SOME CONSIDERATIONS ON THE ADVANCE DIRECTIVE DOCUMENT

A) Need for reflection

The Bioethics Committee of Catalonia believes that the import of making an advance directive document (ADD) entails the need to think about its objectives, requirements, limits, forms and consequences. This guide aims to contribute to this reflection and spread it to citizens and professionals (on health and law).

B) What is the basis and the objective of an ADD?

The cornerstone of the ADD lies in the respect for and the promotion of the patient's autonomy, which is prolonged by the ADD when the patient cannot decide for himself.

Making an ADD, and particularly the process of reflection and information involved in the execution of the document, makes it possible to know the patient's desires and values in order to impact any future decisions that may concern him. It is a way of continuing to exercise one's right to be respected with one's own values, ensuring that this respect will be maintained in the event of a situation of greater vulnerability.

Formalising an ADD must be seen as a positive process affording citizens responsibility in decisions pertaining to their health. This must make it possible to have a more transparent and trust-based relationship between patients and health professionals.

As far as possible, the making of an ADD should be the expression of a process of thought carried out on the basis of the personal values of the person involved, but it should also herald the opportunity to insert this thought process into the relationship with our doctor, thus serving as a tool to enhance communication between professional and patient.

C) Legal support for the ADD: Law 21/2000

The legal acknowledgement of the basis of an ADD is provided by Law 21/2000, which addresses the patient's rights to information on health and independence and clinical documentation, expressed thus:

"*Article 8*

Advance Directives

1. The advance directive document, addressed to the attending doctor, in which an adult with sufficient capacity freely expresses the instructions to be taken into account when he is in a situation in which prevailing circumstances do not allow him to express his will personally. In this document, the person may also appoint a representative, who is the valid and necessary person for dealings with the doctor or health team, to represent him if he cannot express his own will by himself.

2. There must be reliable proof that this document has been executed in the conditions mentioned in section 1. To this end, the declaration of advance directive must be formalised by means of one of the following procedures:

a) In the presence of a notary public. In this case no witnesses are required.

b) In the presence of three adult witnesses with full capacity to act, of whom two at least have no kinship up to second degree and have no other type of patrimonial relationship with the person formalising the document.

3. Advance directives including provisions contrary to the legal code or to good clinical practice will be disregarded, or those which do not exactly correspond to the de facto supposition made by the patient in formalising the AD. In these cases, the relevant note must be made in the patient's clinical history.

4. If there is an advance directive, the person who has made it, his relatives or representative must deliver the document containing it to the health centre where the person is attended. This advance directive document must be added to the patient's clinical record.

This Law follows the spirit of article nine of the Convention of Human Rights and

Biomedicine of the Council of Europe signed in Oviedo in 1997.

D) What is an ADD?

An ADD consists of instructions or guidance to be followed, which may be more specific if the probable course of evolution of a given disease is known, or more vague it is unknown or if the signatory is not currently affected by any disease. It also provides for the possibility of naming a representative (surrogate). This person is important, both to help to interpret and defend the fulfilment of these instructions or for taking decisions. The representative, whether or not he is a relative of the patient, is therefore the valid intermediary with the professionals and must know the values of the person he represents.

In a few words, the ADD may be the compilation of a series of instructions to be taken into account (it is the so-called living will), may entail the appointment of a representative or both at once, an option which seems to be the most advisable.

E) Possible content of an ADD

Thus, and while the advance directive document is unique, some basic parts may be recommended:

- 1. **Criteria** that take into account the prioritisation of personal values and expectations, albeit without being precise, and when any such type of decision is far away.

- 2. The specific health **situations** in which the instructions are to be taken into account.

- 3. More specific **instructions and limits** in medical action in the case of foreseeable decisions, particularly when there is information on evolution probabilities.

- 3. **The representative** is the person appointed to act as the valid and necessary intermediary with the doctor or health-care team, so that if the signatory were unable to express his will by himself, he would act as a surrogate in the interpretation and application of the instructions, criteria and principles expressed.

  The representative must know the wishes of the signatory and must be empowered to interpret and apply them. He cannot contradict the contents of the document and must act according to the criteria and instructions which the signatory of the ADD must have issued formally and expressly in the document. But the representative may also express his opinion in aspects not expressly contained in the ADD, in the informed consent and in the assessment of the circumstances, foreseeable progress in medical technology or techniques, the oportuneness of donation of organs or scientific research, etc.

  In view of the capital importance of the functions and decisions entrusted to the representative, it is advisable for him to be free of any type of conflict of interests, and to make sure that the decisions are taken in the patient's best interest; to this end the representative should not be, for example, one of the witnesses to the document, nor the doctor in charge who will have to implement his decisions, nor any health personnel related in any way; this does not mean that people related either by kinship or emotionally with the patient and who may be presumed to give priority to the patient's best interests cannot be representatives.

- 4. **Other considerations** may also be specified, such as ratifying the wish to be an organ donor, etc.

In the case of ADD signed by way of prevention and which is general in scope, without a specific provision for disease or medical operations or treatment, special importance will be attributed to the expression of the potential patient's attitude to life and personal options, his hierarchy of values and consequently the criteria that must underpin any decision to be taken vis-à-vis a possible medical intervention involving legal, human, personal, moral elements, etc.

An ADD may also be executed when the signatory is already in the throes of a known pathological condition, which may have more foreseeable outcomes, and when the consequences of the decision may be known better. This section can also be completed by redrafting and correcting the existing one.

It is advisable for the family to know who the representative will be. The professional looking after the patient cannot be his representative.

F) Questions that should be addressed when making an ADD

Validity of the document

For the document to be valid, the signatory's identity must be guaranteed, as well as his capacity, that he is aware of the content and that the latter is a faithful expression of his will. To guarantee these validity requirements, the ADD must be executed in the presence of a notary public or before three witnesses.

a) The ADD in the presence of a notary public

In the notarial document, the notary public guarantees by attestation and on his own responsibility the capacity of the signatory, that he has been duly informed of the content of the document, that it expresses his will, that the content of the document has not been changed and that it will be permanently safeguarded and produced on request. This document can be executed either in the office of the notary public or wherever the patient is if he is unable to go to the aforementioned office.

b) The ADD in the presence of three witness

The witnesses, who must declare that they are in no way incompatible, will sign the advance directive document in the presence of the signatory, will be provided by the latter and must guarantee, on their own responsibility, the identity of the signatory, his capacity, that he is aware of the content of the document and that it is the freely given and informed will of the signatory.

The Law requires the witnesses to be adults, they must have full capacity to act and at least two of them cannot be related by kinship up to the second degree and have no patrimonial relationship with the signatory; nevertheless, and in view of the important guarantor function entrusted to them by the Law, the witnesses should be able to act with full independence, whereby it is convenient to avoid, beyond the strict conditions of legal incompatibilities, any possible conflict of interests, such as that which might arise with the condition of representative, possible beneficiaries of provisions pertaining to succession, doctor in charge and related medical and health staff, etc.

The safeguarding and submittal of the document

Theoretically, the person making the advance directive document should deliver it to the doctor in charge; or, in the event of the patient’s de facto incapacity, his family or the person chosen by him as representative.

The document may also be taken to the health centre where the patient is being attended to for it to be added to his clinical history so that it may be taken into account should the need arise.

Inclusion in the clinical history

The document, once it has been delivered to the doctors in charge or to the centre, must be added to the patient's clinical history, in primary, hospital, social-health or mental health care.

Each clinical history must contain a visible section which indicates whether the user has or has not made an ADD for the knowledge and accessibility of the professionals attending the person. This document is subject to legally established confidentiality guarantees.

Renewal and withdrawal

Renewal of the document may arise from changes of opinion, to reaffirm a wish that was already stated some time ago, or else to extend it and adapt it better to situations about which more is known.

The ADD can be withdrawn and cancelled any time merely at the wish of the signatory.

The modification or extension of the advance directive document must be carried out in compliance with the same requirements that are applicable to its initial execution.

The same requirements of form should also be observed in the revocation of the document, unless this is not possible, in which case, and depending on prevailing circumstances, a revocation in a written document signed by the patient will also be admissible.

In any event, the same publicity given to the prior advance directive document should also be given to any document of revocation, modification or extension.

G) Use and limits in practice

The existence of advance directive documents entails the obligation to take them into account when taking decisions.

However, taking them into account does not signify following them literally, as they should always be read critically and prudently, both in terms of the expression of the document and general practice, which must lead us to a reflection that makes it possible for the decision to be based primarily on the respect for the wishes of the patient.

The limits stated by the Law on this point are:

1- When the advance directive is an action against the explicit legal code.

2- When it heralds a medical action against established good practices. It is a different matter when the will expressed does not consent to or limits medical action, which can be done. This point must be developed further: following the sense of the informed consent (of which the ADD is an extension), the limitation or refusal to treatment is legitimate, even although the action proposed to the patient is a good clinical practice and is therefore rational and even life-sustaining. Despite this, the patient has the right to reject it, either personally or through an ADD.

3- When the situation that arises is unexpected. And this casts reasonable doubts as to whether in this specific case the patient would have upheld the contents of the ADD.

The decision to be taken must be consensus-based with the appointed representative, or with the family if there is no appointed surrogate. It is a good idea to have the reasons behind the decision to be taken included in writing in the clinical history; particularly, as is stated by the Law, if it does not match the provisions of the ADD. And more precisely, decisions at odds with the provisions of the ADD should not be taken individually.

H) Help from the health-care ethical committee

In cases where there are difficulties in interpreting the wishes expressed, by the relatives or by related persons, the representative or the professional, the centre's ethical health committee, if it exists, may provide effective help. The opinion of a multidisciplinary association, which is rational and is based on an acknowledged methodology, may afford depth and be more credible.

I) Information and clarification of doubts in centres

Health centres must offer help in the drafting of the ADD in the form of professionals with the knowledge and training required to give this guidance. These professionals must information on the technical possibilities in drawing up the document, evaluating (also without going into the specific content in depth) whether the person:

- is above the age of 18 years and has the capacity to do so.
- is under coercion or some type of excessive influence.
- understands the scope of the decision. Whether he has been informed as to possible alternatives and undesired consequences.
- has talked enough with the doctor who is aware of his process as to the future document and its content, and knows the disease and its evolution.
- has or has not informed the representative he wishes to appoint.
- is aware of the possibility of renewing, amending or cancelling the document.
- knows the limits provided for by the Law:
  - claims against the legal code,

- claims for action against good clinical practices,
- and the problem of the unexpected situations.

J) Advice to professionals

Professionals must look upon the ADD as an expression of the patient's autonomy for cases where they have no evidence of his will. Therefore, they must look upon it as an aid to be more respectful and act with greater certainty.

They must remember that they are obliged to:

- accept these documents;
- include them in the clinical history;
- take them into account in decision-making;
- to reason in writing, in the actual clinical history, the final decision and, as the case may be, why the instructions of the document could not be followed.

But the professional should go even further than this; and in this regard,

- he should inform his patients of the help the ADD may provide;
- he should faithfully help any patients who ask for it to draft the document realistically, avoiding coercion at all times;
- he should help to interpret documents that have already been written and suggest updating them when possibilities the patient had not provided for arise, and
- he should ask to meet the representative before taking any difficult decisions, treating him as the privileged surrogate.

K) The centralised register of advance directives

The Department of Health and Social Security will promote the constitution up of a centralised register of advance directive documents to facilitate access thereto wherever the signatory is.

L) The document model

Increasing social diversity and the plurality of life options involved lead certain institutions and groups to formulate their own proposals for a model of the Advance Directive.
Out of respect to these different initiatives, the Committee of Bioethics of Catalonia deems it suitable to formulate, by way of example only, some sections that may be included in advance directive documents.

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