



**NATIONAL COUNCIL OF ETHICS FOR THE LIFE SCIENCES**

**59/CNECV/2010**

**OPINION No. 59 OF THE  
NATIONAL COUNCIL OF ETHICS  
FOR THE LIFE SCIENCES**

**OPINION ON THE BILL CONCERNING  
ADVANCE HEALTH CARE DIRECTIVES**

**(December 2010)**



## NATIONAL COUNCIL OF ETHICS FOR THE LIFE SCIENCES

The CNECV [National Council of Ethics for the Life Sciences] analysed (\*) Bills no. 413/XI, 414/XI, 428/XI and 429/XI at the request of the Parliamentary Health Committee (made on 18<sup>th</sup> October 2010), and has approved the following Opinion:

1. The CNECV recognizes the desirability of legislatively regulating the way citizens, who are of legal age and in full possession of their capacities and rights, may declare their will with regard to treatments and other procedures related to their health. So, if they lose their ability to express their will, this can be known as the one previously expressed.

2. Since the issues of informed consent and access to health information, also the focus of attention of one of the Bills analysed, already have enough regulations in the Portuguese legal system, this Opinion of the CNECV will focus only on the regulation of *advance health care directives*, in two of its dimensions:

- i) the written provisions about what is intended or refused (usually called “living will”);
- ii) appointment of Health Care Proxy.

3. It recalls that there is no need for an *advance directive* like that now under discussion for refusal of therapeutic obstinacy to be considered good medical and ethical practice i.e. not carrying out treatment that is futile or obstinate; the CNECV also recalls that it is the person’s legal right to refuse treatment, and that one case or other are not procedures comparable to acts of euthanasia.

4. The CNECV considers that the *advance health care directives* are a legitimate expression of the will of the person signing them and believes they are an element of utmost importance for ascertaining the real wishes of the person (more than for reading the literal sense of the document) on the part of health teams in situations of great complexity.

In this same sense, and assuming that imprecise or ambiguous *advance health care directives* can give rise to doubts over interpretation, it may also prove very useful to collect the *history of values* of that person.

5. The CNECV considers that the *advance health care directives* and the informed consent are based on the principle of respecting the autonomy of the person authorizing or refusing an intervention in their health; other principles, namely those of beneficence and non-maleficence will always be present when making decisions about people unable to express themselves.

The primacy of respect for autonomy, however, has to be taken into account in the case of *advance health care directives*, without it being a principle of absolute application.

6. Regardless of other provisions, the CNECV recognises it legal that, when appointed in writing by the person, there is a Health Care Proxy empowered to represent the person when the latter is devoid of understanding or will.

Any person of legal age and in possession of his/her capacities and rights may be appointed, if he/she accepts, a Health Care Proxy.

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\* The Memorandum that served as a working document for the preparation of this Opinion is also on CNECV’s site ([www.cnecv.pt](http://www.cnecv.pt)).



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7. The CNECV recommends that, given that an *advance health care directive* may contain provisions for refusal and provisions where specific requests are made, the legislation treat, explicitly and distinctly, these declarative variants, particularly as to their binding force, since considering the principle of autonomy and other factors also relevant from an ethical standpoint:

7.1. in the case of intervention or therapeutic refusals, such refusals shall be binding provided that there is compliance with the requirements for ensuring authenticity of the directive set out below;

7.2. in the case of intervention or therapeutic requests, compliance must be weighted with the need to observe and respect the laws in force, of good clinical practice and technical independence of the professionals involved, as well as feasibility of the request itself.

8. The CNECV recommends that the legislation be clear with regard to the formal requirements that give effect to the provisions of refusal.

Thus, the formalisation in writing of the *advance health care directive* before a notary public or equivalent authority must be a factor in ensuring the document's validity, by attesting as to the capacity and freedom of the declarant and its effective date.

9. Since people are free to make their decisions, refusing assistance relating to their health and that their interest is to do so in possession of adequate information, the CNECV considers that the legislation should contain provisions that facilitate access to this information.

For these reasons, health teams, that must include doctors, have a duty to inform the person in the context of preparing *advance health care directives*.

It should also be made clear that any person who is able may choose not to want to be informed, without affecting the validity of his/her decision.

10. The CNECV considers it imperative that the law makes clear that an *advance health care directive* may be revoked at any time; this can be done verbally by its author, without prejudice to further formalisation.

11. The advance directive and its update are the declarant's responsibility, and the elapsed time should not be a factor for expiry of the *advance health care directive*.

However, the CNECV recommends updating it every five years, and that the health teams use extrinsic elements to consciously collect the person's current will, especially taking into account the time that elapsed since it was written, the health circumstances at that time and subsequent evolution of medical science.

12. Although the legislator may, as a guideline, create models of *advance health care directives*, the CNECV considers that there are no forms or scripts that can anticipate every eventuality, and that the expression of real will in those forms or scripts can be limited, and therefore suggests that the *advance health care directives* be made in free text.

13. The CNECV recommends the disclosure of information about the possibility to register the *advance health care directives* in its different modalities (written provisions and/Health Care Proxy).



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14. The CNECV considers that conscientious objection can only be invoked on a case by case basis, with incidence expressed in each of the provisions of the *advance health care directives*.

Should conscientious objection be invoked, the ill person should be sent in due course to another professional or health care team. If necessary, the institution will be notified.

15. The CNECV considers the existence of a national register of *advance health care directives* to be pertinent.

This register should work on a computer platform, under public supervision and validated by the National Committee for Protection of Personal Data. The register may be inspected by health professionals, upon justification that is recorded at the time of access. The CNECV recommends that the author of the *advance health care directive* and the Health Care Proxy, if any, be automatically notified of all these accesses.

It also recommends that unjustified access be criminally or disciplinarily punished.

Lisbon, 17th December 2010

The Chairman

Miguel Oliveira da Silva

It was approved in the plenary meeting of 17th December 2010. Besides the Chairman, the following Counsellors were present:

Lucília Nunes (Rapporteur)  
Michel Renaud (Rapporteur)  
Rosalvo Almeida (Rapporteur)  
Ana Sofia Carvalho  
Carolino Monteiro  
Duarte Nuno Vieira  
Isabel Santos  
Jorge Reis Novais  
Jorge Sequeiros  
José Germano Sousa  
José Lebre Freitas  
Lígia Amâncio  
Pedro Nunes