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KNMG Guideline End-of-Life Decisions

Approved by the KNMG Federation
Board on 18 November 2021

18 november 2021



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Introduction

The KNMG Guideline on End-of-Life Decisions (2021) replaces the *KNMG-standpunt Euthanasie* (KNMG Guideline on Euthanasia) (2003), the *KNMG-standpunt De rol van de arts bij het zelfgekozen levenseinde* (KNMG position paper on the Role of the Physician in the Voluntary Termination of Life) (2011) and the *KNMG-standpunt: een nadere uitleg van het standpunt Euthanasie* (KNMG Guideline: A Further Explanation of the Guideline on Euthanasia) (2012). The present guideline combines the Royal Dutch Medical Association's (KNMG) existing guidelines and insights. As a result, all the available information is presented in a more clear and structured manner, making it more accessible to physicians.

In addition, it incorporates certain new insights and recent developments, particularly on euthanasia in special situations or circumstances, such as euthanasia in the case of dementia.

Context

In this Guideline on End-of-Life Decisions, euthanasia and assisted suicide are placed within the context of other end-of-life decisions and care activities. In addition, the role, responsibilities, possible actions and limits of the physician are discussed. There are frequent references to other professional standards that are relevant for the physician. This guideline gives physicians an overview, and through this, the KNMG wants to assist physicians in the assessment they need to make when providing end-of-life care.

Euthanasie in Dementia

The considerations involved with regard to euthanasia and dementia are discussed as part of this guideline. This section has been formulated in the context of the KNMG project '*Euthanasie bij dementie*' (Euthanasia in Dementia). The project was initiated to clarify the KNMG's standpoint on this issue. In addition, the project aimed to provide physicians with tools for dealing in a responsible manner with requests for euthanasia from patients in the various stages of dementia. You will find this section in **Chapter 3**. The project is explained in detail in **Appendix 1**.

He or she

For the sake of readability, we have chosen to use the gender-neutral 'they', 'them' or 'their' throughout this guideline. This may be read as 'he/she' or 'his/him/her' as well.

1 End-of-life decisions

As a patient nears the end of their life, a physician may have to deal with various medical interventions and decisions, for example, in relation to pain management, symptom management, palliative sedation or the withholding or withdrawal of treatment. These are considered normal medical procedures.¹ Physicians may also have to handle situation where patients refuse treatment, have prepared an advance directive or wish to themselves hasten the end of life. Euthanasia and assisted suicide are regarded as exceptional medical procedures.²

This chapter discusses these decisions and medical interventions. The professional principles guiding physicians and how they deal with end-of-life decisions have been described. The chapter also addresses the physician's general responsibilities with respect to end-of-life care, such as supervising the entire process and discussing the patient's wishes in a timely manner.

The aforementioned end-of-life interventions and decisions may occur simultaneously or sequentially. But although these may follow from one another, each has its own characteristics and indications.

1.1 Role of the physician in end-of-life care

As a patient approaches the end of life, the physician has several professional responsibilities. Firstly, it is important to have a timely conversation with the patient about their values, wishes and needs. In addition, it is part of the physician's professional responsibility to supervise the end-of-life care process. In doing this, they must guard against any overtreatment or undertreatment.

Timely discussion with the patient about the end of life

It is part of the physician's professional responsibility to have a timely discussion with the patient about the end of life. This is not always easy for either patients or physicians. Nevertheless, it is important to discuss the patient's needs and wishes together. This can help prevent misunderstandings about what constitutes appropriate care in the final stages of life.

During this talk, the physician can discuss the patient's values, wishes and needs as well as what is possible or not possible and the physician's own limits. For this, the physician can refer to the KNMG guide [Tijdig praten over het levenseinde](#) (Timely Discussion about the End of Life). This guide contains specific discussion points the physician can use to explore the patient's questions and expectations. Together with patient organisations, the KNMG has also developed a [public version of this guide](#).

Proactive and guiding role of the physician

It is also the physician's professional responsibility to proactively review, with the patient, what constitutes appropriate care in the final stages of life, now and in the future. Although other caregivers and relatives of the patient may also play an important role, the attending physician is the one who oversees the entire process.

Physicians can use the Advance Care Planning (ACP) method for this. The ACP is a proactive and cyclical process through which the patient discusses, and possibly records, their wishes, goals and preferences for end-of-life care with the physician.³ During this process, the physician and the patient together consider the care and treatment goals that best align with the patient's

¹ The term 'normal medical procedure' relates to activities and interventions based on the professional standard for physicians. This concerns the indicated procedures, with a concrete treatment objective.

² The term 'exceptional medical procedure' indicates that termination of life is not part of normal medical procedures. Termination of life is subject to standards prescribed based on not only medical but also social considerations.

³ This guideline uses the term 'Advance Care Planning'. This is in line with [the international definition of Advance Care Planning](#). Advance Care Planning is also referred to as prospective or proactive care planning, as seen in the [Quality Framework for Palliative Care](#).

values, beliefs and health status. In consultation with the patient, the physician can also involve the patient's relatives or other care providers in these discussions. Subsequently, the physician determines the type of care and treatment appropriate in the short term and indicates the direction to be followed for appropriate care and treatment in future scenarios. This makes the ACP not just a one-time intervention, but a cyclical process. In this context, see the **Advance Care Planning Toolkit** for end-of-life care of the National Advisory Group on Primary Geriatrics Care (*Landelijke Adviesgroep Eerstelijns geneeskunde voor Ouderen*) and the report **Passende zorg voor kwetsbare ouderen door advance care planning** (Appropriate Care for Vulnerable Elderly Persons through Advance Care Planning) from the Association of Elderly Care Physicians (*Vereniging van Specialisten in ouderengeneeskunde, Verenso*)

Appropriate care in the final stages of life

Often, patients do not receive appropriate care in the final stages of their lives.⁴ For example, the care they receive is not aligned with the patient's values, wishes and needs. Or too little attention is paid to the patient's quality of life, which can result in palliative undertreatment. It can also involve overtreatment, whereby patients in the final stages of life are treated longer than necessary and desirable. This is something that relates not just to patients with oncological diseases but also, for example, to vulnerable elderly persons or chronically ill patients.

There are many reasons for overtreatment. For example, for many people, it is not yet customary to talk about the end of life, and 'Don't give up' is the basic attitude of some people. In addition, it is often easier for both physicians and patients to justify 'doing' rather than 'not doing' something. Also, physicians sometimes find it difficult to tell patients that there are no further curative treatment options available. Moreover, impending death may be difficult for the physician to talk about, and patients may have difficulty accepting this fact.

The risk of overtreatment can be reduced by having timely discussions at regular intervals (e.g. by applying the ACP process). Physicians are expected to focus on a patient's overall situation and not just on what is medically possible. What is important here is that the patient is properly and fully informed and that the physician is honest about the expected results and any negative consequences of a treatment. In addition, the information provided by the physician must match the patient's cognitive capacity and health literacy levels.

To avoid overtreatment in the final stages of life, such as an unwanted hospitalisation, it is especially important that the physician makes a note in the patient's medical records of the agreements made in this regard. This is part of the physician's record-keeping obligations and is important in the context of ensuring the continuity of care.

Moreover, this information should also be accessible to other care providers, such as locum physicians, physicians at the out-of-hours GP service, home care staff or nursing home staff.

The KNMG report 'Just Because We Can, Doesn't Mean We Should', describes the consequences of overtreatment more extensively. It also provides tips and suggests measures to break through the mechanisms underlying overtreatment.

1.2 Palliative care

Palliative care is intended for patients who are faced with a life-threatening condition or vulnerability.⁵ This type of care is focused on preventing and relieving the suffering of patients and improving the quality of life of both the patients and their relatives. To this end, it is essential to identify problems at an early stage and carefully assess and treat these problems. This may include physical and psychological problems as well as problems of a social and spiritual nature. Throughout the course of the disease or vulnerability, palliative care will be offered as far as

⁴ For more information, see the KNMG dossier *Niet alles wat kan hoeft* (Just Because We Can, Doesn't Mean We Should) or the article *Nog te vaak chemo bij maag- en slokdarmkankerpatiënten in laatste levensfase* (Chemo Still Used Too Often for Gastrointestinal Cancer Patients in the Final Stages of Life)

⁵ See the *Quality Framework for Palliative Care*.

possible while trying to retain the patient's autonomy, access to information and ability to make choices.

Palliative care may be provided by various care providers in close collaboration with the patient, their relatives and any volunteers. A multidisciplinary collaboration is the starting point in palliative care. The attending physician is expected to coordinate with other care providers on who is responsible for what and ensure that it is clear who the contact person is for the patient and their relatives.

If the attending physician has questions or doubts about palliative policies, they should consult a colleague who has expertise in this area. They may also consult, via telephone, a consultant from the palliative care consultation team within their own region. For more information, see the [Quality Framework for Palliative Care \(PDF\)](#). More information about the consultation teams is available on [Palliaweb](#). Guidelines for diagnosis and treatment in the context of palliative care are available on the [Pallialine](#) website.

Possible side effects of pain and symptom management

Palliative care aims to adequately manage the patient's suffering, which may include pain, tightness of the chest, nausea, anxiety, agitation and delirium. This is part of the normal medical procedures performed by the physician.⁶

In some cases, the patient's end of life may be unintentionally hastened as a result of pain and symptom management. There are circumstances under which this unintended effect or side effect is defensible and is, therefore, accepted because the patient's situation necessitates this treatment. What is important here is that the nature and extent of the doses used can be justified from the perspective of necessary pain and symptom management. The normative element here is the professional opinion regarding the choice of drug and the necessity of the applied dosage in view of the individual patient's situation.

The purpose of the procedure may shift from pain and symptom management to the termination of life. Pursuant to the (*Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*, WtI; hereinafter referred to as 'the Act'), termination of life may only be carried out after a voluntary and carefully considered request by the patient and if the patient's suffering is considered unbearable, with no prospect of improvement. All the other due care criteria of this Act must also be met. **See Section 2.7.**

Palliative sedation

Palliative sedation is the deliberate lowering of a patient's level of consciousness in the final stages of life.⁷ The purpose of palliative sedation is to relieve the patient's suffering. Lowering the level of consciousness is a means to that end. Palliative sedation may be administered intermittently or continuously, where continuous palliative sedation is used only when life expectancy is less than two weeks.

The indication for palliative sedation arises if there are one or more untreatable symptoms (refractory symptoms) that lead to unbearable suffering for the patient. The [Guideline on Palliative Sedation](#) describes the indications, preconditions, decision-making process and administration of palliative sedation.

When administered carefully and in accordance with the Guideline, palliative sedation does not shorten life. The patient dies of the underlying disease. This is how palliative sedation differs from euthanasia, whose purpose is to end the patient's life at the patient's request.

⁶ The term 'normal medical procedure' relates to activities and interventions based on the professional standard for physicians. This concerns the indicated procedures, with a concrete treatment objective.

⁷ See the [KNMG-richtlijn Palliatieve sedatie](#) (KNMG Guideline on Palliative Sedation) (PDF)

1.3 Refusal of treatment

An important principle in medical care is that the patient's consent is always required for medical treatment or research.⁸ If the patient does not give their consent, then in principle no treatment may be provided. The prerequisites for this are that the patient is decisionally competent in this regard, has been adequately informed and understands and accepts the possible consequences of providing or withholding treatment. Even if a treatment is life saving or can be life prolonging, the patient has the right to decline that treatment.

To be able to give their consent for a treatment, the patient needs information that is appropriate to their cognitive capacity and health literacy levels. Therefore, before seeking consent, a physician must provide the patient with information about the proposed research or treatment, among other things.⁹ The physician's duty to inform and the requirement to obtain the patient's consent are referred to as 'informed consent'. In addition, a process of shared decision-making is important. This means that the physician and the patient jointly decide on what is best for the patient in a given situation. No treatment may be provided if the physician has not fulfilled the duty to inform, except in exceptional and emergency situations.

A patient may not be able to give consent on their own, for example, due to decisional incompetence in this regard. In that case, the physician must first try to obtain substitute consent from the patient's representative. Sometimes, in an emergency situation, the physician will nevertheless have to provide treatment without obtaining consent if doing so prevents serious harm to the patient.¹⁰

1.4 Withholding or withdrawing medically futile treatment

There are situations where starting or continuing treatment is futile from a medical perspective. In such cases, the physician should withhold or withdraw treatment. Indeed, it is the physician's duty to refrain from medically futile interventions.

The following situations involve a medically futile intervention:

- The expected effect of the treatment is insufficient (effectiveness).
- There is no longer a reasonable relationship between the intended objective and the means to be used for it (proportionality).
- It is no longer possible to achieve a targeted minimum level of functioning.

There is often a grey area in this respect, where discussions may arise with the patient or their relatives as to whether a medically futile intervention is involved. The assessment regarding a medically futile intervention is ultimately a matter of medical and professional judgement, and it is the physician's duty to refrain from medically futile interventions. A patient and/or their relatives cannot demand that the physician perform interventions that are medically futile. Of course, the physician will always consult, inform and assist the patient (or their representative).

The physician must carefully arrive at the decision that a treatment is medically futile and therefore should not be initiated or continued. This implies that a treatment that needs to be carried out by a team must be discussed within the treatment team. Moreover, one or more colleagues who are not involved in the treatment should preferably – and in case of doubt always – be consulted. The KNMG has developed an **Ethics Toolkit** that can be helpful in making careful assessments.

Withholding or withdrawing a treatment assessed as being medically futile is part of normal medical procedures. If a patient subsequently dies as a result of the underlying condition, it is considered a natural death.

⁸ Medical Treatment Contracts Act (*Wet op de geneeskundige behandelingsovereenkomst, WGBO*), part of Book 7 of the Dutch Civil Code.

⁹ The patient must also be informed of the option of forgoing the treatment, other tests and treatments offered by other care providers, the treatment period and its expected duration.

¹⁰ Section 466(1) of Book 7 of the Dutch Civil Code.

1.5 Advance directives

An advance directive is a written statement prepared by a decisionally competent person in anticipation of becoming decisionally incompetent in this regard in future. If the patient is still decisionally competent, the advance directive can serve as an important document for the discussion between the physician and the patient, but the patient's current wishes are always the decisive factor.

There are different types of advance directives, such as the negative advance directive, the positive advance directive and the written power of attorney.

Negative advance directive

In a negative advance directive, a patient describes the form of care or treatment they no longer wish to receive in a given situation. This may include, for example, resuscitation attempts or other life-prolonging treatment. The law provides that a written refusal of a particular treatment, intervention or care must be respected. This is in line with the general rule that a treatment should not be provided without consent.

If there are 'valid reasons' for doing so, a physician may deviate from a negative advance directive.¹¹ For example, in case of ambiguity about the authenticity, signature or contents of the advance directive. Certain medical developments may also make the advance directive obsolete. Apart from that, even if the patient has drawn up a negative advance directive, the physician is still obliged to relieve any suffering the patient may be undergoing as adequately as possible, in consultation with the patient's representative.

Positive advance directive

In a positive advance directive, a patient requests a physician to perform certain interventions or to initiate or continue a treatment. For example, a patient may write that, if a particular situation arises, they would like to have surgery or be treated with antibiotics. The physician is not obliged to comply with a positive advance directive and may even ignore this if it deviates from the professional standard. Nor is the physician required to comply with the advance directive if the intervention called for by the advance directive is medically futile. In other words, the positive advance directive is a non-binding request to the physician.

An advance directive for euthanasia is a special form of positive advance directive regulated by Section 2(2) of the Act. Simply having an advance directive for euthanasia does not guarantee that euthanasia will be performed. Such a directive also does not entitle the patient to euthanasia. For more information on the advance directive for euthanasia, see **Section 2.7.1**.

Representation in cases of decisional incompetence

If a patient is unable or no longer able to give their consent to treatment or other care ('is decisionally incompetent in this regard'), they will need to be represented by another person. If an advance directive had been drawn up when the patient was still considered decisionally competent, that statement will be the guiding principle for both the representative and the physician in terms of the care to be provided.

The Medical Treatment Contracts Act¹² uses the following order of precedence to determine who qualifies as a representative of an adult patient who is decisionally incompetent:

1. a guardian or mentor (court-appointed);
2. an attorney appointed by written power of attorney by the patient;
3. a spouse, registered partner or other life partner;
4. a parent, child, brother, sister, grandparent or grandchild of the patient.

If several people within the same group qualify, they must choose one person from among them. If they cannot agree among themselves, it is ultimately the physician who will appoint the representative or submit a request to the court for the appointment of a mentor.

¹¹ Section 450(3) of Book 7 of the Dutch Civil Code.

¹² Section 465(3) of Book 7 of the Dutch Civil Code.

The representative should conduct themselves as a 'good representative'.¹³ If the personal preferences of the representative are in conflict with the obvious interests of the patient, the physician must disregard the representative's decision if, by following that decision, they would not be acting as a good care provider. The care provider should act in accordance with the professional standard. In doing so, sometimes it may also be part of the professional responsibility of the care provider to deviate from the representative's decision.

Since euthanasia is a patient's personal decision, a request for euthanasia may not be made on their behalf by another person, such as the patient's representative.

Validity of the advance directive

An advance directive is valid only if the patient was decisionally competent at the time the advance directive was drafted and if the advance directive includes a name, date and signature.¹⁴ Furthermore, the patient must be 16 years of age or older.¹⁵ To ensure that the physician has no doubt about the patient's intentions, it is helpful if the patient describes, as far as possible in their own words, their wishes and the specific situations to which these wishes apply. It is part of the physician's professional responsibility to discuss any ambiguities in the advance directive directly with the patient and to remain in conversation with the patient about their advance directive(s). In actual practice, it can happen that the patient's wishes change, especially in the final stages of life. Depending on whether the request or wishes have changed, it is important to renew or update the advance directive.

The physician stores the advance directive in the patient's medical records by scanning it and saving it securely in the records. After that, the physician may destroy the original advance directive or return it to the patient.

1.6 Patient's wish to hasten the end of life

The vast majority of people die naturally.¹⁶ However, a patient may also decide to hasten their own end of life, for example, by consciously choosing not to eat and drink or by taking certain drugs or combinations thereof. The patient may also request the physician for euthanasia or assisted suicide.

Consciously choosing not to eat and drink

When a decisionally competent patient consciously chooses not to eat and drink to hasten the end of life, it is important to provide them with proper medical and nursing care. The initiative to consciously choose not to eat and drink may come from the patient themselves, but the physician may also point out this option to the patient and provide information about it.

When faced with a patient who says they want to stop eating and drinking, there may be doubts in the physician's mind about the patient's decisional competence. However, if the patient has arrived at this decision after careful consideration, is mentally capable of assessing the pros and cons of treatments and understands the consequences, the physician must respect this patient's decision.

The physician always has a duty of due care with respect to the patient, even if they do not agree with the patient's decision to consciously choose not to eat and drink. During this process, the physician's role is to provide adequate guidance and care, with the goal of alleviating the patient's suffering and supporting their relatives. This kind of care provided by the physician is considered normal medical care. More information on this topic, including practical tools for

¹³ Section 465(3) of Book 7 of the Dutch Civil Code.

¹⁴ Section 450(3) of Book 7 of the Dutch Civil Code.

¹⁵ In principle, it makes no difference whether a person has drafted an advance directive on paper or, for example, wears the advance directive in the form of a pendant on a chain around the neck. A do-not-resuscitate pendant is also a negative advance directive.

¹⁶ See infographic.

care providers, can be found in the **Zorg voor mensen die bewust afzien van eten en drinken** (Care for people who consciously choose not to eat and drink so as to hasten the end of life) guide published by the KNMG and the Association of Nurses (*Beroepsvereniging Verzorgenden Verpleegkundigen, V&VN*).

Method involving the use of drugs

In some cases, patients may deliberately end their life or intend to do so by taking a certain drug or a combination of different drugs that they have collected. The physician has a professional obligation to initiate a conversation with a patient who indicates an intention to do this. After all, the desire to die may actually mask a request for help.

In principle, it is not a punishable offence for physicians and other persons if they provide information about suicide methods. The primary emphasis should be on what a patient should not do. However, it is punishable to incite someone to suicide or to assist the patient in their suicide. Such assistance may include, for example, giving instructions or orders in this regard or performing any actions that may lead to suicide or to supervise this process. The physician is advised not to be present during a patient's suicide.¹⁷

Euthanasia and assisted suicide

Euthanasia and assisted suicide are an extreme remedy in situations in which there are no reasonable treatment options to relieve the patient's suffering. It is essential that, when talking about end-of-life care, the physician and the patient consider the entire range of end-of-life care options. **Chapter 2** further discusses euthanasia and assisted suicide and the conditions applicable to them.

1.7 Deliberate termination of life of newborns

A special group of minors is made up of newborns between 0 and 12 months of age who have very severe abnormalities and cannot make a request for a termination of life themselves. When dealing with a newborn infant as described above, a physician may be faced with complex and drastic choices, including those relating to the end of life. These choices do not fall within the framework of the Act. However, the **Regeling beoordelingscommissie late zwangerschapsafbreking en levensbeëindiging bij pasgeborenen** (Regulations of the Assessment Committee for Late-Term Abortions and Terminations of Life (Neonates), LZA/LP) and the associated **Instructions** are applicable to this group. If a physician decides, after consulting and obtaining the consent of the parents, to terminate the life of the newborn so as to avoid an unnecessary prolongation of the dying process and suffering, the physician must notify the Assessment Committee for Late-Term Abortions and Termination of Life (Neonates) of this termination of life. In contrast to what is stated in the Act, every such termination-of-life notification is submitted to the Public Prosecution Service.

In this context, the **KNMG-standpunt Medische beslissingen rond het levenseinde bij pasgeborenen met zeer ernstige afwijkingen** (KNMG Guideline on Medical End-of-Life Decisions for Newborns with Very Severe Abnormalities) is relevant. This document provides physicians with guidance for situations in which further treatment of a newborn has become medically futile and/or termination of life is being considered.

The Ministry of Health, Welfare and Sport is currently examining whether the current LZA/LP Regulations can be extended to children aged between 1 and 12 years.

¹⁷ This section deals with the situation in which a patient deliberately decides to commit suicide using collected medication and not via physician-assisted suicide. A physician may assist with the suicide only if they comply with the due care criteria under the Act. See Chapter 2 for more information on euthanasia and physician-assisted suicide.

2 Euthanasia and assisted suicide

Euthanasia means intentionally ending the life of another person at their explicit request. Assisted suicide means intentionally prescribing and/or providing the means with which the patient can end their own life. Only physicians are authorised to perform the euthanasia or assisted suicide procedure.

A request for euthanasia or assisted suicide is relatively rare¹⁸ but is one of the most distressful and onerous requests a patient can make to a physician. Most physicians find it difficult to carry out euthanasia or assisted suicide procedures. Therefore, it is important to have proper guidance, so that the right considerations can be taken into account at those times.

This chapter outlines the professional standards and legal framework for physicians who receive a request for euthanasia or assisted suicide from a patient. We discuss the moral background for a request for termination of life, the support provided by and consultation with other physicians and the due care criteria of the Act. We conclude the chapter with some special situations, such as requests for euthanasia from patients with a mental disorder, intellectual disabilities or an accumulation of age-related diseases. Euthanasia in case of dementia is dealt with in a separate chapter.

Step-by-step Plan for Euthanasia*

Stage	Activities performed by physicians
Patient makes a specific request for euthanasia to the physician.**	<p>Discussion with the patient with the purpose of:</p> <ul style="list-style-type: none"> • exploring the request for help and the request for euthanasia, e.g. why is the patient requesting euthanasia at this time? • discuss the legal due care criteria. What exactly does unbearable suffering constitute? Are there any reasonable alternatives? Has the patient been properly informed about their situation and prospects? • discussing further procedures. Indicate that both parties need some time for reflection: <ul style="list-style-type: none"> - For the patient: to reconsider things for themselves or discuss things with relatives. Refer to information on euthanasia at thuisarts.nl, if necessary. - For the physician: to consider whether they can support the request and may need further information.
Physician considers the request	<ul style="list-style-type: none"> • Obtain additional information, for example, about the patient's medical condition(s), alternatives or the procedure for euthanasia (optional). • Assess whether the due care criteria can be met. The Report Template for the Attending Physician can be used as a guide for this. • Sometimes, it may be necessary to pay several visits to the patient to arrive at a proper decision. • In case of doubt, for example, about the decisional competence of the patient, or if in need of support, consult a colleague or an external expert. A SCEN physician may be asked to provide support (this is the S of SCEN).

¹⁸ See infographic.

Physician decides whether to accede to the euthanasia request

- If acceding to the request: communicate this and discuss the time frame with the patient and their relatives.
- Inform the patient that they are free to withdraw the request at any time.
- Explain that consultation with a SCEN physician is mandatory and what the SCEN physician's task is.
- If necessary, hand out the **SCEN patient brochure**.
- Discuss the wishes of the patient and those of the physician about the possible timing of the euthanasia procedure. Indicate that this depends on when the SCEN physician can be consulted and what their advice is. A very concrete and fixed appointment creates expectations in the patient's mind and places undue pressure on the SCEN physician. Also, keep in mind that the SCEN physician usually cannot have the report ready on the same day.
- Discuss with the patient the method to be used for performing the procedure. Choose between an IV (euthanasia) or oral administration (assisted suicide).***

Physician initiates the procedure with a SCEN physician

- Consult a **SCEN physician by phone**. For this, you need to call a general telephone number first, after which you will be called back by the SCEN physician.
- Discuss the request with the SCEN physician and provide the relevant information from the medical records.
- Inform the pharmacist in advance of a possible upcoming euthanasia request, provide the relevant information and communicate the possible method to be used.

SCEN physician gives opinion on whether due care criteria have been met

- Communicate the SCEN physician's opinion to the patient.
- If the opinion is positive: make further arrangements about the time (agree on a precise time) and who among the relatives will be present.
- Inform the patient that the physician will once again ask the patient on the day of euthanasia whether they stand by their request but that there will be no further detailed conversation at that time.

Physician prepares the euthanasia procedure, possibly with the help of other professionals

- If necessary, request a colleague to assist with euthanasia. An assistant may insert the IV cannula and prepare the drugs but is not allowed to administer the drugs. This task is reserved for the performing physician.
- The IV cannula for euthanasia should preferably be inserted earlier and not just before the actual performance of the procedure. You can do this yourself the day before the euthanasia procedure or arrange for someone else to do it: for example, a colleague or an ambulance staff member. Ensure that this is done no earlier than 24 hours in advance.
- In case of assisted suicide: administer an antiemetic to the patient the day before the performance of the procedure.
- Inform the municipal forensic pathologist of the time of euthanasia so that they can take this into account. If the euthanasia procedure is scheduled to take place outside office hours, it is a good idea to communicate this in time and during office hours.

- Inform fellow physicians about not being available for a specific period of time.

Physician prepares for the euthanasia procedure with the pharmacist

- Discuss the desired method, day and time with the pharmacist.
- Discuss any premedication (in case of assisted suicide: the antiemetic) with the pharmacist.
- Agree with the pharmacist about who will prepare the euthanasia drugs and at what time the pharmacist will hand these over to the physician.
- Agree with the pharmacist on a time to return any leftovers, equipment and emergency kit.

Day of performing euthanasia: preparation

- Complete the general section of the performing physician's report template in advance and take this, along with the SCEN physician's report and the municipal forensic pathologist's report template, to the patient so that they can be handed over to the pathologist immediately after the euthanasia procedure.
- If the IV cannula has not been inserted before, do this a few hours in advance or have someone else do this.
- When the euthanasia drugs are handed over by the pharmacist: check that the set is complete, the dosages are correct, all the syringes are filled and there is a spare set present.***
- Make sure to be with the patient on time and that you are not disturbed (mobile phone switched off).

Day of performing euthanasia: performance of the procedure

- Arrive at the appointed time with the euthanasia drugs.
- Ask the patient if they stand by their request for euthanasia.
- Briefly explain what you are going to do. Explain that the patient may experience some reactions such as light or heavy coughing, a strange taste in their mouth or a strange odour. The administration of propofol or thiopental may produce a pain sensation. The drug used for assisted suicide may have a foul taste.
- Allow those present to say their goodbyes and withdraw for a moment, if necessary.
- Administer the drugs in accordance with the most recent **guidelines of the KNMG and the Royal Dutch Society for the Advancement of Pharmacy (KNMP)**.
- Once the patient has passed away, confirm the death and offer condolences to those present.
- Contact the municipal forensic pathologist to report the death.

Day of performing euthanasia: after the death

- Complete both report templates in full: the **Report Template for the Attending Physician** and the **Report Template for the Municipal Pathologist**.
- Wait for the arrival of the municipal forensic pathologist.
- The pathologist inspects the body.
- The pathologist completes their own forms and checks the physician's forms.

- The pathologist sends all the forms to the relevant Regional Euthanasia Review Committee (*Regionale Toetsingscommissies Euthanasie*, RTEs).
- Return any leftovers and spare euthanasia drugs to the pharmacy and briefly discuss the course of events with the pharmacist. Any particular details relating to the performance of the procedure may be reported using a **form provided by the KNMP**.

RTE

- You will be notified by the RTE within one to two weeks that the forms have been received.

RTE

- You will be notified by the RTE within two to six weeks whether all the due care criteria have been met.****

*This step-by-step plan is based on the most common requests for the performance of euthanasia for a decisionally competent patient by the GP at the patient's home. In other situations, such as for euthanasia in hospitals or other institutions, the process may be different.

In case of complex requests, such as those from patients with a mental disorder or patients with dementia, the physician should exercise extra caution.

The Dutch Association for Psychiatry (*Nederlandse Vereniging voor Psychiatrie*, NVvP) has developed a separate **guideline** for patients with a mental disorder. There is also a separate **guideline** on euthanasia for people with a reduced level of consciousness.

Often, the end of life and euthanasia have been discussed with the patient in a general sense at an earlier stage and the physician has already provided information at that time and made it known that they are, in principle, willing to cooperate. However, this is not a requirement. Physicians can refer to the **Timely Discussion about the End of Life guide. There is also a **patients' version** of this guide.

***The KNMG/KNMP **Richtlijn Uitvoering Euthanasie en hulp bij zelfdoding** (Guideline on the Performance Euthanasia and Assisted Suicide Procedures) provides guidance on the performance of euthanasia and assisted suicide procedures.

****The entire review procedure (including any follow-up steps undertaken by the Health and Youth Care Inspectorate (*Inspectie Gezondheidszorg en Jeugd*, IGJ) and the Public Prosecution Service) is explained on the **website of the RTEs**.

This step-by-step plan is a publication of the KNMG and the Dutch College of General Practitioners (*Nederlands Huisartsen Genootschap*, NHG). This plan is also part of the **End of Life and Euthanasia continuing education course**, developed jointly by the NHG and the KNMG.

For comments: kenniscentrum@nhg.org. Version: April 2021.

2.1 Basic principles in a nutshell

Euthanasia and assisted suicide are an extreme remedy in situations where both the patient and the physician feel they have their backs against the wall because the patient's suffering is unbearable, with no prospect of improvement.¹⁹ A request for euthanasia or assisted suicide can only be granted if the request comes from the patient themselves and there are no further reasonable treatment options to relieve the patient's suffering. Hereinafter, for the sake of readability, whenever 'euthanasia' is referred to, this may also be understood to mean 'assisted suicide'.

Euthanasia is an exceptional medical procedure. The physician is not obliged to perform euthanasia, and neither is the patient entitled to euthanasia. This is because euthanasia crosses a fundamental, irreversible boundary. After all, a human life is being ended. The legal regulations for euthanasia and assisted suicide are laid down in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (*Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*, Wtl; hereinafter referred to as 'the Act').

Euthanasia is a punishable offence in the Netherlands unless:

- it is performed by a physician;
- all the due care criteria in the Act have been met; and
- the physician notifies the municipal forensic pathologist of the euthanasia, who forwards the notification to the RTEs.²⁰

Punishability may be precluded if the RTEs find that the physician has acted in accordance with the legal due care criteria under the Act²¹ (see also **Section 2.8**).

2.2 Moral background

When faced with a situation of unbearable suffering combined with a request for euthanasia from the patient, a physician faces a conflict of duties. On the one hand, there is the duty to protect the patient's life. On the other hand, there is the obligation to try as far as possible to alleviate, prevent or put an end to the further suffering of the patient – suffering that is deemed unbearable and with no prospect of improvement – even if this means terminating the patient's life at their request. When faced with a conflict of duties, the physician may decide that their duty to honour a patient's request to end their suffering outweighs the duty to preserve that patient's life. In that case, the physician acts out of compassion or mercy. The Dutch Penal Code (Articles 293(2) and 294(2)) contains a statutory defence that may be invoked solely by physicians who act in accordance with the Act and report the euthanasia.

Respect for autonomy plays an important role in justifying euthanasia. However, respect for autonomy does not mean that people also have the right to euthanasia or that respect for autonomy alone is sufficient for euthanasia to be performed. After all, in order to perform euthanasia, there must be a question of unbearable suffering with no prospect of improvement, which leads to the aforementioned conflict of duties. An autonomous desire to die and a request

¹⁹ In the case of euthanasia, the physician administers the lethal drugs to the patient. In the case of assisted suicide, the physician supplies the lethal drugs that the patient takes in the physician's presence. In principle, there is no further distinction between euthanasia and assisted suicide. In both cases, physicians are expected to observe the same legal due care criteria. However, in terms of the severity of the penalty, the Dutch Penal Code makes a distinction between euthanasia (up to 12 years or a fine of the fifth category) and assisted suicide (up to 3 years or a fine of the fourth category). Psychologically, the physician may perceive the performance of euthanasia as a more drastic intervention than assisted suicide. After all, in the case of euthanasia, the physician must administer the lethal drugs themselves, while in assisted suicide, the patient takes the drugs independently.

²⁰ If a patient dies as a result of euthanasia, this is regarded as death by unnatural causes. See the *Handreiking (niet-)natuurlijke dood (Guide to Natural and Unnatural Deaths)*.

²¹ The performance of euthanasia or assisted suicide procedures by a physician is subject to appeal based on a special statutory defence. The punishability of performing euthanasia or assisted suicide procedures may be precluded solely for physicians.

to do so do not confer a right to assistance in dying. However, such a request is an essential requirement: no euthanasia may take place without a request from the patient themselves.

In the Act, respect for patient autonomy is expressed in the criteria that the patient's request must be voluntary, must be carefully considered and must originate from the patient themselves. These criteria ensure that the patient has actually chosen for euthanasia on their own, without outside pressure.

Euthanasia, as mentioned above, is neither a patient's right nor a physician's duty. However, the physician must always take a request for euthanasia seriously. Euthanasia should be a topic that is open to discussion. This also means that the physician must inform the patient in a timely and clear manner if they cannot comply with a request for euthanasia. A physician should be open to the patient's views and communicate openly about their own views as well. (See **Section 2.4**).

2.3 Support, decision-making and consultation

The Act requires the physician to always consult an independent physician before acceding to a request for euthanasia. In addition, it may be advisable to consult others for support and help in making decisions.

Support, decision-making and consultation

What	Details	Optional or mandatory	By whom
Support	<ul style="list-style-type: none"> • legal; • ethical; • communication aspects; • social-emotional aspects; 	<ul style="list-style-type: none"> • optional; 	<ul style="list-style-type: none"> • fellow physicians; • SCEN physician (support); • Euthanasia Expertise Centre (<i>Expertisecentrum Euthanasie</i>).
Decision-making	<ul style="list-style-type: none"> • sub-aspects of the due care criteria; • actual problem areas; 	<ul style="list-style-type: none"> • optional; 	<ul style="list-style-type: none"> • expert; • SCEN physician; • multidisciplinary consultation (<i>multidisciplinair overleg</i>, MDO); • moral deliberation;
	<ul style="list-style-type: none"> • due care criteria; • decisional competence; 	<ul style="list-style-type: none"> • professional standard for mental disorders; • legal criterion in cases of advanced dementia; 	<ul style="list-style-type: none"> • independent physician with specific expertise (also referred to as the 'second physician' or 'second opinion').
Consultation	<ul style="list-style-type: none"> • due care criteria; 	<ul style="list-style-type: none"> • legal criterion; 	<ul style="list-style-type: none"> • SCEN physician.

Support

To obtain support, a first logical step is to contact colleagues (from a group of fellow physicians). A SCEN physician may also be consulted. 'SCEN' stands for **Support and Consultation in Euthanasia in the Netherlands**. A SCEN physician is an independent and expert physician trained for this purpose by the KNMG. During the consultation stage, the SCEN physician assesses whether the first four due care criteria of the Act have been met.

A physician may also request a SCEN physician for support earlier on in the process. For example, if they have questions about the legal, ethical and communication aspects of euthanasia or

about the medical and technical aspects of performing the procedure. This is usually a one-off meeting. In addition, a physician may contact a SCEN physician if they want to talk about the burden, emotional or otherwise, placed on them by the request for euthanasia.

Only physicians may contact a **SCEN physician**. If a SCEN physician provides support and therefore considers themselves no longer independent, another SCEN physician must perform the consultation required by the Act (see **Section 2.7.5**). This is to ensure that the opinion of the physician performing the consultation is impartial and independent.

The **Euthanasia Expertise Centre** also offers advice and guidance to physicians. For this, it uses the services of consultants who answer questions, provide information or guide physicians during the euthanasia process. The Euthanasia Expertise Centre also offers an **information hotline for care providers**.

Decision-making

Since a request for euthanasia can be complex, it is advisable to consult experts. This allows the performing physician to arrive at a balanced decision. Such a consultation may include identifying various sub-aspects of the due care criteria or taking a closer look at the actual problem areas. To this end, the physician may specifically contact an independent expert or SCEN physician.

For ethical and legal practice dilemmas, physicians may contact the **Physician Information Hotline**. A moral deliberation process can be set up for discussing the ethical aspects.²² Organising a multidisciplinary consultation may also be helpful for shedding further light on the euthanasia request from different perspectives. A multidisciplinary consultation may involve practitioners who have treated the patient earlier as well as staff responsible for the patient's daily care.

If, while considering a euthanasia request, a physician involves other parties in their decision, the principle of doctor-patient confidentiality requires that they inform the patient (or, if the patient is decisionally incompetent with respect to the euthanasia request, the patient's representative) about this and agree with them about how this will be done. If possible, the physician should avoid sharing any (or as little as possible) information that can be traced back to the individual.

If the request for euthanasia comes from a patient with a mental disorder or with advanced dementia, various professional standards dictate that specific expertise is called for, and the necessary experts must therefore be involved. For a euthanasia request from a patient with a mental disorder, see **Section 2.10.3**, and for such a request from a patient with advanced dementia, see **Section 3.4.5**.

Sometimes, it is necessary for the expert to visit the patient. In that case, it is important that the purpose of this visit be properly communicated in advance: it must be absolutely clear to the patient, the performing physician and the expert that the visit is for the purpose of forming an opinion in a particular area and that it is not a formal consultation within the meaning of the Act. This will avoid creating any false expectations.

In all cases, the performing physician remains solely responsible for their choices and the justification thereof.

Consultation

If a physician is, in principle, willing to perform euthanasia on a patient, they must, pursuant to the Act, consult at least one other independent physician. This independent physician must see the patient and provide a written opinion on compliance with at least the first four legal due care criteria. The purpose of this consultation is to verify whether the due care criteria have been met and to reflect on the euthanasia request before the physician takes the final decision to proceed

²² For more information on the moral deliberation, see [this article](#).

with euthanasia. The professional norm dictates that the independent physician consulted be a SCEN physician. See **Section 2.7.5**.

2.4 Objections of the physician

The professional norm states that physicians must inform their patients, clearly and in time, about their personal views on euthanasia. Therefore, the physician should determine for themselves at an early stage whether they are, in principle, prepared to perform euthanasia in a given situation. They should not inform the patient about this only at a stage when there is little time or opportunity left to discuss alternative solutions. If a physician is not prepared to comply with a patient's euthanasia request, they should not initiate the formal consultation or any other procedure. This avoids creating possibly unwarranted expectations for the patient.

A physician may have certain objections on principle to euthanasia based on philosophical or ethical views. A physician may also have situational objections, for example, because of an excessive workload, temporarily or otherwise, or due to their personal circumstances. If a physician objects to euthanasia, colleagues and patients should respect that. After all, physicians are not obliged to cooperate in euthanasia.

Objections on principle of the physician

If a physician objects to euthanasia on principle, they must explain to the patient why they cannot accede to the request. Also, the physician should give the patient the opportunity to approach a colleague who does not have such objections. The physician has no legal duty to refer, but they do have a moral and professional responsibility to help the patient find the aforementioned colleague in a timely manner. It is preferable for the physician to transfer the patient to a colleague within a local or regional group practice who, in principle, is willing to consider euthanasia. The physician may also refer the patient to the Euthanasia Expertise Centre. This Centre provides care to patients who cannot see their own practitioner and assists physicians in complex euthanasia cases. See also Section 2.5.

Situational objections

It is also possible that a physician cannot or can no longer proceed with euthanasia because of situational objections, even though they do not object on principle to euthanasia and even though the due care criteria have been met. This may, for example, be due to temporary emotional difficulties or a prolonged absence. In such cases, the physician must explain to the patient why they cannot or can no longer comply with the request. In addition, they must transfer the patient in a timely manner to a colleague who may be willing to perform the euthanasia procedure. Even if euthanasia is not or no longer an option, the physician naturally has a duty of care to consider, together with the patient and their relatives, what the most appropriate care options would be in the final stages of life.

Refusal of treatment and difference of opinion

It is up to the patient to decide for themselves in a given situation whether to undergo a proposed treatment. The basic premise is that a patient is not obliged to seek treatment or admission to an institution. A difficult situation may arise if the physician assesses that, by their refusal, the patient is putting themselves in a situation involving unbearable suffering, with no prospect of improvement. Although the patient is always entitled to refuse treatment, withholding a reasonable treatment option (i.e., treatment that would relieve or eliminate suffering) may result in euthanasia not being possible, or at least not for the time being. Indeed, under the Act, euthanasia may only take place when there are no longer any reasonable alternatives to relieve suffering.

Moreover, there may be a difference of opinion between the physician and the patient about the assessment of, for example, the unbearable nature of and/or the lack of prospects of improvement for the patient's suffering. In such a situation, the physician should at least try to understand why the patient perceives their suffering as unbearable and feels that there is no prospect of improvement. In this case, there may be reason for conducting another thorough

problem analysis. If a substantial difference of opinion persists between the physician and the patient, the latter is free to seek another physician.

2.5 Substitution and handover

It may be that an attending physician is unavailable, temporarily or otherwise, and that a locum physician takes over their tasks. If this locum physician receives a euthanasia request, they are, in principle, also permitted to perform the euthanasia procedure, provided they are satisfied that the due care criteria have been met. In general, however, restraint is desirable when changing physicians shortly before performing euthanasia. In such a situation, an important question that can be asked is: what are the circumstances that make it impossible to wait until the return of one's own attending physician?

If the locum physician eventually ends up handling the request for euthanasia, it is important that they take the time to make their own carefully considered decision and determine whether the legal due care criteria have been met. To do so, they must form their own idea of the patient's situation and take the time to get to know the patient sufficiently. They must guard against a situation where, due to an actual or perceived time pressure, it is no longer possible to properly form their own professional opinion. If a consultation has been carried out by the SCEN physician, as requested by the attending physician, the locum physician should contact the SCEN physician. The SCEN physician must be independent of the locum physician.

The locum physician should not rely solely on the observations of the previous attending physician. There is also no question of a shared responsibility. If the locum physician decides to proceed with euthanasia, they themselves are responsible for their decision and must also account for this by notifying the RTEs.

In this situation as well, a careful handover of the patient's medical records is essential, as is good communication between the physicians. The previous attending physician has a duty to cooperate to the maximum possible extent in this regard. Of course, the handover and exchange of information should take place in coordination with the patient, after this has been clearly communicated to them.

2.6 Role of other parties involved

There are often other people involved in the request for euthanasia, such as the patient's relatives or staff at the institution where the patient is staying. In that case, the following guidelines apply for the physician.

Relatives

In most cases, the patient's relatives will be closely involved in the request for euthanasia. But the patient and their relatives, or even the relatives themselves, are not always in agreement on this matter. For euthanasia, the patient's request is of paramount importance. The physician may take the opinions of relatives into consideration, but these opinions can never replace the required voluntary and carefully considered request from the patient. This applies even if the relative is the patient's representative. This is because euthanasia is a personal decision of the patient.

The patient may also not want to discuss the euthanasia request with relatives. In view of doctor-patient confidentiality, a physician may, in principle, only consult the relatives if the patient has given permission for this. For more information in this regard, see **Section 2.7.1**.

Institutions

There may be an institutional policy with regard to euthanasia. The institution and the attending physician are expected to clarify the existing policy to the patient early on in the process. For a physician working at a health care institution, this institutional policy can provide guidance and support. Sometimes, the institutional policy precludes euthanasia. However, this does not take away the fact that the physician has a professional responsibility towards the patient. Therefore,

this need not deter physicians from nevertheless, providing the necessary assistance in individual cases. The physician will always have to ascertain whether euthanasia can be performed in a responsible manner at the institution under such circumstances. If this is not feasible, they should explore the possibility of performing the euthanasia procedure at the patient's home or elsewhere.

2.7 Due care criteria in the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act

The due care criteria, as stated in the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act, (hereinafter: 'the Act') are that the physician must:

- A. be satisfied that the patient has made a voluntary and carefully considered request (see **Section 2.7.1**);
- B. be satisfied that the patient's suffering is unbearable, with no prospect of improvement (see **Section 2.7.2**);
- C. have informed the patient about their situation and their prospects; (see **Section 2.7.3**);
- D. have come to the conclusion, together with the patient, that there is no reasonable alternative in view of the patient's situation (see **Section 2.7.4**);
- 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 referred to under (a) to (d) have been fulfilled (see **Section 2.7.5**); and
- F. have exercised due medical care in performing the termination of life or assisted suicide procedure (see **Section 2.7.6**).

These due care criteria are elaborated further in the sections below. This has been done based on the Act as well as on how these criteria have been interpreted over time by the medical profession, in court rulings and other decisions, and in the review practice of the RTEs.

2.7.1 Voluntary and carefully considered request

A request for euthanasia must always be made by the patient themselves and be expressed voluntarily and after careful consideration. If the physician is not convinced of this, they will be unable to accede to the request. This request is usually made verbally, but if the patient is decisionally incompetent in this regard, an advance directive for euthanasia may replace the verbal request. For this, see **Subsection 3.4.1**.

A request for euthanasia is regarded as voluntary:

- provided that, when making the request, the patient was considered decisionally competent in connection with the euthanasia request ('internal voluntariness'); and
- provided that the patient has made the request without being unduly influenced by others ('external voluntariness').

A request is 'carefully considered' if a patient was capable of making a well-thought-out decision based on complete information and a clear understanding of their situation, in terms of health or otherwise. Below, we explain these elements in more detail.

Internal voluntariness

In the context of a request for euthanasia, we refer to internal voluntariness when the patient is considered decisionally competent. A decisionally competent patient:

- can communicate about the request for euthanasia in a comprehensible manner;
- can understand the relevant medical or other information and is aware of their situation, in terms of their health or otherwise;
- can assess the situation, the implications of euthanasia and any possible alternatives; and
- can clearly communicate why they desire euthanasia.

If the patient is decisionally competent, an advance directive for euthanasia is not required by law. A verbal request is sufficient in such a situation. However, it is important that the physician record the verbal request and the discussions regarding this in the patient's medical records. The added advantage of an advance directive for euthanasia is that it can assist the physician in their discussions with the patient and help clarify the situation. This is particularly true if the patient has difficulties in communicating verbally.

A patient's ability to communicate verbally is often diminished or hampered by illness. When this happens, the patient may still be able to communicate in other ways, for example, via hand gestures, blinking of the eyes or a speech computer. Behavioural expressions may also sometimes be seen as forms of communication. In such situations, the physician must make a reasonable case that what the patient is able to communicate in this manner can be regarded as a carefully considered and voluntary request.

A previously drawn-up advance directive for euthanasia can be used as a supporting document in such situations. The physician will need to consider this request in combination with what the patient is able to express at that point of time. If a patient is no longer able to record a request in writing, an alternative may be to make an audio and/or video recording and add this to the medical records. However, in that case, it must be clearly indicated when this recording was made and to whom the patient addressed the request.

It is important for the physician to be able to clearly explain the reason and basis for their conviction that this involves a voluntary and carefully considered request. They can do this, for example, by making a note in the medical records of their discussions with the patient, the patient's relatives, the healthcare professionals involved and/or any other physicians who have previously treated the patient.

The extent of decisional competence may change over time. Also, since decisional competence is task dependent, a patient may simultaneously be considered competent to make a particular decision (e.g. requesting euthanasia) yet incompetent to make some other decision (e.g. choosing a mortgage).

If the physician has doubts regarding the patient's decisional competence in relation to the euthanasia request, it is important that they consult an expert in the field – other than the SCEN physician – to assess this. This may include experts such as a psychiatrist, geriatrics specialist, clinical geriatrician or physician registered with the **Association of Physicians for the Indication of Care Needs and Advice (Vereniging van Indicerende en adviseerende Artsen, VIA)**.

External voluntariness

External voluntariness means that the request for euthanasia is made by the patient of their own free will, without any influence and pressure exerted by others. The physician will need to ascertain this. To assess this, it is essential that the physician also speak with the patient alone.

The patient's relatives or representative may not request euthanasia on behalf of the patient. They may, however, draw the physician's attention to the fact that the patient has a desire for euthanasia, so that the physician can discuss this with the patient. Relatives may also inform the physician about any advance directive for euthanasia prepared by the patient, including in the event that the request for euthanasia had been prepared previously, in case the patient is no longer able to communicate or to do so properly.

While it is important to involve the patient's relatives in the euthanasia request, their consent is not necessary. It is, however, often complicated for the physician to perform euthanasia if all or some of the relatives object to this. Therefore, it is in the patient's best interest that the physician properly understands these objections and tries to address them as far as possible.

Occasionally, a patient's request for euthanasia is partly prompted by their feeling of becoming a burden to those close to them. The physician should be attentive to such feelings. If this occurs,

it is important that they examine this situation and discuss it with the patient, and also possibly with the patient's relatives. Such a feeling does not necessarily mean that the request for euthanasia is not voluntary. The feeling of being a burden may contribute to the unbearable suffering experienced by the patient, although it does not in itself provide sufficient grounds for assuming unbearable suffering.

Careful consideration

In addition to being voluntary, a request for euthanasia must also be a carefully considered decision. This is believed to be the case if the patient has made a careful assessment based on sufficient information that is understandable to them. They must also have a clear understanding of their own situation, with respect to their health and other relevant aspects. The physician must verify that the patient is not making the request based on an impulse or because they find themselves in an acute situation. If the patient reveals doubts, for example, by giving out mixed signals, this means there is reason for extra caution. This also applies if the patient is not consistent in their request.

In general, it is best if the patient and physician address the euthanasia request over multiple discussions. After all, the patient's situation in terms of their health or otherwise and their wishes may change over time. It is also important to align the wishes and expectations of the physician and the patient. However, a request for euthanasia does not necessarily have to be a long-term request, in the sense that the request can be granted only if it is a persistent request over an extended period of time. After all, it is possible that a patient's health or overall situation may deteriorate rapidly, as a result of which there is only a short or even very short period of time between the request and the performance of euthanasia. Therefore, no minimum period of time has been prescribed for the procedure. There is also no minimum number laid down for the discussions that the physician should have with the patient.

Advance directive for euthanasia

In an advance directive for euthanasia, a patient may indicate the circumstances under which they would want euthanasia. However, such a request does not guarantee that euthanasia will be performed. This is because a physician is never obliged to perform euthanasia. Moreover, an advance directive for euthanasia is not in itself sufficient for performing euthanasia, since all the due care criteria of the Euthanasia Act must first be met. An advance directive for euthanasia may, however, serve to replace a verbal request if the patient is no longer competent to make a decision in this regard at the time of the euthanasia.²³ Such a situation may arise gradually, as in the case of dementia, or it may occur suddenly, for example, if the patient has a stroke or an accident. An advance directive for euthanasia is a legal requirement only in situations in which the patient has become incompetent to take such a decision. In **Section 3.4.1**, you can read more about advance directives for euthanasia in the case of people who are considered decisionally incompetent in this regard.

An advance directive for euthanasia is only considered valid if the patient was decisionally competent and 16 years of age or older at the time of making the request.²⁴ In addition, this request must include the patient's name and date of birth, the date of drafting the request and the patient's signature. Furthermore, the request must include a description of the specific circumstances under which a patient desires euthanasia. This means that the patient should try to draft the euthanasia request in their own words as far as possible, clearly indicating what they consider to be hopeless and unbearable suffering.

Standard statements often do not provide the physician with sufficient guidance and certainty to determine whether the patient's situation at a specific point of time is such that the euthanasia request is applicable. This also includes the use of terms or phrases that are too general, such as 'I wish to be euthanised in a situation that is demeaning to me'. The physician should point this out to a patient who wishes to make an advance directive for euthanasia and assist them with

²³ See also the *Handreiking schriftelijk euthanasieverzoek (Guide to Advance Directives for Euthanasia)*.

²⁴ Section 2(2) of the Euthanasia Act.

proper information. It is ultimately the patient's responsibility to discuss the advance directive for euthanasia with the physician, both when formulating and when updating the request. The physician should remind the patient of this personal responsibility.

If the patient wishes, the physician may help the patient think about how best to articulate the advance directive for euthanasia. Others may also assist the patient with this. A relative of the patient may also write out the statement on the patient's behalf or help them with this, if the patient is no longer able to personally put this in writing. This may still be regarded as a voluntary and carefully considered request, provided the patient is decisionally competent in this matter.

Discussing the advance directive for euthanasia

When a physician receives an advance directive for euthanasia, rather than simply filing it away, it is important that they discuss this with the patient. The physician may consider the advance directive for euthanasia as an invitation to engage in a discussion with the patient about the patient's wishes and expectations. Such discussions between the physician and the patient add greater weight to the request for euthanasia and make it clearer. It is important that the physician makes a record of the discussions with the patient and adds this to the patient's medical records.

During these discussions, the physician should also address what is possible and what is not in connection with an advance directive for euthanasia. It is essential to prevent and remove any unreasonable expectations. The physician must also clearly indicate whether they are willing to perform euthanasia in the described situation. The patient should be aware that an advance directive for euthanasia is not a guarantee that euthanasia will be performed and that they cannot simply 'arrange' for it in such a way. In fact, at the time the situation described in the advance directive for euthanasia arises, euthanasia may not be possible from a legal and professional perspective, for example, because all the due care criteria in the Euthanasia Act have not been fulfilled.

But even if the euthanasia is not performed, an advance directive for euthanasia of a patient, who later becomes decisionally incompetent in this regard, may be important. It can provide guidance to the physician, the patient or the patient's representative in deciding whether to initiate care procedures or refrain from life-sustaining treatments.

Validity period and number of discussions

An advance directive for euthanasia has no legally defined period of validity, nor does it need to be updated periodically by law. However, in general, the older the advance directive for euthanasia, the more doubts there may be about whether the request still reflects the patient's actual wishes at the time. If the patient has regularly updated the advance directive for euthanasia, the physician will be able to rely more on the statement than if this were not the case. The same applies if the patient has verbally reconfirmed the content of the request after drafting it.

There is no defined standard for the number of discussions between the physician and patient regarding the advance directive for euthanasia. After all, this depends to a large extent on the patient's circumstances. It is important to properly document the discussions with the patient, as well as with any relatives and other caregivers, in the patient's medical records. In case the patient moves to a different residential or care setting or is being treated by a different physician, it should be ensured that the information is handed over properly, preferably in person, and that the entire history from the patient's medical records is also transferred. This is particularly important for patients who are expected to become less decisionally competent in future.

2.7.2 Unbearable suffering, with no prospect of improvement

The second due care criterion in the Euthanasia Act is that the physician is satisfied that the patient's suffering is unbearable and that there is no prospect of improvement. The physician will assess and weigh both the above aspects separately and together.

It should be possible to trace back the patient's suffering to a medical basis or to a condition that can be considered a disease or combination of diseases or symptoms. This medical basis may be somatic or psychological in nature. The patient need not be suffering from a life-threatening condition or have reached a terminal stage.

The suffering may have various dimensions, such as somatic, psychological, psychosocial and spiritual. It may result from an accumulation of symptoms and conditions, such as pain and anxiety, overwhelming exhaustion and fatigue, physical deterioration or a feeling of hopelessness or dependence. Suffering may result from pain, but it may also arise from a sense of disillusionment or loss of dignity. Moreover, it may stem from a fear of an ever-increasing disillusionment or the prospect of not being able to die with dignity.

Suffering with no prospect of improvement

A patient's suffering is considered to be without any prospect of improvement if:

- the diseases or conditions causing the suffering are not curable; and
- it is not possible to alleviate the symptoms to remove the suffering experienced by the patient as unbearable. This should take into account the degree of improvement that can be achieved by a medical intervention, the burden that such an intervention would place on the patient and the period of time over which improvement can be expected.

To assess whether the suffering is without any prospect of improvement, the physician's professional opinion about the remaining prospects for treatment and care plays an important role. The physician should base this opinion on their medical and professional insight that the situation in which the patient finds themselves can no longer be averted or improved.

Unbearable suffering

The extent of the patient's suffering is estimated based, on the one hand, on the medical assessment of their prognosis and, on the other hand, on the actual or perceived suffering as experienced by them. Suffering can be defined as the state of undergoing pain or distress. It involves a serious situation, which is also consciously felt and experienced as such by the patient. Only the patient can say whether the suffering is unbearable for them. It is up to the patient to clearly indicate what makes the suffering unbearable for them. This is influenced by personal experiences and interpretations as well as by cultural values and norms.

The physician must be satisfied that the suffering is unbearable in order to accede to a request for euthanasia. This involves a professional assessment of the lack of any prospect of improvement in terms of the unbearable nature of the patient's suffering. Words such as 'understand' or 'empathise' are often used in this context. In order to understand the feeling of unbearable suffering, it is helpful to see the patient's suffering in the light of the patient's life story, medical history, personality, norms and values, and physical and psychological capacity to cope. Since unbearable suffering is a personal experience, the physician must be careful not to judge the patient's suffering based on their own view of suffering. Therefore, it is not about whether the physician would ask for euthanasia in a similar situation, but whether the unbearable nature of the suffering is understandable to the physician from the patient's perspective.

The physician must examine all the aspects that together make the patient's suffering unbearable. For this, they are advised to draw on the expertise of other physicians, care providers and/or the patient's relatives.

Assessing the extent of suffering

The following questions may be helpful in assessing whether the patient's suffering is unbearable, with no prospect of improvement:

- Is it likely that the patient's condition will improve to a sufficient extent? Or is it only likely to deteriorate further?

- What can the physician offer as an alternative, and how reasonable is this alternative for the patient?
- How does the burden of the treatment weigh up against the patient's capacity to cope?
- How severe is the loss of function? What more can be done about this?
- Can the patient still lead a meaningful life?

2.7.3 Information for the patient

A necessary condition for a carefully considered decision about euthanasia is that the patient has been properly informed about their situation and prospects. This is also the third criterion of the Euthanasia Act. Specifically, this means that the physician must inform the patient, fully and in a manner comprehensible to the patient, about the diagnosis, prognosis and any further treatment options and alternatives that may still be available. The physician should help the patient understand what exactly is wrong with them, the chances of improvement and other ways in which the suffering can be relieved. The physician must also verify whether the patient has been adequately informed and that they have understood the information.

2.7.4 No reasonable alternative

The fourth due care criterion in the Euthanasia Act is that the physician and the patient must jointly come to the conclusion that there are no reasonable alternatives. This criterion is more or less implicit in the earlier criteria that there is no prospect of improvement in terms of the suffering. The added value of this fourth criterion is that the patient and physician should jointly consider the remaining options and whether these are still realistic.

The question is whether or not there is a real prospect for treatment based on accepted and objective medical standards. There is a real prospect for treatment if:

- there is a possibility of improvement with adequate treatment, based on current medical insights;
- such an improvement can be expected in the foreseeable future; and
- there is a reasonable relationship between the expected results and the burden of the treatment on the patient.

If a physician does not possess the sufficient expertise to assess the treatment options, they should consult a colleague who is knowledgeable in the matter. This may be a physician who was involved in the treatment earlier or another colleague with the desired expertise. In certain circumstances, such as those involving existential questions, it is appropriate to consult other experts, such as psychologists, social workers or spiritual caregivers, and work with them to assess whether appropriate interventions are still possible.

The patient always has the right to decide not to undergo or stop undergoing certain palliative or other treatment options. But if a patient refuses a treatment option that offers a genuine prospect of easing their suffering, this may mean that their request for euthanasia cannot be met. After all, the due care criterion states that there must no longer be any reasonable treatment options for the patient's situation. If the patient chooses not to undergo the treatment, this may later lead to an irreversible situation involving unbearable suffering, with no prospect of improvement. The physician can only accede to the euthanasia request if all the due care criteria of the Euthanasia Act are met in this situation.

Therefore, the patient plays an important role in the assessment of whether an alternative is reasonable. This assessment includes the treatments previously undergone by the patient, possible side effects of a treatment and the expected outcome, the stage in the course of the disease, the patient's age, life history and medical situation, and their physical and psychological capacity to cope. A lot depends on the specific situation. For example, the situation of a patient who refuses a stressful chemotherapy treatment is different from that of a patient who refuses any kind of pain relief. Of course, it is not necessary to try out every conceivable intervention. Sometimes, enough is enough. A patient may have good reasons for refusing certain forms of care, such as a fear of becoming drowsy or losing consciousness, as can happen with intensive pain management or palliative sedation. The patient's context, in the light of their values, norms

and life history, must be carefully taken into account. Ultimately, it is the physician who decides whether the legal due care criteria have been met and whether they can accede to the euthanasia request.

2.7.5 Consulting an independent physician

As the fifth due care criterion, the Euthanasia Act requires the performing physician to consult another independent physician. This refers to a formal consultation based on a targeted question and carried out for the purpose of assessment. In this context, independence means that the physician acting as consultant is capable of giving their own, unbiased opinion. This implies independence with respect to both the physician seeking the consultation as well as the patient. Even the mere semblance of a lack of independence must be avoided. The professional norm is that the independent physician consulted is a SCEN physician.

The main question in this consultation is whether the first four due care criteria (from (a) to (d), see **Section 2.7**) have been met. The SCEN physician assesses this and issues a written opinion in a consultation report. The performing physician is responsible for ensuring the quality and consistency of this consultation report and should, if necessary, bring up any issues to the SCEN physician. The performing physician must take due note of this report before proceeding to perform the euthanasia. In the [Royal Dutch Medical Association \(KNMG\) guideline 'Goede steun en consultatie bij euthanasie' \(PDF\)](#) (Proper Support and Consultation for Euthanasia) outlines the requirements to be fulfilled by the SCEN physician and the consultation process and report.

The performing physician is not obliged to accept the SCEN physician's opinion, since this is not a binding opinion. But if the performing physician deviates from this opinion, they must be able to adequately substantiate their reason for doing so. If the SCEN physician gives a negative opinion and the performing physician disagrees with this, it is advisable to consult a second independent SCEN physician. This also applies if the performing physician has doubts after receiving the SCEN physician's opinion and in situations where exceptional caution is required, such as if patients with a mental disorder or with dementia are involved. This second SCEN physician must also be informed of the opinion issued by the first SCEN physician. If the second SCEN physician also gives a negative opinion, the performing physician must consider whether it is responsible to carry out the euthanasia. It is not professionally responsible to repeatedly consult a new SCEN physician until a positive opinion is obtained. Deviating from the opinion of the SCEN physician may lead to additional questions from the RTEs.

In addition, it is important that the physician not make any commitment to the patient about the euthanasia before the SCEN physician has given their opinion. If a commitment has already been made prior to the consultation, for example, by agreeing on the date and time of the euthanasia, this may have a negative impact on the possibilities for a proper consultation. Such a commitment may create false expectations and place the SCEN physician in an awkward position.

Occasionally, additional requirements may be issued for consulting an independent expert. See **Section 2.10.3** and **Section 3.4.5** in this regard.

2.7.6 Exercise of due medical care

The final due care criterion of the Euthanasia Act is that the euthanasia must be performed with due medical and pharmacological care. The *Richtlijn Uitvoering euthanasie en hulp bij zelfdoding* (Guideline for the Performance of Euthanasia and Assisted Suicide Procedures) of the KNMG and the Royal Dutch Society for the Advancement of Pharmacy (KNMP) provides physicians and pharmacists with practical guidelines for the feasible, effective and safe performance of euthanasia and assisted suicide procedures.

It is important for the physician to contact the pharmacist in time, for example, when they consult the SCEN physician. The pharmacist may choose to refrain from supplying the euthanasia drugs for reasons of principle. In such a case, the pharmacist will give the performing physician the opportunity to contact a fellow pharmacist. The physician is ultimately responsible for performing

the euthanasia with the exercise of due medical care. Only the performing physician is permitted to administer (in case of euthanasia) or offer (in case of assisted suicide) the euthanasia drugs. The placement of an intravenous cannula and the connection, if necessary, to a continuous to-keep-vein-open infusion in advance are not defined as acts of administration relating to the euthanasia drug. However, all activities subsequent to these are considered acts of administration.²⁵

In practice, euthanasia is chosen more often than assisted suicide. Both options must be carefully considered and examined. It is important to be prepared for complications during the performance of euthanasia. The physician must remain in the close vicinity of the patient during the euthanasia or assisted suicide procedure.

It is important that the patient and the persons close to them are properly informed about how the termination of life procedure will proceed, including the practicalities. The patient may also have certain wishes, which the physician and patient should discuss in advance. In addition, they should discuss how and when the euthanasia will be performed and how to proceed in case of complications.

Since this a procedure that a physician performs very rarely and that is so drastic and irreversible, it is especially important that the preparations be made in a calm and careful manner. The physician is advised to make clear arrangements with the patient and the persons close to them about the date and time of the euthanasia and about who will be present during the procedure. They can do this only after the SCEN consultation has taken place.

2.8 Notification and procedure

Euthanasia is a punishable offence, unless it is performed by a physician, all the due care criteria have been met and it has been notified to the municipal forensic pathologist, who subsequently forwards this notification to the RTEs.²⁶

In order to invoke the statutory defence, notifying the municipal forensic pathologist is an essential part of the procedure. After performing the euthanasia or assisted suicide procedure, the physician is not authorised to issue a certificate of natural death.²⁷ To notify the municipal forensic pathologist, the physician must complete the **notification form**. This is a report supported with reasons based on the due care criteria. The legal duty to notify rests with the physician who has actually performed the euthanasia procedure and administered the euthanasia drugs. In every case, a single physician is responsible for performing the euthanasia procedure. Only this physician should make the notification to the municipal forensic pathologist.

Such notification is important because it ensures that the physician is accountable for an exceptional medical procedure such as euthanasia. It makes the decision-making process and actions of the physician transparent and verifiable. Moreover, it is important that the physician's report is of a high quality. The physician must state, giving reasons, the considerations that led to the decision to perform euthanasia.

The physician is advised to give timely notice to the municipal forensic pathologist of the fact that they are going to perform euthanasia on a patient. The pathologist can then take this into account and make the necessary time available when the euthanasia procedure is supposed to take place. This prevents the performing physician and relatives from having to wait a long time for the pathologist to arrive.

The municipal forensic pathologist will send the notification form with the physician's report to the relevant RTE. To this form, they should attach all the relevant documents provided by the

²⁵ The placement, under the instructions of the physician, of an intravenous cannula by a nurse in the context of euthanasia is permitted because this is an act of preparation. The physician must perform the actual euthanasia or assisted suicide procedure, such as the intravenous administration of euthanasia drugs.

²⁶ See also the [Guide to Natural and Unnatural Deaths](#).

²⁷ Section 7(3) of the Burial and Cremation Act (*Wet op de lijkbezorging*).

physician, such as the relevant part of the medical records, any letters from specialists, any advance directive for euthanasia and the SCEN physician's report. The RTE will form an opinion within 6 to 12 weeks about whether the physician has complied with the due care criteria under the Act.²⁸ The physician is then notified in writing of the results of this opinion. If the RTE finds that the due care criteria have been met, the case is considered closed. If necessary, the RTE may ask additional questions (in writing or by telephone) or invite the physician for an interview. If the RTE concludes that the due care criteria have not been met, the Public Prosecution Service and the IGJ are notified. Both these authorities may then decide to investigate the case further. For more information about the procedure, see the [website of the RTEs](#).

2.9 After completion of euthanasia

After the euthanasia procedure is complete, it is important to ensure aftercare for the relatives and any caregivers involved. Basically, this aftercare is the same as in the case of a natural death. However, specific questions may arise about the euthanasia procedure performed. Aftercare may also be necessary for the physician. Talking with colleagues, other caregivers involved or the SCEN physician concerned may also help, not only regarding the technical aspects but also in relation to the social-emotional aspects (see also **Section 2.3**).

2.10 Euthanasia in special situations or circumstances

Sometimes, a physician may be confronted with a request for euthanasia in a special situation or context. For example, if the patient is underage, has a mental disorder or is suffering from an accumulation of age-related diseases. Such a situation may give rise to other questions and considerations. Therefore, in this section, we will address some of these situations. Here, we will leave out one such special situation, i.e. euthanasia in the case of dementia. This is because euthanasia in that situation is dealt with in Chapter 3.

2.10.1 Underage patients

Pursuant to the Act, a physician may respond to a euthanasia request made by a minor aged 12 years or older.²⁹ The condition is that the minor should be capable of making a reasonable assessment of their interests. In addition, for minors aged between 12 and 16 years, it is mandatory to have the consent of the parent(s) with custody or that of the guardian. For minors aged between 16 and 18 years, the involvement of the parent(s) or guardian is necessary, but their consent is not. In practice, euthanasia will almost always take place in agreement between the physician, the minor and the minor's parent(s) or guardian.

2.10.2 Patients with an accumulation of age-related diseases

Many older people have various health conditions that are not life-threatening in themselves but that make them vulnerable. They experience a loss of both physical and mental vitality. Somatic disorders and cognitive degeneration often go hand in hand. Furthermore, multimorbidity significantly increases the likelihood of depression, and therefore vulnerability. Vulnerability stems not only from health problems and the ensuing limitations but also depends on the extent to which people have social skills, financial resources and a social network. Vulnerability affects the quality of life and opportunities for recovery.

Such an accumulation of age-related diseases can therefore lead to unbearable suffering, with no prospect of improvement. In this case, euthanasia is an option, provided that the suffering has a primarily medical basis. This need not involve a serious medical condition, whether life-threatening or otherwise.

Against this background, physicians may take into account the vulnerability of the patient, including a loss of function, loneliness and loss of autonomy, in their assessment of a request for euthanasia. A patient's increasing deterioration may lead to an unacceptable quality of life and

²⁸ In the *EuthanasieCode* (Euthanasia Code), the RTEs provide an overview of how the due care criteria of the Act are assessed.

²⁹ Section 2(3) and (4) of the Act

therefore unbearable suffering. This deterioration may be caused by a non-linear summation and complexity of symptoms that are often not fatal in themselves. These patients frequently experience severe physical (or cognitive) decline that they are unable to cope with. As various other ailments and complications such as disorders affecting vision, hearing and mobility, falls, confinement to bed, fatigue, exhaustion and loss of fitness take hold, so too does their degree of dependence.

Such cases can be sufficiently linked to the medical domain to permit the physician to act within the confines of the Act. However, the physician must first explore – if necessary, in consultation with specialists in geriatrics, clinical geriatricians or other experts – whether there may still be appropriate interventions or reasonable alternatives to relieve the patient's suffering. In addition, they must, of course, also comply with the other due care criteria specified in the Act.

2.10.3 Patients with a mental disorder

Suffering caused by a mental disorder may also be regarded as 'unbearable suffering, with no prospect of improvement' as referred to in the Act. The source of suffering does not determine its severity. A life-threatening condition or a limited life expectancy is not a prerequisite for the performance of euthanasia.

Assessing a euthanasia request made by people with a mental disorder is usually complex and requires extra caution. Unlike most somatic and psychogeriatric illnesses, a mentally ill patient's desire to end their life may be a symptom of the psychiatric illness. The disease can also seriously affect the patient's powers of judgement and therefore the patient's capacity to exercise their decisional competence in this regard. This can make it difficult to determine whether the due care criteria are met, such as the criterion that the request is voluntary and carefully considered. It may also sometimes be difficult to determine whether there are any reasonable alternatives to relieve suffering.

The **NVvP-richtlijn Levensbeëindiging op verzoek bij patiënten met een psychische stoornis** (Guideline on the Termination of Life on Request for Patients with a Mental Disorder of the Dutch Association for Psychiatry) describes the procedure to be followed by physicians in case of a request for euthanasia prompted by suffering that is the result or primarily the result of a mental disorder. An important part of this guideline is the mandatory consultation of an independent psychiatrist who is an expert in the field of the particular disorder.

2.10.4 Patients with a combination of disorders

Occasionally, a patient's suffering is caused by a combination of somatic and mental disorders (comorbidity). If such a patient requests euthanasia, the physician and the consultant must explicitly examine the impact of the patient's mental health problems on the extent to which the request can still be regarded as being voluntary and carefully considered and the possible remaining treatment options for the patient. In such cases, it is recommended that advice be sought from a physician who is an expert in the field, such as a geriatrics specialist, clinical geriatrician, psychiatrist, neurologist or internist.

2.10.5 Patients with a reduced level of consciousness

It may be that a patient who has requested euthanasia falls into a coma or into a state of reduced consciousness. In principle, euthanasia is no longer permissible if there is no unbearable suffering involved at present. It is important for a physician to make this clear in advance in their conversations with the patient and their relatives. This is particularly important if the patient's condition is such that a reduced level of consciousness is reasonably possible. The **KNMG-richtlijn Euthanasie bij een verlaagd bewustzijn (PDF)** (KNMG Guideline on Euthanasia in case of Reduced Consciousness) describes what the physician should do in case of patients whose level of consciousness has reduced after euthanasia has been agreed upon and scheduled within a reasonably short period of time.

2.10.6 People experiencing existential suffering

In some cases, a patient's suffering may be existential in nature, whereby they have a sense of a 'completed life'. In such a situation, a request for euthanasia may be complied with only if there is a medical basis, meaning a condition that can be defined as a disease or combination of diseases/symptoms. This medical basis may be somatic or psychological in nature. Among the people who experience existential suffering and feel that they have a 'completed life', many are often suffering from a combination of medical and psychological problems and an accumulation of age-related diseases. As a result, this group of people may fall within the framework of the Act.

This does not apply in case of purely existential suffering without a medical basis. Such a situation is beyond the scope of the Act.³⁰ You can read more about this in the document [Lijden aan het leven \('voltooid leven'\)](#) (Existential Suffering ('Completed Life')).

2.10.7 People with an intellectual disability

Sometimes, physicians encounter a euthanasia request from a person with an intellectual disability. This usually occurs in case of severe and untreatable suffering or a gradual but unmistakable decline in that person's quality of life. Although cases of euthanasia among people with a mild intellectual disability are rare, they too can make a voluntary and carefully considered euthanasia request, with the other due care criteria also being met. If a physician receives such a request, they must exercise extra caution when assessing this and pay particular attention to the decisional competence of the patient in question. See also the guide to [Omgaan met vragen om levensbeëindiging bij wilsonbekwame mensen met een verstandelijke beperking \(Dealing with Requests for Termination of Life from Decisionally Incompetent Persons with an Intellectual Disability\) of the Netherlands Society of Physicians for Persons with Intellectual Disabilities \(Nederlandse Vereniging Artsen Verstandelijk Gehandicapten, NVAVG\) \(PDF\)](#).

2.10.8 Duo-euthanasia

Sometimes, a joint request for euthanasia may be made by a couple (married or otherwise). In such a situation, it is advisable to consider whether the two requests can be assessed and carried out separately. Since a married couple usually have the same GP, it is assumed that another physician will be involved for assessing one of the euthanasia requests. In such cases, two different SCEN physicians must also be consulted, both of whom speak individually to the various partners as part of the formal consultation. This is necessary to ensure that each case is assessed individually and to prevent partners from putting pressure on each other and on the performing physician.

2.10.9 Organ donation after euthanasia

A patient requesting euthanasia may also wish to donate organs and/or tissue. Usually, this is not possible due to the patient's medical condition. But it is sometimes possible, for example, in case of patients with a neurodegenerative disease, such as MS, ALS and Parkinson's, and in case of patients with a psychiatric disorder. Honouring such a request can help give meaning to the inevitable death of the patient. Since the organs must be removed shortly after the euthanasia procedure, the death will always have to take place in a designated hospital. This may lead to an additional burden for the physician, patient and relatives.

The basic premise of organ donation after euthanasia is that it involves two strictly separate procedures: the euthanasia request and the organ donation. What this means is that the physician cannot contact a hospital to make specific arrangements until it is clear that the due care criteria for euthanasia have been met. It is also important for the quality of care to be maintained in the final stages of life and for the patient and their relatives to be properly informed of the consequences of this decision. More information can be found in the [Richtlijn orgaandonatie na euthanasie](#) (PDF) (Guideline on Organ Donation after Euthanasia).

³⁰ Section 2(3) and (4) of the Act

3 Euthanasia and dementia

3.1 Introduction

Among a certain part of the population, there is a great fear of developing some form of dementia in later life. However, when viewed from the perspective of the person with dementia, it appears that dementia does not necessarily result in suffering.³¹ People with dementia, especially in the beginning, are not solely preoccupied with issues relating to the disease and care. Often, they are more concerned with what dementia means in daily life, now and in the near future, and how their relationships may change. People with dementia are full-fledged members of society and are entitled to be treated as such. This resonates with other **initiatives relating to a dementia-friendly society** and the social approach to dementia.

However, dementia can have a major impact on the perceived quality of life of the person with dementia. In addition, the feelings of loss can result in negative emotions. Therefore, it is essential to ensure guidance and care that is well-aligned with the needs of the person with dementia.³² In this respect, the physician is sometimes faced with the question of whether they may – based on an advance directive for euthanasia – perform euthanasia on a patient with dementia who is decisionally incompetent in this regard. Although this is permitted by law, there is debate in society and among physicians as to whether euthanasia is acceptable in this case.

Several ethical and medical questions come into play when considering the acceptability of euthanasia in the case of decisionally incompetent people with dementia. These questions are reflected in the opinions issued by the RTEs in recent years in a number of euthanasia cases involving patients with advanced dementia where the RTEs found that the physician had not acted in accordance with the legal due care criteria. In one case, the Supreme Court handed down two rulings in April 2020: one in a criminal case and one in a disciplinary case.³³ The Supreme Court ruled that euthanasia in patients with advanced dementia is permissible within the framework of the Act. However, the requirement for this is that the patient should have previously made an advance directive for euthanasia while they were still decisionally competent. In addition, all the legal due care criteria for euthanasia must be met. The rulings included an explanation of the legal framework.

Views of the KNMG on euthanasia in case of advanced dementia

The Supreme Court's ruling that euthanasia in case of advanced dementia falls under the legal framework under certain circumstances does not, however, resolve all the dilemmas faced by physicians and patients. An important question in medical ethics is the extent to which the views of the 'former self' should be respected (the decisionally competent person who made an advance directive for euthanasia) or those of the 'present self' (the person with advanced dementia)?

The KNMG's opinion is that the life of a person with advanced dementia is worth protecting, regardless of what the patient has previously put down in writing in this regard. The current wishes, interests and preferences of a person with advanced dementia deserve to be respected. Having said that, the previous advance directive for euthanasia could still be respected in exceptional situations. In that case, it is only considered justified if the performance of euthanasia is consistent with the previous advance directive for euthanasia and if there are no contraindications for this (for example, clear signs that the patient no longer wants euthanasia). In addition, there must be actual unbearable suffering of the patient.

³¹ This has emerged from a [systematic review](#).

³² For this, see the [Zorgstandaard dementie 2020](#) (Care Standard for Dementia 2020) and the [Dementiezorg voor elkaar](#) (Dementia and Caring for Each Other) programme.

³³ Supreme Court, 21 April 2020, [ECLI:NL:HR:2020:712](#) (criminal case) and [ECLI:NL:HR:2020:713](#) (disciplinary case).

If, in case of a decisionally incompetent patient with advanced dementia, there is any doubt as to whether one or more of the due care criteria have been met, the physician must refrain from performing euthanasia and instead try to alleviate the suffering in some other way.

Many physicians are reluctant and/or unwilling to perform euthanasia on patients with advanced dementia when they are no longer decisionally competent in this regard. Indeed, in such a situation, it is not or no longer possible to talk with the patient properly about their current wishes and the unbearable nature of the suffering. The KNMG understands this reluctance on the part of physicians and requests patients, their relatives and society as a whole to respect this. It is important that the physician and the patient engage in discussion from the outset and never lose sight of the broad range of end-of-life care. If euthanasia is not possible, the physician may, in consultation with the relatives or the patient's representative, consider the advance directive for euthanasia as an indication for withholding or withdrawing life-prolonging treatments.

At the same time, the KNMG understands that there are physicians who are willing to perform euthanasia on decisionally incompetent patients with advanced dementia. The KNMG also wants to provide these physicians with the necessary support. Euthanasia in advanced dementia requires great caution and particular attention. The KNMG offers guidance to physicians, who are willing to perform euthanasia in this exceptional situation, on how to act in a professionally responsible manner. We explain the legal framework, as confirmed by the Supreme Court and rendered in the [Euthanasia Code of the RTEs](#), and translate this into specific tools and professional standards. These clearly indicate the caution physicians are expected to exercise in this situation and how they can act in a professionally responsible manner in such cases. This chapter discusses euthanasia both in case of advanced dementia as well as in the earlier stages of dementia.

This KNMG guideline is based on the Euthanasia in Dementia project. You can read the substantiation of the guideline [here](#).

3.2 Dementia and the end of life

Timely diagnosis is essential for people with dementia. This allows the patient to subsequently manage the care process themselves and indicate to their attending physician their wishes regarding the disease and the end of life. It is part of the physician's professional responsibility to have a timely discussion with the patient about the end of life. Preferably, the attending physician should take the initiative to initiate the end-of-life conversation, provided the patient desires this. A [Dementia Case Manager](#) can also be called in to initiate end-of-life conversations.

Talking about the end of life

One way to guide a patient with dementia is via the Advance Care Planning (ACP) process.³⁴ The ACP is a proactive and cyclical process through which the patient discusses, and possibly records, their wishes, goals and preferences for end-of-life care with the physician.³⁵

Following the diagnostic interview, the physician talks with the patient about their health situation, about what the patient considers important at this stage of life and about their wishes regarding the end of life. The knowledge and insights gained about the patient during these conversations also help the physician anticipate possible future health situations, treatments and interventions. Euthanasia may be included as one of the topics of discussion, as part of a [broader conversation](#) on how to give meaning to life, palliative care and other treatment options or alternatives associated with the end of life.

³⁴ See the report on [Passende zorg voor kwetsbare ouderen door advance care planning](#) (Appropriate Care for Vulnerable Seniors through Advance Care Planning) and this article on [advanced care planning for seniors with dementia](#).

³⁵ This guideline uses the term [Advance Care Planning](#). In this, we adhere to the international definition of Advance Care Planning. Advance Care Planning is also referred to as prospective or proactive care planning, as seen in the [Quality Framework for Palliative Care](#).

Of course, these discussions should be tailored to the needs of the individual patient. Not every patient with dementia will want to talk about the end of life (yet). It is important to indicate why it is desirable to talk in a timely manner about the end of life, in case of dementia. In agreement with the patient, the physician may also offer to discuss this at a later time.

Since both the situation and the patient as a person may change, it is important to remain engaged in conversation with the patient and discuss possible scenarios. In this context, the physician must always be clear about what is and is not possible, for example, if the patient asks something of the physician that is not possible given the legal framework or that goes beyond the physician's own limits. In addition, it is important to always make a note in the patient's medical records of the discussions and the physician's assessment of the patient's decisional incompetence in this regard.

If the patient is no longer able to participate in these ACP conversations, they will initially be carried out with the patient in the presence of their relatives (supportive decision-making). As the level of decisional competence declines, there will be a gradual shift to substitute decision-making, which means talking only with the patient's relatives or representatives. See also later in this section, under the heading **Role of caregivers and relatives**.

Euthanasia

Euthanasia in patients with dementia is rare, especially in case of advanced dementia.³⁶ **A consultation of physicians** organised in 2019 also revealed that a majority of physicians are unwilling to perform euthanasia on patients with advanced dementia who are considered decisionally incompetent in this regard. An important factor in such a situation is that one cannot or can no longer properly talk with the patient about their current wishes and the unbearable nature of the suffering. This makes it difficult for the physician to determine whether the earlier advance directive for euthanasia should actually be complied with.

Even in the early stages of dementia, a request for euthanasia may involve complex considerations. For a patient with dementia who has a desire for euthanasia, determining when to perform this can give rise to several dilemmas. Some patients request euthanasia in the early stages of dementia. For them, unbearable suffering often consists of the fear of further deterioration and a further loss of autonomy and dignity. But many patients with dementia continue to experience a sufficient quality of life in the early stages and have no desire for euthanasia at that time. Also, an earlier desire of euthanasia may get pushed into the background as the patient has greater difficulty in expressing their wishes or intentions, loses interest in the future and forgets about the euthanasia request. The patient may not have a sufficient understanding of the disease for them to realise that they would have chosen for euthanasia earlier in this situation.

In addition, many patients experience a sense of losing control and a diminished understanding of their own situation. This is inherent to the disease of dementia. The physician should point out to the patient that various scenarios may arise, such as the patient becoming decisionally incompetent or an impending need for admission to a nursing home. This also poses a dilemma for the physician: to what extent should they take charge and point out to the patient that the dementia is progressing and that, perhaps, at some point, euthanasia may no longer be possible? And how do they do that without being too controlling? Building on previous conversations, the physician will need to explore the boundaries with the patient each time, inform them further and, depending on the patient's level of comprehension and health literacy, discuss the various scenarios with them and their relatives. The physician must be alert to the fact that euthanasia is a personal decision of the patient and that no pressure should be placed on the patient in any way.

If the physician is unwilling to perform euthanasia in a certain situation, for example, when it is no longer possible to communicate with the patient, they should indicate this clearly and in a timely

³⁶ See the [infographic](#)

manner and explain why they cannot comply with the request. In this case, the physician should allow the patient to approach a colleague who may be willing to perform euthanasia in such a situation. Even if euthanasia is not or no longer an option, the physician naturally has a duty of care to consider, together with the patient and their relatives, what the most appropriate care options would be in the final stages of life.

Role of caregivers and relatives

The physician plays an important role during the course of dementia. Other caregivers (such as spiritual counsellors, case managers, caregivers and psychologists) may also play a role.³⁷ The physician should give them the needed space, while continuing to discuss the mutual division of roles and responsibilities, such as the question of who will take the initiative for which task when certain scenarios occur? The physician must put these mutual agreements in writing and ensure that the point of contact for each task is clear for the patient and their relatives.

When a patient has limited capabilities or is unable to communicate, the contribution of relatives can play a major role. However, relatives may not make a request for euthanasia on behalf of the patient. The physician should discuss and agree with the patient on whether, and to what extent, their relatives should be involved. If the patient has become decisionally incompetent in this regard, the patient's representative will usually be present during end-of-life discussions. But even in this situation, it remains important to speak to the patient alone, if this is still possible.

Relatives can help in interpreting the advance directive for euthanasia correctly and clarifying the patient's wishes (see also **Section 3.4.1**). They are the right people to do this because, for example, they were involved in the earlier end-of-life discussions with the physician. Or because they helped the patient prepare the advance directive for euthanasia or record a video in which the patient expresses and/or explains their desire for euthanasia. The physician may take the relatives' opinions into account when considering the case and for assessing the due care criteria, but these opinions can never replace the required voluntary and carefully considered request from the patient. This is applicable even if the relative is the representative. It must be kept in mind that euthanasia is a personal decision of the patient.

3.3 Euthanasia in the different stages of dementia

The care process for persons with dementia can be divided into various stages. For example, the **Care Standard for Dementia** refers to the initial stage of noticing that things are not quite right, the diagnostic stage, the stage of living with dementia, and the terminal and aftercare stage. Physicians also use certain scales for the medical classification.³⁸ When it comes to euthanasia for patients with dementia, the degree of decisional competence in this regard is an important part of the assessment to be made by a physician. That is why this guideline has chosen for a division into three stages: the early, middle and late stages of dementia.³⁹ This distinction is essentially based on the decreasing level of decisional competence. In the sections below, we outline the considerations involved in euthanasia depending on the stage of dementia.

3.3.1 Early stage of dementia

In the early stage of dementia, a patient is usually considered decisionally competent with regard to a request for euthanasia and is usually still living at home. The patient may visit the physician with an advance directive for euthanasia at this stage, or the patient may have earlier, prior to the diagnosis of dementia, set out certain provisions relating to dementia in an advance directive for euthanasia. This should prompt the physician to talk with the patient about their wishes and mutual expectations. While doing so, the physician must be clear about the legal framework, their personal views and limits and their possible readiness to perform euthanasia in the situation described by the patient.

³⁷ See also this [article](#) in this context.

³⁸ Such as the *Clinical Dementia Rating* or the *Global Deterioration Scale*.

³⁹ This [division into stages](#) is used by *Alzheimer's Netherlands (Alzheimer Nederland)*.

If a patient diagnosed with dementia is decisionally competent in this regard and the patient makes a request at the time in question, the regular consultation procedure is usually sufficient. If a patient in the early stage of dementia makes a euthanasia request, the physician must determine whether the due care criteria under the Act are met. In addition to the current deterioration in the patient's cognitive abilities and functioning, the fear of future suffering may also contribute to the unbearable suffering. These fears may include the fear of losing one's personality and autonomy, of significant humiliation and increasing dependence on others and of not being able to die with dignity. This fear of future suffering may factor into the assessment of whether there is a question of unbearable suffering, with no prospect of improvement.

3.3.2 Middle stage of dementia

The course of dementia is gradual and patient-dependent. Typically, the level of decisional competence of a dementia patient decreases over time and may fluctuate. It is important for the physician to determine whether the patient is still decisionally competent enough with regard to the euthanasia request.

Decisional competence is linked to a particular context: a patient may be decisionally incompetent in one area but still competent in other areas. In the case of a euthanasia request from a patient with dementia, it is important to examine whether the patient is decisionally competent in connection with the request. This involves issues such as: does the patient understand what their disease implies, what this means for the future, what their options are and what euthanasia means? If the physician has doubts about the patient's decisional competence in this matter, they should consult another physician with expertise in the field, such as a psychiatrist, geriatrics specialist, clinical geriatrician or physician registered with the VIA. It may also be important to verify whether the patient understands the information on euthanasia. This can be done in various ways, for example, by asking the patient about the method by which the procedure will be performed and the consequences of euthanasia. To this end, the physician can refer to the [Landelijke Huisartsen Vereniging \(LHV\)-praktijkaart Wilsonbekwaamheid](#) (Practical Guide on Decisional Incompetence of the National Association of General Practitioners).

If a patient diagnosed with dementia is decisionally competent in this regard and the patient makes a request at the time in question, the regular consultation procedure is usually sufficient.

It is also possible that a patient may no longer be able to properly express themselves verbally but is still able to exercise their decisional competence in this regard. In that case, it is important to look at other issues relevant to the euthanasia request. These include, for example, the course of the disease/medical history, any previous advance directives or requests for euthanasia, the quality of life experienced at the time and the heteroanamnesis. It helps if a physician knows the patient and their past history and has spoken to the patient several times about their desire for euthanasia. The physician can ask the same questions each time to determine if the patient is consistent in their answers or if their perspective has changed. Here, the primary source of information is the patient.

For relatives, it can be distressing and painful to watch the progress of the dementia and how their loved one gradually forgets their euthanasia request. Especially if they know that the patient 'didn't want' the situation they are in now. At the same time, practical experience often shows that a patient's views of dementia and perceived quality of life change during the disease. A situation that the patient previously thought was unacceptable may be perceived as less serious or be perceived differently in the moment. The physician may take the opinions of relatives into consideration, but these opinions can never replace the required voluntary and carefully considered request from the patient. This is applicable even if the relative is the representative. It must be kept in mind that euthanasia is a personal decision of the patient.

3.3.3 Late stage of dementia

In the late stage of dementia – also known as advanced dementia – the patient is completely dependent on others and considered decisionally incompetent as far as a euthanasia request is

concerned. At this stage, euthanasia is possible only on the basis of an advance directive for euthanasia prepared by the patient themselves when they were still decisionally competent in this regard. If the patient can no longer formulate and express their wishes, the previously drafted advance directive for euthanasia may replace a current oral request (see **Section 3.4.1 Advance directive for euthanasia**). However, the **other due care criteria** must still be met. If a patient is decisionally incompetent with respect to the euthanasia request and has not prepared an advance directive for euthanasia, the euthanasia may under no circumstances be performed.

Euthanasia in advanced dementia, based on an advance directive for euthanasia, is relatively infrequent: this occurs one to two times per year on average. The Supreme Court confirms that caution is required in such a situation. It has stated that the due care criteria under the Act must be complied with in such a way that this takes into account the particular nature of advanced dementia (see **Section 3.4**). This is because it involves the termination of the life of someone who is suffering from a progressive disease and who, at the time of the performance of euthanasia, is no longer decisionally competent in this regard.

The Supreme Court emphasised that it is up to the physician to determine, based on their medical and professional opinion, whether euthanasia in a patient with advanced dementia is acceptable within the legal framework. Moreover, a patient is never entitled to euthanasia, and a physician is never obliged to perform it. Whatever the physician decides, they must inform the patient and any relatives of their views in a timely manner and explain why they cannot or can no longer comply with the request. In this context, see also **Section 3.2 Euthanasia**.

3.4 Legal and professional framework for euthanasia for patients with advanced dementia

The physician's medical and professional opinion, within the framework of the Act, is the basis for the decision on whether to perform euthanasia on a decisionally incompetent patient with advanced dementia.⁴⁰

In this section, we examine in more detail the legal and professional framework applicable to euthanasia in patients with advanced dementia who are decisionally incompetent in this regard. We will do this based on the due care criteria of the Act. These due care criteria are also extensively dealt with in **Chapter 2** of this guideline. This section is supplementary to that chapter. The text in this section clearly indicates whether any legal criteria are involved. It is also mentioned whether these KNMG standards are supplementary in nature. The key points are always summarised in a box at the start.

If it concerns a decisionally incompetent patient with an advance directive for euthanasia, the due care criteria of the Act 'apply mutatis mutandis'. This means that the due care criteria will be complied with in a manner that does justice to the particular nature of such cases. Hence, the physician must take the patient's decisional incompetence into consideration when assessing the due care criteria. For example, the physician must keep in mind the fact that the patient can no longer express their wishes in this regard with words or gestures and that it is no longer possible to communicate with the patient about, for example, their euthanasia request or the suffering they are experiencing. Of course, even if the patient is decisionally incompetent in this regard, the physician will have to be convinced that all the due care criteria have been met before they can carry out the euthanasia procedure. Needless to say, a necessary condition is that there must be an advance directive for euthanasia that was prepared by the patient when they were still decisionally competent. Without such a previously prepared advance directive for euthanasia, this procedure may not be performed on a patient who has subsequently become decisionally incompetent.

⁴⁰ The framework that guides the physician when performing euthanasia is formed by law, case law and various professional standards. The Euthanasia Code is also an important source, because it provides an overview of how the due care criteria under the Act are assessed by the RTEs. There is a great deal of overlap with respect to the aforementioned sources.

3.4.1 Due care criterion 1: voluntary and carefully considered request

The first due care criterion in the Act is that the physician must be convinced that there was a voluntary and carefully considered request from the patient (see **Section 2.7.1** for a general explanation of this due care criterion).

Communication remains key

Even if a patient has become decisionally incompetent as a result of advanced dementia, it is essential that the physician keeps making an effort to communicate with the patient.

- It is the physician's task to examine whether the patient is still decisionally competent with respect to the request for euthanasia.
- However, the physician is not legally required to verify the patient's current desire for death if the patient is no longer able to express this wish due to advanced dementia. This means that euthanasia may be performed under certain circumstances in situations where it is no longer possible to verify an advanced dementia patient's current desire for life or death. In this case, the advance directive for euthanasia may replace a current oral request.
- Within the limitations imposed by the disease of dementia, the physician will have to make an effort to communicate meaningfully about the intention, time and actual performance of euthanasia. The KNMG emphasises that the physician should not assume too quickly that communication, meaningful or otherwise, with the patient is no longer possible. In this context, they could seek the advice of a multidisciplinary team, if necessary, to understand and interpret verbal and non-verbal reactions. The physician should tailor the communication to the patient's situation and level of comprehension. The physician may decide not to try to communicate with the patient only if it is highly detrimental to the patient's condition to communicate about euthanasia, for example, because it causes severe agitation or distress. In this case, the physician should note down the reason for this in writing in the medical records and in the notification form.
- The physician must always remain alert to any communications or behaviours of the patient that contradict the advance directive for euthanasia. These communications or behaviours may be a reason for refraining from performing euthanasia. See also **Section 3.4.1 Alertness to communications and behaviours that contradict the advance directive for euthanasia (contraindications)**

Advance directive for euthanasia

There must be an advance directive for euthanasia that was prepared by the patient while they were still decisionally competent.

The physician must be convinced that the patient's advance directive for euthanasia is voluntary and carefully considered.

The patient's advance directive for euthanasia must be judged based on all the circumstances of the case and not merely the literal wording of the directive.

- The physician must be satisfied that the patient was decisionally competent when they made the advance directive for euthanasia and that the directive was voluntary and carefully considered.
- The physician must be able to verify that the patient's current situation is the situation meant by the patient in their advance directive for euthanasia. Therefore, the advance directive for euthanasia will have to clearly indicate the reason for euthanasia, the circumstances under which the patient wants euthanasia and the exact nature of the unbearable suffering anticipated by the patient .
- Whether the advance directive for euthanasia can replace the oral request depends, first and foremost, on the contents of the advance directive for euthanasia. The physician must take into consideration all the circumstances of the case and not just the literal wording of the advance directive for euthanasia. This implies that there is room for interpretation with respect

to the advance directive for euthanasia. The physician must try to ascertain the patient's intentions based on the advance directive for euthanasia.

- Other relevant sources of information that can be used by the physician for their assessment include: the medical records, the present or former GP or any other physician who has treated the patient, other care professionals, relatives and independent experts. In addition, observations of the patient and their behaviour may also provide valuable information, both for interpreting the advance directive for euthanasia and with regard to the other due care criteria of the Act. The physician may carry out these observations themselves or reach their conclusions partly based on the observations of other care providers. All such observations should preferably be carried out over several occasions and at different times, so that different signals can be observed at different times of the day. These observations should be noted in the medical records and, if necessary, in the notification form. This can be done in writing or with the help of audio or video material.
- Substantial ambiguities or inconsistencies in the advance directive for euthanasia may interfere with the performance of the euthanasia procedure. This means that a mere interpretation of the contents of the advance directive for euthanasia will not resolve all the ambiguities present in it. The physician will always have to be convinced that there is a voluntary and carefully considered request and that the patient's current situation corresponds to the situation meant by the patient in the advance directive for euthanasia. The physician will also need to be alert to any verbal communication or behaviours of the patient that contradict the advance directive for euthanasia. These communications or behaviours may be a reason to refrain from performing the euthanasia procedure, especially in case of clear verbal communication or consistent behaviour (See also **Section 3.4.1 Alertness to communications and behaviours that contradict the advance directive for euthanasia (contraindications)**)
- The physician faced with the euthanasia request may not be the same physician who discussed the euthanasia request with the patient when the patient was still decisionally competent. In that case, the KNMG advises the physician to, preferably and if possible, contact the physician who spoke with the patient earlier when the patient made the request and was decisionally competent to do so. The purpose of this conversation would be to ascertain that the patient was indeed decisionally competent at the time of the request, that the request was voluntary and carefully considered and that the patient had been properly informed. This would also help clarify any ambiguities in the advance directive for euthanasia. In this way, the physician can get an idea of the relevant circumstances necessary for making a careful assessment. For example, this allows the physician to assess whether the situation described in the advance directive for euthanasia has occurred. This also emphasises the importance of handing over the information and entire history from the patient's medical records properly, and preferably in person, when the patient is being treated by a different attending physician, for example, because of a change in the residential or care setting.
- Since the patient must be properly informed before they draft the advance directive for euthanasia, it is important to ensure that one or more conversations have taken place between a physician and the patient, during which the advance directive for euthanasia was discussed at the time when the patient was still decisionally competent in this regard. At this stage, the physician can get a good idea of what the patient has in mind regarding the euthanasia request. Discussing the euthanasia request is a shared responsibility of the patient and physician. If an advance directive for euthanasia from a patient, who has since become decisionally incompetent in this regard, has never been discussed with a physician and is not part of the medical records, and there is no indication in the medical records of previous discussions about the request, the KNMG considers this as grounds for not performing the euthanasia procedure based on the advance directive. Indeed, it is more difficult for a physician in such a situation to be convinced that the due care criteria have been met.
- Although it is ultimately the physician who decides whether the legal due care criteria for euthanasia have been met, it is useful if the physician discusses the advance directive for euthanasia with the patient's relatives. The relatives, especially in the case of a decisionally incompetent patient, can and may bring an advance directive for euthanasia to the physician's attention. They are an important source of information for the physician for interpreting the request for euthanasia and understanding the patient's wishes. The physician

may take the opinions of relatives into consideration, but these opinions can never replace the required voluntary and carefully considered request from the patient. This is true even if the relative is the legal representative. It must be kept in mind that euthanasia is a highly personal decision of the patient.

- It is also common for relatives to disagree among themselves about a euthanasia request. Again, these opinions may be important in interpreting the euthanasia request, but it is ultimately the physician who decides whether all the criteria of the Act have been met.
- But even if euthanasia is not performed, an advance directive for euthanasia from a patient, who has in the meantime become decisionally incompetent in this regard, may be meaningful because this indicates, for example, that the patient no longer wants any life-prolonging treatments.

More information about the advance directive for euthanasia can be found in **Section 2.7.1**.

Alertness to communications and behaviours that contradict the advance directive for euthanasia (contraindications)

The physician must be alert to contraindications or communications and behaviours of the patient that contradict the advance directive for euthanasia. These communications or behaviours may be a reason for refraining from performing euthanasia even if the advance directive for euthanasia is clear in itself.

- Contraindications may arise at two points in time:
 1. during the period when the patient is still decisionally competent in this regard;
 2. during the period when the patient is not or becomes decisionally competent in this regard due to advanced dementia.
- Both types of contraindications are important.⁴¹ The communications and behaviours in the first category may be construed as a sufficiently clear expression of the wish to withdraw a current or earlier advance directive for euthanasia. It is different for the second category, because these communications or behaviours of a decisionally incompetent patient cannot or can no longer be directly construed as an expression of the desire explicitly aimed at withdrawing or modifying the earlier request. The physician will have to assess whether to attach any significance to the behaviour of the decisionally incompetent patient with advanced dementia and whether the communications of the patient support or contradict the contents of the advance directive for euthanasia. This does not refer to occasional utterances but to consistent and clear behaviours or communications. If the patient in this situation consistently and clearly exhibits behaviour or communicates in a way contrary to the advance directive for euthanasia, the physician must conclude that the situation – as described by the patient in the euthanasia request – has not occurred. Hence, despite a clear advance directive for euthanasia, euthanasia is not possible. Examples of contraindications are behaviours indicating that the patient still has the desire to live or that the patient is satisfied with their current situation, even though they have indicated in their advance directive for euthanasia that they do not want to be in this situation.
- Examining the contraindications is also relevant for assessing whether the suffering can be regarded as unbearable suffering, with no prospect of improvement (see also **Section 3.4.2**).
- If the physician and the treatment team concerned are uncertain about how to assess the communications or behaviours, the physician should involve an independent physician with the relevant expertise in this assessment (see also **Section 3.4.5**).

3.4.2 Due care criterion 2: unbearable suffering with no prospect of improvement

The second due care criterion in the Act is that the suffering of the patient must be unbearable, with no prospect of improvement (see **Section 2.7.2** for a general explanation of this due care criterion).

⁴¹ Verbal or other communications of the patient may be essential for assessing any possible contraindications as well as the patient's current level of suffering.

For an advance directive for euthanasia to be complied with, the patient must, under all circumstances, be undergoing unbearable suffering, with no prospect of improvement, when the time comes for euthanasia to be performed.

- It is possible that the patient has indicated in their advance directive for euthanasia that they consider their suffering to be unbearable if they are in an advanced state of dementia. However, this indication alone is not sufficient to conclude that the patient's current level of suffering can actually be considered unbearable at that point of time.
- The mere fact that a person has advanced dementia is insufficient grounds for euthanasia. The patient must be observably suffering at the time in question. This means that the patient must be able to perceive this suffering themselves at that moment. A patient with advanced dementia may suffer unbearably in several ways. This suffering may be both psychological and physical and result from the dementia or from another concomitant condition. Even in the absence of any other health condition, it may be possible to infer from the patient's behaviour that they are suffering from their advanced dementia to such an extent that their suffering can be considered unbearable.
- When assessing whether the suffering is unbearable, the physician must exercise great caution. Besides studying the medical records, it is important for the physician to observe the patient for an extended period of time at several times during the day. In addition, according to the KNMG, the physician must always consult one or more expert physicians in the field (see also **Section 3.4.5**). The KNMG also recommends speaking with the patient's relatives and consulting other caregivers with a treatment relationship with the patient either now or in the past or who are involved in the patient's daily care. The observations and considerations made by the physician must always be carefully noted in the patient's medical records and on the notification form.
- Dementia is a disease for which there is no cure as yet. In this sense, there is no medical hope for patients with dementia. But it cannot be concluded from this that the suffering associated with dementia is also always without any prospect of improvement. Nor does dementia necessarily mean suffering, whether unbearable or otherwise, for every patient. Therefore, a physician should always examine whether there are other ways to relieve or, if possible, reduce suffering. The KNMG recommends consulting an expert in the field to see if there are other opportunities to improve the quality of life.
- If a problematic behaviour is involved, a careful analysis of that behaviour in relation to the unbearable nature of the suffering is essential. All of the patient's communications – verbal or otherwise and whether related to this condition or not – can play a role in this analysis. The KNMG stresses the importance of analysing and looking for possible solutions to the problematic behaviour. See also the [Richtlijn Probleemgedrag bij mensen met dementie](#) (Guideline on Problematic Behaviour in People with Dementia) from Verenso.

3.4.3 Due care criterion 3: information for the patient

As its third due care criterion, the Act states that the patient must be adequately informed about the situation in which they find themselves and about their prospects (see **Section 2.7.3** for a general explanation of this due care criterion).

The physician must be convinced that the patient, when they were still decisionally competent in this regard, was adequately informed about their situation, in terms of health or otherwise, and prospects as well as about the significance and consequences of their advance directive for euthanasia.

- The basic principle is that, even if a patient has since become decisionally incompetent, the physician should make an effort to communicate with the patient about their situation and prospects. They will have to do so within the limitations that have arisen due to the patient's condition. Also see **Section 3.4.1 Communication remains key**.
- Once a patient is decisionally incompetent in this regard, it is usually no longer possible for a physician to provide information to the patient. If another physician has informed the patient,

the KNMG advises the performing physician to, preferably and if possible, contact the other physician (see also **Section 3.4.1**).

3.4.4 Due care criterion 4: no reasonable alternative

The fourth due care criterion is that the physician must have come to the conclusion, together with the patient, that there is no reasonable alternative for the situation in which the patient finds themselves (see **Section 2.7.4** for a general explanation of this due care criterion).

The physician must be convinced, based on medical insight and in the light of the patient's advance directive for euthanasia, that there is no reasonable alternative for the patient's current situation. Since the patient can no longer express their wishes, a great deal of importance is attached to what they have indicated about this in their advance directive for euthanasia and whatever they said about this when it was still possible to communicate with them.

- The physician must thoroughly consider options other than euthanasia to eliminate or alleviate the patient's suffering. Examples of other options include palliative care or changes in care or medication.
- Sometimes, a patient will have mentioned in their advance directive for euthanasia that they do not want to be admitted to a particular residential or care setting. However, the mere fact that this is mentioned does not mean that euthanasia will always be carried out if the patient is admitted to that particular residential or care setting. Firstly, the advance directive for euthanasia must clearly show what exactly constitutes unbearable suffering for the patient now or in the future. Moreover, euthanasia can take place only if the physician is satisfied that all the due care criteria have been met. This means that a physician can accede to a euthanasia request only if the patient is observably suffering at the time in question. In addition, the physician must also consider whether an admission can be expected to relieve the patient's current suffering. Since the patient can no longer express their wishes, a great deal of importance is attached to what they have indicated about this in their advance directive and whatever they said about this when it was still possible to communicate with them. Also see **Section 2.7.1 Advance directive for euthanasia**.
- Despite the fact that the patient has indicated in the advance directive for euthanasia that they do not want to be admitted to an institution, admission is sometimes unavoidable due to a need for critical care or in other situations, such as if the current living situation is no longer considered responsible or if relatives can no longer handle the care tasks. Once a patient is admitted to a different residential or care setting, it may take some time for them to get used to the new situation. Therefore, it is necessary for the physician to also take some time to assess whether all the due care criteria are met in this case and whether, if necessary, the euthanasia request can be complied with.
- To determine whether there are reasonable alternatives to alleviate the patient's suffering, the physician is advised to consult a relevant expert (see also **Section 3.4.5**). If the suffering arises due to problematic behaviour, the physician can refer to the **Richtlijn Probleemgedrag bij mensen met dementie** (Guideline on Problematic Behaviour in People with Dementia). If it is subsequently decided to proceed with palliative sedation, the physician can consult the **Handreiking Palliatieve sedatie bij refractair probleemgedrag bij mensen met dementie** (Guide to Palliative Sedation for Refractory Problematic Behaviour in People with Dementia).

3.4.5 Due care criterion 5: consultation

According to the fifth due care criterion in the Act, the performing physician must, prior to performing the euthanasia procedure, consult at least one other independent physician. In principle, this must be a SCEN physician. See **Section 2.7.5** for a general explanation of this due care criterion.

In situations involving patients with advanced dementia who have prepared an advance directive for euthanasia, it is always advisable to consult – in addition to the SCEN physician – a second independent physician with specific expertise in this area.

- If the patient cannot express their desire for euthanasia with words or gestures or communicate the unbearable nature of their suffering, the physician must rely partly on the interpretation of their communications and behaviours and of the wording of their advance directive for euthanasia. This calls for extra caution and great procedural care. The KNMG believes that an independent expert on the subject should always be requested to advise the physician on whether the due care criteria have been met. This may include, for example, a geriatrics specialist, geriatric psychiatrist, neurologist or clinical geriatrician. The physician must consult this external expert before consulting the SCEN physician. This expert must visit the patient and evaluate their situation for themselves. While the KNMG recognises that it may be difficult for the patient to undergo the consultation with both the independent expert and a SCEN physician, the importance of a careful and cautious procedure takes precedence.
- In the case of a euthanasia request from a patient with advanced dementia, the KNMG recommends that, prior to the consultation stage, the performing physician also consult other persons, such as previous practitioners and staff involved in the patient's daily care (see also **Section 2.3**). The physician should duly report this in the medical records and on the notification form.
- If the performing physician intends to perform euthanasia and has already consulted an independent expert, they must subsequently consult a SCEN physician (see **Section 2.7.5**).⁴² The SCEN physician must see the patient in person and make an effort to communicate with the patient, even though this may prove difficult in practice.
- In addition to their own observations, the SCEN physician must also obtain information from the performing physician and additional information from others to arrive at an opinion and make their report. This information includes the medical records, letters from specialists, the advance directive for euthanasia, information communicated verbally by the requesting physician, relatives and/or caregivers, and the opinion of the independent expert consulted. In case of a patient with advanced dementia, it is advised that, given the specific dilemmas that may arise, the SCEN physician should also discuss the medical and technical aspects of performing euthanasia in their consultation report.
- The performing physician is responsible under the Act, and the independent expert's advice and the SCEN physician's opinion are not binding. In situations calling for extra caution, such as in the case of patients with dementia, if the SCEN physician gives a negative opinion and the performing physician disagrees with this, it is advisable to consult a second independent SCEN physician. This second SCEN physician must also be informed of the opinion issued by the first SCEN physician. If the second SCEN physician also gives a negative opinion, the performing physician must consider whether it is responsible to carry out the euthanasia procedure. If the performing physician decides to deviate from the negative opinions, they must provide a proper substantiation for this. Deviating from the opinion of the SCEN physician may lead to additional questions from the RTEs. It is not professionally responsible to repeatedly consult a new SCEN physician until a positive opinion is obtained.

More information on the consultation on euthanasia can be found in **Sections 2.3** and **2.7.5**.

3.4.6 Due care criterion 6: with exercise of due medical care

The final due care criterion in the Act is that euthanasia must be performed with exercise of due medical care (see **Section 2.7.6** for a general explanation of this due care criterion).

If there are indications that the euthanasia procedure may give rise to distress, agitation or aggression in a patient with advanced dementia, the physician may decide, in exceptional situations, that premedication is appropriate, without being able to communicate with the patient about this.

- Euthanasia must be performed with the exercise of due medical care and in the most comfortable manner for the patient.

⁴² Dealing with people with dementia requires specific skills. Not every SCEN physician is adequately equipped for this. It is part of the SCEN physician's professional responsibility to determine whether they are competent to do this. If necessary, the SCEN physician may involve others when forming their opinion, or they may hand over the responsibility for the consultation to an expert fellow SCEN physician.

- The **KNMG/KNMP Richtlijn Uitvoering Euthanasie en hulp bij zelfdoding** (Guideline on the Performance Euthanasia and Assisted Suicide Procedures) also outlines the framework for the exercise of due medical care in case of euthanasia in a patient with advanced dementia.
- For a patient with advanced dementia, special attention must be paid to the preparation for performing euthanasia. If there are indications that the euthanasia procedure may give rise to distress, agitation or aggression in this patient, the physician may conclude, in exceptional situations, that premedication is appropriate, without being able to communicate with the patient about this. The premedication is intended to put the patient in a light sleep.⁴³ The KNMG stresses the need to carefully assess and justify the administration of premedication, because it is no longer possible to agree on this with a decisionally incompetent patient.
- The KNMG advises the physician to discuss the possible administration of premedication in advance with the patient when they are still decisionally competent and to make a note about this in the medical records. But even if the physician has done this, it does not mean that premedication is always justified. The physician will have to assess, on a case-by-case basis, whether premedication is appropriate and necessary.
- Even if the patient is decisionally incompetent, the guiding principle for the KNMG is that the physician should try to communicate with the patient about euthanasia and the method by which this will be carried out. In any case, the physician should make a few attempts at communication, unless this is detrimental to the patient, for example, because it causes severe agitation or distress. The physician should make a note of the considerations in the medical records and the notification form. The physician should also discuss the administration of the premedication with the patient's legal representative and/or relatives.

⁴³ See the **KNMG/KNMP Richtlijn Uitvoering Euthanasie en hulp bij zelfdoding** (Guideline on the Performance Euthanasia and Assisted Suicide Procedures) for a further definition of premedication.

Appendix 1. Euthanasia in Dementia project – justification and results

Introduction

In the Euthanasia in Dementia project, the KNMG studied the conditions under which it is professionally responsible to perform euthanasia on people in different stages of dementia. The outcome of this project is described in Chapter 3 of the present KNMG Guideline on End-of-Life Decisions. This project is based on various sub-studies. Below is an account of the set-up of the entire project and sub-studies, the results and how the results of the sub-studies have been incorporated in **Chapter 3** of this guideline.

Reason and purpose of the project

There is an ongoing debate in society about whether euthanasia is acceptable in the case of decisionally incompetent people with dementia on the basis of an advance directive for euthanasia. This public debate has partly arisen because the RTEs have concluded on a number of occasions in recent years that physicians did not act according to the legal due care criteria in the case of euthanasia in patients with advanced dementia. In one case, the Supreme Court handed down two rulings in April 2020: one in the criminal case and one in the disciplinary case.⁴⁴ In this case, the Supreme Court confirmed that euthanasia in patients with advanced dementia is covered under the framework of the Act in some situations.

The social unease caused by the discussion was also reflected in the media. This was partly prompted by the 'Niet stiekem bij euthanasie' (No Backdoor Euthanasia) campaign, in which a group of physicians signed a petition expressing reservations about euthanasia in decisionally incompetent people. This was followed by various opinion pieces by advocates and opponents.

What also contributes to the social unease and the pressure on physicians is the lack of clarity in society (and among our supporters) about the KNMG's standpoint. There is a perceived discrepancy between statements made by the KNMG in 2012 and 2015 with regard to euthanasia in people with advanced dementia.⁴⁵

In addition, the third evaluation of the Act also indicates that there is currently an ambiguity regarding the KNMG's position on euthanasia for advanced dementia.

In a response to the above evaluation and the resulting social unease, the KNMG has pledged to develop a guideline on this issue so as to remove this ambiguity. Discussions with the KNMG's federation partners and the physicians concerned have shown that, apart from clarity about the KNMG's standpoint, there is also a need for guidance for physicians on how to handle, from a professional perspective, a request for euthanasia from patients in different stages of dementia.

To this end, the Euthanasia in Dementia project was launched. The purpose of this project was to formulate a vision for the KNMG outlining the professional standard for issues relating to euthanasia for people with dementia. The project aimed to set out the conditions under which it is professionally responsible to perform euthanasia on people with dementia.

Management of the project

The Euthanasia in Dementia project began in June 2018. The project was managed by the KNMG. In addition, a project group was set up with representatives from the KNMG's federation

⁴⁴ Supreme Court, 21 April 2020, [ECLI:NL:HR:2020:712](#) (criminal case) and [ECLI:NL:HR:2020:713](#) (disciplinary case).

⁴⁵ In 2012, the KNMG stated that it is necessary for SCEN physicians to be able to communicate with the patient at all times to assess whether the due care criteria under the Act have been met. In December 2015, the KNMG collaborated on preparing the *Handreiking schriftelijk euthanasieverzoek* (Guide to Advanced Directives for Euthanasia), which states: 'However, very exceptional situations may arise where, in addition to the dementia, the patient suffers unbearably from additional physical symptoms such as a severe tightness of the chest or pain. Anxiety, aggression or agitation may also contribute to unbearable suffering. In those rare cases, a physician may comply with the request for euthanasia even if the patient can no longer confirm this request with words or gestures.'

partners: the National Association of General Practitioners (*Landelijke Huisartsen Vereniging*, LHV), the Association of Elderly Care Physicians (*Vereniging van Specialisten in ouderengeneeskunde*, Verenso), the Association of Medical Specialists (*Federatie Medisch Specialisten*), the Association of Medical Students (*De Geneeskundestudent*), the National Association of Salaried Doctors (*Landelijke vereniging van Artsen in Dienstverband*, LAD) and the Association of Public Health Physicians (*Koepel Artsen Maatschappij en Gezondheid*, KAMG). The project group was assisted by an advisory group consisting of 15 physicians with varying visions, expertise and experiences. Their task was to provide both solicited and unsolicited advice to the project group.

Sub-studies

The KNMG conducted several sub-studies in order to arrive at a broadly supported and practical vision. With this, the KNMG tried to gain an insight into the diversity of medical and social views. The design and conclusions of the various sub-studies are briefly described below.

Sub-study A. Analysis of current guidelines

This sub-study analysed the KNMG's documents on euthanasia from 2002 to 2018. The purpose of the analysis was to create an overview of what the KNMG has written about euthanasia in dementia over the years, with a specific focus on advanced dementia. The documents were studied and compared based on four predetermined key concepts that play a role with respect to euthanasia in dementia. These key concepts are suffering, communication, decisional incompetence and the advance directive.

Conclusions

The main conclusions from this analysis are as follows:

- If an earlier guideline is not rejected in clear terms, it becomes unclear whether that guideline is still valid. It is recommended that relevant information from previous publications should be presented coherently and by topic, so that important information is no longer scattered throughout the earlier texts.
- It is often unclear whether a reference is being made to the law in order to describe the situation or whether the KNMG is taking over the information and incorporating it into its own vision. This creates ambiguity about what falls under the professional framework and what does not.
- The words 'may' and 'can' are not always used in the proper context. 'Can' refers to the possibility of something. 'May' refers to the moral desirability or acceptability of something happening.

Based on the above analysis, the KNMG decided to formulate an overarching Guideline on End-of-Life Decisions, which combines existing guidelines and replaces certain guidelines. This is better than simply stacking up the guidelines and helps provide clarity on the validity of the guidelines.

Sub-study B. Ethical and legal analysis

This sub-study reviewed the literature on legal and medical ethics in relation to euthanasia in cases of dementia, advanced or otherwise. Relevant case law, RTEs' opinions, annual reports and euthanasia codes were also analysed.

Analysis of annual reports, codes and RTEs' opinions

The annual reports (1998 to 2019), the Code of Practice (2015) and the Euthanasia Code (2018) were studied, with a particular focus on the passages on dementia and decisional competence or incompetence. In addition, a selection was made from the published opinions of the RTEs on euthanasia in dementia in the period 2012-2019 (n=95).⁴⁶ The selected opinions (n=36) were further analysed.⁴⁷ This selection includes reports in which the RTEs found that the due care criteria

⁴⁶ From 2012 onwards, the RTEs have published their opinions online.

⁴⁷ This is a qualitative study. The RTEs' opinions do not always clearly indicate the patient's situation. The selection was made based on published opinions. The selection criterion for publication is that the opinion is or may be of interest for the development of norms regarding euthanasia in general and for improving the expertise of physicians and other interested parties in particular.

had not been met, regardless of whether there was a question of incipient or advanced dementia. The notifications for which the RTEs found that the due care criteria had been met were analysed in more detail if they involved advanced dementia cases or any actual or potential bottlenecks.

Some key findings:

- Since 2009, a total of 1,033 notifications on euthanasia in dementia have been reviewed by the RTEs (out of a total of 54,469). In 2011, euthanasia in a patient with advanced dementia was notified to the RTEs for the first time (Case 7, RTEs' annual report). In 2012, the RTE ruled for the first time that the due care criteria of the Act had not been met in a case of euthanasia performed on a patient with advanced dementia (RTE ruling 2012-08). In relative terms, there has been no increase in the number of euthanasia notifications for patients with dementia. In the period 2014-2019, the aforementioned notifications are between 2 and 2.5% of the total number of notifications.
- There are six notifications of euthanasia in dementia in which the RTEs found that the due care criteria under the Act had not been met. Three patients had incipient dementia, and three had advanced dementia. In two of the opinions related to incipient dementia, the RTEs found that the due care criterion of consultation or exercise of due medical care had not been met or not been met in the right manner. In the three notifications where the patient had advanced dementia, one or more key criteria were not met: such as the criterion of a voluntary and carefully considered request or that of unbearable suffering with no prospect of improvement.
- According to the RTEs, in the case of patients with dementia, it is necessary to always (and not only in the later stages) pay extra attention to the legal due care criteria; in particular, the criteria relating to decisional competence and unbearable suffering. In the case of euthanasia at a later stage, the RTEs believe that the physician should consult a SCEN physician as well as an expert physician in the field (such as a geriatrician, a geriatrics specialist or an internist-geriatrician).
- The RTEs attach great importance to ensuring that an advance directive for euthanasia is updated and discussed when the patient is still decisionally competent to do this. A long-term/good treatment relationship between physician and patient is also considered important. The RTEs also value good record-keeping, where both the physician and the consultant meticulously formulate the considerations and the underlying facts and circumstances.
- Although there is much discussion of and attention for patients with advanced dementia, euthanasia in this group of patients occurs rarely, if at all. The advance directive for euthanasia rarely replaces the actual oral request. About 10 to 11 notifications show that, as a whole, patients were completely unable to communicate about the desire for euthanasia. Indeed, the advance directive for euthanasia tends to be used as a supporting document, especially when communication with the patient becomes more difficult because of the state of dementia. From the legal perspective, there is a clear distinction between euthanasia based on an oral request at the time in question and one based on an advance directive for euthanasia. But this distinction is less clear in practice. There is a lack of clarity about the patient's condition in some of the RTEs' opinions on euthanasia in patients with dementia. This is partly due to the use of ambiguous terms when describing the stage of dementia or the patient's situation. Until now, cases of euthanasia in patients with advanced dementia have occurred at most twice a year. But that does not mean that, in all the other cases of euthanasia in dementia, there was never any doubt, for example, about the decisional competence of the patient, or that there were no communication issues. In other words, by no means are all or all the remaining patients definitely in the early stage of dementia.

Case law

Since the introduction of the Act, two cases on euthanasia in dementia have been brought before the court. In one of these cases (RTEs' opinion 2016-85), the Supreme Court gave its ruling on 21 April 2020 and set out frameworks for euthanasia in case of advanced dementia. The ruling relates to both the criminal and the disciplinary case that occurred earlier in the case. In another case (RTEs' opinion 2017-103), the Regional Healthcare Disciplinary Board (*Regionaal*

Tuchtcollege voor de Gezondheidszorg, RTG) issued a ruling. The Public Prosecution Service did not prosecute in this case.

The main conclusion from the Supreme Court's ruling is that the law allows a physician to perform euthanasia on a person who has previously prepared an advance directive for euthanasia but who, due to advanced dementia, is no longer able to express their wishes about their desire to die. However, for a patient with dementia, an advance directive for euthanasia alone is not sufficient. If the physician wishes to act on the basis of a previously prepared advance directive for euthanasia, they will need to be convinced, just as in the case of other requests for euthanasia, that all the due care criteria prescribed by the Act have been met. Euthanasia in a patient with advanced dementia is an exceptional situation and must be handled with a great degree of caution, according to the Supreme Court.⁴⁸

The RTG ruling emphasised that a qualitatively inadequate SCEN report cannot serve the purpose of a SCEN consultation, i.e. to contribute to careful decision-making. If a physician is not satisfied with the quality of the SCEN report, the performing physician should not accept it but should 'return it' with a request to adjust the report or consult another independent SCEN physician. Moreover, the RTG ruling implies that, although the responsibility for the decision to proceed with euthanasia lies with the performing physician, an adverse opinion with critical questions from the SCEN physician should lead to a sufficient and more detailed reflection/examination by the performing physician. Particularly in the case of euthanasia for a patient with advanced dementia (which is the subject of debate both within and outside the profession and especially in the Netherlands), the RTG believes that this should be handled with even greater caution than normal.⁴⁹

Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act in relation to other legislation and international law

In the Netherlands, there is debate among legal experts about the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (*Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding*, WtI; hereinafter: 'the Act') in relation to international law and the right to self-determination. The highest court of justice in the Netherlands, the Supreme Court, has set out, in cassation, the framework for euthanasia in cases of advanced dementia. The main conclusion is that, in the Netherlands, the Act allows physicians to perform euthanasia on persons who have previously prepared an advance directive for euthanasia but who, due to the state of advanced dementia, are no longer able to express their wishes about their desire to die. There is no case law from which it follows that the Act – in particular, the provisions of Section 2(2) – is contrary to European or international law. For the KNMG, the currently applicable law and case law are the starting point for its Guideline on End-of-Life Decisions.

There are also questions about the relationship between the Act and the Care and Compulsion (Psychogeriatric and Intellectually Disabled Patients) Act (*Wet zorg en dwang psychogeriatrische en verstandelijk gehandicapte cliënten*, Wzd). In this regard, we note that euthanasia is not the same as care within the meaning of the Wzd. The Wzd and the Act are two different laws with two different contexts. The Wzd deals with whether involuntary care may be used. The Act applies when a request for euthanasia is involved. Only the Wzd contains exceptions to the principle of voluntariness, and therefore to acting without consent. Under the Act, a physician may only perform euthanasia at the patient's request. Even if this request is an advance directive for euthanasia, from a patient who is no longer decisionally competent at the time of euthanasia, it must be a voluntary and carefully considered request. If the physician concludes that the patient's request cannot be regarded as voluntary and carefully considered, euthanasia will not be performed. This is in line with Minister De Jonge's explanation of the relationship between the two laws, as outlined in various letters to Parliament.⁵⁰

⁴⁸ See also this [news article](#)

⁴⁹ RTG Amsterdam 17 August 2020, [ECLI:NL:TGZRAMS:2020:93](#).

⁵⁰ Letter from the Minister of Health, Welfare and Sport to the President of the Senate dated 28 August 2018, [Parliamentary Papers I 2017/18, 31 996, F](#) and letter dated 28 September 2018, [Parliamentary Papers I 2018/19, 31 996, G](#).

Ethical perspective

The relevant literature was identified and reviewed from the perspective of legal and medical ethics. Based on this literature, we examined the ethical issues involved in cases of euthanasia in advanced dementia. Key questions that arise from this are: Can the person 'from the past' take decisions about the person they may be in the future, or in other words, 'the present person'? And can a previously prepared voluntary and carefully considered advance directive for euthanasia by a person be relied upon as a voluntary and carefully considered request by that same person at a later time, if that request can no longer be expressed? And can it actually be determined whether the suffering of a decisionally incompetent person is 'unbearable' if that person can no longer clearly indicate this themselves?

In conclusion, the ethical dilemmas posed by euthanasia in advanced dementia cases cannot be unequivocally resolved. But this does not mean that euthanasia in persons with advanced dementia based on an advance directive for euthanasia is entirely unjustifiable and must be ruled out. However, the existence of these ethical dilemmas necessitates extra caution when deciding on such a euthanasia request. This requires a careful consideration of all the circumstances of the specific case, where a proper assessment of the various interests can be made only on a case-by-case basis.

Sub-study C. Roundtable discussions

Two roundtable discussions were held in the spring of 2019 with experts in ethical, legal and social aspects and delegates from social, professional and patients' organisations to discuss the conditions under which it is professionally responsible to perform euthanasia on people in different stages of dementia.

During these discussions, the following dilemmas were addressed from different perspectives (patient, relatives and physician):

Dilemmas faced by the patient

- The patient faces the spectre of living with dementia. They do not want the disease to make them a different person from who they were before. Euthanasia seems to be the only way out. Through this, they hope to bring clarity and save their relatives trouble and grief.
- The patient discusses this with their GP and their relatives and prepares an advance directive or request for euthanasia. The GP stores the document in the patient's medical records. In many cases, the patient and relatives think this matter has been settled for good.

Dilemmas faced by relatives

- For the relatives, it is sad and painful to witness the gradual deterioration and loss of dignity for the patient. If this last stage continues for a long time, the burden can become very heavy. If the patient has prepared an advance directive for euthanasia, relatives feel responsible for ensuring that this is complied with. Especially if the patient is decisionally incompetent and can no longer speak for themselves. The relatives see this as the last thing they can do for the patient.
- The relatives will talk to the responsible physician if they want the advance directive for euthanasia to be complied with. They assume that this statement is adequate because the patient has prepared it in consultation with the GP. They do not expect to face any problems, even if another physician has taken over the responsibility for care in the meantime.

Dilemmas faced by the physician

- A physician must fulfil the legal due care criteria. One of these criteria is that the patient must undergo unbearable suffering. Sometimes, the physician may perceive this differently than the patient and/or the relatives.
- The patient's advance directive is often not clear.

- There are so many forms of dementia that it is difficult to predict how a patient will experience the different stages of their disease. For example, they may appear content one day and clearly unhappy the next.
- The patient's suffering may be partly caused by deficiencies in care. This is what the physician needs to discuss with the patient and/or relatives. To what extent is quality of care a factor in the request for euthanasia?
- Relatives have their own interests and views. There may be feelings of guilt ('I promised this wouldn't happen to them'), and the burden of care may also play a role ('How long does this have to go on?'). How does the physician take the family's input into account in their assessment? And what if the relatives disagree among themselves?
- The end-of-life conversation often starts late, possibly even too late. The focus is often purely on the patient's advance directive/euthanasia request. This conversation with the patient and their relatives should be carried out earlier on in the process and in depth.

Sub-study D. Quantitative study (Panel of Physicians)

In summer 2019, the KNMG conducted a quantitative survey among the physicians on its Panel of Physicians. A total of 853 physicians participated in this survey.

Key results:

- Slightly more than half of the physicians surveyed think they would definitely or probably be willing to perform euthanasia in future on a decisionally competent patient with dementia.
- According to the physicians, the chance is much smaller that they will do the same for a decisionally incompetent patient with dementia based on an advance directive for euthanasia. In such a case, 1 out of 10 physicians think they would definitely or probably be willing to perform euthanasia. The likelihood of being willing to do this in future is rated the highest by medical specialists (23% 'Definitely'/'Probably'). Physicians who have experience with euthanasia rate this likelihood the lowest (3% 'Definitely', 9% 'Probably').
- Of the physicians surveyed, 79% agreed with the statement 'It is not professionally responsible to perform euthanasia on a decisionally incompetent patient with dementia solely on the basis of an advance directive for euthanasia'. Geriatric specialists (93%) and GPs (87%) tend to agree with this more often.
- Of the physicians, 67% agree with the statement 'Euthanasia in case of dementia is only professionally responsible at the stage when a person can still communicate in some way about their suffering and the desire for death. Geriatric specialists (82%) and GPs (77%) tend to agree with this more often.
- A majority of physicians feel that administering a sedative without the patient being aware of this is not professionally responsible. Physicians with experience with euthanasia are more likely to find this not professionally responsible than physicians without experience (73% vs. 61%). Compared to other specialists, geriatric specialists (71%) and GPs (69%) are more likely to consider this as not being professionally responsible.
- In response to an open-ended question about what standpoint the KNMG should adopt in the matter of euthanasia in cases of dementia, the most frequent response (27%) was 'Exercise restraint'.

Sub-study E. Qualitative study (focus groups)

The focus groups described below were set up on the instructions of the KNMG and conducted by Pallas health research and consultancy.

Focus groups with informal caregivers

Together with Alzheimer Nederland, 2 focus groups were organised in early 2020 with a total of 15 informal caregivers of people with dementia. These meetings discussed end-of-life issues and euthanasia.

Key findings:

- Most of the informal caregivers indicated that they themselves had contacted the GP or another physician to initiate the end-of-life conversation. If the patient is still living at home, the

GP should initiate the discussion regarding end-of-life wishes and options. Sometimes, it is easier to simply talk with the specialist, since they have greater expertise in the field of dementia.

- Once the diagnosis has been made, there should be a plan on how to proceed, what needs to be taken care of, what the potential issues may be, etc. The physician must draw up the plan or take the initiative for this. However, it should be kept in mind that the patient and their relatives may not be open to such a conversation at the time of diagnosis. In that case, it is better to have the conversation about the end of life at a later time. Even so, it is important to initiate the end-of-life discussion in time to ensure that the patient has the chance to express or formulate their own wishes.
- For the informal caregivers, it is important that the GP or other physician concerned is a good discussion partner and is open to the conversation even if, for example, they are not in favour of euthanasia.
- A GP or other physician concerned may also take the initiative to review the patient's wishes or needs every six months so that the information is up to date. At the same time, it is also important that they trust the opinions and expertise of the informal caregiver. Informal caregivers prefer to be in charge when the authorities pay a visit and want to talk to the patient. The informal caregiver knows what works best for the patient.
- The GP or other physician concerned often takes a medical approach to the situation, while the psychosocial aspect of the disease and life is also important. A dementia coach would be a good counterpart to talking to the physician.
- The end-of-life process and saying goodbye is essentially a family matter; how this is handled varies from culture to culture. It is indicated that there is too little knowledge about the end of life and intercultural care.
- It is also indicated that the patient themselves should be in charge when it comes to euthanasia. If the patient can no longer decide for themselves, informal caregivers feel that they should take the decisions on behalf of the patient. Relatives often have a good idea of what a patient would want. For example, the patient could designate someone they trust to take the decision on their behalf. The patient should clearly state their wishes for different scenarios and situations. However, it can be difficult for a patient to look ahead. The GP or other physician concerned can further explain the prospects in a better manner and help the patient with this.
- Some informal caregivers feel that the earlier formulated opinion of a person with dementia should count at all times. They want their loved one to be able to fulfil the wish they had while making the advance directive, even if this means that a patient must be sedated during euthanasia. However, it must be ensured that the patient's wishes have been clearly expressed at an earlier stage. Checklists can be used for this, with the help of which all possible scenarios can be thoroughly discussed in advance.
- There are people who indicate that they find this difficult. Dementia patients are capable of stretching their limits, and their personality may also change over the course of the disease. One of the dilemmas mentioned is that one no longer knows exactly what is going on in the patient's mind. As an informal caregiver, you do not know what it is like to have dementia. Is someone really suffering, or do you, as an informal caregiver, feel that someone is suffering? Also, this suffering can vary from day to day. If a person no longer expresses a desire for euthanasia, it is difficult to allow the euthanasia procedure to proceed. This also applies to sedation, when the patient no longer knows or understands what is happening and cannot express what they think about this.

Focus groups with physicians

In late 2019/early 2020, 27 physicians participated in 3 focus group meetings. The purpose of these focus group meetings was to gain insight into the decision-making process of physicians when faced with a euthanasia request from a patient with dementia, with a focus on advanced dementia. What factors play a role? This also helped us gain an understanding of how the due care criteria are applied. Most physicians (n=25) had encountered a request for euthanasia from a patient with dementia at some point during their career (either as an attending physician or as a SCEN physician). More than half the physicians (n=16) had experience in performing euthanasia on a patient with dementia.

Key findings:

- With regard to decisional competence: if patients can no longer express themselves properly using language, it is important to look at the course of the disease/medical history, previous advance directives and the heteroanamnesis. It helps if a physician knows the patient and their past history well and has spoken to the patient several times about their wishes. The physician can ask the same questions each time to determine if the patient is consistent in their answers.
- When it is no longer possible to talk to patients about their suffering, a physician may rely on observations. These include behavioural characteristics such as aggression, screaming, self-injury, confusion or other behaviours that show a person is suffering severely.
- It helps if a physician knows the patient's life story, has spoken with them often, knows what they were like before the onset of the disease and how this relates to the current manifestations. Coordinated and integrated care and proactive care planning are important: care providers who know the patient well should be involved as early as possible in the care process; future care and end-of-life decisions should be discussed with the patient early on.
- An advance directive in itself does not provide a sufficient basis for performing euthanasia. The due care criteria must also be met. A physician assesses the patient's current communications and takes into account any inputs from the patient's surroundings; these should be clear and consistent.
- In euthanasia cases, it is important to consider the combination of unbearable and untreatable suffering. In a multidisciplinary context, options for reducing the psychological or other forms of suffering should be explored.
- There is debate about whether unbearable suffering can be clearly established in decisionally incompetent patients and whether euthanasia should be possible for this group. Some physicians believe that euthanasia in decisionally incompetent patients calls for a separate law, because the application of euthanasia to decisionally incompetent patients is fundamentally different from that in case of decisionally competent patients. An assessment process carried out in advance, rather than after the fact, could potentially reduce anxiety and uncertainty among physicians.
- As a physician, it is important to alert the patient to the progress of dementia and discuss the available options with them (proactive care planning). The purpose of this conversation is not only to discuss the options relating to euthanasia, but also to allow the physician to indicate the framework applicable to them and the limits thereof.
- As far as possible, patients should be prevented from changing their physician at a late stage. It is exceedingly difficult for a physician who does not know the patient well to assess the information in an advance directive and pursue a course of euthanasia.
- The 'right' time for euthanasia is difficult to determine. The law allows euthanasia to be performed on decisionally incompetent patients, but in practice, people want to avoid this situation.
- The questions relating to decisionally incompetent patients who struggle or resist at the time of euthanasia evoke varying reactions among physicians. Some consider resistance as a definite 'no go'. Others indicate that it is crucial to interpret the patient's resistance: is it a response to a physical stimulus (e.g. a needle) or is it about the euthanasia itself? It is important to go over all the potential scenarios with the family beforehand; suddenly terminating the euthanasia procedure is an extreme measure.

Publication details

KNMG – Leading the way for physicians and health care

The KNMG Guideline on End-of-Life Decisions of the Royal Dutch Medical Association (*Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst*, KNMG), approved by the Federation Board on 18 November 2021.

Leading the way for physicians and health care. The KNMG works to enhance the quality of our health care and ensure that over 65,000 physicians and medical students can practise their profession in an optimal manner. To make sure that physicians can provide care to those who need it.

The KNMG consists of the following member organisations: the Association of Medical Students (*De Geneeskundestudent*), the Association of Medical Specialists (*Federatie Medisch Specialisten*), the Association of Public Health Physicians (*Koepel Artsen Maatschappij en Gezondheid*, KAMG), the National Association of Salaried Doctors (*Landelijke vereniging van Artsen in Dienstverband*, LAD), the National Association of General Practitioners (*Landelijke Huisartsen Vereniging*, LHV), the Netherlands Society of Occupational Medicine (*Nederlandse Vereniging voor Arbeids- en Bedrijfsgeneeskunde*, NVAB), the Netherlands Society of Insurance Medicine (*Nederlandse Vereniging voor Verzekeringsgeneeskunde*, NVVG) and the Association of Elderly Care Physicians (*Vereniging van Specialisten in ouderengeneeskunde*, Verenso).

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KNMG Guideline End-of-Life Decisions
is een uitgave van artsenfederatie KNMG
18 november, 2021, Utrecht