

CHAPTER I

AUTONOMY FOR INCOMPETENT PATIENTS AND ADVANCE DIRECTIVES

1. Introduction

This book deals with the legal status and the social practice of treatment directives:¹ written documents in which the author gives instructions to health-care providers while he or she is still competent, to be implemented by them in the event he or she becomes incompetent.

Treatment directives must be understood against the background of growing acceptance of the doctrine of informed consent. Once informed consent was recognized as fundamental to the relationship between doctors and patients, the problem had to be faced of persons not capable of expressing consent at the time decision-making concerning treatment takes place. Awareness of the problem was stimulated both by reflection on the implications of recognition of the principle of autonomy of the patient and by the increasing number of cases in which medical technology enables doctors to keep non-competent patients alive indefinitely. These developments have called increasing attention to the following question: Is it possible to extend the principle of autonomy, specifically the right to give or refuse consent, to incompetent patients? Treatment directives represent a potential answer to this question.

¹ For the definition of 'treatment directive', usually referred to as 'living will' in North American literature, see the next paragraph.

The problem of respect for the autonomy of incompetent patients can be approached from several perspectives. I indicate here three that appear to be particularly relevant:

- an *ethical perspective*: is there a moral foundation to the claim that incompetent patients retain some autonomy?
- a *legal perspective*: do legal systems recognize a right to autonomy for incompetent patients and, if so, what tools do they offer to effectuate this right?
- a *sociological perspective*: supposing that legal tools exist to effectuate autonomy when a person becomes incompetent, how do they work in practice?

The legal and sociological perspectives will be the central focus of this book. As far as the ethical perspective is concerned, I briefly present in the last section of this chapter the arguments for and against treatment directives generally given in the bioethical discussion.

My research will adopt a comparative approach in considering the legal aspects of patient autonomy and treatment directives and in presenting the results of empirical studies carried out by others. My own empirical research focuses on the Netherlands.

Although treatment directives have been legally recognized in the Netherlands since 1995 and despite considerable interest in the subject,² information concerning the actual use and working of these documents is unavailable. No systematic research has dealt specifically with such questions. An evaluation of the Dutch law on patients' rights did not deal with this part of the legislation.³ As a result, very little is known about the practical effects of the legislative recognition of treatment directives.

2. Definitions

Over the years a number of terms have been used in the discussion of treatment directives. The idea of such a document was introduced by Luis Kutner, a human rights lawyer and activist, in an article that appeared in 1969.⁴ Although rejecting the legalization of 'euthanasia', Kutner addressed the situation where a patient cannot express his will concerning medical treatment.⁵ The author's proposal was to extend the right to refuse treatment to incompetent patients by means of a document he called a "living will". He described the document in the following way:

² Legemaate 1995; Dillmann and Kastelein 1994; Dillman 1995; Dilmann et al. 1997.

³ Dute et al. 2000.

⁴ Kutner 1969.

⁵ Under the then current legislation (1969), a constructive consent was always presumed when a patient was not able of giving consent.

[...] the individual, while fully in control of his faculties and his ability to express himself, indicates to what extent he would consent to treatment. The document indicating such consent may be referred to as “a living will” [...].⁶

Such a document was also referred to by Kutner as a “declaration determining the termination of life”, a “testament permitting death”, a “declaration of bodily autonomy”, a “declaration for ending treatment”, and a “body trust”. None of these expressions was particularly successful and, eventually, the term “living will” became the common way to refer to these documents, at least in the US. The term refers only to written instructions concerning the consent to or refusal of a specific treatment.

Other kinds of instructions can be contained in a document written in advance concerning health-care decisions. In particular the author can appoint a health-care agent, who will decide on behalf of the principal should he become incompetent and authoritatively interpret any specific instructions contained in the document. In some countries, such as the United States, the appointed health-care representative is referred to as having been given a ‘durable power of attorney’. The document that provides for such an appointment is therefore generally called a ‘durable power of attorney’ or ‘medical power of attorney’, but it may also simply be referred as ‘advance appointment of a representative’ or, simply, ‘proxy directive.’

In the North American bioethical, medical and legal debate another label grew in popularity, one that covers documents containing a living will, a durable power of attorney, or both: *advance directive*. This label (or some variation of it, as “advance care directive”) is at the moment commonly used, and this is reflected in the choices made by the most influential scholars dealing with the subject. For example, Capron gives the following definition:

An advance directive is a statement made in advance of an illness about the type and extent of treatment one would want, on the assumption that one may be incapable of participating in decision-making about treatment when the need arises. [...] It may name a person to make decisions on one’s behalf, give instructions on what treatments should or should not be provided or do both.⁷

The success of the label is also confirmed by its use in more popular sources such as Internet medical encyclopedias. An example follows:

“Advance Directives” [...] pertain to treatment preferences and the designation of a surrogate decision-maker in the event that a person should become unable to make medical decisions on her or his own behalf.⁸

⁶ Kutner 1969: 551.

⁷ Capron 1999: 261.

⁸ Source: www.medicinenet.com, visited on 10/11/2004.

In the Netherlands the terminological situation is complicated by the fact that advance requests for euthanasia are also provided for in law. The general word that more or less corresponds to ‘advance directive’ is *schriftelijke wilsverklaring* (literally: written statement of will). The term that specifically indicates a request for euthanasia is *euthanasieverklaring* (literally: euthanasia statement). However, it is not rare that requests for euthanasia are understood to be included in the general concept of *schriftelijke wilsverklaring*, and, viceversa, that the term *euthanasieverklaring* is meant to include refusals of treatment and/or the appointment of a representative.

The best terminological distinctions in the Netherlands can be found in the standard forms supplied by the NVVE, the Dutch Association for Voluntary Euthanasia. Each form contains three parts:

- a *behandelverbod* (prohibition of treatment), that is, a refusal of treatment;
- a *volmacht* (mandate), that is, the appointment of a representative;
- an *euthanasieverklaring*, that is, an advance request for euthanasia.

However, such precise terminology has not become widespread and it is common to encounter confusion when talking about written medical directives. For example, notaries, one of the professionals who may assist people in drafting treatment directives (as we will see in chapter 6) call all three sorts of documents simply *euthanasieverklaringen*, not distinguishing among their contents. And if a doctor is asked how many of his patients have an advance directive (*schriftelijke wilsverklaring*), he usually includes in his answer requests for euthanasia.

This terminological confusion was a constant problem during the empirical parts my research. It is therefore important to clarify the terms I will use in this book.

Advance treatment directive (shortly referred as ‘treatment directive’) refers to a document in which the author specifies the treatment he does or does not want under specified conditions. A treatment directive can be addressed directly to the responsible doctor, or indirectly via an appointed representative, or both. It corresponds to the expression ‘living will’ especially popular in North America.

A treatment directive can be either positive or negative. An example of a negative directive is the refusal of mechanical breathing support under specified conditions, such as a persistent vegetative state. In a positive directive the author requests specific life-prolonging treatment (such as resuscitation). However, if a given treatment is not medically indicated, it is doubtful that even a patient who is competent at the time could force a doctor’s hand by insisting on it, and this applies a fortiori to a request made in advance. The legal significance of positive directives is therefore limited. The

major importance of negative treatment directives derives from the fact that in an increasing number of cases medical technology enables doctors to keep patients who are no longer competent alive, imposing on them life-sustaining treatment they would not have wanted and that can add to their suffering and that of their families.

A **proxy directive** is a document in which the author – either as an alternative to or in combination with a treatment directive – empowers another person to express the author’s wishes concerning treatment on his behalf. The mandate can be unconditional, or dependant on specific wishes or values stated by the author.

Advance care directive (shortly referred as ‘advance directive’) is the term I use as an umbrella-concept to indicate a document written by a competent person (author) containing instructions concerning health-care to be applied in case the author should become incompetent. The term ‘advance care directive’ is therefore general and does not specify if the document contains a treatment directive, an appointment, or both.

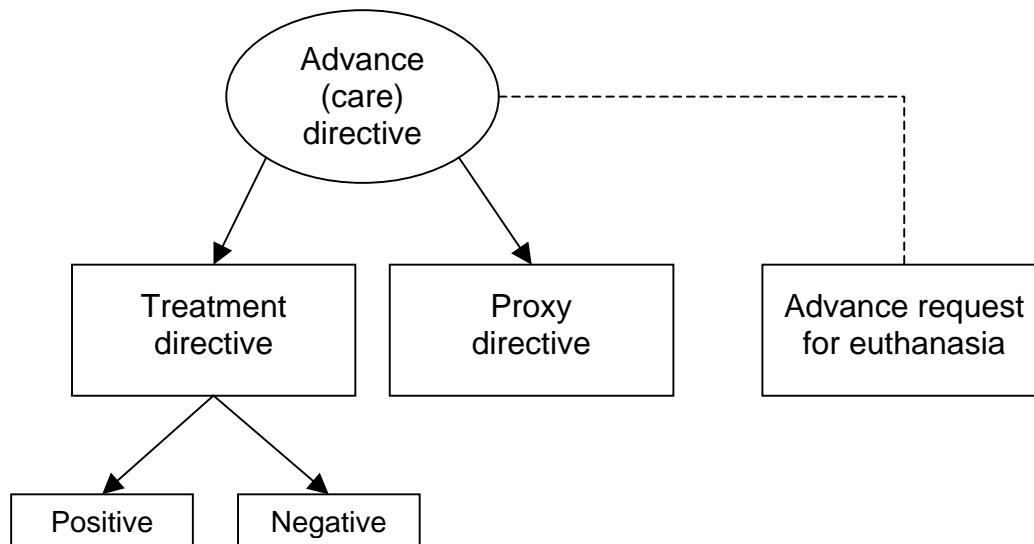
A final label must be introduced specifically for the Netherlands: **written advance request for euthanasia** (also referred with the Dutch term *euthanasieverklaring*). This is a document containing a request for the responsible doctor to perform euthanasia, should the author of the document become incompetent.⁹ The term ‘advance’ in the label is important to avoid confusion with another kind of document, namely the written request of a competent patient to document his or her firm and persistent request for euthanasia.

This book deals with treatment directives, in particular negative treatment directives. However, as always noted, in field research it is often difficult to disentangle the different sorts of advance instructions. Therefore, especially when engaged in international comparison and analysis of the social practice in which these documents play a key role (based on the existing empirical literature), I will sometimes use the general label ‘advance directive’. In the empirical part concerning the Netherlands, where I present the results of my own surveys, sometimes some flexibility in the use of terms was necessary. Behavior connected with the social practice of treatment directives is not always actually separable from other forms of medical instructions given in advance. At the beginning of each empirical chapter, I will make explicit the terminological problems I encountered and the solution I adopted in order to minimize

⁹ The only countries which explicitly give legal status to advance written requests for euthanasia are the Netherlands and Belgium (respectively available on www.nvve.nl/assets/nvve/info/euthanasiewet.pdf, and www.gbs-vbs.org/wetgeving/2002009590.asp, accessed on 2.6.2005). Several commentators on these laws have held that euthanasia for incompetent patients on the basis of an advance written request would nevertheless be unlawful, failing to fulfill the other requirements stated in the legislation legalizing euthanasia. See van Delden 2003; Wind et al. 2002.

ambiguity. The following figure summarizes the relationship among the various labels I will use.

Figure 1. Conceptual scheme of the labels used in the book



3. The ethical perspective: Autonomy for incompetent patients

If it is the autonomy of a competent patient on which the right to give or withhold informed consent rests, one might suppose that the same principle could be applied in the case of consent or non-consent expressed in advance. In fact, advance consent is regularly asked of patients about to undergo an operation, regarding decisions the doctor may have to make while the patient is anaesthetized. At first glance, there would seem no reason why the same principle would not apply to expressions of consent – or withholding of consent – concerning possible future treatment, should the patient be non-competent at the time. Advance directives¹⁰ are in effect an extension of the principle of respect of autonomy of incompetent patients, permitting people prospectively to express their autonomous choices about medical treatment.

Support for the ethical and practical value of advance directives can be found in the book of Norman Cantor, *Advance Directives and the Pursuit of Death with Dignity* (1993). Cantor argues that autonomy can be seen as a fundamental aspect of personal liberty, both under common and constitutional law (he refers to the American

¹⁰ In this paragraph, I generally use the label 'advance directive', since it is common in the ethical literature.

situation), and the same applies to prospective autonomy, that is the exercise of autonomy by a competent person for a future situation of incompetence.¹¹ Cantor recognizes that there are practical difficulties connected with the prospective exercise of autonomy by means of advance directives, but he argues that these difficulties should not stand in the way of acceptance of the instrument.

Beauchamp and Childress, in their influential book on biomedical ethics, take generally the same position. Although they recognize that autonomy is not an absolute value which should determine all medical decisions, they do accept the argument that it should include prospective autonomy, stating that:

[...] we respect the previously expressed autonomous wishes of the now severely demented incompetent person because of our respect for the autonomy of the person who made the decision, as well as our own interest in securing control over our lives prior to becoming incompetent. Interventions against autonomous advance directives infringe the principle of respect for autonomy [...]. (page 132)

Nonetheless, several authors take a more critical position. Two main groups of criticisms can be distinguished: the first concerns practical problems that make the implementation of advance directives difficult, and the second concerns the nature of prospective autonomy. Both criticisms are connected with the temporal span between the drafting and the implementation of a directive.

The first group of criticisms are synthesized by Cantor as problems connected with the complexity of medical decisions in a broad range of possible future situations, and problems due to the “distance of the competent person looking toward future events.”¹² In both cases, the author concludes that these difficulties can be overcome and argues that:

*while a comprehensive directive anticipating all possible situations might not be possible (given the limits of human imagination), every competent person is capable of addressing a few precepts or guidelines regarding future medical care. [...] The difficulties of remoteness and perspective in making future-oriented death-and-dying decisions ought not to preclude giving binding effect to advance medical directives.*¹³

¹¹ As Cantor notes, prospective autonomy has found legal recognition in case of post-mortem dispositions (for example organ donation or use of the body for research purposes). Also in the case of refusal of treatment on the basis of religious beliefs (for example, Jehovah's Witnesses refusing blood transfusions), the prospective autonomous decision of the currently incompetent patient is unambiguously accepted. The same can be said, as already noted in the text, of the everyday situations in routine medical practice where the problems that prospective autonomy can give rise to are latent but in practice no objection is made.

¹² Cantor 1993: 25-26.

¹³ *Idem*: pp.25-27.

Cantor concludes, in short, that practical concerns, although important, do not undermine the idea of prospective autonomy. There are no fundamental reasons to think that stating one's preferences and wishes in advance concerning health-care is any less possible than accepted practices of giving similar prospective instructions in many other fields of life.

The second group of criticisms appears to be more fundamental. It addresses the philosophical question of personal identity and continuity of the self. Some authors argue that the incompetent person (in particular, a demented patient) is so different from the person who was once competent that it is possible to talk of different selves.¹⁴ It is therefore not ethically acceptable to base medical decisions for non-competent patients (especially decisions that potentially shorten their life) on previously stated wishes and preferences. Care-givers and families should decide on the basis of the present best interests of the incompetent patient. One of the most influential supporters of this position, Rebecca Dresser, considering also the practical problems mentioned before, concludes:

*these shortcomings of advance decision-making are reasons to assign less moral authority to precedent autonomy than to contemporaneous autonomy.*¹⁵

An elegant rejection of this argument is given by Ronald Dworkin, who underlines the importance of the *integrity of a person's life as a whole*, a value that overrides the current welfare of the non-competent person as assessed by others. In his words, the best argument on which to found the right to autonomy of incompetent persons

*emphasizes the integrity rather than the welfare of the choosing agent; the value of autonomy on this view, derives from the capacity it protects: the capacity to express one's own character – values, commitments, convictions, and critical as well as experiential interests – in the life one leads.*¹⁶

For Dworkin, therefore, promotion of the current welfare of the person is not a sufficient reason to frustrate the wishes and priorities he stated when competent. Respect for autonomy entails respect for a person's choices concerning the character of his life as a whole, and how he chooses to be remembered is a crucial aspect of autonomy, supporting "a genuine doctrine of precedent autonomy".

Summing up, although there are certainly problems concerning the practical implementation of advance directives, there is enough philosophical ground to accept respect for prospective autonomy as a legitimate principle on which to base decision-making for incompetent patients. I will assume this position in my study and I will not

¹⁴ Especially Dresser and Robertson 1989. Based on the philosophical premises of Parfit 1984.

¹⁵ Dresser 1995.

¹⁶ Dworkin 1993: 224.

go further into this discussion. I am aware of the complexity of the arguments and of the interconnection between practical and substantial criticisms concerning advance directives, but the purpose of this book is not to take part in this debate. For my purposes, the ethical debate has been definitively settled in the form of legal decisions (cases and statutes) recognizing the legal force of treatment directives. In the coming chapters I will focus on the legal answers that the problem of autonomy for incompetent patients has received and on the consequences that these choices have had on the actual practices connected with the decision-making process of the medical shop-floor.

