Self-Determination, Dignity and End-of-Life Care

Regulating Advance Directives in International and Comparative Perspective

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TREATMENT DIRECTIVES IN THE NETHERLANDS: THE GAP BETWEEN LEGAL REGULATION AND MEDICAL PRACTICE

Sofia Moratti* and Cristiano Vezzoni**

This chapter describes the regulation of advance treatment directives under Dutch law, within the framework of the law governing end-of-life decision-making in the Netherlands.

I. END-OF-LIFE DECISION-MAKING IN THE NETHERLANDS

The concept of ‘end-of-life decisions’ encompasses various sorts of medical behavior, as shown in Dutch and international research. The sort of end-of-life decision that takes place with the highest frequency in medical practice is withholding or withdrawal of life-prolonging medical treatment, when (further) treatment is thought not to benefit the patient. “Terminal sedation”, that is, maintaining the patient in a state of unconsciousness until death, and administration of palliative drugs “in doses that may shorten life” take place with a much lower frequency. As a

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matter of fact, recent medical research shows that sedatives and opioids probably do not shorten the life of the patient, even if administered in large doses and the issue is currently disputed in the scientific literature. The last two sorts of end-of-life decisions, euthanasia and assisted suicide, take place very rarely. In clinical practice, euthanasia consists of receiving a lethal injection and assisted suicide of swallowing lethal pills. However, in the Netherlands, the term “euthanasia” encompasses both, as they are subject to essentially the same regulation. Euthanasia in the Dutch sense refers to the behavior of the doctor who ends the life of a severely suffering and incurably ill patient on the competent patient’s express, well-considered and voluntary request. In clinical practice, euthanasia is performed on patients who are not dependent on life-prolonging treatment. In principle, euthanasia is not considered, when it is possible to let nature take its course by withholding or withdrawing life-prolonging treatment that is not beneficial or not acceptable to the patient.

The current Dutch regulation of end-of-life decisions is based on the dichotomy between “natural” and “non-natural death”. Withholding and withdrawal of treatment and administration of very large doses of palliative drugs are held to be natural causes of death. More precisely, the actual cause of death is taken to be the patient’s underlying disease and

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The latter is subject to doubt when the drugs used are neuromuscular blockers. Sofia Moratti, “Ethical and Legal Acceptability of the Use of Neuromuscular Blockers (NMBs) in
not the doctor’s action or omission. On the other hand, the euthanized patient dies a non-natural death. The doctor must report his action to regional review Committees, consisting of an ethicist, a doctor, and a legal expert who chairs the Committee. If the (majority of the) Committee finds that the behavior of the doctor was consistent with a number of “requirements of careful practice”, the case is closed. If the Committee finds that the doctor has departed from the requirements, the case is handled over to the local Prosecutor, for further investigation and possibly prosecution. In the Netherlands, the criminal justice system allows for prosecutorial discretion. Dutch prosecutors are not under an obligation to prosecute every case that comes to their attention.

The current regulation of end-of-life decisions is the result of a process of de facto legalization of euthanasia that started in the 1980s. A few doctors who had ended the lives of a patient (and had subsequently reported the fact) were acquitted by Dutch criminal courts in the 1980s and 1990s. The courts held that the defendants had acted in a “state of necessity”. The doctors were caught between the two fundamental

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ethical imperatives of the medical profession: prolonging life and relieving suffering, the courts argued. The medical profession played a crucial role in the process of regulation of euthanasia. The Dutch Medical Association defined the conditions of permissibility of euthanasia in a number of professional reports and position statements, that were taken very seriously by the courts. The courts decided for or against acquittal in individual cases, depending on whether the doctor had followed the requirements laid down in the professional reports by the Medical Association. There are two sets of “requirements of careful practice” for legal euthanasia. “Substantive” requirements refer to the condition of the patient and his (or her) request for euthanasia. The patient must be suffering unbearably and his or her condition must be hopeless, which means, without prospects for improvement. The patient must be competent and his or her request for euthanasia must be voluntary and well-considered. “Procedural” requirements concern the decision-making process and the mechanisms of control over the doctor’s behavior. The doctor responsible for treatment must consult with at least one independent colleague before the euthanasia is carried out. The consultant must see the patient and speak with the patient, and advise on whether the “requirements of careful practice” have been met. Finally, as we have seen, the doctor who carried out the euthanasia must report his action to the regional review committee, by means of standard forms that cover every aspect of the decision-making process and of the patient’s condition and request.

During the late 1980s and 1990s, decisions not to prosecute became standard prosecutorial practice in cases of euthanasia, on condition that the doctor concerned had followed the requirements of careful practice.

14 See Griffiths, supra note 6 and Griffiths, Weyers & Adams, supra note 7.
15 The “requirements of careful practice” are also known as “due care criteria”. Hilde M. Buiting, Joseph K.M. Gevers, Judith A.C. Rietjens, Bregje D. Onwuteaka-Philipsen, Paul van der Maas, Agnes van der Heide, Johan J.M. van Delden, “Dutch Criteria of Due Care for Physician-Assisted Dying in Medical Practice: A Physician Perspective”, 34 Journal of Medical Ethics (2008), e12 and Griffiths, Weyers & Adams, supra note 7.
16 There is a nationwide organization that provides this service. SCEN (Support and Consultation on Euthanasia in the Netherlands) is a network of doctors who are specially trained consultants in individual cases, when euthanasia is considered. The SCEN project was implemented gradually throughout the Netherlands between 1999 and 2002. Compare Marijke C. Jansen-van der Weide, Bregje D. Onwuteaka-Philipsen, Gerrit van der Wal, “Quality of Consultation and the Project ‘Support and Consultation on Euthanasia in the Netherlands’ (SCEN)”, 80 Health Policy (2007), pp. 97–106 and Griffiths, Weyers & Adams, supra note 7.
The Dutch prosecutorial system is presided over by a Committee, consisting of the five chief prosecutors attached to the five Dutch Courts of Appeals. The Committee periodically dictates guidelines of prosecutorial policy, that must be followed by all prosecutors in the Netherlands.

In 2002, the Dutch Parliament enacted a statute, known as the “Euthanasia law”. The articles in the Criminal Code prohibiting killing on request and assistance with suicide were amended. A new provision was included in the Code, exempting from liability doctors who perform euthanasia, follow the “requirements of careful practice” and properly report their action. As we will see, the Euthanasia law marked an important step in the process of regulation of advance treatment directives. It became possible to request euthanasia in a written advance directive.

II. Regulation of Treatment Directives in the Netherlands

In the Netherlands, there are three sorts of treatment directives. In a treatment directive, the person can either refuse medical treatment (“negative” directive), appoint a representative for healthcare decisions, or make a request for euthanasia. The three sorts of directives have different legal statuses. However, it is not easy to distinguish among the three in practice. The patient often gives different sorts of instructions in one document.

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18 College van Procureurs-Generaal, literally: Committee of Procurators-General.
20 In Dutch, the three sorts of documents are referred to as behandelverbod, volmacht, and euthanasieverklaring, respectively.
21 Cristiano Vezzoni, Advance Treatment Directives and Autonomy for Incompetent Patients: An International Comparative Survey of Law and Practice, with Special Attention to the Netherlands (Lewiston, N.Y., 2008), p. 92. By supplying standard forms clearly divided into three sections (refusal of treatment, appointment of a representative and written advance request for euthanasia), the Dutch Association for Voluntary Euthanasia has taken into account the distinction among different sorts of treatment directives. However, the standard forms are subject to a number of limitations. People opposed to euthanasia are not likely to trust the Association as a source. Secondly, distribution is only to members of the Association. And thirdly, a standardized form is no substitute for concrete, expert advice from someone who knows exactly what the medical condition of the patient is and can discuss with him or her in detail precisely what sort of treatment he or she does not want under precisely which circumstances. Compare Vezzoni, p. viii.
A. Negative Treatment Directives

Negative treatment directives received statutory recognition in 1995, in the framework of the “Law on Contracts for Medical Treatment”\(^\text{22}\). One of the grounds on which the Law rests is article 11 of the Constitution, which states the right to bodily integrity. To implement this right, the Law provides that all medical treatment requires the informed consent of the patient. The doctor must comply with the informed refusal of treatment, no matter the reasons underlying the refusal and however dire its consequences. The Law also provides that medical intervention can be refused in advance. If a patient is no longer competent, refusal of treatment can take the form of a written directive, drafted while competent. The relevant passage reads:

In case a patient sixteen years of age or older cannot be considered capable of a reasonable assessment of his relevant interests, the healthcare provider and [the personal representative] shall follow the patient’s apparent views laid down in writing when he was still capable of such reasonable assessment and containing a refusal of consent […]. The healthcare provider may depart herefrom if he considers that there are well-founded reasons for doing so.\(^\text{23}\)

In order to be valid, the directive must be written\(^\text{24}\) and the identity of the author must be certain. Furthermore, there should be no doubt about the authenticity of the document. Finally, the author should be older than sixteen and competent at the time of the drafting, but no longer competent when the directive is implemented. Healthcare providers are in principle bound by the refusal of treatment expressed in a valid negative directive, unless there are “well-founded reasons” to disregard it. This formula has been criticized for its vagueness.\(^\text{25}\) It is generally accepted that the doctor’s personal views, medical professional standards, and the possible life-shortening effect of foregoing treatment, are not “well-founded reasons” for giving treatment against the patient’s express wishes. According to

\(^{22}\) *Wet op de Geneeskundige Behandelingsovereenkomst* (WGBO).


\(^{24}\) A number of considerations may suggest that an oral refusal would also be binding. Moreover, in everyday medical practice, oral instructions (e.g. of a person about to undergo total anesthesia) are surely binding within the context of the implied contract for medical treatment. See Vezzoni, *supra* note 22, p. 84.

Van Veen,26 the phrase “well-founded reasons” refers to situations of uncertainty with regard to:

- the identity of the patient,
- the patient’s competence at the time of the drafting,
- the actual correspondence between the content of the directive and the wishes of the person at the time of the drafting,
- the actual correspondence between the conditions of applicability in the directive and the current situation of the (formerly competent) author.27

The occurrence of situations of uncertainty can be prevented by taking a number of precautions,28 that are, however, not required by the Law on contracts for medical treatment.

The presence of witnesses to the drafting can prevent controversy over the identity and the competence of the author. It is in general difficult to assess the person’s competence,29 and it often happens that, between the drafting and the implementation, there has been a change of treating doctor, following, for example, the patient’s admission to a nursing home. The notarial authentication of the document would be another way to prevent controversy over the identity and the competence of the author.

Although the law does not set a time requirement for the validity of a treatment directive, a recently drafted or renewed document can minimize the uncertainty concerning the consistency between the instructions in the directive and the current wishes of their author.

The involvement of a medical expert (for example, the patient’s general practitioner) in the drafting, may help towards more effective implementation, making the content of the document more adherent to medical practice.

Finally, perhaps the most important thing that can be done to facilitate the interpretation of a directive is to include in it the appointment of a representative, to interpret and supervise the implementation of the

27 The last two points can be partly traced back to the category of ‘interpretation problems’. See de Jong, supra note 26, pp. 214–216.
28 Vezzoni, supra note 22, pp. 85–86.
29 For a more general discussion of the assessment of competence under the Law on contracts for medical treatment, see van Veen, supra note 27, pp. 43–46.
author’s instructions. As we will see, this possibility is provided for under the Law on contracts for medical treatment.

There are sanctions for disregarding the patient’s refusal of treatment in an advance directive, in the absence of a “well-founded reason”. The legislator chose to include the regulation of patient’s rights in the Civil Code and gave a contractual character to the relationship between doctor and patients. Therefore, a treatment directive is in effect part of the contract between the two parties. It follows that sanctions for infringement are primarily civil. However, a major violation of the requirement of informed consent could in principle give rise to tort liability and to penal sanctions, because the patient’s denial of informed consent removes the legal justification for an invasion of bodily integrity. All of this remains largely speculative: only two cases involving disregard of a treatment directive have been brought to court and both of them involved persons found after having attempted suicide. The decisions did not significantly contribute to legal clarification, for different reasons. The first case was decided prior to the enactment of the Law on contracts for medical treatment, and the authenticity of the refusal was unclear because the document was neither signed nor dated. In the second case, the treatment directive was not available at the beginning of the treatment, and changes in the document made the identity of the appointed representative unclear.

B. Appointment of a Representative

The Law on contracts for medical treatment provides for the appointment in writing of a representative for healthcare decision-making, should the author of the directive become incompetent. The relevant passage states:

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30 “The mentor is a natural person, appointed by a judge, who represents a person who has reached the age of majority but cannot be considered capable of evaluating his non-material interests because of mental or physical deficiency.” Hondius and van Hooft, supra note 24, p. 15, note 24.

31 TvoGR 1990/63 and 1993/66. Charges were brought against a doctor who had performed resuscitation on a woman after she had attempted suicide. The woman had left a note, stating that she did not want attempts made to resuscitate her, under any circumstance. The doctor was acquitted because there was insufficient ground to determine whether the request of the woman was authentic, giving that the note was unsigned and undated.

If an adult patient cannot be considered capable of a reasonable assessment of his relevant interests and he has not been placed under guardianship or had a mentor appointed for his benefit, then the obligations on the part of the healthcare provider towards the patient arising from the Law on contracts for medical treatment, shall be fulfilled towards the person authorized in writing by the patient to act on his behalf.33

Except where a guardian or a mentor has been appointed by a court, in the decision-making process over administration of life-prolonging treatment, the proxy appointed by the patient in a written directive takes precedence over the patient’s family members. The healthcare proxy must behave as a “conscientious representative”, he must try to involve the patient as much as possible in the decision-making process, and the proxy’s decisions should reflect the patient’s wishes. If the behavior of the healthcare proxy is “not compatible with the level of care expected from a conscientious care provider”, doctors and nurses can refuse to comply with the representative’s instructions. The autonomy of the incompetent patient is further protected by the provision that, even when consented to by the healthcare proxy, medical treatment cannot be performed when the patient strongly resists it, with the exception of medical treatment that “is clearly necessary to avoid serious harm to the patient’s health”.34

C. Written Advance Request for Euthanasia

The Euthanasia Law, enacted in 2002, provides for the possibility of a directive requesting euthanasia under specific conditions, should the author become incompetent. The relevant article reads:

> If a patient aged sixteen years or older is no longer capable of expressing his will, but prior to being in this condition was considered capable of a reasonable assessment of his relevant interests, and has made a written statement containing a request for termination of life, then the physician may carry out this request. The requirements of due care [referred in the preceding paragraph of the law] are applicable in such a case.35

There is a major difference between implementing a written request for euthanasia while the patient is still competent or after the patient has become incompetent. In the former case, the written request only serves as evidence that the patient actually requested euthanasia. The request is

33 Article 465, para. 3. Translation partly based on Hondius and van Hooft, supra note 24.
34 Article 465, paras. 4, 5 and 6.
35 Article 2, para. 2. Translation based on Vezzoni, supra note 22, p. 90.
included in the dossier that accompanies the doctor’s formal report of the case to the regional review Committee. The competent patient can at any time (orally or otherwise) withdraw the request for euthanasia. If the patient has become incompetent, the written directive itself is the basis on which the euthanasia is performed. Written advance requests for euthanasia are unambiguously recognized in the Euthanasia Law. However, doubts persist about the actual permissibility of performing euthanasia on an incompetent patient based on a previously written request. A prominent Dutch ethicist, Hans van Delden, has argued that euthanasia performed after the patient has become incompetent and pursuant to a written request cannot be consistent with the “requirements of careful practice” and would therefore constitute a criminal offence. In medical practice, a request for euthanasia is often included in the advance directive together with a negative treatment directive.

Between the enactment of the Euthanasia law and 2009, no cases of euthanasia involving demented patients with an advance written request for euthanasia were reported, “despite the fact that the only real innovation of the Euthanasia law [with respect to the previous regulation of end-of-life decisions] consisted precisely in allowing physicians to act upon such directives”.

### III. Conclusions

The Dutch have much experience with regulating end-of-life decision-making and advance directives. However, the implementation of advance directives in the Netherlands is not unproblematic, especially in the case of patients who suffer from a condition that causes cognitive impairments that worsen over time, such as Alzheimer’s disease. In a written directive drafted while still competent, the patient may choose to set a specific boundary that he or she would never like to cross (for example, not being able to recognize one’s own children). After that boundary has been

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crossed, the alert but incompetent patient may appear altogether serene and smiling, notwithstanding his or her condition and severe cognitive impairment. In that situation, the caregivers may be unsure whether (and when) to carry out the end-of-life decision requested by the patient in his or her treatment directive.

The strongest resistance to implementation is found with regard to written advance requests for euthanasia. The literature offers two explanations. Firstly, almost all severely demented patients are institutionalized in a nursing home, and institutional policies are often more restrictive than Dutch law with regard to euthanasia; in addition, most Dutch elderly care doctors subscribe to these policies. Secondly, if the demented patient is alert but no longer competent, it is difficult to determine whether he or she is suffering “unbearably and hopelessly” (one of the “requirements of careful practice” for lawful euthanasia). Very recent research explored both issues in depth.

A. Institutional Policies and Doctors’ Views

De Boer and colleagues administered a questionnaire to all elderly care doctors in the Netherlands. Almost all respondents (94%) report that the institution where they work has a policy regarding euthanasia in cases of dementia. Roughly three-quarters of respondents say that it is the policy of their institution not to comply with advance written request for euthanasia in cases of dementia. The remaining doctors report that in their

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39 These explanations did not change after the enactment of the Euthanasia law. See Bregje D. Onwuteaka-Philipsen, Joseph K.M. Gevers, Agnes van der Heide, Evaluatie Wet toetsing levensbeëindigend handelen op verzoek en hulp bij zelfdoding [Evaluation of the implementation of the Euthanasia Law] (Den Haag, 2007).


41 Because 92% of all patients with dementia are admitted to a nursing home in an advanced stage of their disease and die there, nursing home doctors are the medical professionals most likely to be confronted with a request to carry out euthanasia pursuant to an advance directive.

42 The policy is almost always (92%) laid down in writing.
institution compliance is an option only when the “criteria of careful practice” are met in the individual case. About 88% of all doctors whose institution has a policy regarding euthanasia for demented patients, approve of the policy. Over 80% of respondents claim that the enactment of the Euthanasia law has not lead them to change their views with regard to euthanasia in cases of dementia, and another 7% say their views have actually become more restrictive. One of the possible explanations of doctor’s skepticism towards written advance requests for euthanasia may be the low technical-medical quality of these documents, partly a consequence of the low involvement of doctors in the drafting phase.43

B. Understanding Suffering in Alert but Incompetent Demented Patients, and the Importance of Meaningful Communication

Almost three-quarters of respondents in the study by De Boer and colleagues do not believe that dementia and a written advance request for euthanasia are “valid reasons” for performing euthanasia on a patient. Roughly the same percentage of respondents think that it is “impossible” to determine when the written advance request for euthanasia should be carried out, if the patient has dementia. Over half of respondents say it is “impossible” to determine whether the incompetent patient with late stage dementia experiences his own condition as “unbearable and hopeless suffering”. Hertogh44 argues that the demented patient may not experience the suffering he or she feared, due to progressive psychological adaptation to his (or her) condition and progressive loss of awareness, and contends that meaningful communication with the patient is a conditio sine qua non for lawful euthanasia. Therefore, he argues, patients with dementia can lawfully obtain euthanasia only in the early stages of their disease, when they can still be considered competent, having preserved “intact recognition” and “executive functioning”. The study by De Boer and colleagues shows that most Dutch elderly care doctors share Hertogh’s views.45

43 Vezzoni, supra note 22, p. 77.