

# Evaluation of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act

## Summary

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## Summary

### Research (chapter 1, §12.2.1, appendices)

The Termination of Life on Request and Assisted Suicide (Review Procedures) Act (WTL) came into force in 2002. This Act makes it compulsory for physicians to report the administering of euthanasia or assisting in suicide to the municipal forensic pathologist. One of five regional euthanasia review committees (RTEs) subsequently determines whether the legally-established requirements of due care<sup>1</sup> have been complied with. The RTE's only forward cases to the legal prosecutor when the requirements for careful practice have not been met. Research has been carried out in connection with the evaluation of the WTL so as to provide insight into practical developments in medical decision-making at the end of life and into the efficacy and side effects of the WTL. In order to achieve this objective, a number of sub-studies have been carried out, each with its own terms of reference and design. A distinction has been made between a legal investigation oriented towards the juridical aspects of the evaluation of the Act, and a practical investigation that concentrates more on studying medical decisions and terminal care in practice. Each of these two parts has been further divided into a number of sub-studies as shown in Box 1. Most of the practical investigation is comparable to previous nation-wide investigations that were conducted in 2001, 1995 and 1990.

#### **Box 1: Sub-studies on the evaluation of the WTL**

##### *Sub-study I. Legal investigation*

- Ia Literature study
- Ib Interviews with relevant parties
- Ic Research into views held by organisations
- Id Research into RTE files
- Ie Interviews with RTE members

##### *Sub-study II. Practical investigation*

- Ila Death certificate study
- Ilb Physicians' study
- Ilc Research into guidelines, conducted at institutions and among physicians
- Ild Focus group research

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<sup>1</sup> The requirements for due care: a voluntary and well-considered request of the patient; unbearable suffering without prospect of improvement; having informed the patient about his situation and prospects; no more reasonable alternatives; having consulted at least one other, independent physician; having terminated the patient's life or provided assistance with suicide with due medical care and attention

## Practice

**Box 2: Estimated frequencies of medical end-of-life decisions and continuous deep sedation in the Netherlands in 2005 and 2001 (death certificate study)**

	2005		2001	
	Abs.	% <sup>1</sup>	Abs.	% <sup>1</sup>
<i>Medical decisions on end of life:</i>				
Euthanasia	2,325	1.7	3,500	2.6
Physician-assisted suicide	100	0.1	300	0.2
Ending of life without an explicit request of the patient	550	0.4	950	0.7
Intensified alleviation of pain or symptoms with hastening of death as a possible side effect	33,700	25	29,000	21
Abandoning potentially life-prolonging treatment	21,300	16	28,000	20
<i>Continuous deep sedation:</i>				
With medical end-of-life decisions <sup>2</sup>	9,700	7.1	8,500	6.0
Without medical end-of-life decisions	1,500	1.1	<sup>3</sup>	

1 Percentage of all deaths

2 Cases of continuous deep sedation in which a medical decision was taken with the shortening of the patient's life as a possible or intended consequence were, depending on the answers given by the physician, classified as abandoning life-prolonging treatment, intensifying the alleviation of pain or symptoms, or (rarely) as ending of life. These cases should therefore not be added to the total number of medical end-of-life decisions.

3 Unknown for 2001

### Medical decision-making at the end of life (chapters 5, 6, 7, §12.2)

Box 2 gives the major frequency estimations of medical end-of-life decisions in 2005 and 2001. Cases were classified as euthanasia when the physician had indicated that decease was caused by a medicine administered at the explicit request of the patient with the explicit intention of hastening the end of the patient's life. One of the most remarkable findings in the practical investigation is the decrease in euthanasia and assistance in suicide in 2005 compared to 2001 and 1995. The number of requests for euthanasia 'in due course' (from 34,700 in 2001 to 28,600 in 2005) and 'within the foreseeable future' (from 9,700 in 2001 to 8,400 in 2005) also have decreased. This decline is linked to a number of other developments. First of all, the absolute number of deaths in 2005 was less than in 2001, whereas the proportion of persons aged 80 and over (euthanasia and assistance in suicide occur relatively infrequently in this age group) was actually greater. Secondly, an increase was found in other methods of controlling the symptoms of patients in the terminal phase of their lives, such as continuous deep sedation. In addition, the majority of the physicians thought there is a clear connection between improvements in palliative care and the decrease in life-terminating action taken by physicians. And finally, the decrease in the number of cases of euthanasia can probably partly be explained in part by changes in opinions on the effects of morphine, which means that physicians are probably less inclined to attribute a life-shortening result to morphine. This has resulted in a decrease in the number of cases of life termination using morphine. We note here that in such cases, it is rather

a question of a different appreciation of physicians of their own actions than an actual change in behaviour.

As in the preceding years of research, euthanasia and assistance in suicide appear to be carried out predominantly by general practitioners, on patients with cancer and patients younger than 80 years of age. The most frequently-cited reasons for administering euthanasia and assistance in suicide (besides the patient's own request for life termination: their hopeless situation, loss of dignity and the presence of serious symptoms) and the degree of estimated shortening of patients' lives are also comparable with previous years. Life termination in the case of patients suffering from dementia who possess a euthanasia advance directive, elderly people who were "tired of life", and life termination at the request of minors took place very seldom in 2005.

### **Knowledge and attitudes towards the law** (chapters 8, 9, 10, §12.3)

A majority of physicians are of the opinion that the WTL has improved their legal certainty and contributes to the carefulness of life-terminating acts. Although nine out of every ten physicians have indicated that they are sufficiently *au fait* with the content of the WTL, their knowledge regarding a number of details appeared to be insufficient.

Physicians almost always adhere to the due care requirements during decision-making on a request for euthanasia, while 25% occasionally experience problems with the assessment of the due care requirements, particularly with regard to the requirements that a patient must suffer unbearably and hopelessly and that the patient must have made a voluntary and well-considered request.

In 2005, the percentage of cases reported was approximately 80%, which is a marked increase compared to 54% in 2001. The major reason for failure to report is that the physician does not regard the course of action as a life-terminating act. This is strongly related to the drugs used. In cases where physicians use drugs that are typical for euthanasia or assisted suicide (barbiturates and/or muscle relaxants), the percentage of cases reported is 99%, whereas this is only 2% if morphine is used.

More than two-thirds of the health care institutions in the Netherlands have a written policy on euthanasia and assistance in suicide, in which euthanasia is usually permissible under certain conditions. About one-quarter of these institutions do not as a general rule acquaint all the physicians and nurses employed at their institutions with this policy view. The majority of the physicians working at institutions is interested in practical guidelines for euthanasia. Six out of every ten institutions have indeed devised guidelines for euthanasia and assistance in suicide, and two thirds of the guidelines were adjusted since the WTL came into force in 2002. About one-third of the guidelines devised or revised since 2002 were actually stricter than the law as regards content. Moreover, the information contained in the guidelines was not always comprehensive, e.g. with regard to advance euthanasia directives, to the way in which the due care requirements should be applied, and to the part to be played by the nursing staff.

## **RTEs, the Public Prosecution and the Health Care Inspectorate** (chapters 10, 11, §12.4)

The five regional euthanasia review committees (RTEs) assess about 2,000 reported cases of euthanasia and assistance in suicide annually. The verdict of non compliance was given in 15 cases during the years 2003, 2004 and 2005. In approximately 6% of all reported cases, RTEs asked for further information from the physician or consultant in attendance because there was uncertainty or doubt regarding one or more of the due care requirements. The requirement that most frequently involved doubts was that concerning unbearable suffering. Generally speaking, the RTEs' performance seems to conform to the intentions of the law. The effectiveness of reviewing is probably mainly due to the fact that physicians' knowledge of how to act in cases of (requests for) euthanasia is continually increasing.

The Public Prosecution only receives the cases assessed by the RTEs as being non compliant. In principle, the prosecution guideline published at the end of 2003 means that prosecution will only be instituted if substantive due care requirements (unbearable and hopeless suffering, voluntary and well-considered request) have not been complied with. This regulation helps ensure physicians' legal certainty. Generally speaking, the Public Prosecution performance is in keeping with the intentions of the law. The way in which the Inspectorate fulfils its duties – geared in particular to a professional approach and professional conduct on the part of the physician – was also found to be adequate.

## **The law**

### **Are the objectives of the law achieved?** (chapters 2, 3, 4, 8, 10, 11, §12.5, §12.8, §12.9)

The legislature had three objectives in mind when drawing up the WTL: legal certainty, transparency/societal control and quality improvement. The underlying basic assumption is the protection of life together with recognition of other values. It has transpired that each of these objectives has been achieved to a greater or lesser extent.

#### *Legal certainty*

In most cases, the system of reporting and reviewing is predictable, and this is also regarded as such by physicians and physicians' organisations. This can also be seen in the increased percentage of reports made. Legal certainty is more limited in border-line cases: this is primarily because the law works with a number of open global concepts (e.g. 'unbearable suffering') with regard to the due care requirements. However, this does not constitute a problem for the vast majority of standard cases.

There is less legal certainty for the patient. Also under the WTL, the patient does not have a right on euthanasia, even though there are sometimes misunderstandings in this regard; the public should be better informed on this point. This does not alter the fact that rejection of a request for euthanasia in a situation where the patient could reasonably expect otherwise in view of the law can pose a real problem. In fact, with regard to the patient's position, it is also important that a clear organisational policy (including guidelines) exists and that adequate information on this policy is given.

### *Transparency/societal control*

In view of the percentage of cases reported (80% in 2005), transparency of practice has further increased since 2001, although this does not alter the fact that approximately 20% of all cases of life termination upon request are not reported. Non-reporting of cases is largely connected with the use of morphine as a means of life termination; in view of the willingness to report cases, societal control is properly carried out insofar as this is possible.

### *Quality improvement*

The degree in which this objective is achieved is linked to the degree in which physicians comply with the law and are willing to be assessed. From the increasing percentage of cases reported and the due care taken by physicians in reported cases, it transpires that quality is improving. A number of factors contribute to quality improvement: professionalisation of the compulsory consultation before complying with a request, reviewing by the RTEs afterwards, publication of the verdicts, and information provided by the RTEs.

If the RTEs see fit to do so, they may invite physicians for an 'instructive' talk, even if their actions have been assessed as 'careful' on balance. In addition, they sometimes consider that such cases should be passed on to the Inspectorate: a clear basis for this should be included in the law.

### **Incorporating into criminal law and relationship with other legislation** (chapters 2, 3, 4, §12.6)

A problem that might arise as a result of incorporating the WTL into criminal law is potential tension between a penal and a medical approach. The evaluation shows that there is indeed a problem due to the various interpretations of the same rulings concerning life termination, particularly in border-line cases in which the nature and dosage of the medicines used give rise to questions in view of the patient's situation. Further elucidation of the boundary between life termination and normal medical treatment is of special importance. Professional organisations and institutions can contribute to this with the aid of guidelines and protocols. One possibility is to include a clause in the Criminal Code (as was already put forward at the time by the Dutch State Commission on Euthanasia) stating that indicated and proportional use of medicines to alleviate suffering does not constitute life termination but is regarded as normal medical treatment.

In order to invoke statutory defence in Article 293 paragraph 2 of the Criminal Code, physicians are now required by law to report euthanasia or assistance in suicide. This puts non-reporting of life termination on an equal footing with its actual carrying out. Criticism of this situation is extended by proposals to implement the punishability of non-reporting in a different way.

Performing euthanasia or assisting with suicide with due medical care and attention is also required in order to invoke statutory defence. However, disciplinary rules are more suitable than criminal law for sanctioning insufficient medical care when terminating life upon request. For this reason, it has been proposed to eliminate due medical care and attention as a condition for invoking statutory defence.

No inconsistencies have been found between the WTL and other Dutch legislation. The main issue in the relationship between the WTL and treaty law is the relationship vis-à-vis the European Convention on Human Rights (ECHR). Here, the compatibility of the law plays a part with the right to life (Article 2 ECHR) on the one hand, and with the criminal principle that nobody is obliged to cooperate in bringing about his or her own conviction on the other hand (*nemo tenetur* principle; Article 6 ECHR). We may assume that the WTL does not contravene the right to life, although only the European Court may pronounce judgement on this. With regard to compatibility with the *nemo tenetur* principle, there is more cause for doubt as to whether the law can stand up to the Strasbourg test.

**Due care requirements, advance euthanasia directives and the position of minors** (chapters 2, 3, 4, 8, 11 §12.7)

#### *Due care requirements*

The fact that physicians and RTEs occasionally encounter problems in the application of material due care requirements (especially with regard to unbearable suffering and the existence of other reasonable solutions) does not in itself constitute a reason to modify these requirements. The requirements have been purposely formulated in an open manner in the law, the idea being that further content will be given to these requirements in case law and in the verdicts given by the RTEs. Physicians do not encounter many problems when interpreting the procedural due care requirements; the RTEs occasionally encounter problems when assessing the independent consultant's actual independence, particularly in hospitals. These problems do not constitute grounds for modification of the requirements because the RTEs can state an opinion on these points in the relevant cases. Moreover, these problems will presumably decrease if more consultations are held in hospitals using SCEN (Support and Consultation on Euthanasia in the Netherlands).

#### *Written advance euthanasia directives*

The WTL states that a previously-drafted advance euthanasia directive by a patient who has meanwhile become incapable of performing legal acts may be regarded as a request. The applicability of the other due care requirements in such a situation has come in for some criticism. The legislature has attempted to overcome this problem by giving the RTEs extra scope to ascertain – all things considered - whether due care and attention has been employed under the circumstances governing the relevant case. There appears to be support among physicians in favour of the advance euthanasia directive scheme, although at the same time, the scheme is applied restrictively in practice. In this connection, there is also a risk that advance euthanasia directives may erroneously raise patients' expectations that euthanasia will be administered as a matter of course if the situation stated in the directive arises.

#### *Minors*

The WTL has adopted a system of age limits when dealing with euthanasia requests from minors. Although this type of system is attended by certain restrictions, the regulation seems to work in practice.

### **The law's ability to stand the test of time** (chapters 3 and 4, §12.10)

Since the WTL has adopted an open system of broad-based rules in which the RTEs are able to refine the standards and develop them further by assessing border-line cases, the law allows scope for views developing in society.

## **Recommendations**

All things considered, the above gives a positive picture: the law has achieved its objectives well, generally speaking. The frequency of euthanasia and assistance in suicide has decreased and the percentage of cases reported has increased; there does not seem to be any question of a slippery slope with regard to life termination, either with or without the request of the patient. Therefore, there is very little incentive for actual substantial law or policy amendments.

This does not alter the fact that there is a basis for improving the effect of the law in practice. The evaluation study has brought a number of recommendations to light, which can be divided into the following: recommendations pertaining to the law, recommendations for improving law-related procedures, recommendations concerning training and provision of information, recommendations with regard to guidelines and organisational policies, and other recommendations.

### **The law**

- We recommend to consider explicit inclusion of the following clause in the Criminal Code: life termination should not be taken to mean indicated and proportional use of medicines to alleviate suffering, even if this means that the physician is hastening the death of the patient. (12.6.1)
- We recommend implementing the punishability of failure to report life termination upon request or assistance in suicide in another way, thereby amending Article 293 paragraph 2 of the Criminal Code in such a way that invoking statutory defence as stated in this regulation no longer requires the physician to report the case of euthanasia or assistance in suicide to the municipal forensic pathologist. (12.6.2)
- We recommend sanctioning insufficient medical care taken when terminating life upon request or giving assistance in suicide using other means than those provided under criminal law, thereby amending Article 293 paragraph 2 in such a way that complying with the requirement for acting with due care is no longer necessary to be able to invoke statutory defence as stated in this regulation (12.6.2).
- It should be explicitly laid down in the law that RTEs have the option of handing over a case to the Health Care Inspectorate, even if this case is assessed as having been handled with due care (12.8.2).

### **Law-related procedures**

- We recommend that the RTEs monitor the quality of their own performance with regard to matters such as the assessment procedure and the methods used when assessing certain aspects of the due care requirements. (12.4.2)
- We recommend to consider limiting the RTEs' term of office to a maximum of two periods of four years. (12.4.2)
- We recommend a uniform policy line for all regions governing the way in which the Public Prosecution Service deals with reports of euthanasia made by the municipal coroner. (12.4.3)
- We recommend extending the model for physicians' reports with the question of why there was no other reasonable solution to the relevant case (if there were any other possible forms of treatment that were rejected by the patient). (12.7.1)
- The 'Nota Bene' in the model for physicians' reports (regarding psychological suffering or patients who may have a diminished ability to express a well-considered request) should be deleted. (12.7.1)
- We recommend rounding off the improving of the model for physicians' reports (Ministerial working group established in 2003) as soon as possible and also examining what alterations to the other forms would be advisable. (12.8.1)
- More experience concerning the database containing reported cases should be acquired (including the area of tension between the guarantee of anonymity and the informative value of published cases) before drawing any conclusions. Attention should nevertheless be devoted to this point in the review committees' reports and in future evaluations. (12.8.2)

### **Training and provision of information**

- Physicians should be further educated on the effects and side effects of morphine and benzodiazepines so that they can select the correct medicines if life termination is the envisaged objective. (12.2, 12.3 , 12.5)
- More attention should be devoted to the content of the WTL at medical faculties in order to augment physicians' knowledge of the Act. (12.3.1)
- We advise improving information for physicians regarding the interpretation of the due care requirements and the requirements governing the compiling of reports. (12.3.1)
- In order to avoid misunderstandings, we advise the provision of information to physicians and the public alike concerning the options and restrictions attaching to advance directives. (12.7.3)

## Guidelines and organisational policy

- Health care institutions must always acquaint professionals in their employment with their organisational policy regarding euthanasia and assistance in suicide. (12.3.2)
- More attention should be devoted to the position of nursing staff in guidelines for health care institutions. (12.3.2)
- Health care institutions should have at their disposal high-quality, up-to-date guidelines for euthanasia, which accurately state the boundaries of the law. In order to support institutions in this, it is advisable to devise a national model guideline for such institutions; umbrella organisations can be of assistance in this regard. (12.3.2 and 12.9.2)
- Guidelines and protocols for institutions and professional medical organisations can contribute to physicians' legal certainty by devoting attention to the boundaries between life termination and other types of terminal care, to the significance of the physician's intention and to the medicines to be administered. (12.5.1 en 12.6.1)
- The Health Care Inspectorate should incorporate institutional policy on euthanasia and assistance in suicide, and the quality of the guidelines devised in this regard, into the regular supervision of institutions. (12.4.4)

## Other recommendations

- Terminal care should be given continual attention in health care policy, medical training and research. (12.2)
- Periodic research whereby insight is also acquired into non-reported cases of euthanasia and grey areas is an important addition to the reporting and reviewing system, since this is the only way of keeping track of cases that have not been reported by physicians. (12.5.2)
- The government must ensure that SCEN (Support and Consultation on Euthanasia in the Netherlands) physicians are employed in hospitals as soon as possible. (12.7.2)
- We recommend that further research be carried out into the course of events appertaining to rejection of requests for euthanasia or assistance in suicide. (12.9.2)

← **Met opmaak:**  
opsommingstekens en  
nummering