

ANNUAL REPORT 2016



CONTENTS

F	DREWORD	
In	troduction	4
Fi	ndings	5
C	HAPTER I DEVELOPMENTS IN 2016	
1	'New style' annual report	9
2	Notifications	
	Number of notifications	11
	Male-female ratio	11
	Ratio between cases of termination of life on request and	
	cases of assisted suicide	11
	Nature of conditions	12
	Dementia	13
	Psychiatric disorders	13
	Multiple geriatric syndromes, combination of conditions	
	and other conditions	13
	Age	15
	Notifying physicians	15
	Due care criteria not complied with	17
	Review procedure in practice	17
	Locations	19
3	Committee procedures – developments	19
	Straightforward and non-straightforward cases	19
	Code of Practice	20
	Reflection chamber	20
	Organisation	21

CHAPTER II CASES 1 Introduction

1	Introduction	23
2	Physician acted in accordance with the due care criteria	26
	2.1 Four representative cases	26
	Case 2016-90 Cancer	27
	Case 2016-95 Neurological disorder	28
	Case 2016-92 Cardiovascular disease	29
	Case 2016-91 Pulmonary disease	30
	2.2 Four cases illustrating one of the due care criteria in the Act	31
	Voluntary, well-considered request	31
	Case 2016-03	31
	Unbearable suffering without prospect of improvement	32
	Case 2016-34	32
	No reasonable alternative	33
	Case 2016-01	33
	Consulting an independent physician	35
	Case 2016-52	35

	2.3 Cases involving patients with a psychiatric disorder,	
	dementia or multiple geriatric syndromes	37
	Psychiatric disorder	37
	Case 2016-41	37
	Combination of psychiatric and somatic disorders	39
	Case 2016-11	39
	Dementia	41
	Case 2016-94	41
	Case 2016-62	42
	Multiple geriatric syndromes	45
	Case 2016-96	45
	Case 2016-44	46
3	Physician did <i>not</i> act in accordance with the due care criteria	47
	<i>Non</i> -compliance with criterion of due medical care	47
	Case 2016-57	48
	Non-compliance with criterion of consulting at least one	
	other, independent physician	50
	Case 2016-45	50
	Non-compliance with criteria of unbearable suffering withou	t
	prospect of improvement and no reasonable alternative	52
	Case 2016-21	52
	Non-compliance with criteria of voluntary, well-considered	
	request and due medical care	54
	Case 2016-85	54

FOREWORD

INTRODUCTION

On 15 February 2016, public service broadcaster NPO aired a documentary featuring three people about to undergo euthanasia. The programme played a major role in the continuing public debate on euthanasia, not least because their cases involved complex issues.

When is euthanasia an option for people with a psychiatric disorder or people with (advanced) dementia? When can it be said that a person regards their life as completed? And when does the suffering of a patient with multiple geriatric syndromes have a medical dimension? In the words of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act ('the Act'), the questions that must be asked include the following. Was the physician satisfied that the patient's request was voluntary and well-considered and that their suffering was unbearable, without prospect of improvement? Did the physician come to the conclusion, together with the patient, that there was no reasonable alternative in the patient's situation?

Making a decision about whether or not to grant a euthanasia request is always an intense process, because it is a matter of life and death. The notifications received in 2016 by the Regional Euthanasia Review Committees (RTE) again showed that physicians who receive such requests handle them with great care. Only in a very few cases did the RTE find that the notifying physician had not fully complied with all the statutory due care criteria.

The key figures concerning notifications received in 2016 are as follows.*

In 2016, the RTE received 6,091 notifications of termination of life on request or assisted suicide. This is 4% of the total number of people who died in the Netherlands in that year (148,973).

Of these cases, 83% (5,077 cases) concerned patients with incurable cancer, neurological disorders (such as Parkinson's disease, multiple sclerosis and motor neurone disease), cardiovascular disease or pulmonary disease.

Around 2% of the notifications concerned patients with dementia and around 1% concerned patients with a psychiatric disorder. Some 4% of

4

the notifications concerned patients with multiple geriatric syndromes.

As in previous years, in the vast majority of cases it was the patient's general practitioner who carried out the termination of life or assisted with suicide (85% in 2016). Four out of every five patients died at home.

The average processing time – the time between receipt of a notification and the moment when the RTE's findings are sent to the physician – dropped to 37 days (from 39 days in 2015).

In 10 of the 6,091 notified cases in 2016 it was found that the due care criteria set out in the Act had not been complied with (0.16% of the total number of notifications).

FINDINGS

Again, the number of notifications rose in comparison with the previous year. In 2016 there were 575 more cases, many of which concerned patients with cancer, neurological disorders and cardiovascular disease. Compared to 2015, there were also more notifications concerning patients with dementia (32 more), a psychiatric disorder (4 more) or multiple geriatric syndromes (61 more).

These increases are not easily explained. Has the willingness to report euthanasia increased among physicians? Are physicians more inclined to grant patients' requests for euthanasia? Are patients more resolute when discussing their wish for euthanasia with their physician? Is the – generally positive – fact that people in the Netherlands are living longer a possible explanation for the rise in the number of notifications? Or is it also related to the demographic composition of the Dutch population?

The results of the third five-yearly evaluation of the Act, to be published in mid-2017, may provide some explanation for the steady rise in the number of notifications.

The key figures and the review procedure in practice give a good overview of the current state of affairs. In almost all cases, euthanasia and assisted suicide take place within the boundaries set by the legislator in the statutory due care criteria. In the vast majority of cases, the reports submitted by physicians who have performed euthanasia and the accompanying documentation, including the reports of the independent physicians, are of high quality. This

6

contributes to the transparency and auditability of euthanasia practice.

These conclusions do not detract from the fact that the public debate on euthanasia remains a lively one. As mentioned earlier, this became apparent after the airing of a documentary in 2016. The debate was rekindled by the publication in late 2016 / early 2017 of two findings by the RTE in cases involving patients in an advanced stage of dementia.**

In line with section 2 (2) of the Act, the physician may grant a euthanasia request if the patient has at an earlier stage asked the physician in an advance directive to end his life in the event that the patient is suffering unbearably in an advanced stage of dementia. The due care criteria set out in the Act then apply '*mutatis mutandis*', according to section 2 (2) of the Act. Granting a request that was made by means of an advance directive can lead to difficult situations in practice. For instance, what should the physician do if a patient in an advanced stage of dementia – who indicated unequivocally in writing when he was still fully decisionally competent that he would want termination of his life in that situation – pulls his arm away when the physician goes to administer the injection? Is the patient's movement prompted by fright and the pain of the injection, or should it be interpreted as a sign that the patient is resisting the termination of his life?

Opinions also differ widely on whether it should in future be made possible to receive assistance with suicide if patients regard their life as 'completed', without there being a medical dimension to their suffering (which falls outside the current legal framework). In many cases where patients are suffering from multiple geriatric syndromes, they phrase their euthanasia request in terms of being 'finished with life' or state that they regard their life as 'completed'. Can a boundary be drawn between 'multiple geriatric syndromes' and 'completed life' that is practicable for both physicians and patients? Does the lack of clarity on where that boundary lies perhaps lead to physicians and independent physicians being more cautious than the Act intended when deciding whether to grant a patient's wish in cases involving multiple geriatric syndromes?

These questions are also the subject of intense discussions in the RTE when they review notifications. In these discussions all the – often highly specific – facts and circumstances of the case are weighed up carefully before a decision is reached. However, the RTE are

committees of experts, not judicial bodies, which is a significant limitation on their lawmaking powers. Yet when it comes to these and other questions, it could be beneficial to patients and their loved ones, physicians performing euthanasia, independent physicians and society at large if they could obtain greater legal certainty than the RTE can give.

If a committee finds in a particular case that the physician has acted contrary to one of the statutory due care criteria, the Public Prosecution Service (OM) or the Health Care Inspectorate (IGZ) may ask the court or a disciplinary board to rule on the case. Since the entry into force of the Act, the Public Prosecution Service has never done this, and the Health Care Inspectorate in only a handful of cases.

Another way to promote lawmaking and greater legal certainty is to introduce the option of cassation in the interests of the uniform application of the law, including in cases where a committee has found that the physician acted in accordance with the due care criteria. This would allow for legally relevant questions on the interpretation of the Act to be put to the Supreme Court, without subjecting physicians who perform euthanasia in good faith to lengthy and painful legal proceedings.

Jacob Kohnstamm LLM Coordinating chair of the Regional Euthanasia Review Committees

The Hague, March 2017



MALE-FEMALE RATIO

Male 3130 Female 2961

CHAPTER I DEVELOPMENTS IN 2016

1 'NEW STYLE' ANNUAL REPORT

For more information on the outline of the Act, the committees' procedures, etc., see pages 6 ff of the Code of Practice. In their annual report, the Regional Euthanasia Review Committees (RTE) report on their work over the past calendar year and thus account for the way in which they have fulfilled their statutory task: reviewing notifications of termination of life on request and assisted suicide on the basis of the due care criteria laid down in 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.

For information on the committees' procedures, see https://english. euthanasiecommissie. nl/the-committees. Another aim of the annual report is to give physicians (including SCEN¹ 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. This year we have also opted for a more compact format.

In early 2016, a completely revamped website (www. euthanasiecommissie.nl) was launched. It has a new search function, which makes it easier to find and access the RTE's findings. For that reason the descriptions of the various cases in this report have been limited to the essential details; readers are referred to the full text of the findings on the website (in Dutch) and the relevant sections of the RTE's Code of Practice. The Code of Practice was published in April 2015 and is currently being updated.

The breakdown of the number of notifications of euthanasia in the five separate regions is no longer included in the annual report, but can be found on the website (https://www.euthanasiecommissie.nl/uitspraken-en-uitleg/p/p-2016 (in Dutch)). The same goes for general information about the legal framework, the role of the RTE and relevant legislation.

SCEN refers to the Euthanasia in the Netherlands Support and Assessment Programme, which falls under the Royal Dutch Medical Association (KNMG). The KNMG drew up a guideline for SCEN physicians in 2011, entitled Goede steun en consultatie bij euthanasie ['Good euthanasia support and independent assessment'].



RATIO BETWEEN CASES OF TERMINATION OF LIFE 10 ON REQUEST AND CASES OF ASSISTED SUICIDE

Termination of life on request	5856
Assisted suicide	216
Combination of the two	19

The text of the Act and relevant sections of the Criminal Code and the Burial and Cremation Act can be found at https:// english. euthanasiecommissie. nl/due-care-criteria. In consultation with the Public Prosecution Service and the Health Care Inspectorate, it was decided that the annual report would no longer provide information on how they dealt with cases in which the RTE found that the physician did not act in accordance with the due care criteria set out in section 2 (1) of the Act, as this was considered not entirely appropriate.

2 NOTIFICATIONS

Number of notifications

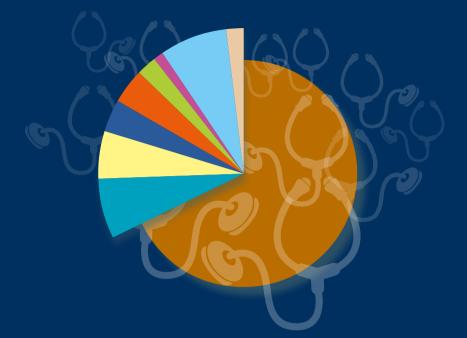
In 2016 the RTE received 6,091 notifications of euthanasia. This is 4% of the total number of people who died in the Netherlands in that year (148,973). In 2015 the RTE received 5,516 notifications, which was 3.75% of the total number of deaths (147,134). The rise in the total number of notifications of euthanasia relative to the number of deaths in the Netherlands was thus very small. In 2016 the RTE received one notification from the Caribbean Netherlands.

Male/female ratio

The numbers of male and female patients were almost the same: 3,130 men (51%) and 2,961 women (49%).

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

There were 5,856 cases of termination of life on request (over 96% of the total), 216 cases of assisted suicide (3.5%) and 19 cases involving a combination of the two (0.3%).



DISORDERS INVOLVED IN 2016

Cancer	4137
Neurological disorders	411
Cardiovascular disease	315
Pulmonary disorders	214
Multiple geriatric syndromes	244
Dementia	141
Psychiatric disorders	60
Combination of disorders	465
Other conditions	104

Nature of conditions

More than 83% of cases (5,077) concerned patients with incurable cancer, neurological disorders (such as Parkinson's disease, multiple sclerosis and motor neurone disease), cardiovascular disease or pulmonary disease. The exact numbers were: 4,137 (cancer), 411 (neurological disorders), 315 (cardiovascular disease) and 214 (pulmonary disease).

Dementia

In 141 cases the patient's suffering was caused by dementia. In 2015 that figure was 109. In the vast majority of these cases, the patients were in the initial stages of the disorder and still had insight into their condition and its symptoms (loss of bearings and personality changes). They were deemed decisionally competent with regard to their request because they could still grasp its implications. Case 2016-94, described in Chapter II, is an example. In a few cases the patients were in an advanced stage of dementia. See cases 2016-62 and 2016-85 (also described in Chapter II). In the latter case the RTE found that the physician had 'not acted in accordance with the due care criteria'.

Psychiatric disorders

In 60 notified cases of euthanasia the patient's suffering was caused by a psychiatric disorder. In 2015 that figure was 56. In 28 of these 60 cases the notifying physician was a psychiatrist, in 20 cases a general practitioner, in 1 case an elderly-care specialist and in 11 cases another physician (for instance a psychiatry registrar). Case 2016-41 (described in Chapter II) is an example of a case involving a psychiatric patient. In some cases the patient's suffering was caused by a combination of somatic and psychiatric disorders. See case 2016-11 in Chapter II.

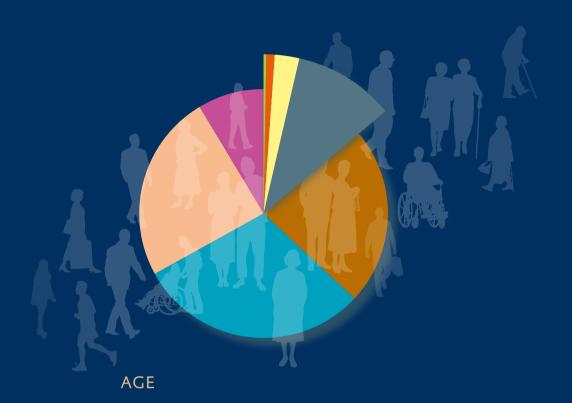
Multiple geriatric syndromes, combination of conditions and other conditions

There were 244 notified cases involving patients with multiple geriatric syndromes and 465 cases involving a combination of conditions. The latter category comprises all notifications that involve a combination of conditions from the above-mentioned categories; for example, the patient's suffering is caused by both cancer and a cardiovascular disease, or by dementia or a psychiatric disorder in combination with COPD. Lastly, the RTE register cases involving conditions that do not fall into any of the above categories, such as chronic pain syndrome, as 'other conditions'. There were 104 such cases.

For points to consider regarding patients with dementia, see pages 27 and 28 of the Code of Practice.

For points to consider regarding patients with a psychiatric disorder, see pages 26 and 27 of the Code of Practice.

Multiple geriatric syndromes can also cause unbearable suffering with no prospect of improvement. See pages 13, 31 and 32 of the Code of Practice.



30 years or younger*	16
9 30-40 years	44
• 40-50 years	152
🔵 50-60 years	631
🛑 60-70 years	1408
70-80 years	1831
🛑 80-90 years	1487
90 years or older	522

* 1 minor

14

Age

The highest number of notifications of euthanasia involved people in their seventies (1,831 cases, 30.1%), followed by people in their eighties (1,487 cases, 24.4%) and people in their sixties (1,408 cases, 23.1%).

In 2016 the RTE received one notification of euthanasia involving a minor between the ages of 12 and 17. See case 2016-58 on the website.

There were 59 notifications concerning people aged between 18 and 40. In seven of these cases, the patient's suffering was caused by a psychiatric disorder.

In the category 'multiple geriatric syndromes' the largest number of notifications concerned people aged 90 or older. In the categories 'dementia' and 'psychiatric disorder', the largest number of notifications involved people in their eighties and fifties, respectively.

Notifying physicians

The vast majority of cases (5,167) were notified by the patient's general practitioner (85% of the total number). The other notifying physicians were elderly-care specialists (216), other specialists (179) and registrars (43).

There was also a large group of physicians with other backgrounds (486), for instance physicians affiliated with the End-of-Life Clinic (SLK) or junior doctors.

The number of notifications by physicians affiliated with the SLK rose from 366 in 2015 to 487 in 2016, an increase of 33%. As is apparent from the notification details, SLK physicians are often called upon in complex cases. Many of the notifications of cases involving a psychiatric disorder came from an SLK physician: 37 out of 60 notifications (almost 62%). Out of all the notifications of cases in which the patient's suffering was caused by a form of dementia, 46 (nearly 33%) came from an SLK physician. Lastly, the RTE received 66 notifications from SLK physicians (27%) involving multiple geriatric syndromes. The records show that physicians may find these cases complex or that physicians refer patients to the SLK for reasons of principle. Some physicians will only perform euthanasia if the patient has a terminal condition. They, too, sometimes refer patients to the SLK.

For points to consider regarding minors, see page 25 of the Code of Practice.

NOTIFYING PHYSICIANS

General practitioner	5167
Elderly-care specialist	216
Specialist working in a hospital	179
Registrar	43
Other physician	486
(e.g. doctors affiliated with the	
End-of-Life Clinic)	

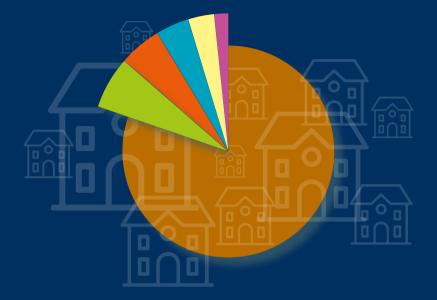
Due care criteria not complied with

In 10 of the 6,091 notified cases, the RTE 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 0.16% of all notifications. In five cases the committee found that the criterion of due medical care was the only one that had not been complied with. In three cases the criterion of consulting at least one other, independent physician had not been complied with. In one case the committee found that the physician was unable to plausibly argue that he could be satisfied that the patient was suffering unbearably and that there were no reasonable alternatives that would alleviate the suffering. In the 10th case the committee found that the physician could not have concluded unequivocally that the patient's request for euthanasia was voluntary and well-considered; furthermore the criterion of due medical care had not been complied with.

Review procedure in practice

Limiting this report to a discussion of only the cases in which the RTE 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 addition, there are many grey areas. In 77 cases (including the 10 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 40 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 final 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 in the future.

Some cases are considered to be so complex that all 45 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 and its draft findings available 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 a broad internal debate. The aim is to ensure the quality of the review is as high as possible and to achieve as much uniformity in the findings as is possible in very diverse cases. Twenty cases were discussed in this way in 2016.



LOCATIONS

Home	4904	
Hospice	367	
Care home	300	
Nursing home	233	
Hospital	199	
Elsewhere	88	
(for instance at the home of a family		
member, in a sheltered accommodation		
centre or a convalescent home)		

Locations

In the vast majority of cases (4,904 cases, 80.5%) euthanasia was performed at the patient's home. Other locations were a hospice (367 cases, 6%), a care home (300 cases, 4.9%), a nursing home (233 cases, 3.8%), a hospital (199 cases, 3.3%) or elsewhere, for instance at the home of a family member, in a sheltered accommodation centre or a convalescent home (88 cases, 1.4%).

3 COMMITTEE PROCEDURES – DEVELOPMENTS

Straightforward and non-straightforward cases

In 2012 the RTE began categorising the notifications immediately upon receipt as 'straightforward' and 'non-straightforward' cases. Straightforward cases and the accompanying files are sent digitally to the committee members on a weekly basis, so that these notifications can be handled within the appropriate timeframe. In 2016, 80% of the notifications received concerned straightforward cases.

Notifications are considered straightforward if the experienced committee secretary, who is a lawyer, can establish that the information provided is so comprehensive and the likelihood that the physician has complied with the statutory due care criteria is so great that the committee will be able to review the notification digitally. Cases 2016-90, 2016-91, 2016-92 and 2016-95 have been included in Chapter II as examples of such straightforward cases.

A small number of notifications that were initially considered straightforward (1%) were later deemed to be non-straightforward, and as a result were discussed in a committee meeting. The arrangement is that if any of the committee members thinks that a straightforward case does raise questions it is referred to the monthly committee meeting for discussion.

The other 20% of the notifications received raised questions that required discussion in person (for instance because of a complex context such as psychiatric disorders or dementia, or because the information submitted by the physician was insufficient) and were reviewed at the monthly committee meetings.

Code of Practice

criteria.

The Code of Practice can be found on the committees' website: https:// english. euthanasiecommissie. nl/the-committees/ code-of-practice

The Code of Practice, published in 2015, outlines the issues that the RTE regard as relevant in performing their statutory task, i.e. the review of notifications of termination of life on request and assisted suicide. Its aim is to provide a clear explanation – particularly for physicians performing euthanasia and for independent physicians – of how the committees apply and interpret the statutory due care

The RTE conducted a mini-survey in February 2016 to establish whether physicians (including SCEN physicians) were familiar with the Code of Practice and if so, to find out their experiences of it. More than 1,000 short questionnaires were sent to physicians who had submitted notifications of euthanasia and to the independent physicians involved in these cases. The survey had an extremely high response rate: 70% of the physicians (including SCEN physicians) responded. While one outcome was that the Code of Practice is rated very positively, a large group – almost 80% of the notifying physicians - were unaware of the existence of the Code of Practice. By contrast, most SCEN physicians (89%) were familiar with the Code. It emerged that the Code of Practice is mainly consulted when physicians have questions about suffering, dementia, 'completed life' and psychiatric issues. A committee is now looking at what sections of the Code of Practice can be improved, revised or worded differently. The Royal Dutch Medical Association (KNMG), the SCEN peer supervision groups and others have been asked for input.

The Code of Practice is now available in English, providing non-Dutch speakers with insight into the Dutch assessment and review process. The English version of the Code can be found on the RTE's website.

Reflection chamber

The RTE recently decided to establish an internal 'reflection chamber' to further a number of aims including enhanced coordination and harmonisation. The reflection chamber will consist of two lawyers, two ethicists and one secretary drawn from the RTE. The chamber can be consulted by a committee if it is faced with a complex issue. The chamber will not review the entire notification, but instead look at one or more specific questions formulated by the committee. Given the time that may be needed for the reflection chamber to do its work, the notifying physician will be informed that there will be a delay in dealing with the notification.

The reflection chamber will begin its work at some point in 2017. An evaluation will take place after two years.

Organisation

The five regional RTE are autonomous and independent. Each committee comprises three members: a lawyer, who is also the chair, a physician and an ethicist. In principle a committee has two alternate members for each discipline. The RTE therefore have a total of 45 members. Each committee is assisted by a secretary, who is also a lawyer and who attends the committee's meetings in an advisory capacity. The RTE members are appointed by the Minister of Health, Welfare & Sport and the Minister of Security & Justice for a period of four years which may be extended for another four years.

With a view to efficiency, the secretariats of the RTE are part of the Ministry of Health, Welfare and Sport. They are incorporated in the Disciplinary Boards and Review Committees Secretariats Unit (ESTT). The RTE secretariat staff work for the review committees only.

The RTE secretariats employ 27 people in 19.25 FTEs. The secretariat staff are responsible for the work that precedes and follows the review of notifications by the committees. They also assist the committees in collective tasks, such as drafting and updating the Code of Practice and compiling the annual reports.

In light of the continuing growth in the number of notifications of euthanasia, a working group established for this purpose commissioned a review of how the RTE are organised and whether they are fit for the future. The review, which was carried out by an external consultancy, provided solutions and proposals for four key themes: optimising the working procedures for the reviews, improving internal consultation, formulating a mission for the RTE, and structuring the provision of public information. On the basis of these themes, proposals were drawn up, which were discussed at a plenary meeting at the end of 2016.

CHAPTER II CASES



1 INTRODUCTION

The text of the Act and relevant sections of the Criminal Code and the Burial and Cremation Act can be found at https:// english. euthanasiecommissie. nl/due-care-criteria. This chapter describes various findings by the Regional Euthanasia Review Committees. The essence of the RTE's work consists of reviewing physicians' notifications concerning termination of life on request and assisted suicide (euthanasia).² 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 RTE. The main documents in the notification file submitted by physicians are the report by the notifying physician, the report by the independent physician consulted (almost always a SCEN physician), excerpts from the patient's medical records, the patient's advance directive if there is one (however a written directive is not required for euthanasia) and a declaration by the municipal pathologist. 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 RTE review notifications in the context of the Act, its legislative history and the relevant case law. They also take previous committee findings into account, as well as the decisions of the Public Prosecution Service and the Health Care Inspectorate. The RTE decide

² As indicated in chapter 1, 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.

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. As regards the other three due care criteria, (a), (b) and (d), the physician must *plausibly argue* that, given the circumstances of the case, he was *reasonably able to conclude* that they had been fulfilled. The way in which compliance with these three criteria is assessed would be described by Dutch lawyers as 'limited review' or a test of reasonableness. It means the RTE do not carry out a full review of compliance with the due care criteria and therefore do not re-examine the same issues as the physician who made the original decision. The RTE cannot do this, as the patient is no longer alive: these are the issues that the independent physician focuses on.

The cases described in this chapter fall into two categories: cases in which the RTE found that the due care criteria had been complied with (section 2) and cases in which the RTE 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 did not comply with one or more of the due care criteria.

Section 2 is divided into three subsections. Subsection 2.1 describes four findings that are representative of the vast majority of notifications received by the RTE, in cases involving cancer, a neurological disorder, cardiovascular disease or pulmonary disease.

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.

There is no separate discussion of 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 his health situation and of his prognosis (see also p. 14 of the Code of Practice). This information is also relevant in assessing whether there is indeed no reasonable alternative, a conclusion which must be reached by the physician and the patient together (see pp. 15 and 16 of the Code of Practice). The due care criterion concerning due medical care (f) is relevant to the cases in which it was found that the due care criteria were not complied with.

Then, in subsection 2.3, we describe several cases involving euthanasia for patients with a psychiatric disorder, patients with dementia and patients with multiple geriatric syndromes. In all these cases the RTE found that the physician concerned had complied with the due care criteria.

In section 3 we describe four cases in which the physician did not comply with one or more of the due care criteria, more specifically a voluntary and well-considered request, no reasonable alternative, consulting an independent physician and due medical care.

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

2 PHYSICIAN ACTED IN ACCORDANCE WITH THE DUE CARE CRITERIA

2.1 Four representative cases

As stated in chapter 1, the vast majority of euthanasia cases involve patients with cancer, neurological disorders, cardiovascular disease and pulmonary disease. The following four cases are examples (all are straightforward cases).

In the first case we have included almost the entire text of the findings, to give the reader an idea of what a complete RTE decision looks like. Identifying information has been omitted, however. Together, the four cases illustrate the issues that the RTE encounter most frequently.

CASE 2016-90 CANCER

FINDING: due care criteria complied with

KEY POINT: straightforward notification

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, had been suffering since 2010 from a colon carcinoma which had metastasised to the liver (a malignant tumour in the large intestine, which had spread). From 2013 his condition deteriorated further, as a result of new liver metastases and new, abdominal and pulmonary metastases (in the abdomen and lungs). 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 constant nausea, frequent vomiting, fatigue, listlessness and loss of energy and strength. There was very little he was capable of doing and nothing gave him pleasure any more. He was suffering from the prospect of further deterioration and the loss of dignity.

The patient experienced his suffering as unbearable. The physician was satisfied that this suffering was unbearable to him 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. About 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.

c. Consulting an independent physician

The physician consulted an independent physician who was also a SCEN physician. The independent physician saw the patient more than a week

before euthanasia was performed, after he had been told about 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 has acted in accordance with the due care criteria laid down in section 2 (1) 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.

CASE 2016-95 NEUROLOGICAL DISORDER

FINDING: due care criteria complied with

KEY POINT: straightforward notification

The patient, a woman in her seventies, was diagnosed in early 2013 with amyotrophic lateral sclerosis, also known as motor neurone disease (an incurable disease that leads to the death of nerve cells, causing muscle weakness). She gradually developed paresis (loss of strength) in her arms and legs, problems with swallowing and speaking. Communicating became increasingly difficult for her. In the final period before her death,

See case 2016-95 on the website for the full text (in Dutch). her condition deteriorated sharply. Motor neurone disease cannot be cured. The patient could only be treated palliatively (care aimed at improving quality of life). She was suffering from extreme fatigue and chest tightness, and had difficulty breathing – all of which instilled fear and dread in her. She could hardly talk. The patient was fed and received medication though a PEG tube (a thin tube inserted into the stomach through an incision in the abdominal wall, through which the patient is given liquid food or medication). She was entirely dependent on others and unable to do anything for herself. The patient, who had always been active and energetic, knew there was no prospect of improvement in her situation and that the only prognosis was deterioration. In her view, the limit had been reached. She experienced her suffering as unbearable.

The physician concluded that the request was voluntary and wellconsidered. He had also consulted an independent physician, who concluded that the due care criteria had been complied with. The physician performed the euthanasia with due medical care.

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

CASE 2016-92 CARDIOVASCULAR DISEASE

See case 2016-92 on the website for the full text (in Dutch). FINDING: due care criteria complied with

KEY POINT: straightforward notification

The patient, a man in his eighties, had been suffering from cardiovascular disease for years. Two months before his death, he developed an abdominal aortic aneurysm (a bulge in the body's main artery which may rupture and leak into the abdomen).

The patient declined further treatment. His condition was incurable. He could only be treated palliatively (care aimed at improving quality of life). In addition, the patient was weakened and suffered from a lack of appetite, weight loss and dizziness. He also was in pain at night, especially in his back. There was very little the patient, who had always been active, was capable of doing and he was bedridden. He was suffering from the futility of his situation, the absence of any prospect of improvement, the loss of control and his further deterioration. He experienced his suffering as unbearable.

The physician concluded that the request was voluntary and wellconsidered. He had also consulted an independent physician, who concluded that the due care criteria had been complied with. The physician performed the euthanasia with due medical care.

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

CASE 2016-91 PULMONARY DISEASE

FINDING: due care criteria complied with

KEY POINT: straightforward notification

The patient, a man in his seventies, had suffered for years from chronic obstructive pulmonary disease, or COPD (an incurable lung disease that permanently narrows the patient's airways, causing them to gradually stop working properly). The disease is progressive and characterised by acute deteriorations. In the month before his death, the patient's condition again deteriorated rapidly, as a result of a blood clot in his lungs. His condition was incurable. The patient could only be treated palliatively (care aimed at improving quality of life). He was suffering from increasing shortness of breath, coughing, exhaustion and decreased mobility. On several occasions he felt as if he were suffocating. He could hardly do anything except sit in a chair. The patient had become completely dependent on others for his personal care. He suffered from the fear of suffocating and the absence of any prospect of improvement in his situation. He experienced his suffering as unbearable.

The physician concluded that the request was voluntary and wellconsidered. He had also consulted an independent physician, who concluded that the due care criteria had been complied with. The physician performed the euthanasia with due medical care.

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

See case 2016-91 on the website for the full text (in Dutch).

31

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

VOLUNTARY AND WELL-CONSIDERED REQUEST

For general points regarding the voluntary and wellconsidered request, see pages 11 ff of the Code of Practice.

The following case has been included in order to show that euthanasia may be granted to patients with an intellectual disability and can result in the finding that the due care criteria have been complied with provided the physician can plausibly argue that he was reasonably able to conclude that the patient in question was decisionally competent in relation to the request for euthanasia.

CASE 2016-03

See case 2016-03 on the website for the full text (in Dutch).

For points to consider regarding patients with an intellectual disability, see page 28 of the Code of Practice. FINDING: due care criteria complied with

KEY POINT: man with an intellectual disability

As a young child, the patient had been diagnosed with tuberous sclerosis complex (a hereditary disease causing abnormal cells to grow in various vital organs, causing loss of function in those organs). Over the years he experienced problems with many of his organs and developed epilepsy. As a result of the disease, he also developed an intellectual disability. Later in life, some years before his death, he was diagnosed with cancer. Metastases were found in the liver and there was increasing tumour growth in his abdomen. The patient's condition was incurable. He could only be treated palliatively (care aimed at improving quality of life).

The patient, by now in his thirties, had discussed euthanasia with the physician before. Two months before his death, he asked the physician to actually perform the procedure to terminate his life. At the physician's request, a physician specialising in the care of people with intellectual disabilities and a psychologist assessed the patient's decisional competence in relation to his request for euthanasia. They concluded that he had insight into his situation and his prognosis. In their opinion he was able to make an independent choice and understand the consequences. They thus established that he was decisionally competent. The physician and the experts concluded that the request was voluntary and well-considered.

Because the man had an intellectual disability, the committee added an extra consideration to its findings. The committee held that in this case, in which an intellectual disability was established in addition to severe somatic suffering caused by the disease, there needed to be a special focus on decisional competence in relation to the request for euthanasia. The committee found that the physician had exercised due care by consulting an expert physician and a psychologist, who established that the patient was decisionally competent in relation to his request for euthanasia. The other due care criteria were also fulfilled.

UNBEARABLE SUFFERING WITHOUT PROSPECT OF IMPROVEMENT

points regarding unbearable suffering without prospect of improvement see pages 13 ff of the Code of Practice.

See case 2016-34 on the website for the full text (in Dutch).

For general Euthanasia may also be granted to patients with medically unexplained symptoms. These symptoms may also lead to unbearable suffering without prospect of improvement. The following case is an example.

CASE 2016-34

FINDING: due care criteria complied with

KEY POINT: medically unexplained physical symptoms (MUPS)

The patient, a woman in her sixties, had had persistent abdominal symptoms for seven years. Over the years she had consulted dozens of specialists, including surgeons, internal medicine physicians, rehabilitation specialists, neurologists, psychiatrists and pain specialists. She had also seen several alternative practitioners. Her symptoms persisted and it remained unclear what was causing them. The woman's symptoms consisted of chronic pain, including abdominal pain, nausea and vomiting, muscle spasms throughout her body, 'locked' muscles, a swollen abdomen, a crick in the neck, problems with swallowing, incontinence, difficulty walking, loss of energy and fatigue. The symptoms were severely debilitating, to the extent that she could not lead a normal life. The patient no longer left the house, had become increasingly bedridden and was socially isolated. She felt she had no quality of life and suffered from the absence of any prospect of improvement in her situation.

The physician was satisfied that this suffering was unbearable to her and that there was no prospect of improvement. The independent physician concurred. Another independent physician, a psychiatrist, was consulted with regard to the patient's request for euthanasia. This physician concluded that her symptoms were not amenable to psychiatric treatment.

In the committee's opinion the physician had exercised due care. He had advised the patient to follow several lengthy courses of treatment to establish the cause of her symptoms. When that proved unsuccessful, the physician concluded, together with the patient, after frequent and intensive contact that her suffering was unbearable and without prospect of improvement. The committee found that the physician could be satisfied that this was the case. The other due care criteria were also fulfilled.

NO REASONABLE ALTERNATIVE

The absence of a reasonable alternative, a due care criterion which must be seen in relation to suffering with no prospect of improvement, is discussed on pages 13 and 15 ff of the Code of Practice.

See case 2016-01 on the website for the full text (in Dutch).

For points to consider regarding patients with a psychiatric disorder, see pages 26 and 27 of the Code of Practice.

Other findings published by the RTE concerning patients with psychiatric disorders can be found at https://www. euthanasiecommissie. nl/uitspraken-enuitleg/p/ psychiatrischeaandoeningen/ documenten (in Dutch).

The physician and the patient must together come to the conclusion that there is no reasonable alternative in the patient's situation. If there are less drastic ways of ending or considerably reducing the patient's suffering, these must be given preference. In the following case, there was initially some doubt about whether there was a reasonable alternative.

CASE 2016-01

FINDING: due care criteria complied with

KEY POINTS: anorexia nervosa with depressive symptoms, a somatic symptom disorder and a personality disorder, absence of acceptable treatment options, need for particular caution in cases involving patients with a psychiatric disorder

The patient, a woman in her sixties, had suffered from anorexia nervosa since her youth. In addition she increasingly suffered from recurrent depressions, and had a personality disorder and a somatoform pain disorder (when a person has numerous physical symptoms for which there is no physical explanation – treatment focuses on psychiatric causes). She had been treated extensively, on both an inpatient and outpatient basis, for anxieties, depressions and a strong death wish. The treatments she received included electroconvulsive therapy (in which an electric current is passed across the brain), pain medication, cognitive behavioural therapy (a form of short-term psychological therapy focusing on the present and future rather than on coming to terms with the past) and treatments focusing on MUPS (medically unexplained physical symptoms). These treatments did not result in any real changes. In the end there was no further treatment offering any prospect of improvement. In the final years before her death, her condition continued to deteriorate. Her condition was incurable.

The patient experienced her suffering as unbearable and asked her physician for euthanasia. The physician was satisfied that this suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion. The physician consulted an independent psychiatrist in order to rule out the existence of any treatment options. In the opinion of the psychiatrist, treatment was theoretically possible. However, she believed it was extremely doubtful that the patient would be able to tolerate the treatment or be able to enter into and maintain an appropriate treatment relationship. This doubt was partly rooted in the fact that the patient had indicated that she was no longer motivated to undergo treatment. The physicians thus came to the conclusion that there were no other means to alleviate the patient's suffering that were acceptable to her. The committee noted that 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. Besides the independent SCEN physician, the physician also consulted an independent psychiatrist. The psychiatrist concluded, partly in view of the patient's limited capacity to cope and her lack of motivation, that there were no relevant treatment options left. The independent physician confirmed the physician's assessment that further treatment would not result in any lasting improvement and that there were no longer any realistic alternatives for her. The committee found that, together, the physician and the patient could be satisfied that there was no reasonable alternative in her situation. The other due care criteria were also fulfilled.

CONSULTING AN INDEPENDENT PHYSICIAN

consider regarding consulting an independent physician, see pages 16 ff of the Code of

For points to The Act states that physicians must consult at least one other, independent physician, who must see the patient and give a written opinion on whether due care criteria (a) to (d) have been fulfilled. As shown by the next case, it may be that the independent physician is of the opinion that this is not or not yet the case. This does not automatically *Practice.* mean that a physician who proceeds with euthanasia in such a case is not complying with the due care criteria in the Act. In these situations, however, the committee usually asks the physician additional questions.

CASE 2016-52

See case 2016-52 on the website for the full text (in Dutch).

FINDING: due care criteria complied with

KEY POINT: physician proceeded with euthanasia despite the fact that the independent physician thought the due care criteria (reasonable alternatives) had not been complied with. Physician has clearly explained why he disregarded the independent physician's assessment

The patient, a woman in her eighties, suffered from a combination of conditions: she had polyarticular osteoarthritis (wear and tear in several joints) in her back, hands, shoulders, knees and feet, suffered from neuropathy (a nerve disorder) and was hard of hearing. In addition she had suffered all her life from depression and obsessive-compulsive disorder (uncontrollable thoughts/actions and a fear that something serious will happen if those actions are not performed). She had received treatment including medication and electroconvulsive therapy (in which an electric current is passed across the brain). Her condition was incurable. She could only be treated palliatively (care aimed at improving quality of life). The patient's suffering consisted of pain, fatigue, dizziness, hearing loss, loss of mobility, increasing dependence on others for care, mood-related problems and obsessive thoughts. Sometimes her legs would buckle and she used a rollator when walking. She was afraid of falling, which was understandable because of the deformity in her feet. In the final weeks before her death she hardly went outside and her social circle had become very small. She was unable to take part in a group conversation. She was at the end of her tether.

The physician was satisfied that this suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion.

The independent physician consulted by the physician found that due to her pain, fear of falling and increasing dependence the patient's suffering was palpably unbearable. In his opinion, however, not all treatment

options had been tried, such as better pain medication or physiotherapy aimed at fall prevention. The independent physician therefore concluded that the due care criteria had not been fulfilled. The physician performed the euthanasia procedure nonetheless.

The committee then invited the physician to provide further information in person. It asked him why he had not followed the independent physician's suggestions and why he been satisfied that there were no more reasonable treatment options, leading to the conclusion that the patient's suffering was without prospect of improvement. The physician replied that adjusting the pain medication would not have made any difference to the patient's suffering from her perspective. Attempts had already been made in that area which had not produced sufficient results and had many side-effects. The only option would have been to give her morphine for the pain, but that would have increased the risk of falling and her constipation, which she had already found to be very troublesome. In the physician's view, she was beyond the stage of taking a fall prevention course. This was not a reasonable alternative, all the more because she had been treated by a physiotherapist for months. Moving her to a nursing home could have helped solve the care problem, but would not have alleviated her suffering. On the contrary, losing her familiar surroundings would have added an extra dimension to her suffering.

The committee found that physicians may disregard a negative recommendation by the independent physician and proceed with euthanasia. According to the Act the physician is responsible, but he will have to explain clearly why he disregarded the independent physician's assessment. In this case the committee is of the opinion that the physician, in his reports and during the interview with the committee, explained in great detail and very convincingly why he thought the patient's suffering was without prospect of improvement and why there were no reasonable alternatives to alleviate the suffering. The committee found that the physician could be satisfied that this was the case. The other due care criteria were also fulfilled.

2.3 Cases concerning people with a psychiatric disorder, dementia or multiple geriatric syndromes

MENTAL DISORDER

For points to consider regarding patients with a psychiatric disorder, see pages 26 and 27 of the Code of Practice.

See case 2016-41 on the website for the full text (in Dutch).

Other findings published by the RTE concerning patients with psychiatric disorders can be found at https://www. euthanasiecommissie. nl/uitsprakenen-uitleg/p/ psychiatrischeaandoeningen/ documenten (in Dutch). It is usually necessary to consult an independent psychiatrist or another expert if the patient's suffering is caused by a psychiatric disorder. The main aim is to obtain an assessment of whether the request is voluntary and well-considered and whether the suffering is without prospect of improvement.

CASE 2016-41

FINDING: due care criteria complied with

KEY POINTS: assessment of decisional competence, need for particular caution in cases involving patients with a psychiatric disorder

The patient, a woman in her forties, had been diagnosed with posttraumatic stress disorder (continually reliving bad experiences in thoughts or dreams) with psychotic features (during a psychotic episode, people experience the world differently from other people; they may hear voices, perceive smells differently or give special meaning to certain thoughts). Every day she relived traumas from her youth while experiencing symptoms of dissociation (a state in which thoughts, emotions, observations and memories are placed outside the person's consciousness). She also suffered from severe sleeping disorders. She was admitted to a specialised hospital several times and received a number of treatments including cognitive behavioural therapy (a form of short-term psychological therapy focusing on the present and future rather than on coming to terms with the past), Eye Movement Desensitisation and Reprocessing (EMDR, a treatment method mainly used with people with post-traumatic stress disorder) and other trauma treatment. She also received medication for depression and psychosis and she took sleeping medication. The effects of these treatments were only temporary. The patient had made an active effort to improve her future prospects by enrolling in education. However, she was unable to follow the course due to her persistent symptoms and constant exhaustion.

At the physician's request, a clinical psychologist assessed whether any further treatment was possible. Starting with treatment again would require strong motivation on the patient's part, because despite a lengthy history of treatment, no progress had been made. She indicated she was unable to summon the motivation. The physician also asked an independent psychiatrist to assess whether there were any other solutions. In the opinion of the psychiatrist, everything possible had been done. After consulting the psychiatrist, 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 noted that physicians must exercise particular caution when dealing with a euthanasia request from a patient suffering from a psychiatric disorder. The physician, a general practitioner, consulted a clinical psychologist and a clinical psychiatrist. The committee found that the physician could be satisfied that the patient was suffering unbearably with no prospect of improvement and that her request was voluntary and well-considered. The other due care criteria were also fulfilled.

CASE 2016-11

See case 2016-11 on the website for the full text (in Dutch).

For points to consider regarding patients with a combination of psychiatric and somatic disorders, see pages 26 and 27 of the Code of Practice.

FINDING: due care criteria complied with

KEY POINT: difference in views between the physician and the independent physician as to whether the request was wellconsidered and with regard to the patient's suffering; the physician consulted another independent physician

The patient, a man in his seventies, had been suffering from frequent migraines for more than 50 years. Treatment with medication, prescribed by a neurologist, had no effect. The patient therefore stopped taking the medication, but from then on reported suffering a great deal from anxiety. Thirty years before his death he had been declared completely unfit to work. In the 10 to 14 years before his death he developed other physical symptoms, including high blood pressure, abdominal pain, pain in his joints, dizziness and balance problems. These symptoms became more severe over the years. In the 25 years before his death the patient received treatment from several psychiatrists in the form of talk therapy and medication for depression. Four years before his death he was briefly treated in a clinic, and two and a half years before his death he spent a year in a clinic after multiple suicide attempts. In that year he was treated with medication for depression and received ECT (electroconvulsive therapy) five times. Because he experienced no perceivable improvement he refused any further ECT. Two years before his death the previous diagnosis (depression) was changed to one of dysthymic disorder (a less severe form of depression), PD-NOS (personality disorder – not otherwise specified) and a pain disorder connected to psychological and physical factors.

His condition was incurable. He could only be treated palliatively (care aimed at improving quality of life). The patient no longer wanted to use medication for his psychological symptoms due to the unpleasant sideeffects. Because of his many physical problems he no longer left the house and as a result of his personality disorder he no longer had a social network. He could no longer watch television or pursue a hobby. All he did was lie in bed aimlessly, waiting for death. He felt that living this way was futile and degrading and he experienced his suffering as unbearable. He asked the physician to help him with euthanasia.

The physician asked an independent psychiatrist to assess whether the patient was decisionally competent and whether there were any realistic treatment options that could alleviate his suffering. In the opinion of the

psychiatrist, the patient was decisionally competent in relation to his request for euthanasia and there were no treatment options left with regard to the psychiatric component of his suffering.

The physician consulted an independent SCEN physician. The independent physician considered the patient to be decisionally competent, but doubted, in view of his personality, whether the wish could be said to be well-considered. The independent physician was also not convinced that the patient's suffering was unbearable and without prospect of improvement. The physician then asked another SCEN physician to visit his patient. This SCEN physician not only contacted the physician asked to perform euthanasia and the psychiatrist he consulted, but the first independent physician as well. He also consulted several fellow SCEN physicians. This enabled him to make a more specific assessment of whether there were any reasonable alternatives that could alleviate the man's suffering. The second independent physician concluded that the due care criteria had been complied with.

The committee observed that when dealing with a request for euthanasia, the physician is not meant to 'shop around' for an independent physician, i.e. keep searching until he has found an independent physician whose opinion is agreeable to him. When an independent physician is of the opinion that the due care criteria have not yet been fulfilled or raises points of criticism, it is up to the physician to explain as clearly as possible why he nonetheless is satisfied that the due care criteria have been fulfilled. The committee also found that the physician made an effort to substantiate his own views and was prepared to enter into discussion about them. The committee found that the physician had acted in accordance with the due care criteria.

41

DEMENTIA

For points to consider regarding patients with dementia, see pages 27 and 28 of the Code of Practice.

Dementia and euthanasia is a topic that has received a great deal of media attention over the past year. There is a distinction to be made between euthanasia for a patient with early-stage dementia (the phase in which the patient generally still has insight into the disease and the symptoms, such as loss of bearings and personality changes) and euthanasia for a patient in a later phase of dementia in whom the disease has progressed to the point that the patient is no longer able to request euthanasia. In the latter situation, an advance directive may take the place of a request for euthanasia.

For points to consider regarding the advance directive, see pages 23 ff of the Code of Practice.

Section 2 (2) of the Act provides for euthanasia on the basis of an advance directive. It reads:

'If a patient aged sixteen or over who is no longer capable of expressing his will, but before reaching this state was deemed capable of making a reasonable appraisal of his own interests, has made a written declaration requesting that his life be terminated, the physician may comply with this request. The due care criteria in subsection 1 apply *mutatis mutandis*.'

CASE 2016-94 EARLY-STAGE DEMENTIA

FINDING: due care criteria complied with

See case 2016-94 on the website for the full text (in Dutch).

Other findings published by the RTE concerning patients with dementia can be found at https://www. euthanasiecommissie. nl/uitspraken-enuitleg/d/dementie/ documenten (in Dutch). KEY POINTS: decisional competence, unbearable suffering

The patient, a woman in her sixties, became forgetful after suffering a TIA (temporary obstruction of a blood vessel in the brain) in late 2011. In early 2013 she was diagnosed with presenile dementia (dementia at a relatively young age). In the years that followed, the disease progressed and more and more of her daily tasks had to be performed by others. In the autumn of 2015 it became clear that she would soon need daycare. The patient's suffering consisted of her not being able to function independently any more and having become fully dependent on others. For instance, she was no longer able to read or write, she had difficulty finishing spoken sentences, she could not drive a car nor could she dress herself. The patient felt trapped in her home. She realised that she was no longer able to take part in society independently and that she had lost control of her life. Having led a very independent life, the patient experienced her suffering as unbearable. The physician was satisfied that this suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion.

From mid-2013 onwards the patient had discussed with the physician the fact that, in due course, she wanted euthanasia. She had also given

the physician an advance directive. She updated the advance directive several times and added a separate signature to the clause on dementia in the directive. In 2015 she spoke more emphatically about her wish and around two months before her death stated that she wanted euthanasia to be performed within three months. She absolutely did not want to go to daycare outside her home, nor did she want to go into a nursing home. She repeated her specific wish for euthanasia in three subsequent conversations with the physician.

The physician concluded that the request was voluntary and wellconsidered. The independent physician stated that the woman was still able to make clear what made her suffering unbearable and that she wanted euthanasia. The committee found that the physician had acted in accordance with the due care criteria.

CASE 2016-62 ADVANCED DEMENTIA

See case 2016-62 on the website for the full text (in Dutch). FINDING: due care criteria complied with

KEY POINT: role of the advance directive in the case of a patient who is decisionally incompetent as a result of advanced dementia

In 2005 the patient was diagnosed with dementia (Alzheimer's disease). He was able to function reasonably well for a number of years, but from 2009 onwards his health deteriorated. In the last year before his death – by now he was in his sixties – his condition deteriorated substantially. The patient had discussed euthanasia with the physician since 2010. In that year he had for the first time written a letter by hand setting out a number of wishes for the future. In 2010 he signed an advance directive, which he supplemented in 2012 after several conversations with the physician, adding a number of more specific circumstances in which he would no longer want to go on living.

Those circumstances were described as follows: if he as a person were to change so much that he felt permanently unhappy, if he were to become aggressive and difficult, if he no longer recognised his loved ones, if he were to end up waiting for death, as had a close family member who also had Alzheimer's disease, if he were unable to take care of himself and became completely dependent on others, if he were suffering unbearably and without prospect of improvement. When he was still able to, the man spoke with both the physician and his family on several occasions about his request for euthanasia at some point in the future, and he updated his advance directive. At a certain point the patient was no longer able to express his request in words, but there were oral and physical expressions that confirmed his wish to die. His wife asked the physician to comply with the written euthanasia request. At that time, his suffering consisted of cognitive problems, apathy, apraxia (difficulty in carrying out actions), agnosia (inability to recognise/name things or persons) and behavioural changes. The patient had become completely dependent on his wife for his personal care. When he woke up in the mornings he was completely disoriented and very sad. He could not remember how to get out of bed. When he was helped with his general daily activities, his facial expressions were of sadness and frustration. He repeatedly indicated he could not and did not want to go on. He was now in a situation in which people expected things of him all day long that he no longer understood. He would then panic, or become startled or angry. He slept a lot. He no longer recognised his children and was no longer aware that he had grandchildren.

At the physician's request an independent elderly-care specialist examined the patient to assess whether he was suffering unbearably. The elderly-care specialist was satisfied that this was indeed the case. According to the specialist, the man was now in the situation that he had previously described 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. According to the physician, the situation corresponded entirely with the circumstances the patient had described in his advance directive as not wanting to experience.

With regard to the request the committee found that it was clear from the documentation that at the time when euthanasia was performed the patient was no longer decisionally competent. It also found that the physician could be satisfied that the patient was capable of making a reasonable appraisal of his own interests when he drew up his advance directive. In consultation with the physician, the patient regularly updated the advance directive after it had been drawn up and signed. On several occasions he subsequently discussed his wish to die at some point in the future orally with family and physicians. When he was no longer decisionally competent, there were verbal and non-verbal signs that he still wanted his life to be terminated. There were no signs to the contrary. In the committee's view, the physician had plausibly argued that he was reasonably able to conclude that the patient's request as worded in the advance directive was voluntary and well-considered.

The committee was further of the opinion that, despite the fact the patient was no longer able to describe it himself, the suffering as

described in the documentation was evident and fully matched the content of the advance directive. Several factors played a role in the physician's process of establishing that the man was suffering unbearably: his own observation of the patient, the process of preparing for euthanasia at some point, which took several years and was guided by him with great care, the conversations with the family, the independent physician's report and the independent elderly-care specialist's report. The committee found that the physician had exercised particular caution, as is recommended for patients in an advanced stage of dementia. This was clear from, for instance, the fact that in addition to an independent physician he had also consulted an elderly-care specialist. who assessed and described the suffering in a way that enabled the independent physician to conclude that the due care criteria had been complied with. The committee found that the physician had plausibly argued that he was reasonably able to conclude that the patient's suffering was unbearable and without prospect of improvement. The other due care criteria were also fulfilled.

MULTIPLE GERIATRIC SYNDROMES

Practice.

See pages 13, 31 and The patient's unbearable suffering without prospect of improvement 32 of the Code of must be caused by a medical condition, in other words it must have a medical dimension. This requirement followed from a judgment by the Supreme Court in the Brongersma case in 2002. The medical condition may be physical or psychiatric in nature. Multiple geriatric syndromes (and related symptoms) may also cause a patient to suffer unbearably without prospect of improvement. Two such cases are described below.

CASE 2016-96

See case 2016-96 on the website for the full text (in Dutch).

Other findings published by the RTE concerning patients with multiple geriatric syndromes can be found at https://www. euthanasiecommissie. nl/uitspraken-enuitleg/s/stapelingvan-ouderdomsaandoeningen/ documenten (in Dutch).

FINDING: due care criteria complied with

KEY POINT: unbearable suffering cause by multiple geriatric syndromes

The patient, a woman in her eighties, had received a full hip replacement and two knee replacements, as a result of osteoarthritis (wear and tear of the joints). She also suffered from rheumatoid arthritis (an auto-immune disease which causes inflammation of the joints) and macular degeneration (which causes cells in the centre of the retina to die). In the last year before her death, the patient's condition deteriorated sharply. Her mobility continued to decline and she always felt cold. She suffered from pains in her knee, while her very limited eyesight and reduced mobility confined her to a chair, and she was able to do less and less. She became increasingly dependent on other people for her care and could no longer watch television, read or write. In the year before her death, she hardly left the house. Although she received help in the daytime from family and professional carers, she was often home alone. On those occasions she was anxious and afraid of falling. The patient did not want to move into a nursing home, as she had previously had bad experiences there following surgery. She felt her life to be futile and she knew that her health would only deteriorate further. She experienced her suffering as unbearable. The physician was satisfied that this suffering was unbearable to her and with no prospect of improvement according to prevailing medical opinion.

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

CASE 2016-44

See case 2016-44 on the website for the full text (in Dutch). FINDING: due care criteria complied with

KEY POINT: unbearable suffering caused by impaired vision

The patient, a man in his eighties, had suffered for 10 years from macular degeneration (which causes cells in the centre of the retina to die) in both eyes, which caused his eyesight to deteriorate. Around the same time, an obstructed blood vessel in the retina caused blindness in his right eye. Six months before his death, his left eye deteriorated so much, despite the start of treatment, that he was no longer able to read, even using aids. In addition to these eyesight problems, he was uncertain when walking, which was aggravated by his near-blindness. In recent years he had become unwell and fallen several times.

Because he had become almost totally blind, the patient could no longer read (which was extremely important to him) or pursue his other hobbies. He was suffering from the loss of these activities, which were essential to him. He also suffered from the loss of self-reliance caused by his impaired vision, and the fact that he knew that there was no prospect of improvement whatsoever. The patient, who had always had a wide range of interests and a great intellectual appetite, experienced his suffering as unbearable.

The committee found that the physician had plausibly argued that he was reasonably able to conclude that the patient's suffering was unbearable to him and without prospect of improvement, and that it was unlikely that optical aids and possibly surgery would enable him to read again. The other due care criteria were also fulfilled.

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

cases in which the physician did not act in accordance with the due care criteria. and which have not been included in this annual report. see cases 2016-23, 2016-24, 2016-37, 2016-53.2016-86 and 2016-87 (in Dutch) on the website.

For the other Cases in which the RTE find that the physician has not acted in accordance with the due care criteria always lead to lengthier findings than other cases. This is because a conclusion cannot be reached in such cases without giving the physician the opportunity to give an oral explanation. The finding 'due care criteria not complied with' often concerns the criterion of consulting an independent physician and the criterion of due medical care. In addition, in the year under review, the RTE found in one case that the physician could not conclude unequivocally that the request was voluntary and well-considered and that he did not comply with the due care criterion of due medical care. Lastly, in one case the RTE found that the physician had been unable to plausibly argue that could be satisfied that the patient's suffering was without prospect of improvement and that there was no reasonable alternative.

NON-COMPLIANCE WITH CRITERION OF DUE MEDICAL CARE

For more information on due medical care, see pages 20 ff of the Code of Practice.

There were six cases in 2016 in which the RTE found that the physician did not comply with the criterion of due medical care in performing euthanasia. Two aspects of this are the substances and doses administered, and appropriate checks to determine the depth of the induced coma. In assessing this due care criterion, the committees refer to the KNMG/ KNMP 'Guidelines for the Practice of Euthanasia and Physician-Assisted Suicide' of 2012 (referred to below as the Guidelines). A distinction is drawn between termination of life on request (when the physician administers the substances) and assisted suicide (when the patient himself takes the substances given to him by the physician). Termination of life on request must be carried out by first injecting a substance intravenously that puts the patient in a coma (e.g. thiopental) and then once the coma is deep enough, administering a muscle relaxant (e.g. rocuronium). In the cases referred to here, the physician deviated from the dosage prescribed in the Guidelines for the coma-inducing substance and/or did not check sufficiently whether the coma was deep enough. Not administering the prescribed dosage of the coma-inducing substance is seen as problematic because the patient may experience negative effects caused by the muscle relaxant. If the physician deviates from the Guidelines, he will have to present convincing arguments in support of his actions.

CASE 2016-57

See case 2016-57 on the website for the full text (in Dutch). FINDING: due care criteria not complied with

KEY POINTS: deviation from the dosages prescribed in the Guidelines, no adequate coma check

In this case, the physician carried out the termination of life on request by intravenously administering 1500mg of the coma-inducing substance thiopental (instead of 2000mg) and 100mg of the muscle relaxant (instead of 150mg).

The committee asked the physician why he deviated from the Guidelines and how he established the depth of the patient's coma before proceeding to administer the muscle relaxant. The physician was asked to explain his actions first in writing and later orally.

In his oral explanation the physician said that it was generally his experience that after thiopental has been administered patients quickly fall into a deep sleep. After half the dosage has been administered patients are usually already far gone. Normally, the physician always administered the maximum dosage of thiopental, immediately followed by the rocuronium. It was not his practice to do a specific coma check. As regards the depth of the coma, he always relied more on his instinct (no breathing, patient completely relaxed) and the knowledge that the prescribed dosage of thiopental constitutes a substantial overdose. Nor had he ever encountered any problems after administering the rocuronium in the sense of a perceptible response from the patient. The same was the case in this specific situation, in which he did not administer the maximum dosage of thiopental.

Inserting the cannula was troublesome, as the patient's veins were difficult to access. A nurse with experience in anaesthesia inserted the cannula and advised the physician not to administer the euthanatic in one dose of 20ml, but to divide it over four doses of 5ml each. In order to handle the small vein with care, the physician followed this advice. When performing the euthanasia procedure, the physician first administered pain medication (lidocaine). He established that the cannula was inserted correctly. When he injected the first dose of thiopental, the patient responded, saying 'ouch'. The physician administered the thiopental slowly because he was afraid the vein would burst. While he was injecting the first dose of thiopental, the patient fell asleep.

When it came to the third dose of thiopental, the physician encountered greater resistance. He thought the patient's circulation was slowing

down and remembered the advice of a colleague not to wait too long before administering the muscle relaxant because the muscle relaxant would not be absorbed by the body if there were no circulation. For that reason he decided to administer the muscle relaxant quickly. Thereupon the physician administered the first and second dose of rocuronium. He did not succeed in administering the third dose. The physician therefore decided to check whether the patient had died. He could hear no heart tones and he established that there was no pupil reflex.

The committee found that the dosage of the coma-inducing substance administered by the physician was too low and that the physician did not do an adequate coma check before administering the rocuronium. As a result it cannot be established that the coma was so deep that the patient would not have been able to perceive any stimuli whatsoever, nor was the physician able to convince the committee that this was the case. Checking the depth of the coma properly was particularly important in this case, because the physician administered less than the prescribed dosage of thiopental. According to the committee, it could not be completely ruled out that the patient was in an insufficiently deep coma and that for that reason she might have perceived the effects of the muscle relaxant. The committee could therefore only conclude that the physician did not exercise due medical care when terminating the patient's life.

For other cases in which due medical care was not exercised, see cases 2016-23, 2016-24, 2016-37 and 2016-87 (in Dutch) on the website. For case 2016-85 see pages 54 ff.

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

For points to consulting an independent physician, see pages

Section 2 (1) (e) of the Act states that the physician must have consulted at consider regarding 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. Independent in this context means that the physician must 16 ff of the Code of be in a position to independently form his own opinion. It concerns *Practice.* independence in relation to the physician as well as the patient.

CASE 2016-45

See case 2016-45 on the website for the full text (in Dutch). FINDING: due care criteria not complied with

KEY POINT: no consultation with an independent physician, relationship of authority and therefore of dependence between the two physicians

In this case a specialist consulted a colleague who worked in the same hospital department. The committee asked the notifying physician to further explain in a meeting the way in which the consultation with an independent physician had been dealt with. In an earlier written response the physician had already explained that he had asked a colleague from his department, who was a member of the hospital's palliative team, who he could approach for an independent consultation. The notifying physician had never performed euthanasia in this hospital before. None of the people suggested by the colleague were available. Given the urgent wish of the patient in question that there be no delay in the procedure on account of logistical issues, the colleague had offered to act as independent physician. The committee remarked at the meeting that SCEN physicians can also respond very quickly, so there would not necessarily have been a delay.

The physician and his colleague had considered the issue of whether their both working in the same department would prevent the colleague from acting as the independent physician. They assumed, however, that the colleague would only be unable to be the independent physician if he had been treating the patient, which was not the case.

As regards the relationship between the physician and the colleague who was consulted as the independent physician, the physician explained that although he was head of the department and therefore formally in a hierarchical relationship with his colleague, the department was a very 'flat' organisation. Everyone managed and was responsible for their own patient group. For that reason the physician was of the opinion that this colleague would be able to give an independent assessment.

The committee considered that the independent physician must be able to give an independent and autonomous assessment. The purpose of the independent consultation is to ensure that the physician's decision is reached as carefully as possible. Any suggestion that he is not independent must be avoided. There can in principle be no question of independence in relation to the physician if the independent physician is from the same medical practice or partnership, if there is a relationship of dependence with the physician, or if there is a family relationship between them. The committee is of the opinion that in this case there was a relationship of authority, and therefore a relationship of dependence, between the physician and the independent physician. This was not changed by the fact that the department was a 'flat' organisation in which everyone was responsible for their own patient group, according to the committee.

The committee found that, although the physician consulted one other physician, who saw the patient and gave a written opinion on compliance with the statutory due care criteria, the due care criterion of consulting an independent physician was not complied with.

For other cases in which the independent consultation did not meet the requirements, see cases 2016-53 and 2016-86 (in Dutch) on the website.

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

points regarding unbearable suffering without prospect of improvement see pages 13 ff of the Code of Practice.

For more information on the absence of a reasonable alternative, see page 15 of the Code of Practice.

See case 2016-21 on the website for the full text (in Dutch).

For general There is no prospect of improvement if the disease or disorder that is causing the patient's suffering is incurable and the symptoms cannot be alleviated to the extent that the suffering is no longer unbearable. Furthermore, there is no prospect of improvement if there are no realistic curative or palliative treatment options that may – from the patient's point of view – be considered reasonable. It is thus clear that the assessment of the prospect of improvement is closely linked to determining whether

> there is a reasonable alternative. The question of whether there is a reasonable alternative must be assessed in light of the current diagnosis.

CASE 2016-21

FINDING: due care criteria not complied with

KEY POINTS: no sufficiently informed assessment of whether the patient's suffering was without prospect of improvement, physician disregarded the neurologist's advice and the psychiatrist's assessment without further enquiry

The patient, a man in his fifties, was diagnosed with Parkinson's disease four years before his death. He was treated with medication and because he was having difficulty coping with the disease, he received psychotherapy and other treatments at various stages of his illness. He twice underwent deep brain stimulation (electrodes implanted in the brain send electrical impulses to suppress specific symptoms); the second procedure took place around five months before his death. None of this achieved the desired result. After the last treatment, the patient's symptoms worsened. This caused tension and feelings of anxiety and helplessness. The patient experienced his suffering as without prospect of improvement and asked his physician for euthanasia.

At the physician's request, the patient was seen by a psychiatrist who found him to be decisionally competent. In the psychiatrist's opinion, there was a psychological aspect, in addition to the Parkinson's disease, that had not yet been treated sufficiently. The psychiatrist recommended a trial course of medication for depression. The patient stopped taking the medication after a few days, as he felt it aggravated his symptoms. He did not want any more psychotherapy to alleviate the symptoms of Parkinson's disease, which could no longer be treated and were increasing.

The attending neurologist found that the patient had a mild form of Parkinson's disease, in which the tremor (shaking movements in the limbs) was largely determined by emotional factors. He was also of the opinion that the man's fear of the future was the dominant factor. The neurologist thought that adequate treatment of this fear and the underlying mood disorder was the appropriate course of action. The neurologist was unable to support the patient's request for euthanasia on the grounds of the severity of his Parkinson's disease. He also considered that, as he was unable to support the request from a neurological point of view and the patient wished no further psychiatric treatment, it was impossible to properly assess whether the man's suffering was without prospect of improvement.

The notifying physician was satisfied that this suffering was unbearable to the patient and with no prospect of improvement according to prevailing medical opinion; he performed euthanasia.

The committee had questions about the absence of a reasonable alternative. The physician was therefore first asked to give a written explanation, later followed by an oral one. The physician was of the opinion that, given the patient's medical history, personality and life history, they had nothing more to offer him. When asked by the committee whether he was satisfied that if it had been possible to treat the stress suffered by the patient, the symptoms of Parkinson's disease would have become milder and therefore the tremors would also lessen, the physician replied that he was not satisfied that that was the case.

The committee referred to the psychiatrist's assessment (that the psychological component had been treated insufficiently) and the neurologist's assessment (that it was a mild form of Parkinson's disease in which treatable psychological factors played a role) and pointed out that the process had taken very little time (the physician had talked with the man twice in eight days). The committee noted that if the process is short it attaches great importance to intensive communication, not just between the physician and the patient, but also between the physician and other persons involved. In such a case the physician must do everything that is reasonably possible to obtain all the information that may be relevant. The committee was of the opinion that the physician should not have disregarded the neurologist's advice and the psychiatrist's opinion without further enquiry. He should have consulted with them or with another specialist who was an expert in the field. Particularly in view of the speed at which the process was conducted and the fact that the physician had only spoken twice with the patient, the physician should have used such consultation to assess his own views against those of the specialists. The committee therefore found that the physician had not plausibly argued that he was reasonably able to conclude that the patient was suffering unbearably without prospect of improvement or that there were no reasonable alternatives that could alleviate his suffering.

NON-COMPLIANCE WITH CRITERIA OF VOLUNTARY, WELL-CONSIDERED REQUEST AND DUE MEDICAL CARE

regarding the voluntary and wellconsidered reauest. see pages 11 ff of the Code of Practice.

information on due medical care, see pages 20 ff of the *Code of Practice.*

For general points It is still possible to grant a request for euthanasia at the stage where dementia has progressed to such an extent that the patient is no longer decisionally competent and is no longer able to communicate (or is able to communicate only by simple utterances or gestures), provided the patient drew up an advance directive when he was still decisionally competent. The directive must be clear, and evidently applicable to the current

For more situation (see case 2016-62).

The physician and the independent physician must consider the entire disease process and any other specific circumstances when assessing the request.

They must interpret the patient's behaviour and utterances, both during the disease process and shortly before euthanasia is performed. At that moment the physician must be satisfied that carrying out euthanasia is in line with the patient's advance directive, and that there are no contraindications (such as clear signs that the patient no longer wishes his life to be terminated). It must also be palpable to the physician that the patient is suffering unbearably at that point.

As noted above, the assessment of the content of the advance directive will have a crucial bearing on this matter.

CASE 2016-85

See case 2016-85 on the website for the full text (in Dutch). FINDING: due care criteria not complied with

KEY POINTS: decisionally incompetent patient without a clear advance directive: failure to exercise due medical care

The patient, a woman in her seventies, began to suffer from forgetfulness nine years before her death. Five years later she was diagnosed with dementia (Alzheimer's disease). A year before her death, the disease began to progress more quickly. She became very anxious, sad and restless. From the afternoon onwards she was sombre, emotional and tearful, and indicated that she wanted to die. When her husband was no longer able to care for her, she was admitted to a nursing home where she had previously gone five times a week for daytime activities.

Shortly before she received the dementia diagnosis, the patient had set out her wishes concerning euthanasia in an advance directive and discussed them with her general practitioner and her geriatrician. According to the physicians she was still decisionally competent at the

time. She renewed this advance directive a year before her death. She also discussed this second directive with her general practitioner, who considered her to still be decisionally competent at that time. In both advance directives she indicated that she did not want to be placed in an institution for elderly people with dementia (dementia clause). She stated that she wanted to say goodbye to her loved ones at a sufficiently early stage, in a dignified manner, and that she did not want to experience the process that her mother had gone through in an institution. In the first advance directive she indicated that she wanted euthanasia when she was 'still to some degree decisionally competent but no longer able to live at home with my husband'. In the second advance directive she wrote that she wanted to make use of the option of euthanasia 'when I myself think the time is ripe'. The closing sentence read: 'Trusting that, by the time the quality of my life has become so poor that [...] euthanasia will be performed at my request.'

Towards the end of the year before her death, the patient's condition deteriorated further and at home she often said she wanted to die. Shortly after, she would often say, 'But not now.' In that period the patient and her husband discussed euthanasia with the general practitioner. During that conversation she indicated that she thought euthanasia was going too far. After the general practitioner explained about possible admission to a nursing home if her condition deteriorated she replied, 'All right, maybe then.'

During the intake interview for the nursing home (seven weeks before her death) the husband asked the physician to perform euthanasia on the basis of the advance directive. The physician subsequently observed the patient frequently and for long periods, and spoke with her. According to the physician, she no longer understood the words 'euthanasia' and 'dementia'. She regularly said to carers in the nursing home that she wanted to die. Reading between the lines, the physician concluded, on the basis of her observations and the conversations, that the patient was expressing a wish to die. But even in this period the patient's response on several occasions when dying was discussed was, 'Not now though, it's not that bad yet.'

The physician who performed euthanasia (an elderly-care physician) twice consulted an independent SCEN physician. The first independent physician, a psychiatrist, established that the patient was decisionally incompetent and that she was suffering unbearably without prospect of improvement. According to the first independent physician the suffering consisted of having completely lost control of her life and being in a situation that she did not understand and did not want. Her life appeared to be a succession of incidents involving aggression, despair, restlessness and exhaustion. As far as this independent physician was concerned, the advance directive took the place of an oral request for euthanasia. The second independent physician also concluded that the due care criteria had been complied with.

The physician performed euthanasia by first administering 15mg of Dormicum dissolved in coffee (as premedication) and then after 45 minutes another 10mg of Dormicum by subcutaneous injection. Around 40 minutes later the physician administered 2000mg of thiopental intravenously, followed several minutes later by 150mg of rocuronium. In her report the physician noted that the patient awoke when the thiopental was being injected and put up physical resistance.

The committee asked the physician for an oral explanation. The committee noted that the patient had been admitted to a nursing home even though she had always rejected that notion. It also noted that she was no longer able to request euthanasia herself, whereas she had always assumed – according to the texts of the various advance directives – that she would be able to ask for it herself. The committee also had questions about the actual euthanasia procedure. (Initially there were also questions about her suffering, but the physician plausibly argued before the committee that she was reasonably able to conclude that the patient was suffering unbearably without prospect of improvement.)

As regards the request, the physician stated that she first met the patient when she was admitted to the nursing home. The patient was decisionally incompetent at the time. The physician thought that she was entitled to euthanasia due to her suffering and the fact that it was clear from her advance directive that she had never wanted to end up in a nursing home. The physician checked with the attending geriatrician and the general practitioner as to whether the patient was decisionally competent when she drew up the advance directives. Both said this was the case.

The physician did not take the patient's response when the thiopental was administered as a sign that she might no longer want euthanasia. As the patient was decisionally incompetent, what she was expressing at that moment was not relevant to the physician. Nor did the physician think it would be appropriate to halt the euthanasia process at that moment.

The committee also put questions to the patient's former general practitioner. These questions concerned the conversations held about euthanasia and the point at which the patient became decisionally incompetent. The general practitioner had several conversations with the patient when she was still decisionally competent. It was clear that she did not want to go into a nursing home, but also that she felt euthanasia was not yet necessary. Later she became less clear about her wishes concerning euthanasia. When it became clear, several months before her death, that admission into a nursing home would become necessary, the general practitioner invited her and her husband to the surgery. At that time, euthanasia was not on her mind, nor did she understand what it meant any more. After the general practitioner explained the meaning of euthanasia, she said she did not want that. When reminded of her wish not to go into a nursing home, she said that then she might want euthanasia after all. When the general practitioner explained to her how it worked, she thought that was 'going too far'. In other words, she was no longer able to indicate what her wishes were concerning euthanasia. The general practitioner was unable say exactly when the patient had become decisionally incompetent in relation to her request for euthanasia. It had happened some time in the year before her death.

In the interview with the committee the elderly-care specialist explained that she had administered the Dormicum dissolved in coffee because the patient was not taking any medication and she would probably have refused had she been asked to take the Dormicum herself. When it became clear that the Dormicum was having insufficient effect, the extra dose was administered. The patient did not like the needle prick. After some time had passed and it was clear the patient was unaware of what was going on around her (moving of furniture etc.) a cannula was inserted. This was difficult and took a long time, but she seemed to be unaware of it. However, when the physician tried to administer the thiopental, the patient sat up. This is what the physician had previously referred to as physical resistance. The family then held her and the physician quickly administered the rest of the euthanatic.

The committee found that the dementia clause written in the year prior to the patient's death, which accompanied the advance directive, could be read in more than one way. It can be inferred from the wording ('when I myself think the time is ripe' and 'at my request'), viewed in the context of the wording of the first dementia clause ('when I am still to some degree decisionally competent'), that when the patient drew up these provisions she assumed that she would be able to request euthanasia herself when the time came and that she would indeed do so. It therefore does not follow necessarily from the text of the advance directive in conjunction with the dementia clause, as revised in the year prior to her death, that it was drawn up to take the place of an oral request in the event that she would be unable to determine or express her wishes as a result of dementia. The committee did realise that a different, wider interpretation was possible which assumed that the directive was indeed drafted to take the place of an oral request. It found, however, that the last dementia clause offered an insufficiently clear basis for such a wider interpretation. Assuming that it did leads to two mutually exclusive interpretations of the clause. In that case, doubt persists as to whether the patient wanted the advance directive to take the place of an oral request. Given this doubt, and taking into account the fact that this was literally a matter of life and death since termination of life is irreversible, in the committee's opinion those involved should have erred on the side of caution and applied the more restrictive interpretation of the dementia clause. It follows that section 2 (2) did not apply.

In the absence of an oral request from the patient asking the physician to actually perform euthanasia and the absence of a clear advance directive to replace such a request, the committee found that the physician could not have concluded unequivocally that she had made a voluntary and well-considered request for euthanasia.

As regards the actual euthanasia procedure, the committee found that the physician's actions overstepped a boundary. By – covertly – administering Dormicum, she wanted to deprive the patient of the possibility to resist the insertion of the cannula or the administering of the euthanatics. The committee found that, when the patient did respond negatively, the physician wrongly failed to consider whether this could be interpreted as an important sign that she did not want a cannula and a needle to be inserted. Although the committee acknowledged that it was extremely difficult for the physician to correctly interpret what the patient was expressing at that time, it found that the physician should at least have taken the time to do so. The committee considered that, although the patient was decisionally incompetent in relation to euthanasia, this did not necessarily rule out that she was able to determine her wishes with regard to actions such as inserting a cannula or a needle, even if she were no longer able to understand the purpose of those actions.

In the committee's opinion the physician should have halted the euthanasia procedure in order to reconsider the current situation instead of proceeding. The committee also considered that, when performing euthanasia, coercion – and anything that might suggest coercion – must be avoided. It therefore concluded that any claim that euthanasia was performed with due medical care is untenable.

PUBLICATION INFORMATION

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

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

April 2017

