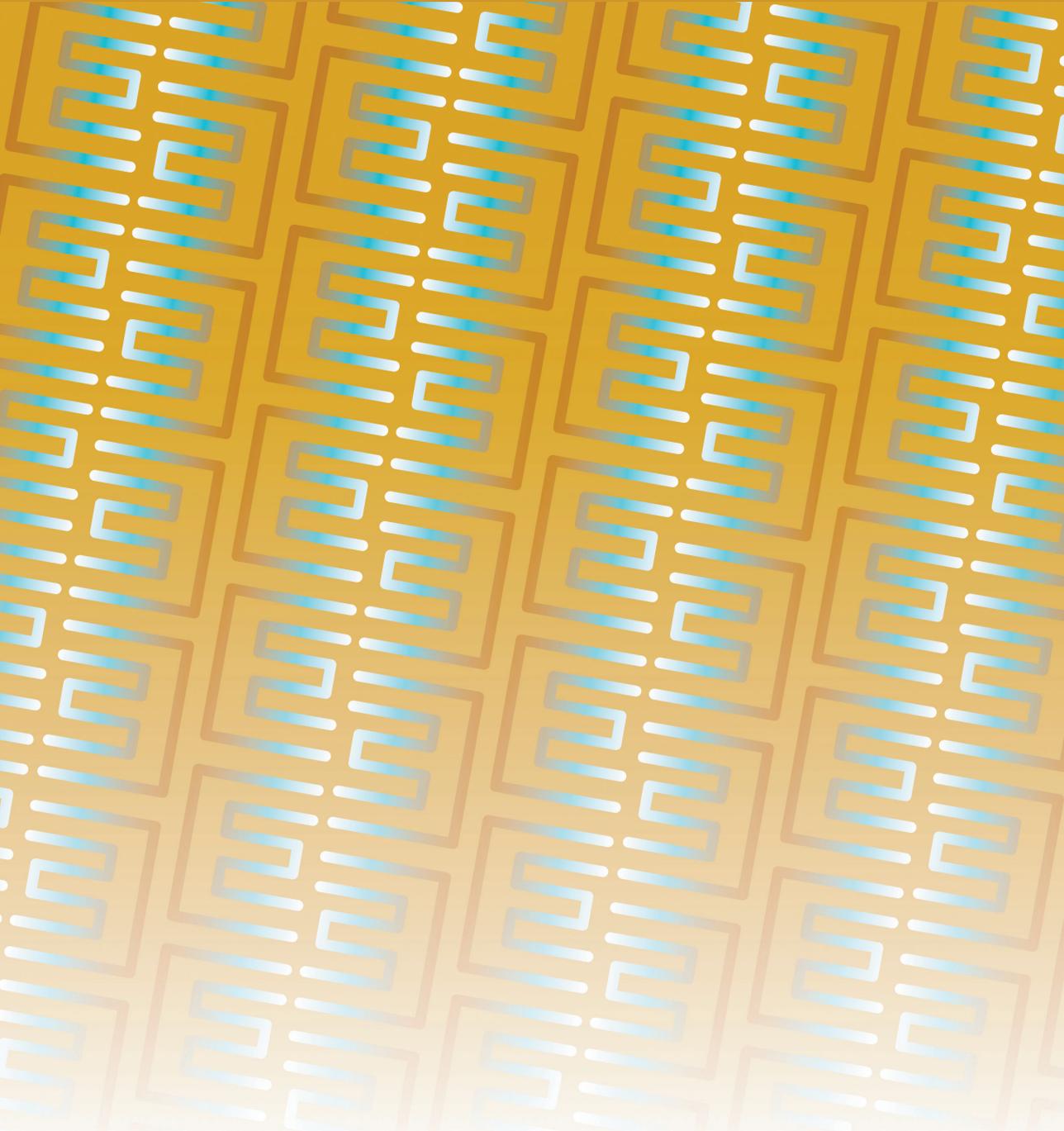


REGIONAL
EUTHANASIA
REVIEW COMMITTEES



ANNUAL REPORT 2018



REGIONAL
EUTHANASIA
REVIEW COMMITTEES



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Note on the translation

The RTEs' aim in providing this translation is to allow an international audience insight into the practice of euthanasia in the Netherlands. For reasons of economy, several sections of the annual report dealing with the RTEs' procedures and organisation have not been included in the translation, as well as a number of illustrative cases and several cases in which the committee found that the physician had not acted with due care. All omissions have been indicated in the text. These findings can be found (in Dutch) on the website of the RTEs (www.euthanasiecommissie.nl/uitspraken-en-uitleg).

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FOREWORD

Public debate

The year 2018 will not go down in history as one in which euthanasia could be taken for granted. This was due in part to debate on requests for euthanasia by patients with a psychiatric disorder and written requests from patients with advance dementia who were no longer able to express their wishes at the time euthanasia was performed. These debates highlighted diverse points of view in the media, in the political arena, among physicians and among the public at large.

The Guidelines on termination of life on request for patients with a psychiatric disorder, published by the Netherlands Psychiatric Association in autumn 2018, will hopefully calm the waters somewhat in the debate on psychiatric disorders and euthanasia. What may also help are the plans of the Royal Dutch Medical Association (KNMG) to provide more guidance to physicians in dealing with the dilemmas that arise when they are asked to carry out a request for euthanasia on the basis of an advance directive drawn up by a patient who has since become decisionally incompetent.

In spring 2018 the Regional Euthanasia Review Committees ('the RTEs') published the Euthanasia Code 2018. This provides a useful overview of how the RTEs interpret the due care criteria in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act ('the Act'). The RTEs are pleased that the Euthanasia Code 2018 has been sent to all general practitioners, thanks to financial support from the Minister of Health, Welfare and Sport. The RTEs consider the Euthanasia Code 2018 to be essential reading for all physicians who receive requests from patients to help them die by means of euthanasia or assisted suicide.

Although psychiatric disorders and advanced dementia clearly pose fundamental and highly complex questions in relation to euthanasia, it should be noted that in 2018, out of the total of 6,126 notifications received by the RTEs, around 1% involved patients with a psychiatric disorder (67) and patients in whose cases euthanasia was performed on the basis of an advance directive (2).

As in 2017, more than 90% of notifications in 2018 (5,553) related to situations in which the patient was suffering unbearably and with no prospect of improvement as a result of an incurable or untreatable condition, such as cancer, cardiovascular disease, early-stage dementia, neurological disorders or a combination of disorders.

Role of the Public Prosecution Service and the Health and Youth Care Inspectorate

In addition, 2018 was an exceptional year because, for the first time in more than 10 years, the Health and Youth Care Inspectorate (IGJ) brought a euthanasia case before the medical disciplinary board. Later that year, the Board of Procurators General ('the Board of PGs') decided for the first time since the Act entered into force in 2002 to prosecute the physician in question. In four other cases in which the RTEs had found in 2017 that the physicians in question had not acted in accordance with one or more of the due care criteria in the Act, the Board of PGs decided to conduct a criminal investigation. Public reaction to these new developments varied from 'a highly undesirable change of course' to 'the Public Prosecution Service is finally doing what the legislator expected of it'.

The Act stipulates that if the RTEs find that a physician has not acted in accordance with one or more of the due care criteria laid down in the Act, that finding must be brought to the attention of the Board of PGs and the IGJ. The IGJ and the Board of PGs then investigate and assess the cases brought before them by the RTEs.

The RTEs, the Board of PGs and the IGJ review the same cases, but they look at them from different legal perspectives. The RTEs determine whether the physician acted in accordance with the due care criteria in the Act. The IGJ assesses whether the physician's actions – in short – possibly constitute a risk to healthcare. The Board of PGs, lastly, decides whether the physician can be held responsible under criminal law. In order to answer these questions, the three institutions employ a variety of investigative methods and procedures.

Cases handled in 2017 and 2018

Looking back on 2017 and 2018, the question arises as to whether the findings and decisions of the RTEs, the Board of PGs and the IGJ lead to a body of unequivocal and clear standards for practising physicians. In other words, do they make it clear to physicians how they should act in comparable situations? And if the conclusions of the three institutions differ, what lessons should be learned from this?

In an attempt to answer these questions, the findings of the RTEs and the decisions of the IGJ and the Board of PGs were reviewed, presenting the following picture.

In 2017 the RTEs found in 12 cases that the physicians involved had not acted in accordance with the due care criteria in the Act. Of these 12 notifications, in eight cases after investigation and an interview the decision was made by the Board of PGs not to prosecute, subject to

certain conditions, the various nuances being set out in the decisions in question.¹ The IGJ was of the opinion that the physicians involved in those cases need not face further disciplinary action. These were cases in which the RTEs found that the independence of the physician consulted was questionable or that the termination of life had not been carried out with due medical care. These two due care criteria in the Act are not considered ‘material due care standards’, as is apparent from the Instructions on prosecution decisions in the matter of active termination of life on request and assisted suicide, issued by the Board of PGs.² The physicians in question agreed with the RTEs’ findings, or at least said they had learned from them, and stated that they would in future abide by the standards as described in the RTEs’ findings.

In these eight cases, the IGJ and the Board of PGs agreed with the RTEs’ finding that there had been a contravention of the Act. However, as the physicians had learned from their disputed actions, the IGJ decided that there was no reason to fear a repetition of events or a risk to healthcare. On almost identical grounds, the Board of PGs was of the opinion in each case that the physician in question could not be held responsible under criminal law, or that it was not in the public interest to prosecute them.

In 2018 the RTEs found in six cases that those involved had not acted in accordance with one or more of the due care criteria in the Act. Five of these notifications have since been reviewed by both the Board of PGs and the IGJ, while one case is still under investigation. In these five cases, the IGJ decided, after speaking with the physicians in question, that there was no reason on the grounds of patient safety to conduct further investigations or take further measures in relation to the physicians’ actions. After investigations and interviews with the physicians in the same five cases, the Board of PGs decided not to prosecute, subject to certain conditions. The Board of PGs agreed with the RTEs’ finding that the due care criteria had not been complied with. However, partly because the physicians in question facilitated the review of their actions and indicated they would ensure that the contraventions in question would not happen again, the Board of PGs decided that the physician could not be held responsible under criminal law and/or that it was not in the public interest to prosecute. The Board of PGs and the IGJ still have to decide on one of the cases in which the RTEs found in 2018 that the due care criteria had not been complied with.

- 1 Decisions of the Board of PGs concerning findings of the RTEs are published at <https://www.om.nl/onderwerpen/euthanasie/beslissingen-college/>.
- 2 The Instructions on prosecution decisions in the matter of termination of life on request and assisted suicide can be found (in Dutch) at <https://wetten.overheid.nl/BWBR0039555/2017-05-17>.

Explicit confirmation of the body of standards applied by the RTEs

Of the 18 cases reviewed in 2017 and 2018 in which the RTEs found that one or more of the due care criteria had not been complied with, 13 cases led to a decision not to prosecute, subject to certain conditions, explicitly confirming the body of standards applied by RTEs, because the physicians in question could not be held responsible under criminal law and/or because a prosecution was not considered to be in the public interest. The IGJ also decided in these 13 cases that the physicians need not face disciplinary action.

Despite the fact that these notifications are investigated and assessed from various legal perspectives by three mutually independent institutions, the outcomes are unequivocal and clear, giving physicians a basis on which to act in comparable situations.

There remain four cases from 2017 in which the RTEs found that the Act had been contravened and in regard to which the Board of PGs announced on 8 March 2018 that ‘criminal investigations would be conducted into possibly unlawful euthanasia’. These four cases involved due care criteria laid down in the Act that the Board of PGs considers to be ‘material due care standards’. They concern the question of whether the physician could reasonably conclude that the patient’s request was voluntary and well considered, and related questions concerning the validity of the advance directive. They also concern the question of whether the physician was able to conclude that the patient’s suffering was unbearable, with no prospect of improvement.

In two of these cases, the Board of PGs has now decided not to prosecute. A notable difference between the findings of the RTEs and the decisions not to prosecute of the Board of PGs in these two cases is that during the investigation carried out by a public prosecutor on behalf of the Board of PGs other facts, some of them new, came to light. In a criminal investigation the Public Prosecutor, unlike the RTEs, questions the physician as a suspect. The Public Prosecutor can also question other persons, such as family members, under oath. Facts may then come to light that were not mentioned in the RTEs’ interview with the physician.

In order to avoid new facts not coming to light until a very late stage, it is recommended that physicians who are asked to give more information at a meeting of the RTE about the euthanasia procedure they carried out prepare even more thoroughly for that meeting, by making all conceivably relevant information – facts and circumstances – available to the RTE. Even though during the interview the physician is not a suspect, the RTEs should show more persistence in uncovering the relevant facts and circumstances.

Summary

In 2017 and 2018 the RTEs reviewed a total of 12,711 euthanasia notifications. In 18 of those cases the RTEs found that one or more of the due care criteria in the Act had not been complied with. In 15 of those 18 cases, the Board of PGs has since decided not to prosecute.

There is no doubt that having their actions reviewed by the RTEs causes the physicians some anxiety, even more if they also have to justify their actions to the IGJ and the Public Prosecution Service. The practice of euthanasia in the Netherlands is monitored very strictly. However, on the basis of the above-mentioned figures there should be no great cause for concern among physicians. The body of standards resulting from this monitoring contribute to the care exercised in the practice of euthanasia, without physicians being unnecessarily faced with legal proceedings.

Compliance with the Guidelines of the KNMG and the NVVP, more guidance from the KNMG with regard to euthanasia and dementia, and intensive consultation of the RTEs' Euthanasia Code 2018 by physicians should ease the tension surrounding the practice of euthanasia, and at the same time further improve meticulous compliance with the due care criteria laid down in the Act.

Jacob Kohnstamm,
Coordinating chair of the Regional Euthanasia Review Committees

March 2019



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

10

| | |
|----------------------------------|-------|
| ● termination of life on request | 5,898 |
| ● assisted suicide | 212 |
| ● combination of the two | 16 |

CHAPTER I

DEVELOPMENTS IN 2018



1 ANNUAL REPORT

For more information on the outline of the Act, the committees' procedures, etc., see the Euthanasia Code 2018 and <https://english.euthanasie-commissie.nl>.

In their annual reports 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. A large part of the report is therefore devoted to descriptions of various cases. We have aimed to make the annual report accessible to a wider public by avoiding the use of legal and medical terms as much as possible, or by explaining them where necessary.

11

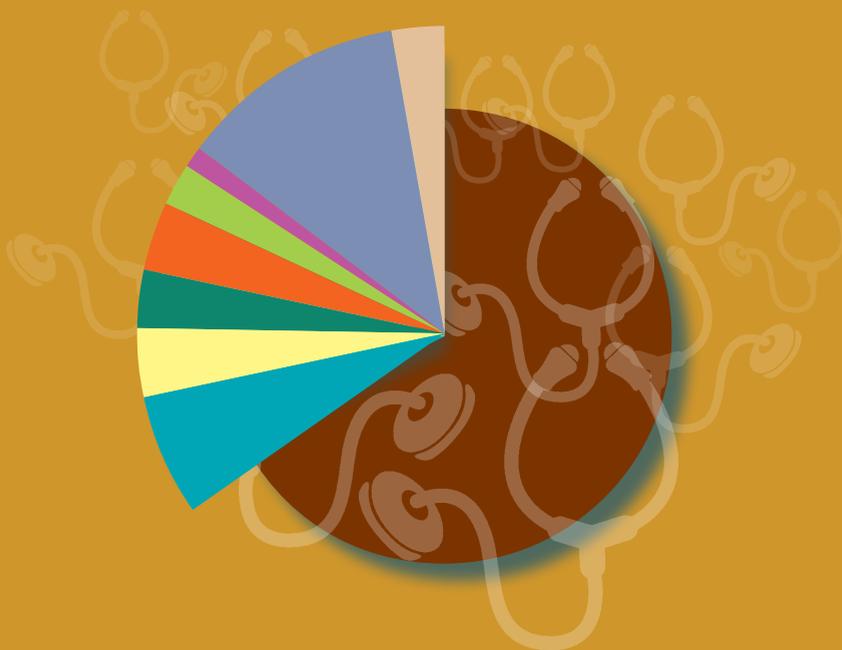
2 NOTIFICATIONS

Number of notifications

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

In 2018 the RTEs received 6,126 notifications of euthanasia. This is 4% of the total number of people who died in the Netherlands in that year (153,328). In 2017 the RTEs received 6,585 notifications, which was 4.4% of the total number of deaths (150,027). This is the first time in years that there has been a decline in the number of notifications, both in absolute terms and in relation to the total number of deaths in the Netherlands. In response to questions from parliament, the Minister of Health, Welfare and Sport said on 6 November 2018³ that a study is currently under way into the number of euthanasia notifications in the period 2003-2018, which may also explain the decline in 2018. The results will be presented to the House of Representatives in spring 2020.

3 House of Representatives of the States General, 2018-2019, Annexe to the Proceedings, no. 521.



NATURE OF CONDITIONS

12

| | |
|---|-------|
| ● cancer | 4,013 |
| ● neurological disorders | 382 |
| ● cardiovascular disease | 231 |
| ● pulmonary disorders | 189 |
| ● multiple geriatric syndromes | 205 |
| ● dementia | 146 |
| <i>early-stage dementia: 144</i> | |
| <i>(very) advanced stage of dementia: 2</i> | |
| ● psychiatric disorders | 67 |
| ● combination of disorders | 738 |
| ● other conditions | 155 |

Male/female ratio

The numbers of male and female patients were almost the same: 3,191 men (52.1%) and 2,935 women (47.9%).

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

There were 5,898 cases of termination of life on request (96.2% of the total), 212 cases of assisted suicide (3.4%) and 16 cases involving a combination of the two (0.3%). A combination of the two occurs if, in a case of assisted suicide, the patient ingests the lethal potion handed to them by the physician, but does not die within the time agreed by the physician and the patient. The physician then follows the usual procedure for termination of life on request, by intravenously administering a coma-inducing substance, followed by a muscle relaxant.

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

Nature of conditions

Most common conditions

90.6% of the cases (5,553) involved patients with:

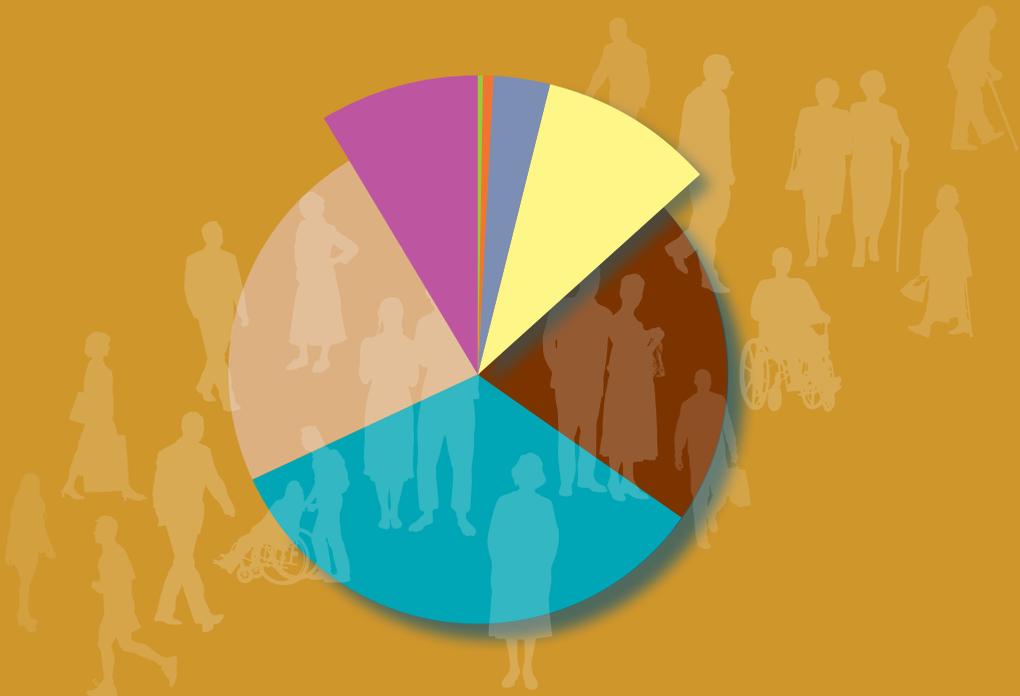
- incurable cancer (4,013)
- neurological disorders, such as Parkinson's disease, multiple sclerosis and motor neurone disease (382);
- cardiovascular disease (231);
- pulmonary disorders (189); or
- a combination of conditions (738).

Dementia

Two notifications in 2018 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. See case 2018-41, described in Chapter II, and case 2018-21, published on www.euthanasiecommissie.nl.

In 144 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 because they could still grasp its implications. Case 2018-123, described in Chapter II, is an example.

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



AGE

| | |
|-----------------------|-------|
| ● 30 years or younger | 25 |
| ● 30-40 years | 43 |
| ● 40-50 years | 181 |
| ● 50-60 years | 574 |
| ● 60-70 years | 1,363 |
| ● 70-80 years | 1,986 |
| ● 80-90 years | 1,442 |
| ● 90 years or older | 512 |

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

Psychiatric disorders

In 67 notified cases of euthanasia the patient's suffering was caused by a psychiatric disorder. In 34 of these cases the notifying physician was a psychiatrist, in 20 cases a general practitioner, in two cases an elderly care specialist and in 11 cases another physician. In these cases, the physician must exercise particular caution, as was done in case 2018-31 (described in Chapter II). In 2018 the Netherlands Psychiatric Association (NVVP) published its revised guidelines on 'Dealing with requests for assisted suicide from patients with a psychiatric disorder'. They describe the procedures the association believes psychiatrists should follow if one of their patients requests euthanasia.⁴

Multiple geriatric syndromes

For points to consider regarding multiple geriatric syndromes, see pages 22 and 23 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 or 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 2018 the RTEs received 205 notifications of euthanasia that fell into this category.

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 155 such cases in 2018.

Age

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

The highest number of notifications of euthanasia involved people in their seventies (1,986 cases, 32.4%), followed by people in their eighties (1,442 cases, 23.5%) and people in their sixties (1,363 cases, 22.2%).

In 2018 the RTEs reviewed three notifications of euthanasia involving a minor between the ages of 12 and 17. These have been published on the website as case numbers 2018-48, 2018-51 and 2018-94.

In addition, there were 68 notifications concerning people aged between 18 and 40. In 42 of these cases, the patient's suffering was caused by cancer and in 10 cases it was caused by a psychiatric disorder.

⁴ These guidelines and other information on this subject can be found (in Dutch) on the association's website (www.nvvp.net/website/onderwerpen/detail/euthanasie).



NOTIFYING PHYSICIANS

16

| | | |
|---|---|-------|
|  | general practitioner | 5,194 |
|  | elderly-care specialist | 294 |
|  | specialist working in a hospital | 293 |
|  | registrar | 64 |
|  | other physician (e.g. doctors affiliated with the End-of-Life Clinic) | 281 |

In the category 'dementia', the highest number of notifications involved people in their eighties (60 cases). In the category 'psychiatric disorders', in 2018 there were 16 notifications involving people in their fifties and 16 involving people in their sixties. In the category 'multiple geriatric syndromes' most of the notifications concerned people aged 90 or older (139 cases).

Locations

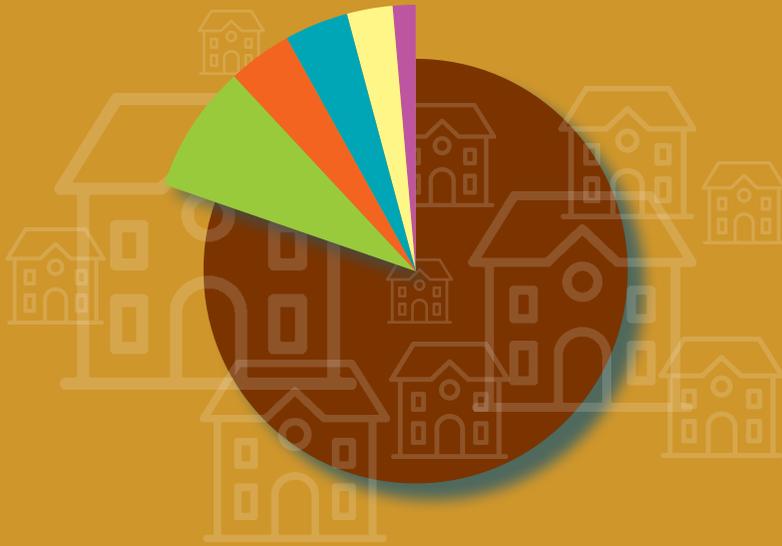
In the vast majority of cases (4,919 cases, 80.2%) the patient died at home. Other locations were a hospice (491 cases, 8.0%), a care home (239 cases, 3.9%), a nursing home (233 cases, 3.8%), a hospital (169 cases, 2.8%) or elsewhere, for instance at the home of a family member, in a sheltered accommodation centre or a convalescent home (75 cases, 1.2%).

Notifying physicians

The vast majority of cases (5,194) were notified by a general practitioner (84.8% of the total number). The other notifying physicians were elderly care specialists (294), other specialists (293) and registrars (64). There was also a large group of notifying physicians with other backgrounds (281), most of them affiliated with the End-of-Life Clinic (SLK).

The number of notifications by physicians affiliated with the SLK (726) showed a slight decline (3.4%) in comparison with 2017, when there were 751 notifications by this group.

As can be seen from the notification details, if a physician considers a request for euthanasia to be too complicated, an SLK physician will often be called upon. This may be initiated by the attending physician, the patient or, at the patient's request, the patient's family. Many of the notifications involving patients with a psychiatric disorder came from SLK physicians: 44 out of 67 notifications (more than 65%). Of the 146 notifications of cases in which the patient's suffering was caused by a form of dementia, 59 (over 40%) came from SLK physicians. Of the 205 notifications involving patients with multiple geriatric syndromes, 81 (39.5%) came from SLK physicians. 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 SLK.



LOCATIONS

| | |
|----------------|-------|
| ● home | 4,919 |
| ● hospice | 491 |
| ● care home | 233 |
| ● nursing home | 239 |
| ● hospital | 169 |
| ● elsewhere | 75 |

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

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.⁵ In 2018 the RTEs received seven notifications indicating that organ donation had taken place after euthanasia.

Couples

In 18 cases, euthanasia was performed simultaneously on both members of a couple (nine couples). Cases 2018-121 and 2018-122 are an example. Of course, the physician must then comply with the due care criteria set out in the Act in both cases separately.

Due care criteria not complied with

In six of the 6,126 notified cases, 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 just under 0.1% of all notifications. These six cases are discussed in Chapter 2.

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 37 cases (including the six mentioned above), 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 35 cases the committee invited the notifying physician (and in a handful of cases the independent physician or the patient's former general practitioner) to answer the committee's questions in person. 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.

⁵ The guidelines, their background and underlying arguments can be found (in Dutch) at www.transplantatiestichting.nl/bestel-en-download/richtlijn-orgaandonatie-na-euthanasie.



MALE-FEMALE RATIO

20

| | |
|--------|-------|
| male | 3,191 |
| female | 2,935 |

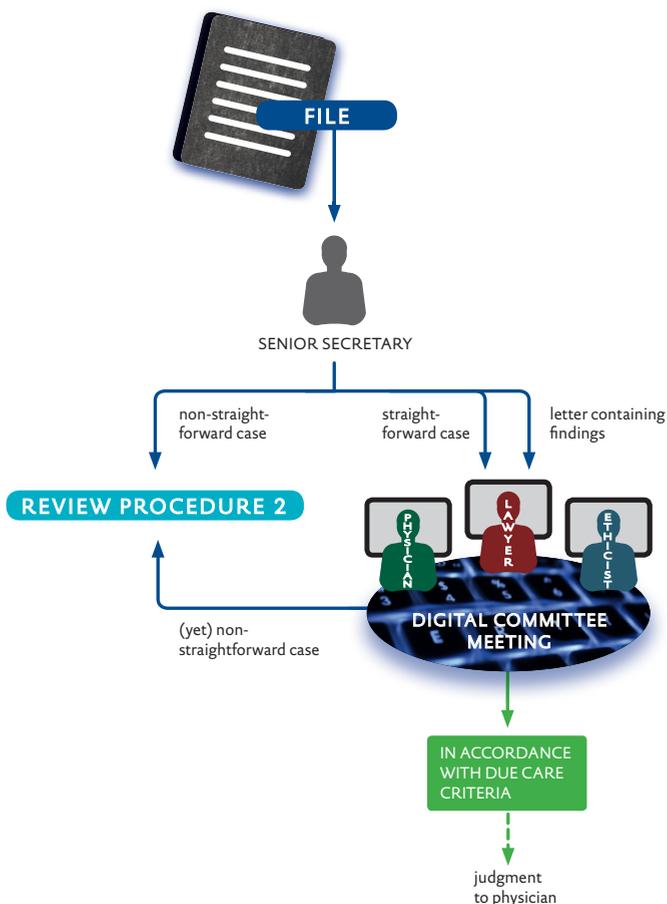
3 COMMITTEE PROCEDURES – DEVELOPMENTS

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). In 2018 a third category was added: the NVO cases for which the full findings are replaced by a short findings letter (ODB). Notifications only fall into this category if the patient's suffering was caused by cancer, chronic obstructive pulmonary disease, motor neurone disease or heart failure, or a combination of two or more of these disorders.

REVIEW PROCEDURE 1

± 85% OF THE NOTIFICATIONS
(STRAIGHTFORWARD CASES)

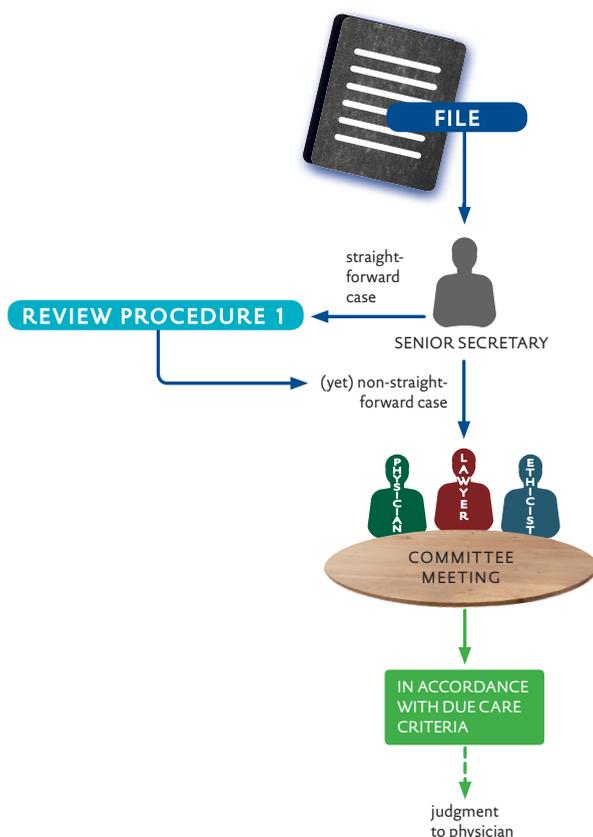


Notifications are categorised as NVO or ODB if the secretary of the committee considers that the information provided is comprehensive and the physician has complied with the statutory due care criteria.

After the initial selection, the committees review the notifications. This is done digitally for the NVO and ODB cases. Cases 2018-116, 2018-117, 2018-118, 2018-119 and 2018-125 have been included in Chapter II as examples of NVO or ODB cases. If the committee agrees that all the due care criteria have been complied with, and the notification can be dealt with by means of a findings letter (a short letter referring to the facts as stated in the notification), the physician is notified in this manner. An example of a findings letter can be found on page 31 of this report. The above-mentioned cases 2018-116 and 2018-117 would have been dealt with by means of a findings letter under the current procedure.

REVIEW PROCEDURE 2

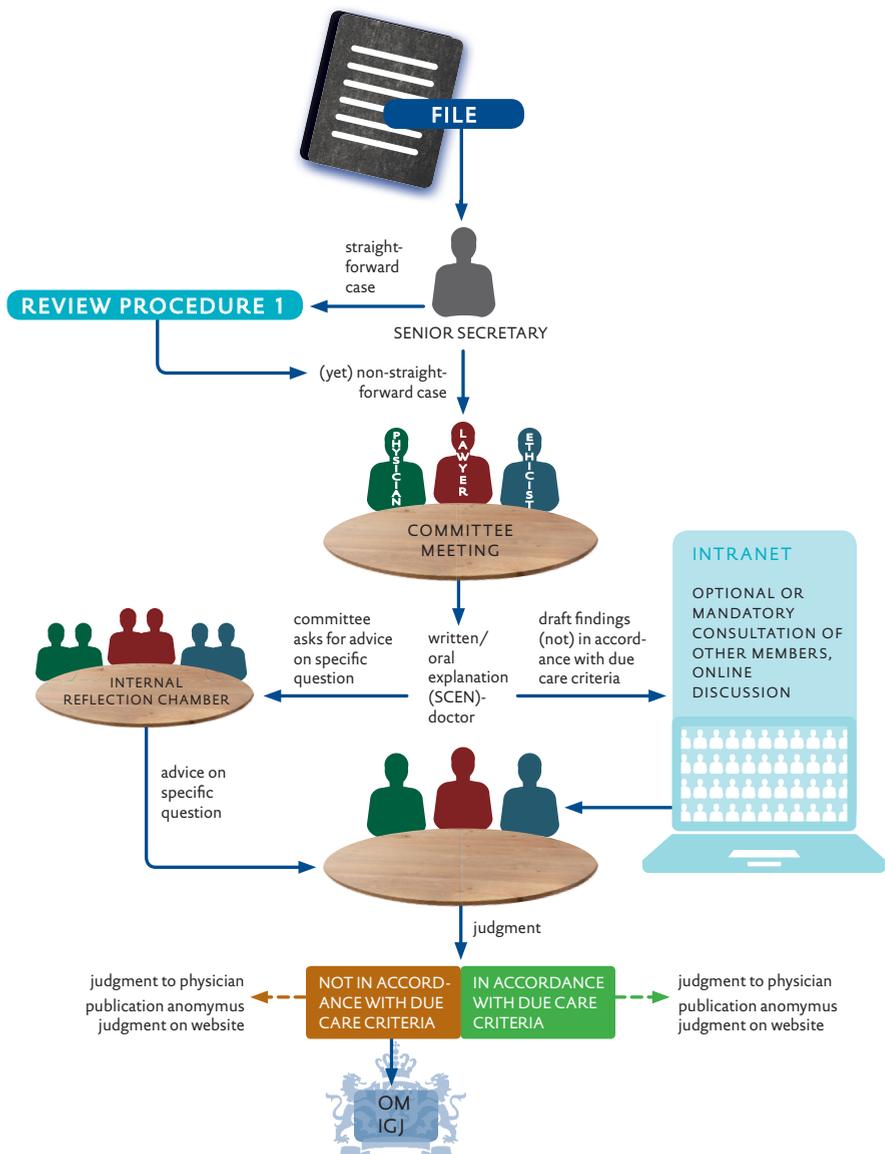
± 14% OF THE NOTIFICATIONS
(NON-STRAIGHTFORWARD CASES)



More efficient allocation of notifications to committee members and changes in administrative procedures have shortened the time between receipt of a notification and the moment when the findings are sent to the physician. The introduction of the findings letter has also considerably reduced processing time. In 2018 the average time that elapsed between the notification being received and the findings being sent to the physician was 37 days.

REVIEW PROCEDURE 3

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



If any of the committee members have questions with regard to a notification that was categorised by the secretary as NVO or ODB, the file will be sent to all committee members for plenary discussion at their monthly meeting. A small number of notifications that were initially categorised as NVO or ODB (42 cases, 0.7 % of the total number of notifications) were later deemed to be non-straightforward (VO), and as a result were discussed in a committee meeting. VO notifications are always discussed orally and reviewed at the monthly committee meeting.

In 2018, 46% of the notifications received concerned straightforward cases. In 39% of the cases, the notifications were dealt with by means of a findings letter to the physician, though of course the findings letters were only introduced in the course of 2018.

Of all the notifications received, 14% (798) were immediately categorised as non-straightforward because, for example, they involved patients with a psychiatric disorder or dementia, or because the case file submitted by the physician was not detailed enough.

Complex cases

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 reviewing 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. Eighteen cases were discussed in this way in 2018, including the cases in which the committee found that the due care criteria had not been fulfilled.

Euthanasia Code 2018

In spring 2018, a revised version of the 2015 Code of Practice was published, entitled 'Euthanasia Code 2018. Review Procedures in Practice'. It outlines the aspects that the RTEs regard as relevant in connection with their statutory task. The aim of the revised Code is to provide a clear explanation – particularly for physicians performing euthanasia and for independent physicians – of how the RTEs apply and interpret the statutory due care criteria. The Euthanasia Code 2018

has been sent to all general practitioners, with financial support from the Minister of Health, Welfare and Sport. An English translation can be found at <https://english.euthanasiecommissie.nl/the-committees/documents/publications/euthanasia-code/euthanasia-code-2018/euthanasia-code-2018/euthanasia-code-2018>.

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 chamber issued three recommendations in 2018. The first concerned the term ‘medical dimension’, the second related to the particular caution that must be exercised in cases involving psychiatric patients and the third concerned advance directives. The reflection chamber will be evaluated in 2019.

Organisation

There are five regional RTEs. 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 conclusion 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. The secretaries attend the committee meetings in an advisory capacity and are supervised by the general secretary. In organisational terms, the secretariats fall under the deputy director of the Disciplinary Boards and Review Committees Secretariats Department (ESTT) of the Ministry of Health, Welfare and Sport. As such, they are Ministry employees. The ESTT consists of more than 70 staff in total, including the support unit (10 staff) and the 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 based at three locations in the Netherlands: Groningen, Arnhem and The Hague. 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 has decided to conduct a reorganisation that will locate the entire secretariat in Utrecht. Currently this has the status of a 'proposed decision on reorganisation'. The definitive decision is expected in early 2020, in the form of an Organisation and Staffing Report.

The types of jobs and number of staff will not change, only the location. This implies quite a significant change for most staff members: from Groningen, Arnhem and The Hague to Utrecht. In addition, the aim is to hold all RTE meetings in Utrecht. The move is planned for early 2020.

Lastly, a few words on costs. In 2018, the costs of the RTEs amounted to over €4.2 million. Of that total, committee members' fees and allowances amounted to €857,000, while costs relating to materials, IT and office accommodation were €998,000. €2,380,000 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 is required by law to report this to the municipal pathologist, who then forwards the notification and the accompanying documents to the RTEs. 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 the physician notes and 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 a SCEN physician, i.e. one who is contacted through the Euthanasia in the Netherlands Support and Assessment Programme (SCEN), which falls under the Royal Dutch Medical Association (KNMG).

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The committees examine 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 in the patient's situation. 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 RTE therefore looks at the way in which the physician assessed the facts and at the explanation the physician gives for their decisions. The RTE thus reviews whether, within the room for discretion allowed by the Act, the physician was able to conclude that these three due care criteria had been met; it also looks at the way in which the physician substantiates this conclusion. The independent physician's report 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 five 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.

In subsection 2.2 we examine the various due care criteria. The main focus is on (a) a voluntary and well-considered request, (b) unbearable suffering without prospect of improvement, (d) no reasonable alternative, and (e) consulting an independent physician. This subsection presents cases that are somewhat more complex than those described in subsection 2.1. We have therefore included more 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 two of the due care criteria: (c) informing the patient about his prognosis and (f) due medical care in performing the euthanasia procedure. The criterion

under (c) 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. Due medical care (f) is explicitly discussed in the cases in which it was found that the due care criteria were not complied with.

Lastly, in subsection 2.3 we describe a number of cases of euthanasia or assisted suicide involving patients in a special category: people with a psychiatric disorder (one case), people with dementia (two cases) and people with multiple geriatric syndromes (two cases). 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 six cases in which the committee found that the due care criteria had not been met. In two of these cases the committee found that the physician had not fulfilled the requirements regarding the patient's suffering and no reasonable alternative; in one case the particular caution that is required in cases involving psychiatric patients had not been exercised; in one case consulting an independent physician was at issue and in two cases the committee found that the procedure to terminate the patient's life had not been carried out with due medical care.

Each case has a number which can be used to find the full text of the findings (in Dutch) on the RTEs' website (www.euthanasiecommissie.nl).

2 PHYSICIAN ACTED IN ACCORDANCE WITH THE DUE CARE CRITERIA

2.1 Five representative cases

As stated in Chapter 1, the vast majority of euthanasia cases involve patients with cancer, neurological disorders, cardiovascular disease, pulmonary disease or a combination of conditions. The following five cases are all examples of straightforward cases.

In the first case we have included almost the entire text of the findings. Only details that could identify persons have been left out. As of mid-2018, in straightforward cases involving cancer, motor neurone disease, heart failure or chronic obstructive pulmonary disease the physician receives a findings letter (ODB, see page 31) instead of a full report of findings. The findings letter states which RTE chair (lawyer), physician and ethicist assessed the notification digitally, and that the committee is of the opinion that the physician has complied with the due care criteria. A full report of findings is issued for all other cases. The following examples show what an RTE's report of findings looks like for a straightforward case. Together, the five cases illustrate the issues that the RTEs encounter most frequently. Occasionally the findings refer to a specific aspect such as admission to a hospice, intellectual disabilities or an unusual method of communication with the patient.

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

CANCER CASE 2018-116

FINDING: due care criteria complied with

KEY POINTS: straightforward notification; under the current procedure, such a case would be concluded with a findings letter sent to the physician.

FACTS AND CIRCUMSTANCES

The reports of the notifying physician and the independent physician, and other documentation received, revealed the following.

a. Nature of the patient's suffering, informing the patient, and alternatives

The patient, a man in his sixties, was diagnosed with a malignant tumour in the parietal pleura in December 2017. His condition was incurable. He could only be treated palliatively (care aimed at improving the patient's quality of life).

The patient's suffering consisted of pain, particularly in the abdomen and head, nausea, vomiting, inability to eat and extreme difficulty drinking. He had difficulty swallowing and was emaciated. He also suffered from constipation, dizziness, debilitation, fatigue and reduced mobility. The patient was suffering from the lack of any prospect of improvement and the likelihood of further physical deterioration leading to complete dependence on care. 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 documents made it clear that the physician and the specialists had given him sufficient information about his situation and prognosis.

b. Request for euthanasia

The patient had discussed euthanasia with the physician before. Three days before his death, the patient asked the physician to actually perform the procedure to terminate his life. The patient later repeated his request. The physician concluded that the request was voluntary and well considered.

c. Consulting an independent physician

The physician consulted an independent physician who was also a SCEN physician. The independent physician saw the patient two days 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. In his report the independent physician gave a summary of the patient's medical history and the nature of his suffering. The independent physician concluded, partly on the basis of his interview with the patient, that the due care criteria had been complied with.

d. The procedure

The physician performed the termination of life on request using the method, substances and dosage recommended in the KNMG/KNMP's Guideline 'Performing euthanasia and assisted suicide procedures' of August 2012.

ASSESSMENT

The committee examines retrospectively whether the physician acted in accordance with the statutory due care criteria laid down in section 2 of the Act. 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 and that his suffering was unbearable, with no prospect of improvement. The physician informed the patient sufficiently about his situation and his prognosis. Together, the physician and the patient could be satisfied that there was no reasonable alternative in the patient's situation. The physician consulted at least one other, independent physician, who saw the patient and gave a written opinion on whether the due care criteria had been complied with. The physician performed the euthanasia with due medical care.

DECISION

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

NEUROLOGICAL DISORDER CASE 2018-117

FINDING: due care criteria complied with

KEY POINTS: straightforward notification; motor neurone disease; communicative limitations; under the current procedure, such a case would be concluded with a findings letter sent to the physician.

Not included here

PULMONARY DISEASE CASE 2018-118

FINDING: due care criteria complied with

Not included here

CARDIOVASCULAR DISEASE CASE 2018-119

FINDING: due care criteria complied with

Not included here

COMBINATION OF CONDITIONS CASE 2018-125

FINDING: due care criteria complied with

Not included here

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

This subsection describes a number of specific cases in relation to four of the due care criteria: the physician must be able to conclude that the patient's request was voluntary and well considered, that the patient's suffering was unbearable, with no prospect of improvement and that there was no reasonable alternative; lastly, the physician must consult an independent physician. Some of the cases have an unusual feature, for instance a patient who has been committed to an institution under a court order, a combination of somatic and psychiatric disorders, or 'double euthanasia' (when two people have euthanasia performed at the same time).

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. This due care criterion may raise further questions in certain situations. In the case below, for instance, the patient had been committed to an institution under a court order on the grounds that he was a danger to others and to himself, partly because he was suicidal. In such a case it must be ruled out that a psychiatric disorder has impaired the patient's powers of judgment.

CASE 2018-80

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification, independent physician recommended that depression be ruled out.

The patient, a man in his eighties, suffered a stroke in 2012, after which he deteriorated physically. In the years that followed he developed various somatic disorders and in late 2017 he was diagnosed with vascular dementia (dementia caused by damage to blood vessels in the brain). From then on, the patient's condition deteriorated further. In March 2018 he was admitted to the psychogeriatric ward of a care institution under a court order. This was because the situation at home had become unmanageable due to changes in the patient's personality. He was aggressive at times. Due to hospitalisation and an emergency admission to a nursing home, followed by permanent admission, his condition initially deteriorated even further. This was caused in part by the many stimuli he experienced during the admissions, the change of surroundings and the examinations. After several weeks in the nursing home his aggressive behaviour subsided and he became calmer.

The patient had become dependent on others for his personal care, which he found terrible. He suffered from the knowledge that there was no prospect of improvement and that his mental and physical capacities would only deteriorate further. He knew that the damage inflicted by the stroke was irreversible and no longer felt he had any quality of life. He was also afraid of suffering another stroke, which could mean that he would no longer be able to make his wishes clear. The patient did not want to experience further deterioration and wanted to die with dignity.

Around a month and a half before his death, the patient first spoke with the physician regarding euthanasia and immediately asked him to perform the procedure to terminate his life. During the physician's conversations with the patient, the patient was able to fully grasp the consequences of his actions, the situation and the decision he had made. The physician considered him to be decisionally competent regarding his request for euthanasia. The physician concluded that the request was voluntary and well considered.

The physician consulted an independent SCEN physician. The independent physician noted that it had been recommended previously that the patient be seen by a psychiatrist because he was suicidal, and this had not yet been done. The independent physician also recommended that the court order be lifted or not extended, so that the patient would have more freedom and could possibly be transferred to a different residential setting that might be better suited to him. He also considered whether it might be necessary to adjust the patient's medication.

In his interview with the committee, the physician said that it had not been the intention to extend the court order; the order had only been necessary in order to ensure the patient was admitted to an institution. The patient was by now much calmer and much more cooperative. The physician indicated that, in his opinion, the patient was anything but depressed. Despite the fact that the physician did not doubt that the patient was decisionally competent, he followed the independent physician's advice and consulted an independent psychiatrist.

The independent psychiatrist saw the patient about a week before he died. He assessed whether depression played a role in the patient's wish for euthanasia. The independent psychiatrist did not observe any signs of major depressive disorder. Though the patient was not suicidal, there were symptoms of low spirits, in response to the loss of independence and the physical and mental deterioration. The independent psychiatrist considered the patient to be decisionally competent

regarding his request for euthanasia. He saw no reason whatsoever to change the patient's psychiatric medication. The medication had already been reduced to a minimum, and the patient's difficulties in functioning had remained the same.

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 were also fulfilled, in the committee's view.

UNBEARABLE SUFFERING WITHOUT PROSPECT OF IMPROVEMENT

The physician must be satisfied that the patient is suffering unbearably and that there is no prospect of improvement. There is seldom only one dimension to the burden of suffering experienced by the patient. In practice, it is almost always a combination of aspects, including the absence of any prospect of improvement, which determines whether suffering is unbearable. The physician must therefore investigate all aspects that together make the patient's suffering unbearable.

CASE 2018-32

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification, combination of somatic and psychiatric disorders, unbearable suffering without prospect of improvement, voluntary and well-considered request, post-traumatic stress disorder (PTSD) and geriatric syndromes

Not included here

NO REASONABLE ALTERNATIVE

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. 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.

CASE 2018-120

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification, no reasonable alternative, pelvic fractures after a fall one week before death. Risky operation with an uncertain chance of success; the patient declined, on the grounds that the chance she would be able to walk again was minimal.

Not included here

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. Sometimes, both members of a couple make simultaneous requests for euthanasia. If both requests are granted, this may be referred to as 'double euthanasia'. In such cases, the committees expect the physician or physicians to consult a different independent physician for each of the partners. This is necessary to ensure that the two cases are assessed separately. Both independent physicians must be satisfied that neither of the partners is exerting undue pressure on the other in relation to their request for euthanasia.

CASES 2018-121 AND 2018-122

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification, consulting an independent physician in cases involving double euthanasia, due medical care

Not included here

2.3 Five cases 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 or other expert, 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 2018-31

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification, particular caution in cases involving patients with a psychiatric disorder, consulting an independent psychiatrist, no reasonable alternative. Combination of anxiety disorder, depression and personality disorder.

The patient, a man in his fifties, had been suffering from psychiatric problems and addiction since late adolescence. He suffered from chronic depression and social anxiety disorders. In addition he suffered from a personality disorder characterised by avoidance and dependence, a limited ability to cope with frustration and difficulty controlling anger.

Since adolescence the patient had intermittently had a wish to die and had previously attempted to end his life on several occasions. He received several courses of medication and therapy, one of which was ECT (electroconvulsive therapy, whereby the patient is anaesthetised and an electric current is passed across the brain through electrode patches), but this produced no lasting result. His symptoms persisted despite the therapy and medication administered according to multidisciplinary guidelines. The patient also suffered from brain damage after the ECT.

The patient's suffering consisted of chronic low spirits, not feeling connected, chronic pain and limited mobility. He was unable to shake off the low spirits and negative thoughts. He had been lacking in motivation for many years, and was unable to put his mind to anything. Not being able to make contact with other people contributed to his

unbearable suffering, as did the absence of any prospect of improvement in his situation. Every day was a struggle. He spent most of his time in bed, because he lacked the energy and the will to be anywhere else. Every day was one too many for him. He experienced his suffering as unbearable.

About two months before the patient's death, at the physician's request an independent psychiatrist examined him. The independent psychiatrist said that there was little chance of long-term, more intensive psychological treatment leading to a considerable and lasting improvement. 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. He had had a clear wish for euthanasia for four years prior to his death. At the time the physician had been considering a number of treatment options in the depression protocol. The patient had cooperated fully with the treatment options proposed by the physician.

The patient's sustained and consistent wish for euthanasia dated from just under a year before his death. About nine months before his death, he asked the physician to actually perform the procedure to terminate his life, after which he consistently repeated his request for euthanasia.

The above-mentioned independent psychiatrist said that the patient's mind was clear and that he was capable of logically coherent decision-making. According to the physician the patient understood the legal framework governing his request for euthanasia and was able to appreciate the consequences of his decision. The physician concluded that the request was voluntary and well considered. The physician consulted an independent physician who was also a SCEN physician and an elderly care specialist. The independent physician saw the patient 11 days before he died. According to the independent physician the patient was able to grasp the consequences of his request for euthanasia. The independent physician was satisfied that the due care criteria had been complied with.

With regard to the request being voluntary and well considered, the suffering being unbearable and there being no prospect of improvement, the committee noted the following: physicians must exercise particular caution when dealing with a euthanasia request from a patient suffering from a psychiatric disorder. The committee found that in this case the physician did so. The physician, who had been the patient's attending psychiatrist for nine years, also consulted an independent psychiatrist in addition to the independent SCEN

physician. The independent psychiatrist confirmed the physician's opinion that, after a long period in which the patient had undergone numerous and intensive courses of psychiatric treatment without any lasting improvement, it could be concluded that there were no longer any realistic alternatives for the patient, that his unbearable suffering was therefore without prospect of improvement and that his request was voluntary and well considered. The independent physician confirmed the physician's assessment that the statutory due care criteria had been complied with.

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

DEMENTIA

There is a distinction to be made between the following situations: 1) euthanasia for a patient with early-stage dementia (the phase in which the patient still has insight into the disease and the symptoms; 2) euthanasia for a patient in a later phase of dementia, where it is uncertain whether they are still decisionally competent regarding their request; and 3) euthanasia for a patient in whom the disease has progressed to the point that the patient is no longer able to request euthanasia. In the last two situations, an advance directive drawn up on an earlier date may take the place of the – often oral – request for euthanasia.

One of the following two cases involves a patient with dementia who was still decisionally competent, the other a patient with dementia who had drawn up an advance directive. In 2018 a notification from 2016 in which the review committee found that the due care criteria had not been complied with attracted a great deal of attention for two reasons: a lack of clarity in the advance directive and the way in which the patient's life had been terminated. The main differences between the 2016 case and case 2018-41 on page 45 are the many conversations the physician had with the patient before she became decisionally incompetent, the fact that the advance directive was unequivocal, and the fact that premedication was administered as part of good medical practice.

CASE 2018-123

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification, decisional competence, impairment of functions which were central to the patient's life.

The patient, a man in his seventies, was diagnosed with Alzheimer's disease in 2014 after a period in which he experienced a number of symptoms. His condition continued to deteriorate.

His suffering consisted of progressive deterioration of his mental capacities, of which he was constantly aware. The patient, whose life had revolved around reading, precise articulation of his thoughts, study and discussion, was no longer able to do any of these things due to his disorder. He misplaced things increasingly often and had difficulty in finding the right words. He constantly felt restless, frustrated and distraught.

The patient suffered from the knowledge that there was no prospect of improvement in his situation and that the only prognosis was

deterioration. He felt desperate and did not want to experience any further loss of dignity. 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 with the physician before. The physician had had several intensive conversations with him over a long period of time. During those conversations the patient was still able to put his thoughts into words. The physician did not doubt the patient's decisional competence. About three months before his death, the patient asked the physician to actually perform the procedure to terminate his life.

Seven months before his death the patient had been seen by an independent psychiatrist due to mood-related problems. According to the independent psychiatrist these mood-related problems could be explained as a reaction to the disorder and its consequences. He was not suffering from clinical depression. The patient was able to clearly state and explain his reasons for his request for euthanasia, and the independent psychiatrist considered him to be decisionally competent regarding his request.

The physician consulted the same independent physician, who was also a SCEN physician, three times. The independent physician saw the patient for the first time about six months before he died. This was an early consultation: at the time the patient had not yet specifically requested euthanasia and he did not yet experience his suffering as unbearable. The independent physician saw the patient for the second time about a month before he died. According to the independent physician, the patient was decisionally competent, not depressed, and consistent in his wish for euthanasia. However, the patient still had not yet specifically requested euthanasia, partly because he found it difficult to decide on a date. The independent physician saw the patient for the third time about two weeks before he died. By now the patient was experiencing his suffering as unbearable and he specifically requested euthanasia. The independent physician was satisfied that the due care criteria had been complied with.

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

CASE 2018-41

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification, advanced dementia, unbearable suffering without prospect of improvement, voluntary and well-considered request, euthanasia based on an advance directive, due medical care, premedication. If euthanasia is based on an advance directive, the committee always invites the physician for an interview.

The patient, a woman in her sixties, was diagnosed with Alzheimer's disease about six years before her death, on the basis of symptoms she had been experiencing for some time. She received medication to slow down the progress of the disease, but this had little effect. Over the years her condition deteriorated gradually. About four years before her death the patient was admitted to a nursing home.

Her psychological deterioration was such that she eventually no longer recognised anyone and became fully dependent on others for her personal care. She was in a permanent state of unease, was liable to panic and often expressed anxiety. For instance, she would be startled by her reflection, probably mistaking it for an intruder. At night she was often upset and wandered the corridors of the nursing home, shouting. The patient was no longer able to express what was bothering her. She no longer understood what people were saying to her and could not give them an answer. It was clear that she was suffering from her inability to go to the toilet independently. She regularly soiled herself and it could be deduced from the cries she uttered that she found this terrible.

The patient experienced her suffering as unbearable. The physician noted that there were no longer any moments of reciprocity or joy. According to the physician it was no longer possible to provide the patient with what she considered to be a dignified existence. 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.

According to the physician the patient had initially still been decisionally competent. After the diagnosis she had immediately indicated that she would want euthanasia if at a certain point the disease had reached an advanced stage and she was suffering unbearably. About five years before her death she had drawn up an advance directive to that effect and discussed it at length with the

physician. In the years that followed, the patient updated her advance directive several times. In it she emphasised that she attached great value to good quality of life and a dignified end to her life. The circumstances that she would experience as unbearable, and in which she would want euthanasia, were those in which she no longer recognised her close relatives, had become fully dependent on other people for her personal care and had lost her dignity.

At several multidisciplinary consultations the circumstances described by the patient in her advance directive were discussed. At first, her relatives found it difficult to assess her situation. However, about five months before her death, they were all of the opinion that the patient's circumstances were now as she had described in her advance directive. They asked the physician in writing to assess her situation.

One of the decisions taken at the next multidisciplinary consultation was that the nursing home's care staff would observe the patient closely and report their findings. These reports showed that at first the patient still appeared to have good moments. However, her situation deteriorated with time. She was no longer able to make any meaningful use of her time and suffered from severe mood-related problems.

About three months before the patient's death, at the physician's request, an independent elderly care specialist assessed the patient. Communication was hampered by problems with speech and comprehension. The patient was unable to focus her attention on the conversation and after a while she walked off. The independent elderly care specialist concluded that she was no longer able to explain her request.

After all this, the physician was satisfied that she could carry out the patient's request on the basis of her advance directive.

The physician consulted an independent physician who was also a SCEN physician. About one month before the patient's death the independent physician spoke with her case manager and five close relatives, after he had been told about her situation by the attending physician and had examined her medical records. After this, he visited the patient together with her case manager.

The case manager informed the independent physician that the patient had expressed her wishes clearly and regularly for as long as she had been able to. In essence, her statements agreed with what she had described in her advance directive. According to the case manager, six months before her death the patient had arrived at the stage which she

had never wanted to reach. At that time there were some brief moments in which some contentment was discernible.

In the months that followed her situation deteriorated rapidly and she became increasingly restless. After a while she had reached a state of permanent anxiety and agitation, in which she regularly thumped on the walls. It was unclear what was causing this, so it could not be remedied. According to the independent physician the patient's relatives gave the impression of being concerned and level-headed and they unequivocally conveyed her wishes.

At the time of the visit, the independent physician did not succeed in communicating with the patient. He observed her and noted that she appeared restless, sad and withdrawn. After a while, the patient walked off and wandered the corridors of the nursing home.

The independent physician established that the patient was no longer able to recognise anyone and had become entirely dependent on others for her personal care. The patient appeared unhappy. According to the independent physician she was receiving the best possible care in the nursing home, but neither that nor her close relatives' loving attention was sufficient to relieve her suffering.

The independent physician concluded on the basis of his observations that the due care criteria had been complied with. Nevertheless, he thought it would be useful for an independent geriatric psychiatrist to assess whether the patient's suffering was indeed unbearable.

This was done about two weeks before the patient's death. The independent geriatric psychiatrist noted that the patient experienced her deterioration as a result of her disorder as catastrophic. She could no longer put her thoughts into words, did not recognise her relatives and seemed agitated, which appeared to stem from helplessness and frustration. He established, partly on the basis of conversation with close relatives, that the patient was not suffering from depression, an anxiety disorder or a psychotic disorder. The independent geriatric psychiatrist concluded that there were no treatable psychiatric problems.

After consulting with the independent physician and an internist specialised in critical care, the physician decided to administer premedication prior to performing euthanasia. She did this because the patient sometimes reacted unpredictably when in contact with other people. The physician could not rule out that the patient might remove the IV cannula from her arm and injure herself. In the morning the

nursing staff gave the patient a tablet containing 7.5mg of Dormicum (which has a calming effect), which she took orally. About 45 minutes later, after administering an analgesic cream and covering it with sticking plaster, the physician administered 10mg of Dormicum subcutaneously and 25mg of Nozinan (used as sleeping medication, enhances the effect of pain relief medication).

After half an hour a nurse from a home care organisation's specialist team inserted the IV cannula. The physician then performed the termination of life on request using the method, substances and dosage recommended in the KNMG/KNMP's Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide, published in August 2012.

The committee found that the physician could be satisfied that the patient's request was voluntary and well considered. It established that in the final period before her death the patient's ability to communicate was such that she could no longer express her wishes. The committee considered that, when the patient drew up her advance directive and updated it, there was no reason to believe that she was already decisionally incompetent.

Statements from the physician, independent physician, case manager, nursing staff and her close relatives showed that the patient had always been consistent in her wish and repeated that wish on several occasions. The committee was satisfied that when the termination of life on request was carried out, the circumstances described by the patient in her advance directive indeed existed.

The committee also found that the physician had plausibly argued that the patient's suffering was unbearable and without prospect of improvement. It was clear from the file that the physician had studied the patient's situation carefully. The physician noted that the patient was suffering severely. At the recommendation of the independent physician, the physician asked an independent geriatric psychiatrist to assess the patient's suffering as well. This assessment too showed that the patient's disorder had led to a complete loss of independence and an inability to understand the world around her. This situation resulted in permanent feelings of anxiety and restlessness and made the unbearable nature of the patient's suffering and the lack of any prospect of improvement palpable to the physician.

The committee found that the physician gave the patient sufficient information about her situation and prognosis while she was still decisionally competent. In addition it was of the opinion that the physician could be satisfied that there was no reasonable alternative in

the patient's situation. The physician's conclusion was supported by the reports of the care staff and the independent physician. Those reports clearly showed that no positive influence could be exerted on the patient's situation and that her suffering was unbearable and without prospect of improvement.

The committee also established from the physician's report and oral explanation that the physician administered premedication prior to performing euthanasia. The reason for this was the fact that in the final period before her death the patient was in a permanent state of restlessness and anxiety, and there was a real chance of a startle response which could cause complications in the euthanasia procedure. The committee found that by administering premedication the physician acted in accordance with good medical practice in these specific circumstances. The physician performed the euthanasia with due medical care.

In this case the physician argued plausibly that she was satisfied that the termination of life on request was in accordance with earlier advance directives and that the other due care criteria had been complied with.

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

MULTIPLE GERIATRIC 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, which result from one or more disorders, that may give rise to suffering which that particular patient experiences as being unbearable and without prospect of improvement. The patient's medical history, life history, personality, values and stamina play an important role. The following two cases involve multiple geriatric syndromes.

CASE 2018-44

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification, unbearable suffering without prospect of improvement, multiple disorders in a patient in her nineties which were not life-threatening as such but did make life unbearable for her.

Not included here

CASE 2018-50

FINDING: due care criteria complied with

KEY POINTS: non-straightforward notification, multiple geriatric syndromes, sight impairment and hearing impairment

Not included here

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 more extensive findings than other cases. This is because a conclusion cannot be reached in such cases until the physician has been given the opportunity to give an oral explanation.

In the year under review, the RTEs found in six cases that the physician had not acted in accordance with the due care criteria in performing euthanasia. These six cases are discussed below, in the order in which the relevant due care criteria are listed in the Act.

NON-COMPLIANCE WITH THE CRITERIA OF UNBEARABLE SUFFERING WITHOUT PROSPECT OF IMPROVEMENT AND THE ABSENCE OF A REASONABLE ALTERNATIVE

In line with the Supreme Court judgment in the 1994 Chabot case, physicians must exercise particular caution when a euthanasia request results (largely) from suffering arising from a psychiatric disorder. Such cases often involve complex psychiatric problems, and require specific expertise. Unlike the independent physician, an expert may recommend treatment where appropriate. The particular caution that the physician must exercise mainly concerns the due care criteria with regard to the voluntary and well-considered nature of the request, the absence of any prospect of improvement, and the lack of a reasonable alternative.

The first of the following two cases shows that if there is a failing in terms of consultation, this may lead to the RTE finding that the physician could not be satisfied that the patient's suffering was without prospect of improvement and that there was no reasonable alternative. The finding also shows that the RTEs hold the notifying physician responsible for the submission of proper reports drawn up by the independent physicians.

The finding on the second case shows that if the independent physician believes that there are realistic treatment options, this must be taken seriously by the physician.

CASE 2018-69

FINDING: due care criteria not complied with

KEY POINTS: non-straightforward notification, unbearable suffering without prospect of improvement, reasonable alternative, consultation, physician is responsible for quality of expert's report.

The patient, a man in his fifties, had suffered from psychiatric disorders for 30 years. Three years before his death – after one of his parents had died – he was referred to the mental healthcare services, where it was established that he had thus far not required professional help thanks to the support and structure provided by people close to him. The diagnosis was: grief reaction in a man exhibiting elements of both autism and psychosis. The patient was a vulnerable man, susceptible to depression when things got too much for him. In the two years before his death, the patient had been briefly hospitalised on a number of occasions because of suicidal tendencies.

The patient had discussed termination of life with his general practitioner, who did not want to perform euthanasia. He then contacted the End-of-Life Clinic (SLK) with a request for euthanasia, over two years before his death. After a visit from an SLK nurse, this request was refused, due to the short time that had elapsed since his parent's death.

The patient was treated with medication, including antidepressants and antipsychotics. There were conversations with a psychiatrist, and a nurse provided support and guidance with a focus on daytime activity. The patient did volunteer work and received art therapy and psychoeducation. After these treatments the symptoms of depression and psychosis were less prominent. However, they had no significant effect on his suffering.

That suffering consisted of the fact that everything was too much for him: the daylight as soon as he awoke and all the things he had to do the rest of the day. He could not remember names, often lost his way and had increasing difficulty with technical activities. He suffered from nightmares, panic and anger attacks, and extreme overstimulation, arising partly from contact with other people. He also suffered from his dependence on professional carers. Due to his rigid and compulsive way of dealing with things he was unable to adapt to constantly having different people around him. He experienced permanent tension and lost control of his daily life. Panic and despair could overwhelm him at any time. He felt unable to function in modern society and was not the

person he wanted to be, a person with a job and a family. In addition he suffered from intestinal problems, which increased his suffering. He experienced his suffering as unbearable.

About 10 months before the patient's death, a psychiatrist involved in his treatment indicated that continuing psychiatric treatment offered no prospect of improvement of the symptoms. The psychiatrist did, however, expect the patient's functioning to improve if he were housed in an adapted setting: a form of sheltered housing with structure, care and people to talk to. About nine months before his death, the patient moved to such a facility. However, partly due to the unavoidable contact with other people, this did not alleviate his suffering.

About a year before his death he again contacted the SLK. Nine months before his death the patient discussed euthanasia with the physician (a psychiatrist) for the first time. On that occasion, the patient also asked her to actually perform the procedure to terminate his life. From just over three months before his death, the physician had four more conversations with him. The physician consulted the patient's general practitioner, a psychiatrist who was involved in his treatment, the mental health nurse, his case manager and his informal carer.

Following the request for euthanasia, the physician consulted an independent psychiatrist for a second opinion on the diagnosis, possible treatment options and their prognosis. About two months before the patient's death the independent psychiatrist concluded that the main diagnosis was autism spectrum disorder (ASD). ASD comprises a range of forms of a disorder (autism) whereby the brain processes information differently. In addition he suffered from an unspecified schizophrenia spectrum disorder with brief psychoses (a psychiatric condition in which a person experiences the world differently from other people, for instance hearing voices or seeing things that are not there) and an unspecified depressive mood-related disorder. According to the independent psychiatrist there were hardly any treatment options for the main diagnosis. There were options for both the psychotic and depressive symptoms, but the patient refused them.

The independent physician consulted by the physician was an independent psychiatrist and SCEN physician. The independent physician noted that the patient appeared to be suffering from psychotic symptoms which did not fall into one of the usual categories of disorders (near psychosis). He saw a person with below-average intellectual abilities, a relatively mild form of autism and compulsive tendencies. The independent physician saw little evidence of major depressive order.

Despite repeated requests, the patient was unable to give the independent physician an unequivocal answer to questions regarding the unbearable nature of his suffering. He was strongly focused on his wish and intention to die by means of euthanasia. However, he did not succeed in making it clear to the independent physician what precisely his suffering consisted of or why it was unbearable and without prospect of improvement. The independent physician believed that, partly due to his mental disorder, the patient was unable to appreciate the available options for improving his physical and psychosocial circumstances. The subjective experience of unbearable suffering could not, according to this psychiatrist, be shared by an objective observer. He believed that there was still a significant amount that could be achieved for this patient. An inability or unwillingness to accept help did not justify euthanasia as a solution, according to the independent physician. He therefore concluded that it could not be established to a sufficient degree that there was a palpable wish to die as a result of unbearable suffering without prospect of improvement, in a patient who was, incidentally, decisionally competent. The independent physician found that the due care criteria had not been complied with.

The physician herself was of the opinion that the patient's suffering was almost exclusively caused by the main diagnosis, ASD. Treatment of the secondary diagnoses, the temporary psychotic and depressive symptoms, would, even if it was successful, make little difference to his suffering. The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion.

The committee had questions for the physician after reading the case file. For instance, they wanted to know how the patient had fared in the sheltered housing setting and why the physician had not requested an extra consultation, given that the independent physician had found that the due care criteria had not been complied with.

As regards the housing, the physician said that the patient had indicated that living in this setting was difficult for him. Although there were some advantages (people he could talk to, pleasant daytime activities) they were outweighed by the disadvantages. He experienced his contact with fellow residents, who were psychiatric patients, as very confrontational and distressing. There was little privacy and it was noisy. This caused constant overstimulation, which made him more unsettled. The patient resisted moving to different accommodation with more privacy. The reason he had moved to the current accommodation was that loneliness caused him a lot of tension as well. He realised that he could end up back in a situation similar to the one

he had previously been unable to cope with, and that he would then regularly have to be hospitalised due to a mental health crisis. This dilemma contributed to his suffering. He could not live alone, but living in the sheltered housing was not an option for him either.

As regards setting aside the independent physician's opinion, the physician said that she disagreed with his conclusion. Speaking in general terms, the physician said that if a SCEN report made her doubt her own findings, she would make a further assessment. In this case the independent physician was unable to sufficiently assess the patient's suffering. According to the physician, this was related to the nature of the patient's disorder. A person who suffers from ASD is unable to properly express his suffering in words. That treatment options might be available and that the patient was unwilling to try them was not further explained in the independent physician's report, even after multiple requests to that effect from the physician. The independent physician was probably referring to the treatment options mentioned by the independent psychiatrist for the secondary diagnoses, including depression. According to the physician, any treatment for depression would not be relevant to alleviating the patient's suffering. Even if there were symptoms of depression, they were reactive and not the primary cause of the patient's suffering. That suffering was caused by the patient's limitations as a result of the ASD. The physician was therefore convinced that there was no reasonable alternative for the patient. The treatment options proposed by the attending psychiatrist had been given a chance, but did not in essence make a difference to the severity of the patient's suffering. As the independent physician's report did not cause any doubt in her mind, the physician saw no reason to consult a second SCEN physician. She also did not think it would be appropriate as it would cause the patient additional distress. This would be even more the case if another second opinion were requested from an independent psychiatrist. The physician also did not want to create the impression that she was 'shopping around'.

The committee argued that, in line with several RTE considerations following the Supreme Court judgment in the 1994 Chabot case, physicians must exercise particular caution when a euthanasia request results largely from suffering arising from a psychiatric disorder. Such cases often involve complex psychiatric problems and require input from someone with specific expertise (see also the guidelines of the Netherlands Psychiatric Association (NVVP) on dealing with requests for assisted suicide from patients with a psychiatric disorder, 2009). The particular caution that the physician must exercise mainly concerns the due care criteria with regard to the voluntary and well-considered nature of the request, the absence of any prospect of

improvement, and the lack of a reasonable alternative (see the Euthanasia Code 2018, paragraph 4.3).

It was established that the attending psychiatrist, the independent psychiatrist and the independent physician, who was also a psychiatrist, considered the patient to be decisionally competent regarding his request for euthanasia. Partly in view of this, the committee found that the physician could be satisfied that the patient's request was voluntary and well considered.

Was particular caution also exercised with regard to the patient's unbearable suffering without prospect of improvement and the absence of a reasonable alternative in his situation? The committee believed it was not. As regards the independent psychiatrist, the committee found that although such a psychiatrist was consulted, the shortcomings in his report were such that it could not be considered an adequate second opinion. The committee found that the physician should not have accepted such a limited report. Exercising particular caution also means paying close attention to the quality of independent physicians' reports. These must show that the case has been examined sufficiently thoroughly. The conclusions must also be sufficiently substantiated. If this is not the case, it is the physician's responsibility to ask the independent psychiatrist to make a further assessment and/or amend the report. If this does not lead to a satisfactory result, it is the physician's responsibility to seek information and advice from other experts in order to substantiate their own findings.

As regards the physician setting aside the independent physician's negative conclusion, the committee held as follows. If a SCEN physician comes to the conclusion that one or more due care criteria as laid down in the Act have not been complied with, this should prompt the physician to think carefully about whether the euthanasia procedure can go ahead. Although the Act stipulates only that an independent physician must be consulted, not that their consent is required, if the independent physician comes to a negative conclusion the physician must carefully substantiate why they have set that conclusion aside (see the Euthanasia Code 2018, paragraph 3.6). According to the committee, if a psychiatric patient requests euthanasia, a negative conclusion by the SCEN physician should be given even more weight. Exercising particular caution then requires that the physician must explain to a greater extent than in other cases why they believe all the due care criteria have indeed been complied with. Although it is not a mandatory requirement, it then makes sense to consult a second SCEN physician (preferably one who is also a psychiatrist). In this respect the committee also refers to the above-mentioned guidelines of the

Netherlands Psychiatric Association (p. 44 of these guidelines, in Dutch), which state that in the event of a fundamental difference of opinion – and the committee found that this was the case – another independent physician should always be consulted.

The committee found the physician's arguments for not doing so to be inadequate. The SCEN report was drawn up by an experienced psychiatrist with a considerable track record. The report argued clearly and frankly why in this case the euthanasia procedure should not take place. Despite this, the physician relied on her own opinion, without seeking further assessment. Leaving aside the question as to whether that opinion was correct, the committee found that in the circumstances (including the limited report by the independent expert) the physician should certainly have consulted a second SCEN physician (preferably a psychiatrist) or a second independent expert. It would then have been possible to establish more clearly whether there was scope to improve the patient's ability to cope (even if the main diagnosis were untreatable). The argument that further examinations would cause some distress to the patient was, in the eyes of the committee, insufficient reason to refrain from taking that step. The same is true for the argument that the physician did not want to create the impression that she was 'shopping around': if anything, approaching a second SCEN physician would in this case have strengthened the physician's position, as she would have been facilitating assessment of her actions and showing herself willing to have another person take a critical look at her intended course of action.

The committee found that the physician did not act in accordance with the due care criteria laid down in section 2 (1) (b) and (d) of the Act. The other due care criteria were complied with.

CASE 2018-70

FINDING: due care criteria not complied with

KEY POINTS: non-straightforward notification, psychiatry, particular caution, unbearable suffering without prospect of improvement, no reasonable alternative

Not included here

NON-COMPLIANCE WITH THE CRITERION OF EXTRA CONSULTATION IN THE CASE OF A PSYCHIATRIC PATIENT

In cases involving patients with a psychiatric disorder the physician must always consult an independent psychiatrist in addition to the regular independent physician who assesses the first four due care criteria. The independent psychiatrist should assess in particular whether the patient is decisionally competent regarding their request, whether the patient's suffering is without prospect of improvement and whether there are no reasonable alternatives. Unlike the independent physician, the independent psychiatrist may recommend treatment where appropriate. If contact with both an independent physician and a psychiatrist poses an unacceptable burden to the patient, it may be sufficient to consult an independent (SCEN) physician who is also a psychiatrist. In the case described below the physician did not consult a psychiatrist.

CASE 2018-42

FINDING: due care criteria not complied with

KEY POINTS: non-straightforward notification, particular caution to be exercised with psychiatric patients, consulting an independent psychiatrist, treatment may be refused

The patient, a woman in her seventies, had suffered from psychiatric disorders since she was 17. Her symptoms were diagnosed as schizoaffective disorder (a psychiatric disorder involving psychoses and mood-related disorders). She experienced periods of severe depression and occasional psychotic episodes. She had made a number of suicide attempts and had been hospitalised several times. The patient had, over time, undergone extensive treatments with medication and psychotherapy for her psychiatric disorders. However, these had not led to improvement in her psychological condition.

About five months before her death, the patient was diagnosed with an aortic aneurysm and needed urgent surgery. She was also found to have lung cancer. The patient refused treatment because she was suffering unbearably without prospect of improvement due to her psychiatric disorders. She had been wanting to die for years. She saw the aortic aneurysm and lung cancer diagnoses as a welcome opportunity to be released from her difficult life.

Her general practitioner did not perform euthanasia for reasons of principle and asked the physician (also a general practitioner) if he would be willing to take over the euthanasia procedure. The patient's

first conversation with the physician about euthanasia took place about two months before her death. Around two and a half weeks before her death, the patient asked the physician to actually perform the procedure to terminate her life. The physician consulted by phone with a psychiatrist at the mental health service where the patient was being treated. This psychiatrist believed that the patient had a realistic wish for euthanasia on the grounds of severe, untreatable psychiatric suffering.

The physician consulted an independent physician who was also a SCEN physician (not a psychiatrist). The independent physician saw the patient about a week and a half before her death. He concluded that the due care criteria had not yet been complied with. In his eyes, the patient had not yet actually made a specific request for euthanasia, nor was she suffering unbearably. The independent physician asked the physician to contact him if these circumstances changed. Two days before the patient's death the independent physician established, on the basis of phone conversations with the physician, that the patient's situation had changed. She had requested euthanasia in the very near future. The independent physician was satisfied that the request was clearly based on a combination of severe chronic psychiatric disorders that could no longer be treated and recently diagnosed, possibly life-threatening somatic conditions. He concluded that the due care criteria had now been complied with.

The committee found the case file submitted to be too limited and asked the physician for a further written explanation. This explanation provided the committee with insufficient clarity, so the physician was invited for an interview. The committee's questions mainly concerned the patient's case file, the physician's conviction that the patient's request was voluntary and well considered and that she was suffering unbearably with no prospect of improvement, and the fact that an independent psychiatrist had not been consulted.

The physician answered that the digital case file was very limited. He had obtained additional information by talking to the general practitioner and the patient's husband. He had also phoned the mental health service where the patient was being treated. It was not entirely clear who was treating her, because at that time cases were being handed over from one psychiatrist to another. In addition, there was by that stage very little contact between the mental health service and the patient.

Asked by the committee whether the patient was still able to refuse treatment in a well-considered manner, the physician answered that he

had thought carefully about this. At all times he had been satisfied that the patient was decisionally competent. There was one moment when he had doubts, and that was when he read the independent physician's first report and did not understand it completely. The independent physician believed that the patient was not yet suffering unbearably because she had not yet expressed an actual request. For a moment, he had a feeling that the patient was being manipulative. He went to see her and also contacted the independent physician. During her conversation with the physician, the patient expressed great disappointment at the independent physician's negative recommendation.

The physician was able to discuss with the patient what her suffering entailed. Every day was one of terrible suffering; she experienced her life as hell. The physician did not feel the independent physician's report supported him sufficiently and therefore did not want to proceed with euthanasia in that situation. Once the patient had clearly and specifically requested euthanasia in the very near future, the physician consulted the independent physician by phone. The independent physician was satisfied that the due care criteria had now been complied with.

As regards consulting an independent psychiatrist, the physician said it had not occurred to him to consult such a person. After all, with her very long case history the patient had been treated by many psychiatrists over the years without any significant result. He did consult several colleagues. In hindsight the physician acknowledged that he did not act entirely correctly. Although he had thought very carefully about whether the due care criteria had been complied with and was fully satisfied that they had, it was now clear to him that he had not exercised the particular caution that is required in cases involving suffering caused by a psychiatric disorder. He should have been more diligent in that respect and have consulted an independent psychiatrist.

The committee noted that physicians must exercise particular caution when dealing with a euthanasia request from a patient suffering from a psychiatric disorder (as follows from the Supreme Court judgment in the 1994 Chabot case). Exercising such caution involves consulting an independent psychiatrist in addition to the regular independent physician.

The independent psychiatrist always assesses the voluntary and well-considered nature of the euthanasia request (due care criterion a). The possibility that a psychiatric disorder has impaired the patient's powers of judgment must be ruled out. Furthermore, a patient cannot make a

well-considered decision without a sufficient understanding of the disease, diagnoses, prognoses and treatment options. For that reason the patient must be given sufficient information about their situation and prognosis (due care criterion c). As regards suffering with no prospect of improvement (due care criterion b) and the absence of a reasonable alternative (due care criterion d), the possibility of other treatment options for the patient must be carefully explored by the independent psychiatrist (see the Euthanasia Code 2018, pages 42 to 44). This does not rule out the possibility that in some cases the SCEN physician and the independent psychiatrist are the same person.

The committee realised that, as a result of the circumstances, the physician was faced with a difficult task. It respected the fact that the physician was willing to take over this complicated case from a colleague. Nonetheless the committee found that the notes submitted by the physician, the physician's further written explanation and the interview with the physician showed that the physician did not exercise the particular caution that may be expected in a case involving a euthanasia request by a patient with a psychiatric disorder.

By not consulting an independent expert, who would have assessed the above-mentioned due care criteria independently, the physician was unable to argue plausibly that the due care criteria laid down in section 2 (1) (a) (b) (c) and (d) of the Act had been complied with. The physician did not give a convincing reason why he had neglected to consult an extra expert. In addition there had been little contact with the attending psychiatrist.

The physician consulted one other, independent physician, who saw the patient and gave a written opinion on whether the due care criteria had been complied with. The physician thus complied with the due care criterion referred in section 2 (1) (e) of the Act. However, the independent physician consulted by the physician lacked the necessary expertise in this type of case to be able to assess due care criteria (a) to (d) in the Act independently.

The committee also noted that the independent physician did not advise the physician adequately. It would have made sense for the independent physician to point out to the physician that, given his lack of specific expertise and the patient's long case history, an independent psychiatrist needed to be involved.

The committee found that the physician had not acted in accordance with all the due care criteria.

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.

CASE 2018-04

FINDING: due care criteria not complied with

KEY POINT: independent consultation required

Not included here

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, they will have to present convincing arguments in support of this action. The physician bears final responsibility for exercising due medical care. Their 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 the correct substances in the correct doses have been received from the pharmacist. Another requirement is that the physician must carry an emergency set of substances, in case anything goes wrong with the procedure. This is because it is considered undesirable for the physician to have to leave the patient alone at this time. As regards the physician's presence during an assisted suicide, the Euthanasia Code 2018 states: 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. In the first case below the physician was not carrying an emergency set of substances and left the patient during the euthanasia procedure. The second case was of an assisted suicide in which the physician left the patient's house after the patient had taken the euthanatic.

CASE 2018-23

FINDING: due care criteria not complied with

KEY POINTS: non-straightforward notification, due medical care required, presence of emergency set, physician left the patient

The patient, a man in his sixties, was diagnosed with a malignant tumour in the parietal pleura about a year before his death. In the final weeks before his death, his condition deteriorated sharply. His condition was incurable. The physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion. Nearly two weeks 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 physician who was also a SCEN physician. She concluded that the due care criteria had been complied with.

At the request of the physician, ambulance personnel inserted an IV cannula. The physician began the euthanasia procedure by administering 1000mg of thiopental (a substance that induces a coma). As the patient did not go into a coma, the physician thought that the thiopental might have ended up under his skin instead of in the vein. He decided not to administer the second injection of 1000mg of thiopental, nor the muscle relaxant. The physician first wanted the ambulance personnel to insert a new IV cannula. Before they arrived, the physician went to the pharmacy to get a new set of euthanatics. Because the IV cannula which the ambulance personnel had meanwhile inserted was not working, the physician then administered 2000mg of thiopental and 150mg of rocuronium (a muscle relaxant) via the first cannula, after which the patient died.

In his interview with the committee, the physician said that the procedure did not go the way he had hoped. In his region there is an arrangement between the physicians and pharmacists that the physician takes one set and the pharmacist always has an emergency set available. This way, no second set has to be prepared unnecessarily, which would then have to be thrown away.

After he had administered the 1000mg of thiopental, the physician noticed that it was taking a long time for the man to lose consciousness. As a result he thought the IV substances had gone under his skin. The physician said he then gave himself a time-out. He wanted to know whether the IV cannula had been inserted properly. When he injected the thiopental, however, he had not felt any abnormal resistance. Meanwhile, the patient became increasingly sedated after all, and at a certain point he was unresponsive. Then, after about 20 minutes the physician checked the patient's eyelash and pupil reflexes. They were absent. However, it had taken so long for the thiopental to take effect that the physician felt it was unsafe to inject the rocuronium.

After he had checked the patient's condition, the physician left for the pharmacy to get a new set of euthanatics. The patient was in a peaceful state and the family were composed. The atmosphere was one of complete calm. The physician decided to go to the pharmacy because that would be quicker than having the pharmacist bring the euthanatics. In the meantime, the pharmacist would be able to prepare the substances. The pharmacy was about one kilometre from the patient's house and the physician drove there by car. He was away for

about 10 minutes in total. A few minutes after the physician had left, the ambulance personnel arrived to insert a new IV cannula. The man was without medical supervision for only a short time. The physician emphasised that if there had been any instability on the part of the patient and/or his family, he would never have left. In that case he would have waited for the pharmacist to bring the euthanatics to him.

The committee found that the fact that the physician left the patient during the euthanasia procedure was not in accordance with the KNMG/KNMP 'Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide' of August 2012, which the RTEs take as their guide. The Guidelines include the following standards which are relevant to this case:

- the physician must have an emergency set of intravenous euthanatics to hand;
- the physician remains present throughout the euthanasia procedure.

The committee found that these norms must be applied and that the physician has a responsibility to be aware of these norms and to act accordingly. The physician did not do so.

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

CASE 2018-75

FINDING: due care criteria not complied with

KEY POINTS: non-straightforward notification, due medical care, assisted suicide, leaving before the patient dies

Not included here

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