physician and several medical professionals treating the patient had all emphasised that no form of communication whatsoever was possible with the patient.

It was clear to the independent physician what the patient meant in her advance directive. He had become convinced that she was suffering unbearably because she was now in a situation that she had not wanted to experience. In fact, her situation was even worse than what she had described in her advance directive. There was no way whatsoever for her to confirm this. Visiting the patient would not have provided any additional information because it was unclear whether she was able to understand what was being said.

When questioned on the matter, the independent physician said that he had thought carefully about whether he should see the patient. He was convinced, however, that this would not have helped him in forming his opinion. Various people had tried on various occasions to make contact

with the patient, but to no avail. The independent physician considered that there was nothing he could have contributed to that. In his opinion it would have been a pointless, purely ritual gesture to visit the patient. He did not feel it left a gap in his ability to form an opinion. The independent physician stressed that he would have visited the patient if he had thought it would contribute something to his forming an opinion.

The committee asked the independent physician whether he had discussed this with the physician. The independent physician replied that he had not.

As concerns the consultation requirement, the committee noted that the physician had consulted an independent SCEN physician, who concluded that the due care criteria had been complied with. Although the independent physician clearly substantiated his conclusion, he did not visit the patient.

Section 2 (1) (e) of the Act stipulates that the independent physician must see the patient. The legislative history includes the following quote from the government on this matter: 'the independent physician must apprise himself of the patient's medical situation and wish to die, by visiting and if necessary examining the patient in person. This requirement is apparent from the use of the term "see". In practice, situations sometimes occur in which, due to the stage of the patient's condition, such a visit may appear superfluous, or in which the patient and the family may consider the visit an intrusion into the intimate atmosphere of the patient's deathbed. From the point of view of due care, however, it is desirable for an unequivocal norm in this respect to be laid down in the Act.' (Parliamentary Papers, House of Representatives, 1998 -1999, no. 3, p. 10.)

The independent physician must form an opinion on the due care criteria, including the criterion that the patient must be suffering unbearably. In this case the independent physician formed his opinion on the basis of the case file, including the advance directives, and conversations with the physician, the patient's family and those who were treating her. Whereas he stated that a visit would contribute nothing to his forming an opinion, the committee found that a visit would have supported that process. He would, at a glance, have received confirmation of his view.

The added value of visiting the patient would have lain in that confirmation. Despite the fact that communication with the patient was no longer possible, the independent physician should have gone to see her for himself. Merely seeing the patient can reveal a great deal. For instance, he could have seen for himself if there were signs of suffering,

or at least himself have established the patient's level of awareness, thus confirming his opinion.

The committee found that, because the independent physician did not see the patient, the required consultation did not take place in accordance with section 2 (1) (e) of the Act.

The other due care criteria were complied with.

THE PHYSICIAN PERFORMING EUTHANASIA SHOULD IN PRINCIPLE HIMSELF CONSULT THE INDEPENDENT PHYSICIAN AND AT LEAST READ THE INDEPENDENT PHYSICIAN'S REPORT

KEY POINTS: non-straightforward notification; requirement that the physician performing euthanasia must in principle himself consult the independent physician and at least take note of the independent physician's findings; published as number 2019-03

After receipt of the case file, it emerged that the termination of life on request had been performed not by the (attending) psychiatrist who had submitted the notification, but by the patient's general practitioner. The psychiatrist had completed the model reporting form and signed it; the general practitioner had also signed it.

In response to questions from the committee, the psychiatrist said that he had guided the entire process, but that several weeks before the procedure was carried out he had agreed with the general practitioner that the latter would carry out the procedure to terminate the patient's life. They decided this because the psychiatrist had little experience in inserting an IV cannula. The psychiatrist had considered having a paramedic do it. However, the general practitioner did not think it was a good idea to have stranger insert the IV cannula when the time came to perform euthanasia. Moreover, he was experienced in the procedure. The general practitioner also felt that if he inserted the IV cannula, he should also administer the euthanatics.

The Act stipulates that the physician who performs euthanasia must also submit the notification. The committee therefore found that in this case the general practitioner should have submitted the notification, not the psychiatrist. The general practitioner then submitted a report.

As regards consulting at least one independent physician, the committee noted the following. It emerged from the reports of the attending psychiatrist and the general practitioner, and from the interview the committee held with the general practitioner that it was the attending psychiatrist who consulted the SCEN physician and took note of the latter's report. The general practitioner had no contact with the independent physician, nor did he read the independent physician's report and was therefore unable to ascertain from her report whether she was of the opinion that the due care criteria had been fulfilled. Instead, he relied on what the attending psychiatrist had told him about this. The general practitioner was therefore also unable to reflect on the independent physician's report before performing euthanasia.

The independent physician did not know that the general practitioner was going to perform the euthanasia procedure (and not the psychiatrist who consulted her). She was therefore not in a position to affirm her independence in relation to the physician.

The committee noted that in this case there was no emergency that required the procedure to be carried out urgently. In fact, the general practitioner and the attending psychiatrist had decided long before euthanasia was performed that the general practitioner would insert the IV cannula and administer the substances. There would therefore have been enough time for the general practitioner to take over the entire euthanasia process at an earlier stage. After all, he had been involved in the process for a year and was himself satisfied that the due care criteria had been fulfilled. In that event, the general practitioner could have consulted the independent physician himself and read her report.

The committee noted that the aim of the physician and the attending psychiatrist had been to perform the procedure in a way that would place the least possible burden on the patient. They both felt strongly committed to the patient and they performed the euthanasia procedure in this way with the best of intentions. Neither of them realised that the physician performing euthanasia should have consulted the SCEN physician and taken note of the independent physician's findings.

The committee found that the physician had not acted in accordance with the due care criteria laid down in section 2 (1) (e) of the Act.

The other due care criteria were complied with.

REQUIREMENT FOR CONSULTATION OF AN INDEPENDENT PHYSICIAN EVEN IF TWO INDEPENDENT PSYCHIATRISTS HAVE BEEN CONSULTED

KEY POINTS: non-straightforward notification; full report of findings; requirement for consultation of an independent physician even if two independent psychiatrists have been consulted; published as number 2019-15

The patient, a woman in her seventies, was diagnosed with various psychiatric disorders due to traumatic experiences at a young age. At the end of her life she felt worn out and powerless. She experienced poor quality of life and wanted to die with dignity. At the request of the physician, two independent psychiatrists made an assessment.

The first psychiatrist considered the patient to be decisionally competent regarding her request for euthanasia. The second psychiatrist also considered her to be decisionally competent and was of the opinion that she was suffering unbearably and without prospect of improvement.

Afterwards, the physician asked the second psychiatrist, who is also a SCEN physician, to assess to what extent euthanasia in this case would be appropriate within the boundaries and insights provided by the euthanasia legislation. However, the second psychiatrist considered her assessment to be a second psychiatric assessment and emphasised in her report that she was not acting in her role as a SCEN physician. She therefore did not comment on all the due care criteria laid down in section 2 (1) (a) to (d) of the Act. The physician subsequently did not consult another, independent physician, whose task would have been to see the patient and give a written opinion on whether the due care criteria had been complied with.

When questioned about the matter, the physician mentioned several reasons for not consulting another physician. First, in his opinion, which he based on information he had received on two occasions from an experienced psychiatrist, consulting a psychiatrist with specific SCEN expertise meant that the due care criteria had been complied with. The second reason was the fact that the patient had developed an aversion to psychiatrists as a result of her many failed treatments. The procedure proposed by the physician, i.e. assessment by two psychiatrists, had required a great deal of effort on her part. The first psychiatrist's visit had unsettled her. After speaking with the second psychiatrist, the patient had become even more unsettled. Lastly, the physician questioned whether consulting an independent physician would be necessary in view of the patient's poor condition and the heavy toll such a visit would take on her. In the

physician's view consulting an independent physician would be nothing more but a formal conclusion of the process. In his opinion he had proceeded with great caution, by consulting two independent psychiatrists about his uncertainty with regard to the psychiatric assessment. Consulting an independent physician would add little, yet would be a burden to the patient. In hindsight the physician realised he should nevertheless have consulted an independent physician.

As concerns the consultation requirement, the committee noted that under section 2 (1) (e) of the Act, before performing euthanasia, a physician must consult at least one other, independent physician who must see the patient and give his opinion on due care criteria (a) to (d) of the Act. The purpose of the independent consultation is to ensure that the physician's decision is reached as carefully as possible. It helps the physician ascertain whether all the due care criteria have been met and reflect on matters before granting the request and performing euthanasia.

If contact with both an independent physician and a psychiatrist poses an unacceptable burden on the patient, it may be sufficient to consult an independent (SCEN) physician who is also a psychiatrist. In that case the physician must realise that the independent physician will give both a psychiatric assessment and his opinion on due care criteria (a) to (d) of the Act (Euthanasia Code 2018, p. 43).

The committee established that the physician did not consult one other, independent physician, whose task would have been to see the patient and give a written opinion on whether the due care criteria had been complied with. The fact that he acted on the basis of what turned out to be incorrect advice from the first psychiatrist does not relieve him of his responsibility to act in accordance with the due care criteria laid down in the Act.

In accordance with article 9, paragraph 5 of the Guidelines on the working procedures of the regional euthanasia review committees (21 November 2006) the committee asked the physician for further information in order to ascertain whether an independent opinion had been formed. If the physician were able to present facts proving that that was the case, the committee could find that the due care criteria had been complied with. In this case, however, the physician was unable to present any facts that pointed to an independent opinion having been formed.

The committee was satisfied that it was the physician's intention to help the patient, whom he had known very well for many years and whose medical situation was very complicated, with respect and the highest degree of professional care. It appreciated the fact that the physician

took it upon himself to deal with a complicated case, as well as the conscientious way he treated the patient.

However, because the physician did not consult at least one other, independent physician who saw the patient and gave a written opinion on due care criteria (a) to (d) of the Act, the committee had no alternative but to find that the due care criterion laid down in section 2 (1) (e) of the Act had not been complied with.

The other due care criteria were complied with.

NON-COMPLIANCE WITH THE CRITERION OF DUE MEDICAL CARE

The physician must exercise due medical care in performing euthanasia. This concerns, for instance, the substances and doses administered, and appropriate checks to determine the depth of the coma which the physician induces before proceeding to administer a lethal substance.

In assessing this due care criterion, the RTEs refer to the KNMG/KNMP 'Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide' of 2012. The Guidelines list substances that may be used and their recommended doses. If the physician deviates from the Guidelines, he will have to present convincing arguments in support of his actions. The physician bears final responsibility for exercising due medical care. His actions are assessed by the committees. The pharmacist has an individual responsibility for the preparation and labelling of the substances. The physician must check whether the correct substances in the correct doses have indeed been received (Euthanasia Code 2018, p. 36).

As regards the presence of the physician during assisted suicide, page 36 of the Euthanasia Code 2018 says the following: 'If the patient wishes, the physician may leave the room after the patient has taken the euthanatic. The physician must however remain in the patient's immediate vicinity in order to intervene quickly if complications arise.'

FINDING: DUE CARE CRITERIA NOT COMPLIED WITH

KEY POINTS: non-straightforward notification; full report of findings; requirement of due medical care; leaving the patient; published as number 2019-57

The patient, a woman in her seventies, was diagnosed with stomach cancer nearly three months before her death. The patient's condition was incurable. The patient experienced 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 the patient's suffering that were acceptable to her. The patient had discussed euthanasia with the physician before. During those conversations it had become clear that the patient had made an explicit choice for assisted suicide because she wanted to maintain control over her own life, including its end.

The physician assisted her suicide by handing the patient Pentobarbital (a lethal substance) in 200ml of liquid, which she drank. After some time the physician left the patient's house and went to her practice. She did this before she had established that the patient had died.

As regards the fact that the physician left the patient, the committee referred to the KNMG/KNMP 'Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide', page 13 of which says: 'During the euthanasia or assisted-suicide procedure, the physician must be and remain present. When the oral method is used (assisted suicide), this may take several hours.' The Euthanasia Code 2018 is in line with this (see above).

In her oral explanation the physician acknowledged that she was familiar with the Guidelines. The independent physician had also mentioned them in his advisory report to the physician. Nevertheless, it was established that the physician had left the patient. She argued that a physician may, with good reason, deviate from the Guidelines. She had done so out of respect for the wish of the patient and her (adult) son to experience the last moments of her life without others present.

The committee noted first of all that it had no reason to doubt the physician's account of the facts and circumstances, nor did it have reason to doubt the purity of her intentions. The physician wanted to respect the wish of the patient and her son. She recognised the risk of problems arising in the performance of the assisted-suicide procedure. She watched how the patient reacted to the ingestion of the Pentobarbital from the kitchen, from where she could see her. According to the physician, after five minutes the patient had become unresponsive; after 12 minutes no breathing was visible.

The physician did not confirm the patient's death at that time. On the basis of her observations the patient did not think any problems were to be expected and she went to her practice. She checked whether the family members had her mobile phone number. The assisted suicide took place on her day off. She had no other work to do and waited for the phone call from the family member. The practice was a three-minute drive from the patient's house. Immediately after receiving the message from the son, 12 minutes later, that his mother appeared to have died, the physician returned. She notified the pathologist of the course of events.

In its findings on case 2018-75, the committee held that in this respect the Euthanasia Code 2018 should be interpreted with caution. Although the facts and circumstances of that case were very different from the present case, the main considerations in those findings were followed here too. Assisted suicide by means of an ingested liquid carries certain risks. The procedure may take longer than when the euthanatics are injected directly into the bloodstream. There is also a risk that the patient, even one who is unconscious, will vomit up the liquid. This

requires immediate intervention and is why it is necessary to strictly follow the instruction that a patient must not be left before their death has been confirmed.

Moreover, the physician had an alternative that would allow her to fulfil the patient's wish: she was able to await the outcome of the procedure in another room, out of sight of the patient and her son. Even though the physician's practice was close by, and she had nothing else to do, there was insufficient certainty that she would be able to act immediately if problems occurred. The physician's respect for the patient's wish was compassionate, but formed insufficient reason to deviate from the Guidelines; it is the physician's task as the expert to monitor any possible medical risks.

In the notification form the physician notified the pathologist and the RTE of the fact that she had left the patient. The physician thus facilitated review of her actions. When giving her oral explanation she showed herself to be aware of the possible risks. By her own account she later acted differently in a similar case, by staying in the direct vicinity of the patient. Nevertheless, the committee attaches great importance to compliance with the Guidelines and the reasoning behind them. There may be justifiable exceptions to the Guidelines, but this case is not one of them. The committee therefore found that the physician had not acted with due medical care in regard to the assisted-suicide procedure. The committee found that the physician had not acted in accordance with the due care criteria laid down in section 2 (1) (f) of the Act.

The other due care criteria were complied with.

PUBLICATION INFORMATION

Published by:
Regional Euthanasia Review Committees
www.euthanasiecommissie.nl

Design:
Inge Croes-Kwee
(Manifesta idee en ontwerp), Rotterdam

Translation:
Translation Department, Ministry of Foreign Affairs

April 2020

RTE