Preface to the revised edition

Following the Supreme Court judgments of 21 April 2020.

This is the revised edition of the Euthanasia Code 2018, amended following the Supreme Court judgments of 21 April 2020 concerning a notification of euthanasia involving a patient with advanced dementia. The judgments prompted the regional euthanasia review committees (RTEs) to revise sections 4.1 ‘Advance directive’ and 4.4 ‘Patients with dementia’ of the Euthanasia Code 2018.

The other sections of the Euthanasia Code 2018 were left unchanged. The RTEs intend to update the entire Euthanasia Code in 2021 on the basis of current developments and comments received on the present version. In the committees’ view, however, the changes prompted by the Supreme Court judgments cannot wait that long and they have therefore opted for this temporary solution. Anyone preferring to use a printed version of the Euthanasia Code 2018 can download and print the supplement.

J. Kohnstamm, coordinating chair of the regional euthanasia review committees
The Hague, October 2020

Supplement containing revised sections of the Euthanasia Code 2018 following the Supreme Court judgments of 21 April 2020 concerning euthanasia for patients with advanced dementia

4.1. ADVANCE DIRECTIVE

Section 2 (2) of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act stipulates that a patient aged 16 or over who is decisionally competent in the matter may draw up a written directive setting out a request for euthanasia ('advance directive'). If at some point the patient is no longer capable of expressing his will (due to, for instance, advanced dementia, aphasia, reduced consciousness or the administration of palliative sedation), the physician may accept the advance directive as a request pursuant to section 2 (1) (a) of the Act. The advance directive thus has the same status as an oral request for euthanasia.[35]

The Act does not limit the validity of an advance directive, nor does it require the directive to be regularly updated. However, the older the directive, the more doubt there may be as to whether it still reflects the patient's actual wishes. The directive will carry more weight if the patient has updated his advance directive, or orally reaffirmed its content. It is important that the patient describe as specifically as possible the circumstances in which he would wish his life to be terminated. It is the responsibility of the patient to discuss his advance directive with his physician when he drafts or updates it. The physician should include this information in his medical records. A personal directive drawn up by the patient in which he gives a description in his own words will generally be regarded as more significant than a pre-printed, standard form.

Due care criteria apply *mutatis mutandis*

Section 2 (2) of the Act states that, in the event of an advance directive, the due care criteria mentioned in the Act apply *mutatis mutandis*. This means, in accordance with the legislative history, that the due care criteria apply to the greatest extent possible in the given situation.[36] In other words: the due care criteria must be applied in a way that does justice to the exceptional nature of such cases. The physician must take account of the specific circumstances of the case; for instance, the patient may no longer be capable of communicating or responding to questions. The physician will generally have spoken with the patient when he was still capable of expressing his will. If a situation subsequently arises in which the patient's advance directive comes into play, information obtained in previous conversations with the patient will be particularly useful to the physician.

If euthanasia is performed on the basis of an advance directive, the due care criteria apply *mutatis mutandis*. The following observations can be made in this respect.

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

The physician must be satisfied that the patient's advance directive was drawn up voluntarily and after thorough consideration. The physician must base his conclusion on his own assessment of the medical records and the patient's specific situation, consultations with other health professionals who are or have been in a treatment relationship with the patient, and consultations with family members, as oral verification of the patient's wishes is no longer possible.

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[35] See the letter from the Minister of Health, Welfare and Sport of 4 July 2014 on the advance directive with regard to euthanasia.

[36] This is set out in the explanatory memorandum to the amendment of the Act, concerning the addition of the second sentence to section 2 (2) (Parliamentary Papers, House of Representatives, 26 691, no. 35).

The physician must also establish that the patient's current situation corresponds to the situation described by the patient in his advance directive. The first step is to establish the content of the advance directive. In doing so, the physician must study the advance directive with a view to determining the patient's intentions. The physician must take note of all circumstances of the case, not just the literal wording of the request. In other words, there is some room for interpretation of the advance directive.

At the very least, it must always be possible to infer from the advance directive that the patient requests euthanasia in situations in which he is no longer capable of expressing his will. If the patient also wants his request to be fulfilled in the event that his unbearable suffering is not of a physical nature, it must also be apparent from the advance directive that the patient considers his expected suffering in this situation to be unbearable for him and that this is the basis for his request.

The physician must be alert to contraindications that are inconsistent with the request for euthanasia, as apparent from verbal utterances and actions on the part of the patient. The physician will have to assess whether any such contraindications preclude the performance of euthanasia. Contraindications from the period when the patient was still capable of expressing his will can be interpreted as a revocation or amendment of the previously drawn up advance directive. In that case euthanasia cannot be performed. Contraindications from the period when the patient was no longer capable of expressing his will (for instance, due to advanced dementia) can no longer be interpreted as a revocation or amendment of the previously drawn up advance directive. They can, however, be interpreted as an indication which, in combination with the patient's condition and behaviour as a whole, is relevant for the assessment of the patient's current physical and mental state. This assessment is also relevant to the question of whether the patient is suffering unbearably, which will be discussed below.

The physician is not required to inquire about the patient's current wish to live or die if the patient is no longer capable of expressing his will. No such requirement is laid down by the Act. The specific position of a patient who is no longer capable of expressing his will means that oral verification of his wishes and his suffering is not possible. A verification requirement would be incompatible with the advance directive, which is specifically intended for situations in which the person who drew it up is no longer capable of expressing his will.

b. The physician must be satisfied that the patient is suffering unbearably and that there is no prospect of improvement

When euthanasia is performed, the physician must be satisfied that the patient is experiencing unbearable suffering.[37] There may be current unbearable suffering caused by physical illness or injuries, but there may also be current unbearable suffering if the patient is in the situation he described in his advance directive as what he expected would cause unbearable suffering to him. However, the mere circumstance that the patient is in the situation described in the advance directive is not a sufficient basis to conclude that the patient is indeed currently suffering unbearably. The physician must always determine in a careful and transparent manner whether the patient is indeed currently suffering unbearably. The physician can base his conclusion on his own assessment of the medical records and the patient's specific situation, consultations with other health professionals who are or have been in a treatment relationship with the patient, and consultations with family members. If the physician is not satisfied that the patient is currently suffering unbearably, euthanasia cannot be performed.

Establishing whether a patient is actually suffering unbearably and without prospect of improvement is a professional medical assessment, and is therefore the prerogative of the physician. The retrospective review by the committee of whether the physician could be satisfied that the patient was suffering unbearably amounts to a limited review of whether the physician could reasonably conclude that the patient was suffering unbearably.

[37] An exception to the criterion requiring physicians to establish that the patient is suffering unbearably is described in section 4.7.

c. The physician informed the patient sufficiently about his situation and his prognosis

The physician must be satisfied that the patient has been informed sufficiently about his situation and prognosis and about the significance and consequences of his advance directive. Within the unavoidable limitations imposed by the patient's condition, the physician must also endeavour to communicate meaningfully about these issues with the patient, unless it is clear that these limitations make that impossible.

d. The physician and the patient have together come to the conclusion that there is no reasonable alternative in the patient's situation

The physician must be satisfied that there is no reasonable alternative in the patient's current situation, both according to prevailing medical opinion and in light of the patient's advance directive. The physician will have to base his conclusion on his own assessment of the medical records and the patient's specific situation, consultations with other health professionals who are or have been in a treatment relationship with the patient, and consultations with the patient's family members. As the patient is no longer capable of expressing his will, it is important that the physician carefully consider what the patient has written about this matter in his advance directive and what he said when he was still able to communicate.

e. The physician must have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out (a) to (d) have been fulfilled

This requirement applies in full to euthanasia for patients who are no longer capable of expressing their will. The Act stipulates that the independent physician must see the patient, which is still possible in this kind of situation. There will be little if any communication between the independent physician and the patient. This means that, in addition to his own observations, the independent physician will have to base his decision and his opinion on information from the physician and other sources. This may include the patient's medical records, oral information from the physician, letters from specialists, the content of the advance directive, and conversations with family members and/or carers. The fact that the patient is no longer capable of expressing his will generally gives cause for consulting a second independent physician with specific relevant expertise (such as a geriatrician, elderly-care specialist or an internist specialising in geriatrics). That expert must give an opinion, based if necessary on his own examination of the patient, on the patient's decisional competence, whether he is suffering unbearably with no prospect of improvement, and possible reasonable alternatives. In addition, it would be appropriate for the physician to give the independent physician and the expert the opportunity to comment on the specific procedure the physician intends to follow when performing euthanasia. If contact with both an independent physician and an expert puts an unacceptable burden on the patient, it may be sufficient to consult an independent (SCEN) physician with specific relevant expertise.

> See also section 3.6 and section 4.7.

f. Due medical care

One element of due medical care is that the physician takes into account possible irrational or unpredictable behaviour on the part of the patient when he is preparing for and carrying out the euthanasia procedure. The euthanasia procedure should be as comfortable as possible for the patient. If the patient is decisionally incompetent and there are signs that he may become upset, agitated or aggressive during the euthanasia procedure, the medical standards that the physician must observe may lead him to conclude that premedication is necessary. If no meaningful communication is possible with the patient as a result of the patient's situation, it is not necessary for the physician to consult with the patient about when euthanasia will be performed and what method will be used. Not only would such a conversation be pointless, because a patient in that situation can no longer comprehend the subject matter, but it could also cause the patient to become upset or agitated.

> See also section 4.4 Patients with dementia
> See also section 4.6 Patients with aphasia
> See also section 4.7 Coma/reduced consciousness
> See also section 4.8 Euthanasia and palliative sedation

ADVANCE DIRECTIVE POINTS TO CONSIDER

* Is the patient no longer capable of forming and expressing relevant wishes with regard to euthanasia?
* Was the patient decisionally competent with regard to his request for euthanasia when he included that request in his advance directive?
* Have the due care criteria been met to the greatest extent possible in the given situation? The due care criteria must be applied in a way that does justice to the exceptional nature of the case.
* The physician is not required to verify whether the patient currently wishes to die.
* Does the patient's current situation correspond to the situation described by the patient in his advance directive? The advance directive must be studied with a view to determining the patient's intentions.
* Are there any contraindications that are inconsistent with the advance directive and preclude the performance of euthanasia?
* Is the patient suffering unbearably?
* Has an expert been consulted in addition to the independent physician?
* Is premedication required? If no meaningful communication is possible with the patient, it is not necessary for the physician to consult with the patient about what method will be used (including the administration of premedication).

4.4. PATIENTS WITH DEMENTIA

In cases involving patients with dementia, there is also reason to exercise great caution when considering whether the statutory due care criteria have been met. This is especially true of the criteria relating to the voluntary and well-considered nature of the request, and unbearable suffering. As a patient's dementia progresses, his decisional competence will decline. After a time, the patient may become completely decisionally incompetent.

Still decisionally competent with regard to the request for euthanasia

In nearly all the cases so far notified to the committees, the patient still had sufficient understanding of his disease and was decisionally competent in relation to his request for euthanasia. Besides the actual decline in cognitive ability and functioning, the patient's suffering is often partly determined by their fear of further decline and the negative impact on their autonomy and dignity in particular (see also section 3.3). The key factor is the patient's perception of the progressive loss of personality, functions and skills, and the realisation that this process is unstoppable. This prospect can cause profound suffering in the present moment.

The regular procedure of consulting an independent physician will generally suffice if a patient with dementia is still decisionally competent with regard to his request for euthanasia. However, the patient must have been diagnosed with dementia according to prevailing medical practice. If there are any doubts as to the patient's decisional competence, it is wise for the physician to seek the advice of another physician with relevant expertise.

No longer decisionally competent with regard to the request for euthanasia

It is still possible to grant a request for euthanasia at the stage where dementia has progressed to such an extent that the patient is no longer decisionally competent, provided the patient drew up an advance directive containing a request for euthanasia when still decisionally competent.[42]
> For more on euthanasia on the basis of an advance directive, see section 4.1.

PATIENTS WITH DEMENTIA POINTS TO CONSIDER
• Is the patient still decisionally competent with regard to his request for euthanasia?
• If not, is there an advance directive? For more on euthanasia on the basis of an advance directive, see section 4.1.

[42] In such cases the review committees always invite the physician to give an oral explanation.