

SPECIAL ARTICLE

Recommendations for end-of-life care by emergency health services

Carmen Boqué Oliva¹, Rodolfo Romero Pareja^{2,3}, Benjamín Herreros^{3,4}

Emergency services' main purpose is to save lives, but that worthy mission cannot always be accomplished. When caring for patients toward the end of life, we have an ethical obligation to talk with them and their relatives to obtain consensus on treatment and possibly limit it or adjust management in accordance with the patient's condition. Emergency department protocols are necessary for optimizing care to provide the greatest possible comfort and control of symptoms in patients at the end of life to prevent unnecessary suffering and preserve dignity. This article sets out recommendations — including the principles and ethical standards that underlie them — so that emergency services can develop end-of-life care protocols for use in their own settings.

Keywords: Adequacy of life support. End of life. Palliative care. Life support care. End of life. Terminal care.

Recomendaciones de cuidados al final de la vida en los servicios de urgencias

Los servicios de urgencias (SU) tienen como objetivo primordial salvar vidas, pero no debemos olvidar que esta misión encomiable no siempre es posible y, cuando se atienden pacientes en la última fase de la vida, existe la obligación ética de dialogar con ellos y sus familiares para conseguir un consenso y limitar o adecuar el manejo clínico de acuerdo a su situación vital. Con este objetivo, los SU deben tener protocolos de cuidados dirigidos a optimizar el confort y control de síntomas de los pacientes en la fase final de la vida, con el fin de evitar sufrimientos innecesarios y preservar su dignidad personal. El presente artículo expone las recomendaciones (con principios y normas específicas) que deben guiar la elaboración de protocolos de atención al final de la vida en urgencias, con el fin de que cada SU pueda elaborar sus propios protocolos.

Palabras clave: Adecuación del soporte vital. Final de vida. Cuidados paliativos.

Introduction

The need to improve end-of-life care is a challenge for nowadays medicine¹. Improving quality of life and respecting individual preferences, so that end-of-life treatment is adapted to patients' wishes, must also involve the emergency department (ED)².

To this end, it is necessary to identify which patients arrive at the ED in a terminal situation in order to be able to talk to them and their families and make decisions that will mark their future trajectory, whether in the hospital or at home. Classically, EDs had the role of saving lives³, but it is increasingly necessary that they also provide quality palliative care to patients at the end of their lives. This is a duty to patients and to society. It should not be forgotten that the aim of medicine is not to heal or "save lives", but health care in a broad sense, and this includes relief and accompaniment when necessary. EDs must therefore be prepared to know how to adapt the intensity of the treatment offered to the individual healthcare needs of each patient. Mortality in hospital EDs, at around 0.2% (10-15% of

overall hospital mortality)^{4,5}, is low considering the large number of patients seen. Mortality in the ED is a quality criterion that all hospitals monitor and which the Spanish Society of Emergency Medicine (SEMES) also defines as a quality indicator⁶.

Patients who die usually respond to 2 typologies⁷: 1) acute patient with severe pathology and unexpected death, e.g., polytrauma, vascular pathology (aneurysm), shock, etc.; 2) elderly, multi-pathological patient or with an irreversible process, the most frequent, whose death is foreseeable and who comes to the emergency department because the clinical situation cannot be contained at home. This patient may require measures that include, in some way, a limitation of life-sustaining treatment. The objectives of the ED should include, in addition to low mortality, quality care for patients in the last phase of life.

The objective of this document is to make recommendations for end-of-life care in the ED, so that professionals of these services can protocolize high quality care for patients presenting with this situation, in accordance with optimal ethical and clinical standards.

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Deontological and legal framework

The Code of Medical Ethics⁸, which is binding on all physicians and, therefore, also on emergency physicians, states in Chapter 7 (Art. 36.1) that “The physician has the duty to try to cure or improve the patient whenever possible. When this is no longer possible, the obligation remains to apply the appropriate measures to achieve the well-being of the patient, even when this could result in a shortening of life”. For its part, the Code of Nursing Ethics, also binding, in Chapter 3 (Article 18) states that “Faced with a terminally ill person, the Nurse, aware of the high professional quality of palliative care, will strive to provide until the end of his or her life, with competence and compassion, the necessary care to alleviate his or her suffering. He/she will also provide the family with the necessary help to enable them to face death when it can no longer be avoided”.

The Spanish regulatory framework, from the Constitution to the Penal Code, passing through the different state laws and case law⁹⁻¹³ (judgments that establish the law on non-legislated aspects), contextualizes what is licit or illicit at the end of life. The right to health care at any time (including at the end of life) and respect for patient autonomy are legislated. In addition, in order to guarantee correct end-of-life care for patients, most of the Autonomous Communities have regulated the medical process of dying, the first to do so being Andalusia in 2010¹⁴⁻²².

The topics covered are generally common to all the autonomous community laws: information and communication at the end of life, limitation of therapeutic effort and therapeutic obstinacy, patients’ refusal of medical interventions, palliative care (including palliative sedation), advanced living will (depending on the Community, called advance directives, living will or advance directives), the role of Health Care Ethics Committees, patient accompaniment, confidentiality, the rights of persons unable to decide or the obligations of professionals regarding end-of-life care.

As regards advance directives, Royal Decree 124/2007 regulates the National Registry of Advance Directives and the corresponding automated personal data file, ensuring its effectiveness and making it possible for advance directives that have been formalized in accordance with the provisions of the legislation of each Autonomous Community to be known throughout the national territory, since it is the Autonomous Communities that have the powers to regulate advance directives and their regulations may differ.

The Organic Law for the Regulation of Euthanasia²³ has recently been passed in Congress. This law introduces into our legal system the right to request and receive the necessary help to die, both euthanasia and medically assisted suicide. The law regulates this right if the required conditions are met, explains the procedure to be followed and the guarantees to be observed. It also determines the duties of the health personnel who attend to the applicants, their framework of action and

regulates the obligations of the administrations and institutions.

However, the aim of this document is to provide guidelines to achieve an adequate response to people with advanced diseases at the end of life in the emergency department, and this involves, fundamentally, providing adequate palliative care in the emergency department, so that the law on euthanasia is not the subject of analysis in this document.

General ethical principles and standards

In the emergency care of patients at the end of life, there are certain ethical principles and standards to be taken into account, many of which are reflected in legal and deontological standards. On the one hand, there are the patients themselves and their relatives, who must define, according to their hierarchy of values, what their options and preferences are. On the other hand, there are the professionals responsible for care, who are in charge of providing information to the patient and his or her environment, as well as providing quality care, which in these cases includes end-of-life care planning. Finally, we must consider the institutions, which must facilitate that this quality care is also provided in the emergency department. However, in this triangle, patient-professional-institution, ethical conflicts often arise, often exacerbated in emergency care because decisions have to be made quickly and the particular situation of some patients is often unknown⁵.

Ethical principles

The bioethical principles of Beauchamp and Childress²³ can be applied to the triangular relationship described:

- **Autonomy:** is the capacity of persons to deliberate about their personal purposes and to act under the direction of the decisions they may make. Every person should be considered and respected as an autonomous moral subject, responsible for his or her own decisions regarding the acceptance or rejection of whatever affects his or her life project. Persons whose autonomy is impaired, even if they are unable to exercise it fully, do not lose this right and must be incorporated into decision-making as far as possible. A person who has delegated care planning to a representative or caregiver or who has made an advance directive document (or advance directive) should be cared for in accordance with the principle of autonomy by substitution, i.e., according to what the representative or the document states.
- **Beneficence:** “Good deeds”, the moral obligation to act for the benefit of the sick, helping them to promote their legitimate interests. In medicine it translates into applying the medical criterion of indication, but considering the opinion of the patient and available resources. The patient assesses what is beneficial

for him/her with the information of the physician. In this sense, it is essential to carry out a correct assessment of the competence of the patient, which must always be in accordance with the complexity of the decision to be made.

- Non-maleficence: it is the *primum non nocere*. The first duty of the physician is not to intentionally cause harm or increase it. It includes not causing pain or suffering (physical, psychological or moral), nor producing incapacity.
- Justice: equitable distribution of health resources-benefits and burdens among members of society. It implies pursuing equity in the distribution of burdens and benefits, so that in the same situation every citizen should have the same opportunities to be treated in the same way.

Ethical standards

The application of legislation, deontology and ethical principles to the practice of end-of-life care results in ethical standards, as described by various scientific societies^{24,25}:

- Patients susceptible to adequacy of life support²⁶, understood as the adaptation of treatment to the conditions of the patient, will be all those facing the final phase of their life, either abruptly and unexpectedly or as a consequence of the evolution of an incurable disease.
- The decision to use adequacy of life support should be adjusted to current medical knowledge and the values of the patient. In case of reasonable doubt, it is advisable to initiate intensive treatment²⁷, with withdrawal conditional on clinical evolution or on obtaining information about the wishes of the patient.
- Individualize the measures. The decision-making process should be adapted to the individual life situation of the patient²⁸. It will probably be necessary to make adjustments according to the idiosyncrasies of each service in order to provide the best possible individualized treatment.
- Paternalistic medical decisions²⁹ should be avoided and medical action without consent should be considered only in critical situations of necessity. For the same reason, action in “therapeutic necessity” mode (without consulting the patient) should be avoided in those situations that can be agreed upon by the medical team responsible and the patient or his or her representative.
- In patients who have an advance directives or advance directives document, this should be consulted, respecting the wishes of the patient (Law 41/2002 on Patient Autonomy) and, if possible, confirming that it agrees with the current wishes of the patient. It is the obligation of all physicians attending patients in this situation to consult the registry of advance directives of the corresponding autonomous community.
- Incapacity and incompetence. Decisions shall be made by delegation or substitution for any incapable or incompetent patient. These decisions will be made

with the legal guardian and, if there is no legal guardian, with his or her representative. This type of decision will also be made in situations of temporary incapacity or incompetence due to an acute clinical situation (a very frequent circumstance in the ED).

- In the case of minors who are not incapable or incapacitated, but who are emancipated or 16 years of age, consent cannot be given by proxy. However, in case of serious risk according to the criteria of the physician, the consent will be given by the legal representative of the minor, once the opinion of the minor has been heard and taken into account (Law 41/2002 and Law 26/2015, of July 28, on the Modification of the Child and Adolescent Protection System).
- Conflicting decisions should be discussed collectively and, as far as possible, should be made by consensus, including the patient and his or her relatives in the deliberation. An attempt should be made to reach an agreement with them through a deliberative communication process, trying to respect the preferences of the patient. Shared medical decisions should be promoted in the ED. In specific cases, the adequacy of life support decision will have to be made individually and, if so, it is recommended that it be discussed a posteriori with the rest of the team³⁰.
- Freedom of conscience must be respected as a fundamental right enshrined in Article 16 of the Spanish Constitution and not be confused with conscientious objection. According to Constitutional Court ruling 15/1982, the right to conscientious objection does not consist of a legal guarantee of abstention from a certain conduct, but rather this right introduces an exception that must be effectively declared in each case.
- Once the clinical decision has been agreed upon, the patient and, if necessary, those close to the patient should be informed, and it is desirable that both understand and accept the situation, avoiding a feeling of abandonment on the part of the professionals. The family and relatives should not be held exclusively responsible for the decision making process.
- The right of the patient to health information may be limited by the proven existence of a state of therapeutic necessity, also known as therapeutic privilege. Therapeutic necessity is understood as the physician power to act professionally without first informing the patient when, for objective reasons, knowledge of his own situation could seriously or irreversibly harm his health. In this exceptional case, the physician will make a reasoned record of the circumstances in the clinical record and will communicate his decision to the persons related to the patient for family or factual reasons³¹.
- Once the decision of adequacy of life support has been made, it is the obligation of the physician not to abandon the patient during the dying process and to guarantee an adequate death by ensuring the symptomatic treatment and comfort measures required.
- Professionals should not accede to demands for futile or disproportionate actions, considered malpractice,

contraindicated and illegal, but should accept the right of the patient to refuse any action even if it is considered medically indicated. Therapeutic obstinacy on the part of the professional should therefore be avoided, as well as the establishment or maintenance of futile treatments.

- The decision to apply adequacy of life support measures to the patient, after rigorous and consensual assessment of the indication and prognostic criteria, allows us to understand death as an inevitable evolution of the disease.
- When necessary, healthcare professionals are responsible for providing the patient with a death without suffering and, in accordance with current legislation, through a process in which decisions must be made by consensus between the medical and nursing team, the patient and the family or representative, with the aim of maximizing the comfort of the patient. This decision must be based on the best available scientific evidence, on the ethical principles mentioned above and on the legal system in force.
- If there are doubts, the decision should be reconsidered, and advice may be sought from a healthcare ethics committee (HCEC). In case of lack of agreement between health professionals or the family or representative, it is also advisable to take into account the recommendation of the HCEC of the center, whose report or recommendation is not binding and must be adapted to the scope of care of the consultation, in this case the ED.
- Adequacy of life support decisions should be recorded in the medical record.
- It is recommended that EDs have their own end-of-life care protocol to improve the decision-making process in complex situations.

Adequacy of life support and palliative sedation

Adequacy of life support is the adjustment of treatments to the clinical situation of the patient³². In adequacy of life support, treatment is modified according to new therapeutic objectives. These objectives are adapted to the living conditions of the patient, aiming at the well-being of the patient and the treatment of symptoms that may cause suffering, while avoiding contributing to the prolongation of a clinical situation that lacks reasonable expectations of improvement³³.

Not all life-prolonging treatments are beneficial to the patient and not everything that is technically possible is ethically acceptable. In end-of-life situations, many tests and therapies can produce more harm than benefit (they are disproportionate).

The Spanish Society of Palliative Care (SECPAL, acronym in Spanish) considers therapeutic obstinacy to be the adoption of diagnostic or therapeutic measures that pursue a curative objective and that are not indicated in the advanced and terminal phase of a disease because they are disproportionate (they produce more

harm than benefit), as well as the use of extraordinary measures (usually invasive) with the aim of unnecessarily prolonging life in the last days or last hours of life³⁴. Therapeutic obstinacy does not prolong life, but rather lengthens the process of dying, making it harmful for patients and their relatives, as well as being unfair to society as a whole, because healthcare resources are spent unnecessarily.

Palliative sedation is an appropriate treatment in those patients who present intolerable suffering and do not respond to adequate treatments. Its aim is to alleviate suffering and calm any refractory symptoms (pain, dyspnea, agitation, anxiety, panic, nausea/vomiting, hyperactive delirium), although this may bring forward the death of the patient, who is already in the terminal phase. Palliative sedation, in addition to being good clinical practice and having an ethical justification, is in line with the current legislative and deontological framework. Adequacy of life support and palliative sedation are procedures of good clinical practice, and therefore criteria of quality of care.

The ethical justification of palliative sedation is usually made through the principle of double effect. The ethical principle of double effect indicates an action or omission that has 2 effects, one considered positive and the other negative. It is ethically acceptable when these conditions are met: 1) that the act to be performed is good or, at least, indifferent to its object; 2) that the positive and negative effects follow from the act, that is, that the positive effect is not obtained by means of the negative; 3) that only the positive effect is sought and the negative is limited to toleration; and 4) that there is a certain proportion between the positive effect desired and the negative effect tolerated, that is, that the positive outweighs the negative, or at least equals it.

In palliative sedation, sedative drugs are administered, alone or in combination, to reduce the level of consciousness of a terminally ill patient. Its aim is to avoid intense suffering caused by one or more refractory symptoms. Palliative sedation requires prior consent from the patient. If this is not possible, the consent of family members or relatives must be obtained. Palliative sedation does not have to be irreversible, it can be continuous or intermittent and its depth is graded in order to achieve the level of sedation that achieves symptomatic relief. For all these reasons, the drugs of choice have a fast half-life. Before applying them, the physician must verify that: 1) there is suffering caused by refractory symptoms; 2) the patient (and if this is not possible, his or her family/neighbors) has given informed consent; 3) the patient has been given the option of satisfying his or her family, social or spiritual needs.

Sedation in agony (or last hours of life) is used when the patient is in the last days or hours of life to relieve severe suffering. In this situation, sedation is continuous, predictably irreversible and as deep as necessary to alleviate suffering. In last hours sedation, it is recommended to maintain only essential drugs, such as

Table 1. Menten Scale. Determination of agonic situation

| Criteria |
|---|
| Cold and white nose |
| Cold extremities |
| Lividities |
| Cyanotic lips |
| Premortem stertors |
| Apneas (15 seconds/1 min) |
| Oliguria (< 300 ml/d) |
| Drowsiness (> 15 h/d) |
| Interpretation: |
| ≥ 4 criteria → Agonal situation: mortality > 90% within 4 days. |
| 1-3 criteria: Pre-acute situation. |

Table 2. Ramsay Scale: Assessment of the level of sedation

| |
|---|
| LEVEL 1: Patient agitated and distressed |
| LEVEL 2: Calm, oriented, and cooperative |
| LEVEL 3: responsive to verbal stimuli |
| LEVEL 4: Sleepy, rapid response to light or sound |
| LEVEL 5: Slow response to light |
| LEVEL 6: No response |

anticholinergics (bronchial antiseptory agents) or opioids, withdrawing others that are not essential, such as antibiotics, nutrition, etc. In this case, it is essential that the responsible physician confirms that the necessary requirements for palliative sedation are met (patient suffering, informed consent and satisfaction of personal needs) and that there is also clinical evidence of imminent or very near death. The Menten Scale has been validated in oncologic patients, but it is also used in other types of patients (Table 1). In addition to the treatment of pain and suffering, anything that increases the discomfort of the patient or uneasiness should be avoided, since the dying process is accompanied by physiological alterations that decrease consciousness and should not be reversed, such as hypercapnia, increased uremia or decreased cerebral perfusion. The ED is not the ideal environment for sedation in agony, but, unfortunately, there are situations that make it necessary to resort to it as the only therapeutic strategy.

There are scales to assess sedation, such as the Ramsay Scale (Table 2), the Sedation Analog Scale (SAS) or the Visual Analog Scale (VAS). The sedation guideline in agony should be composed of a combination of drugs including a benzodiazepine and an opioid, which set the level of sedation or analgesia. Other drugs can be added to this regimen to alleviate other symptoms such as delirium, hiccups, vomiting, secretions, etc. The drugs and doses most frequently used in sedation are listed in Table 3. It is worth insisting that in terminal sedation no dose limit should be considered, since the purpose is the control of refractory symptoms, and the recommended route of administration will be intravenous or subcutaneous, depending on the resources and the specific clinical case.

It is recommended to consider the possibility of increasing the degree of sedation (there is no maximum dose limit) in the following situations: patient request, respiratory distress, tachycardia, hypertension, diaphoresis, crying, vocalization with movements, facial gri-

Table 3. Most common drugs in palliative sedation

| | EV bolus dose | Duration of the effect | EV perfusion |
|-------------|---------------|------------------------|------------------|
| Midazolam | 1-3 mg | 4-9 hours | 0.05-0.25 mg/k/h |
| Morphine | 3-5 mg | 3-4 hours | 0.5-4 mg/h |
| Fentanyl | 0.05-0.1 mg | 0.5-2 hours | 0.5-2 µg/k/h |
| Haloperidol | 5 mg | 2-4 hours | 3-5 mg/h |

Other drugs used are: remifentanyl, propofol, levopromazine, chlorpromazine, phenobarbital, scopolamine, according to the protocol established in each center.

EV: endovenous.

macing or restlessness. On the other hand, if in an ED it is necessary to resort to sedation in the last hours and the patient is intubated, it is convenient to use sedative drugs in advance to avoid a sudden increase in dyspnea after the withdrawal of mechanical ventilation, and a dose 2 or 3 times higher than that previously received on an hourly basis may be administered.

Recommendations for the protocolization of the appropriateness of life support in emergency departments

In accordance with the above (legislation, deontology, principles and general ethical standards), and having made the pertinent conceptual clarification with respect to adequacy of life support and sedation, the following recommendations are proposed for the development of protocols for quality care of patients at the end of life in the ED:

1. Adequacy of life support is justified when the team responsible for the patient considers that active treatment does not improve the clinical condition of the patient, is futile or harmful, as well as when it is considered to be inefficient and, therefore, disproportionate.
2. An attempt should be made to reach consensus (not unanimity) among the team treating the patient and, if necessary, the opinion of other professionals should be considered to assist in decision making. This consensus should include the patient/representative and, when necessary, those close to the patient.
3. It is essential to take into account the autonomy of the patient, and consideration should be given to the possibility of the patient having an advance directive or, in the case of complex chronic patients, an advance decision making plan. If this is not the case, the consent of the patient-representative or close relatives should be obtained after receiving the information in a clear, truthful and comprehensible manner, all of which should be saved in the medical record.
4. A therapeutic communication strategy will be proposed with the patient and his or her relatives, offering clinical options to meet their physical, psychosocial and spiritual needs.
5. It is in this communicative strategy that the adequacy of life support should be presented to the pa-

- tient-representative/neighbors, guaranteeing confidentiality, explaining the reasons for the adequacy of life support and the measures to be carried out, reinforcing that the relief of the pain and suffering of the patient will be sought, and stressing the importance of the wellbeing and comfort of the patient.
6. If there are doubts about the decision, if the clinical situation permits, it is recommended to postpone the decision for a few hours or days.
 7. If necessary, professionals who, for reasons of conscience, do not agree with the consensus decision should be removed, respecting their right to conscientious objection. This type of decision should not be left to the physician on duty, but on rare occasions (and not being the most advisable), clinical urgency will mean that he/she will have to make this decision.
 8. Once the adequacy of life support decision has been made, a plan for compliance and management of possible complications should be established.
 9. At all times, the patient will be accompanied by his or her family and relatives, and maximum intimacy will be ensured, thus facilitating an adequate mourning process afterwards.
 10. In the event that the adequacy of life support decision is not accepted by the patient or his/her relatives, a waiting/reflection time shall be considered and, if necessary, a consultation shall be made with the HCEC.
 11. In case of a request by the patient or relatives for disproportionate measures or measures of proven therapeutic futility, it should be explained that such measures are harmful to the patient and should be limited, even against the wishes of patients or relatives.
 12. If there are changes in the diagnosis of the patient or prognosis, adequacy of life support decisions will be re-evaluated.
 13. In all cases, the decisions and actions taken should be recorded in the medical record, reflecting, when they exist, the refractoriness of the symptoms. Once a decision has been made on VSA, the medical record should reflect which measures are withdrawn (vasoactive drugs, mechanical ventilation or any other supportive treatment) and which are not, as well as the pertinent order not to perform cardiopulmonary resuscitation.
 14. It is essential that EDs have protocols for palliative sedation and sedation in agony, including the appropriate drugs, doses and routes of administration. If possible, these protocols should be agreed with the palliative and oncology units, as well as with the HCEC.
 15. In palliative sedation, drugs should be individualized according to the refractory signs or symptoms presented by each patient. The use of pain and sedation scales is recommended in order to adapt the doses of medication to the situation of the patient.
 16. It is recommended to foresee all the possibilities that may occur, such as prolonged agony or even the survival of the patient. The moment of death should never be predicted.
 17. In situations of the last hours or days, the best location for the patient and his/her relatives should be sought, guaranteeing the maximum comfort of the patient and the accompaniment of his/her relatives.
 18. The assessment of suffering, a broader concept than pain, implies knowledge of the values of the patient through dialogue with the patient and his or her relatives. It is therefore recommended that professionals improve their skills in recognizing and minimizing situations of suffering in the terminally ill patient.
 19. Finally, it should not be forgotten that both hospital and prehospital EDs attend daily to patients with severe neurodegenerative, neurological and end-stage cardiorespiratory diseases, many of whom do not require active medical treatment or curative surgery, and that these patients can be considered potential donors. The inclusion of transplants in the portfolio of services, as well as the culture of donation, are essential for these areas to become generating units of potential donors. Organ and tissue donation is a right of the patient and part of end-of-life care. It is our duty to inquire about the possible existence of prior instructions and, in the absence of these, the representative or relatives of the patient should be asked about the willingness of the patient to be a donor.

Glossary

- Adequacy of Life Support (ALS) is defined as “the decision not to implement or withdraw therapeutic measures when it is expected that they will not be of significant benefit to the patient”.
- Comfort: subjective perception of well-being, which requires a series of specific, realistic, proportionate measures adapted to the emergency setting, with special emphasis on the control of situations that cause discomfort. To achieve this, pharmacological treatment of the symptoms should be started early, as well as anticipating the appearance of the different complications.
- Advanced incurable disease: a disease with a gradual and progressive course, unresponsive to available curative treatments, which will progress to death in the short or medium term in the context of progressive frailty and loss of autonomy.
- Terminal disease: it is an advanced, progressive and incurable disease, without reasonable chances of response to treatment, with a survival prognosis of less than 6 months, which is accompanied by multiple, variable and multifactorial symptoms.
- Oncological terminal disease: a terminal disease in which it has been proven that the histology of the tumor has no influence on the patient’s survival.

- Euthanasia: procedure by which the anticipated death of the patient is sought, in a deliberate manner and by administering drugs at lethal doses to end the patient's suffering. In contrast, sedation seeks to lower the level of consciousness with the minimum dose of drugs so that the patient does not perceive the refractory symptom. Therefore, the main difference between terminal sedation and euthanasia is the intention in the procedure employed and in the outcome.
- Futility: a futile treatment is one that does not obtain the expected result, despite having a precise indication and being correctly applied. It is up to the physician to recognize when a treatment is no longer effective. Futile medical actions should not be initiated or should be withdrawn if they have already been initiated.
 1. Physiological futility: it is impossible for the treatment to achieve the intended physiological response and, therefore, it fails to restore or improve the altered function.
 2. Quantitative or probabilistic futility: interventions performed to provide a benefit to the patient have a high probability of failure based on data from clinical trials and studies. There is no agreement on the probability of success that would allow therapeutic measures to be considered futile. The most widely accepted threshold figure is a probability of success between 1% and 5%.
 3. Qualitative futility: the professionals consider, in the light of their own experience and previous studies, that the intervention to be carried out has little chance of achieving a functional recovery and quality of life that can be perceived by the patient as satisfactory.
- De facto incapacity: a situation in which people lack sufficient understanding and will to govern their lives autonomously, without necessarily having a judicial resolution of incapacitation.
- Responsible physician: the professional in charge of coordinating the information and health care of the patient or user, who is the main interlocutor of the patient or user in all matters relating to his/her care and information during the care process, without prejudice to the obligations of other professionals involved in the care process.
- Potential donor: patient with catastrophic brain damage with a high probability of progressing to encephalic death in a short period of time and with no apparent medical contraindications for organ donation.
- Potential donor: patient who has progressed to encephalic death and without medical contraindications for organ donation.
- Representative: a person of legal age and capacity who gives consent on behalf of another, having been designated for this function by means of a declaration of anticipated vital will or, if there is no such declaration, following the legal provisions in force on the matter.
- Sedation in agony: is a therapeutic decision prescribed only by physicians, to treat a physical or psychological symptom refractory to other treatments.
- Palliative sedation: is the administration of drugs to

reduce the level of consciousness of a patient with advanced or terminal illness in order to avoid intense suffering caused by one or more refractory symptoms. It can be continuous or intermittent and its depth is graded in order to achieve a minimum level of sedation that achieves symptomatic relief. Palliative sedation need not be irreversible. The drugs of choice are those with a short half-life.

- Difficult symptom: it is a situation that requires for its clinical control the implementation of therapeutic measures beyond the usual ones.
- Refractory symptom: a symptom that cannot be adequately controlled despite efforts to find a tolerable treatment within a reasonable period of time without compromising the consciousness of the patient.
- Agony: the phase preceding death when death occurs gradually and in which there is intense physical deterioration, extreme weakness, high frequency of cognitive and consciousness disorders, as well as difficulty in relating to others, with a prognosis of life limited to hours or days.
- Life-sustaining treatment: health intervention aimed at maintaining the vital signs of the person, regardless of whether or not such intervention acts therapeutically on the underlying disease or biological process that threatens the life of the person.
- Inappropriate treatments: those that are not beneficial or of uncertain benefit or are disproportionately costly. It is considered ethical not to administer a treatment when it is considered futile, inappropriate, contrary to the interests of the patient or when there are insufficient resources.

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Addendum

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