

END-OF-LIFE CARE

Position statement from the Medical Association of Barcelona

June 2018

1.- Introduction

There is a broad consensus when it comes to accepting the objectives of 21st-century medicine defined by Daniel Callahan as early of 1996 in the *Hastings Center Report* and in subsequent publications^{4,13}: to prevent and cure diseases and help people to die in peace. At the 3rd Congress of the Medical Profession of Catalonia (Girona, November 2016)¹ the duty of all doctors was made clear, regardless of the area and sector why they practice: to ensure proper end-of-life care, observing the *lex artis*, complying with the rules of the Ethical Code, respecting people's wishes and agreeing and making decisions and plans in advance whenever possible.

In the last few months, the social and political debate on people's right to decide on own lives in situations of severe disability or at the end of their lives has been revived in Spain following a bill presented to the Spanish Parliament by the Catalan Parliament, and other initiatives by various parliamentary groups. The issue has also been dealt with recently by the European Parliament. It is important to point out that the debate on regulating and decriminalising euthanasia is not only a medical debate – it is also social, political and even ideological. But, as it is directly responsible for caring for the sick and regularly witnesses their suffering, the medical profession can contribute to drawing up possible regulations to help clarify concepts, looking out for the interests and dignity of patients, the quality of the action taken and the legal security of the doctors involved in each case.

Society and its political representatives must be supported and encouraged to reflect on the important issue of end-of-life care so that this debate can be held under conditions of maximum respect for the various existing sensitivities, getting away from prejudices. Regardless of the orientation the legislators want to give to the recognition of patients' rights to autonomy in terminal situations or conditions of severe disability, the Medical Association of Barcelona (CoMB) believes attention must not be diverted from the priority that the health system as a whole must be able to provide a response to ensure adequate material, human and organisational resources to care for those suffering from advanced chronic disease that is within the reach of everyone throughout the area.

This document is not intended to be an in-depth analysis of the problems conditioning the treatment of this type of patient at the different levels of care, nor is it meant to provide clinical guidelines. It is an attempt to clarify terms and concepts that are sometimes confused and, above all, to stimulate sensitivities, activate the "palliative view" and encourage proactive attitudes by professionals in end-of-life situations.

2.- Identifying end-of-life patients

Identifying people with palliative care needs in the health and social services for advanced chronic conditions (ACC) is the first step in implementing a people-focused treatment plan aimed at providing the right information (what patients can and want to take in); finding out their values and preferences; identifying their clinical, physical, psychological and spiritual needs (multidimensional valuation); raising the awareness of the family and carers of the complexity of the situation and coordinating the participation of all professionals likely to be involved (service integration). Advance care planning (ACP) must be implemented, with the active participation of patients and their carers, to provide a dignified end of life, in accordance with patients' values and preferences and without futile interventions^{2,3,7}.

Recently, various tools have been developed, not with the aim of establishing a prognosis or, still less, stigmatising chronically ill patients, but in order to identify those who need palliative care so this can be planned and begun early. As well as the natural prognosis assessment the doctor normally carries out with a chronic patient, the NECPAL (need for palliative care) tool has been evaluated in our environment. This very valuable tool promotes equity, access and the meeting of needs, as well as the exercise of patient autonomy^{9,10,11,14}. Also in our environment, criteria for advanced chronic disease have been drawn up. This also covers the need for palliative care in the different chronic non-cancer diseases¹⁸.

3.- Communication with patients

Communication is more than just giving information. To achieve the aim of drawing up advance care planning with the patient, it is not enough merely to inform them about their current situation, its possible development and the options that must be considered. The conversation must be begun as early as possible, as soon as the patient is identified as having an advanced chronic condition (ACC) and, of course, before death is imminent. Ideally, it should be done before there is any deterioration in the patient's competence to decide. We need to know the information patients want, and do not want to be given and to find out and explore their priorities. We also need to know who they want to be the points of contact among family members and carers, and who they want to take part in decisions.

Communication with patients must allow professionals to find out about their fears and concerns concerning their clinical state. Knowledge of the possible development of their disease should make it possible for them to talk about situations that are unacceptable for them and their preferences concerning the treatment they should receive, where they should receive it and the team that should provide it. Through communication, the care team must be able to assess patients' physical, functional, psychological and spiritual needs and their values and preferences. The sensitivity, abilities and attitude required for this communication process are required from all doctors who have to treat this kind of patient.

4.- Respect for the patient's wishes

The first essential condition so that patients can freely exercise their right to autonomy is that they should have received proper information on their state of health, expectations and the decisions to be made, bearing in mind that information does not consist of isolated actions but is a complete process that must end with checks by the doctor providing the information that the patient has achieved a sufficient level of understanding for making decisions. Informed consent, advance care planning (ACP) and the living will (LW) are tools that ensure the patient's wishes are respected.

If the person is not competent to decide and it has not been possible to draw up ACP, and in the absence of an LW, decisions will have to be made by with a valid contact person, generally from the family, who must also be well informed. Faced with disagreements between different members of the family concerning the decisions to be made, it may be very useful to consult the corresponding Care Ethics Committee (CEC), which will help the doctor decide in the patient's best interests.

5.- Supporting an advanced chronic patient

Having identified advanced chronic patients, established good communication with them and supplied them and their families with correct information, our current Ethical Code says the aim of the care team will be (rules 68 and 70)¹⁹, "not to shorten or lengthen their lives but to promote the maximum possible quality of life, preventing suffering and anguish", as "everyone has the right to live with dignity until their death and the doctor must make sure this right is respected". We must therefore get away from therapeutic obstinacy and avoid futile actions (treatment, examinations, admissions, etc.) that do not improve the patient's well-being in any way, in fact rather the contrary. Unnecessary referrals to hospital accident and emergency departments, so frequent in the last months of life of many chronic patients, must also be avoided.

Having identified the symptoms causing suffering or discomfort, as well as the patients' fears, anguish and spiritual needs, support must be aimed at meeting all these needs, with the cooperation of the principal carer and the family and the help, if necessary, of the expert views of a psychologist and a social worker. Although any care team should have to have the sensitivity and attitude to provide this basic support, skills, knowledge, experience and coordination with palliative care teams, which are fortunately well developed in our area, will become essential in more complex cases.

6.- Support for a peaceful death

To achieve the aim of providing terminal patients with the highest possible quality of life until the time of death, avoiding distress and suffering, they need to support them at this time using procedures and attitudes that also avoid therapeutic obstinacy.

6.1.- Adapting therapeutic effort

This is the procedure through which life support methods (mechanical ventilation,

vasoactive drugs, blood dialysis, artificial feeding, etc.) or other specific treatments (antibiotics, chemotherapy, etc.) are not begun or are withdrawn from patients when it is considered that they do not offer any benefit (futility) in an irreversible situation that will lead to death in the short term. The adaptation of therapeutic effort also involves limiting the admission of hospitalised patients to ICUs or avoiding, as far as possible, the unnecessary hospital admission of people who are at home or in residential care. A note should also be made in the clinical history to warn of the futility of resuscitation in the case of cardiac arrest (order not to resuscitate) or carrying out unnecessary examinations and tests.

This measure must be taken with the consensus of the whole care team and as a result of having drawn up an ACP with the patient or the existence of a LW. Consensus with the family or legal representatives must always be sought, noting all the details in the history. Not beginning or withdrawing futile treatment under no circumstances means abandoning the treatment necessary to maintain the patient's comfort or support for the family.

6.2.- Palliative or terminal sedation

In palliative treatment, sedation is understood as the administration of appropriate drugs to reduce the patient's level of awareness, with the aim of controlling refractory symptoms – in other words symptoms that do not respond to normal treatment⁶. The refractory symptoms most often requiring sedation are delirium, dispnea, pain, haemorrhage, nausea/vomiting and emotional distress. The term “terminal sedation” is reserved for cases when palliative sedation is applied during the actual process of dying.

Palliative sedation is a legally and ethically supported therapeutic procedure, as it would be utterly wrong to allow a patient to suffer for fear that sedation could, as an unintended side effect, advance an already expected death. The application of the procedure will require certain knowledge and skills, once it has been confirmed that the symptom to be treated is refractory. It must be borne in mind that the aim is to relieve the patient's suffering and not to alleviate the suffering of the family or the fatigue of the care team.

It is generally accepted that it is not necessary to obtain signed written consent in order to apply palliative sedation. Consent can be obtained explicitly (verbally from the patient), implicitly (by knowing the values and wishes the patient has been telling the care team), or delegated (via legal representatives). However, a record must always be made of it in the clinical history. The clinical history will also have to show the monitoring of the effectiveness and the adjustments of doses and drugs, depending on developments.

6.3.- Euthanasia and assisted suicide

There is no question that palliative care can save many incurable patients from desperation and the desire to die. This does not, however, prevent some people, as a result of their serious clinical situation and beliefs, their scale of values and possibly other

variables, and with full competence, exercising their own autonomy, wanting to end their own lives and asking for medical assistance in order to do so. Palliative treatment and requests for euthanasia or assisted suicide are therefore not mutually exclusive. However, lack of access to palliative treatment should not be a reason for anyone wanting to die.

Euthanasia and assisted suicide are illegal in Spain. Contrary to what has been said on many occasions, the debate on legalisation – or decriminalisation – of these practices is not only a medical debate: it is an ethical and social issue which must be dealt with in parliament. However, as has been said in the introduction to this document, in regulating these procedures the opinions of professionals – as people who witness suffering and offer support to patients at the end of their lives – must be borne in mind. Meanwhile, the concepts must be clarified:

Euthanasia. “Actions carried out by other people at the repeated express request of patients suffering physically or mentally in a way they experience as unacceptable or undignified as a result of an incurable disease to prevent suffering by causing the patient a safe, quick, painless death.” This definition allows no adjectives (passive, indirect, involuntary), as they only create confusion with other normal ethically and legally backed procedures of end-of-life care. The adaptation of therapeutic effort is not “passive euthanasia”; terminal sedation is not “indirect euthanasia; and causing the death of a patient without an express request from him/her is not “involuntary euthanasia”, it is murder. Euthanasia, as it is currently accepted bioethics, is always active, direct and voluntary^{8,16,17}.

Assisted suicide. “Action of people suffering from irreversible diseases to put an end their own lives with the help of others who provide them with the knowledge and the means to do so. When the person who helps is a health professional, we speak of medically assisted suicide¹⁷”.

6.4.- Euthanasia vs. terminal sedation

Even today, among the general public and also among health professionals, a degree of confusion can be detected in discriminating between the two concepts. In particular, terminal sedation is sometimes interpreted as a kind of euthanasia by stealth. The difference between the two procedures is clear, firstly in terms of the **intent** behind them. The intent of sedation is to relieve suffering, even at the expense of reducing consciousness, while the aim of euthanasia is to cause death in order to eliminate suffering. Secondly, the **procedure** is also different. While for sedation the drugs and the dose are adapted to the patient’s response and can therefore be adjusted depending on the development of the symptoms to be treated, for euthanasia lethal drugs and doses are required to ensure a quick death. Finally, there is the **result**. In sedation, the procedure is successful if suffering is relieved, whereas for euthanasia, success is a quick, safe, painless death⁶.

Conclusions and position of the CoMB

1. The debate on the regulation and decriminalisation of euthanasia is not only a medical debate – it is also social, ethical and political. The outcome is therefore the responsibility of society, through its democratic representatives.
2. In any case, any regulations would have to guarantee rights and provide legal protection for all those involved. The right to conscientious objection by health professionals must also be taken into consideration, together with the participation of doctors on the committees or bodies that have to make decisions on requests for help to die.
3. Regardless of the orientation the legislators wish to give to patients' rights to autonomy in terminal situations or when there is severe disability, it is essential that this initiative also promotes the equal access of patients involved in an end-of-life process to complete, decent, high-quality palliative care in terms of material and human resources.
4. Over the last few decades, Catalonia has rolled out a system of care for terminal cancer patients involving the leadership of health professionals. This has achieved great prestige and has become a reference model in the sphere, according to the WHO. Despite the fact that some Spanish autonomous communities (regional governments) have also rolled out the same model, a large part of the Spanish population is not benefiting from it.
5. Providing a complete, integrated, decent response for people with advanced non-cancer diseases in an end-of-life situation must also now be a priority. We therefore call on the public authorities and those in charge of health care institutions and organisations to prioritise financial resources and training to make this possible. We also urge all professional organisations to offer incentives for this to become the focus of specific training (including bioethical and management aspects) to ensure quality end-of-life care.

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