CHAPTER IV

TREATMENT DIRECTIVES IN THE NETHERLANDS

In this chapter I present the legal situation concerning treatment directives in the Netherlands and describe the results of existing empirical studies that have dealt with the subject. This information forms the background for the empirical surveys presented in the second part of the book.

1. Treatment directives in Dutch Law

In the Netherlands, (negative) treatment directives received legal recognition in 1995, in the framework of the Law on Contracts for Medical Treatment (Wet op de Geneeskundige Behandelingsovereenkomst, WGBO 1995). One of the grounds on which the law rests is article 11 of the Constitution, which states the right of all persons to the inviolability of the body.[1] To implement this right, the law provides that any medical treatment requires the informed consent of the patient. If a patient refuses to give consent for a treatment, the doctor must comply with the refusal, no matter what the reasons may be underlying the refusal and however dire its consequences. The WGBO provides that a refusal of consent can also be given in advance.[2] Under Article 450, if a patient is no longer competent, refusal of consent can take the form of

[1] Grondwet, Art. 11: 'Ieder heeft, behoudens bij of krachtens de wet te stellen beperkingen, recht op onaantastbaarheid van zijn lichaam.'
[2] Positive treatment directives, demanding particular treatment in a specific situation, are not included in the WGBO.

a treatment directive written while he was still competent. The relevant passage (Art. 450.3) reads in part as follow:

> *In case a patient sixteen years of age or older cannot be considered capable of a reasonable assessment of his relevant interests, the health care 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 health care provider may depart herefrom if he considers that there are well-founded reasons for doing so.*[3]

In principle, such a directive, if valid, has the same force as the current refusal of a competent patient. What are the requirements for a treatment directive to be valid?

First of all the document must be in writing[4] and the identity of the author must be certain. There should be no doubts about the authenticity of the document. Secondly, the author must be older than sixteen and competent (capable of a reasonable assessment of his interests) at the time of drafting the document. Thirdly, the patient must no longer be competent at the time of implementation. There are no other requirements for a valid treatment directive.

A treatment directive binds all care providers. The law only allows deviation only if there are "well-founded reasons" [*gegronde redenen*] to do so. This formulation is vague.[5] It is generally accepted that a doctor's personal views concerning the instructions expressed in a treatment directive cannot amount to a "well-founded reason" to depart from it. The same should be said for conflicts between the professional medical standard and the instructions in the document. The fact that following a treatment directive will cause or hasten the death of the patient is not a sufficient reason not to comply with it.[6]

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[3] "In het geval waarin een patiënt van zestien jaren of ouder niet in staat kan worden geacht tot een redelijke waardering van zijn belangen ter zake, worden door de hulpverlener en een persoon als bedoeld in de leden 2 of 3 van artikel 465 [de persoon die daartoe door de patiënt schriftelijk is gemachtigd in zijn plaats op te treden], de kennelijke opvattingen van de patiënt, geuit in schriftelijke vorm toen deze tot bedoelde redelijke waardering nog in staat was en inhoudende een weigering van toestemming als bedoeld in lid 1 [voor verrichtingen ter uitvoering van een behandelingsovereenkomst is de toestemming van de patiënt vereist], opgevolgd. De hulpverlener kan hiervan afwijken indien hij daartoe gegronde redenen aanwezig acht." Translation partly based on Hondius et al. 1996.

[4] One can doubt whether the statutory requirement of a directive in writing excludes the force of an oral advance refusal by a patient that is competent at the time of the advance refusal. The following considerations suggest such a refusal would also be binding: (a) it it excludes the possibility of a resumption of consent; (b) surrogate decison-makers as a doctor or a representative are required, in the absence of written instructions, to implement the patient's views to the extent these are known; (c) 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.

[5] Compare De Jong 1997: 206.

[6] Doubts can exist on this point when the patient has a high chance of a good recovery after the intervention. For example, it is not clear if, confronted with a patient who has written a do-not-

Van Veen[7] suggests that the situations where a 'well-founded reason' can be said to exist are those in which there is uncertainty with regard to:

- the identity of the author of the directive;
- his competence at the time of the drafting;
- the correspondence between the directive and the wishes of the author when he drafted the directive;
- the correspondence between the conditions of applicability in the directive and the current situation of the (now incompetent) author.[8]

If one of the situations above occurs, caregivers can consider not complying with the wishes expressed in a treatment directive. In order to reduce the possibility of such doubts a number of precautions can be considered, although these are not required by the WGBO.

The *presence of witnesses* to the drafting of a treatment directive can minimize doubts about the identity and competence of the author. Evidence of the competence of the author can be a matter of concern for at least two reasons: it is in general difficult to decide if a person is or is not competent for such a task,[9] and it often happens that, between the moment of drafting and that of implementation, there has been a change of treating doctor. In the case of a patient with a written treatment directive who is admitted to a nursing home, for example, the doctor who is supposed to implement the directive did not know the patient at the time of drafting. The existence of witnesses and their availability at the time of implementation can give the necessary confidence that the author was competent at the time he drafted the treatment directive.

Notarial authentication of the document would be another way to resolve doubts about the identity and the competence of the author. Moreover the assistance of a notary in the drafting phase should assure the document meets all the legal requirements.[10]

Although the law does not set a time requirement for the validity of a treatment directive, a *recently drafted or renewed document* can avoid problems concerning the

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resuscitate directive but who could easily recover from his underlying condition after resuscitation, the doctor should or should not resuscitate. For an impressionistic example, see Kleijer 2005.

[7] In Legemaate 1995: 48.

[8] The last two points can be partly traced back to the category of 'interpretation problems' mentioned by De Jong 1997: 214-216.

[9] For a more general discussion about the assessment of competence under the WGBO, see Van Veen 1995: 43-46.

[10] In Chapter 6, I will present empirical evidence on the involvement of notaries in the drafting of treatment directives.

correspondence between the instructions in the directive and the current wishes of the author. In fact, a common reason given in the literature for disregarding treatment directives is that the request expressed no longer reflects the real wishes of the patient, for example in the case of a demented person whose treatment directive rejects any kind of treatment if he can no longer recognize his loved ones, but who now appears smiling, happy and demented. To neutralize this argument against following a directive, the Dutch Society for Voluntary Euthanasia suggests including in a treatment directive a statement that the patient accepts this risk.

The *assistance of a medical expert* (for example, the patient's family doctor or, later on, the treating doctor) in the drafting phase might help to assure more effective implementation, given the fact that achieving concreteness and specificity is not a simple task for a person who lacks medical knowledge.

Finally, perhaps the most important thing that can be done to ease the process of interpretation of a directive is to include in the directive the *appointment of a representative*. This possibility is provided for under the WGBO, as we will see in the next paragraph.

Since the legislator chose to put the law on patient's rights in the civil code, and to give the relationship between doctor and patients a contractual nature, a treatment directive is in effect a part of the contract between the two parties. It follows that sanctions for infringement are primarily civil (prospective and retrospective). However, a serious violation of the requirement of informed consent could also give rise to liability in tort and to penal sanctions, the patient's denial of informed consent removing the justification for an invasion of bodily integrity. Disciplinary sanctions are presumably also a possibility. All of this remains largely speculative: only one relevant case has been published, and it was decided prior to the enactment of the WGBO.[11]

Summing up, we can say that treatment directives have a strong legal status in the Netherlands. The relevant provisions are contained in the WGBO. The explicit legal requirements for a valid treatment directive concern the written form of the document, the author's age (above sixteen), the identity of the author and his competence at the time of drafting.

[11] TvGR 1990/63 and 1993/66. A woman who attempted to commit suicide left a unsigned and undated note stating that she did not want any attempt made to resuscitate her, should she be found still alive. A criminal case was brought against the doctor who reanimated her, but the doctor was acquitted because there was insufficient ground to determine whether the request of the woman was authentic.

A valid treatment directive is binding on all caregivers, unless there are "well-founded reasons" to depart from it. In order to keep the grounds on which "well-founded reason" could be based to a minimum, a number of elementary precautions can be suggested; the presence of witnesses, notarial authentication, recent drafting or updating, inclusion of an explicit provision by which the author accepts the risk he might have changed his mind, the assistance of a doctor in the formulation of the instructions, and the inclusion of a provision appointing a representative to interpret and supervise the implementation of the author's instructions.

Table 8. Summary of the requirements for a valid treatment directive under Dutch law

Requirements explicitly mentioned in the WGBO	Precautions in order to increase chances of a valid treatment directive
• in writing • identity of the author • competence of the author at the time of drafting the treatment directive • current incompetence of the author	• witnesses • recent drafting or renewal • provision that the author accepts the risk of changing his mind • assistance of a medical expert in drafting • written appointment of a representative

2. Other kinds of advance directives under Dutch law

Although they are not the subject of this book, we should remember that, under Dutch law, two other kinds of advance directive are recognized: the appointment of a representative (proxy directive) and a written advance request for euthanasia (*euthanasieverklaring)*. Positive treatment directives have no independent legal status in the Netherlands, although they may of course be relevant in connection with treatment decisions, for example when 'quality of life' considerations play a substantial role in deciding whether to withdraw or withhold treatment on 'quality of life' grounds.

2.1. Appointment of a representative

The WGBO provides for the appointment in writing of a representative for health-care decision-making, should the person doing so become incompetent (Art. 465.3). The relevant passage states:

> *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*[12] *appointed for his benefit, then the obligations on the part of the health care provider towards the patient arising from the WGBO, shall be fulfilled towards the person authorized in writing by the patient to act on his behalf. […]*[13]

Except where a legal guardian or a mentor has been appointed by a court, a representative appointed by the patient takes precedence over the family members provided for as default representatives in the WGBO itself. The representative must behave as a "conscientious representative" (Art. 465.5), he must try to involve the patient as much as possible in the decision-making, and decisions should reflect the patient's wishes (again Art. 465.5). If the behavior of a representative is "not compatible with the level of care expected from a conscientious care provider" (Art. 465.4), a health care provider can refuse to comply with the representative's instructions. In this sense, the strength of a refusal of treatment by a representative is qualified in a way that refusal by a competent patient is not.[14]

2.2. Written advance request for euthanasia (euthanasieverklaring)

The euthanasia law enacted in 2002 provides for the possibility of a positive directive requesting euthanasia under specific conditions, should the author become incompetent. The relevant article reads (Art. 2.2):

> *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.*[15]

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[12] "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." Quoted from Hondius et al. 1996: 15, note 24

[13] "Indien een meerderjarige patiënt die niet in staat kan worden geacht tot een redelijke waardering van zijn belangen ter zake, niet onder curatele staat of ten behoeve van hem niet het mentorschap is ingesteld, worden de verplichtingen die voor de hulpverlener uit deze afdeling jegens de patiënt voortvloeien, door de hulpverlener nagekomen jegens de persoon die daartoe door de patiënt schriftelijk is gemachtigd in zijn plaats op te treden. […]". Translation partly based on Hondius et al. 1996

[14] The autonomy of the incompetent patient is further protected by the provision that, despite the consent of the representative, a treatment cannot be performed if the patient strongly resists it. The only exception is if the treatment "is clearly necessary to avoid serious harm for the patient's health" (Art.465.6).

[15] *"Indien de patiënt van zestien jaren of ouder niet langer in staat is zijn wil te uiten, maar voordat hij in die staat geraakte tot een redelijke waardering van zijn belangen terzake in staat werd geacht, en een schriftelijke verklaring, inhoudende een verzoek om levensbeëindiging, heeft afgelegd, dan kan de arts aan dit verzoek gevolg geven. De zorgvuldigheidseisen, bedoeld in het eerste lid, zijn van overeenkomstige toepassing." Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding [valid since: 01-04-2002], Art. 2.2. Translation by Kim Goossens.*

An *euthanasieverklaring* is not the same as a current written request of a competent patient to receive euthanasia. In the latter case, the document only provides a proof that the patient actually requested euthanasia. Such a document will be included in the dossier which accompanies the doctor's formal report on the case. However, in such a case the patient is still able to communicate and can at any time - orally or otherwise - reaffirm or withdraw his request. In the case of an *euthanasieverklaring*, the patient has become incompetent and it is the document itself that is the basis on which the termination of life takes place.

Although *euthanasieverklaringen* are unambiguously recognized in the euthanasia law, many doubts persist about the actual possibility of performing euthanasia in the case of an incompetent patient on the basis of a previously written request. In this study, I do not deal with *eutanasieverklaringen* because the problems that they raise are very different from those related to negative treatment directives. However, in practice, a request for euthanasia is often included in an advance directive together with a negative treatment directive, and sometimes, as we will see in the following chapters, it proved in field research practically impossible to distinguish between the two kinds of documents.

3. The existing empirical data for the Netherlands

By contrast with euthanasia, actual practice connected with the making and implementation of treatment directives has received little attention in the Netherlands. In 1999 a large-scale evaluation study of the WGBO took place, but nothing is reported as far as treatment directives are concerned.[16] Some tangential information can be obtained from the national studies of euthanasia and from two academic studies. Data coming from the member-panel of the NVVE are also relevant. The following paragraphs present the main findings of these studies that provide some indication concerning the social practice of treatment directives in the Netherlands.

3.1. The national studies of euthanasia

In 1990, 1995 and 2001, three large national studies took place concerning end of life practices in the Netherlands, especially focusing on euthanasia.[17] Some information was produced concerning previously written instructions to caregivers, but unfortunately the data do not distinguish the kind of instructions involved and the condition of the patient as far as competence is concerned. Only in 2001 do the data explicitly concern the presence of a treatment directive in the case of withholding or

[16] Dute et al. 2000.
[17] See Van der Maas 1991, Van der Wal et al. 1996 and Van der Wal et al. 2003.

withdrawing treatment without discussion with the patient: in only 1,3% of such cases was a treatment directive present.[18]

The research of 2001 paid specific attention to the situation where a demented patient (who subsequently died) had made written request for euthanasia.[19] The researchers estimate that for the whole of the Netherlands there are in approximately 2200 such cases per year. Twenty-nine percent of the interviewed doctors had ever experienced such a situation, while 13% had experienced it in the preceding two years. These percentages are much higher in the case of nursing home doctors (66% and 50% respectively). Despite the apparently relative high frequency of demented persons who have completed a written request for euthanasia, doctors are not keen to fulfill these requests. Only 3% of them have ever performed euthanasia for a demented patient on the basis of a written request. Of the remaining doctors who have not done so, 44% consider it at least conceivable, while 54% do not. Specific questions were addressed only to nursing home doctors who had had a patient with a *euthanasieverklaring*. Although in 67% of these cases the patient had arrived at the situation he had specified in the document, euthanasia was actually performed in only 7% of the cases. Much more often (88%), there was some decision to withhold or withdraw treatment. However, the main element that influenced such decisions was the medical situation of the patient (76%), followed by the personal opinion of the doctor (60%). The presence of a *euthanasieverklaring* had much less influence (31%).

3.2. Two other studies

As far as the frequency of treatment directives is concerned, a European comparative study on end-of-life medical behavior, already mentioned in chapter 3, reports for the Netherlands that in 13% of cases where an end-of-life decision was taken a treatment directive (referred to as a 'written living-will') was present.[20] The frequency in the Netherlands is the highest among the six countries considered, being for all other countries less then 5%. However the study remains very vague on the precise sort of document involved and it does not give any details on their actual contents nor on the nature of the end-of-life decision.

In 2002, an ethnographic study on withholding artificial administration of food and fluids from elderly people with dementia in Dutch nursing homes was published.[21] The study was carried out in two nursing homes and analyzed the decision-making process for a total of 35 patients. Once again, the study fails to distinguish among different sorts of directives, in this case between treatment directives and *euthanasieverklaringen*. Nonetheless, and despite the very small size of the sample,

[18] Computation based on CBS 2003: 23.
[19] See Van der Wal et al. 2003: 110-117.
[20] Van der Heide et al. 2003.
[21] See The et al. 2002.

the study gives some tentative indications. First of all, very few patients (the precise number is not given) had any kind of written directive. When a directive was present, it appeared to influence the decision to withhold life-prolonging treatment. However the final decision was mainly based on the medical condition of the patient, the wishes of the family, and the quality of life of the patient as judged by his care providers. At the end of the day, the role of written directives seemed of limited importance in Dutch nursing home practice.

3.3. NVVE member panel

In the Netherlands, one of the most important promoters of treatment directives is the national right-to-die association (NVVE). The NVVE has developed a standard form for advance directives that contains all three kinds of instructions: a treatment directive, a proxy directive and a *euthanasieverklaring*. The form is available only for members (although an unknown number of others, including some professionals such as doctors and notaries, make use of it as a model in advising patients or clients).

The NVVE carries out a regular panel study among its members. A few of the questions concern the completion of written advance directives using the form supplied by the organization. In the most recent panel study (Autumn 2002), 64% of the 429 panel members said that they had completed the advance directive form, and 20% had received the form but had not yet completed it. It is interesting to note that among the members who had completed the form, almost everyone had included a refusal of treatment. If these results are representative for all members of the NVVE (approximately 104.000 people), then quite a large number of these treatment directives are present in the Dutch population, especially among older patients exposed to end-of-life decision- making, the large majority of members of NVVE being above 55 years old.[22]

[22] See NVVE 2002.