Ethical points of reference in caring for people nearing the end of life

Issues linked to ageing and the end of life are complex and sometimes painful. The questions surrounding this topic are sensitive and cannot have a simple response. They challenge our sense of solidarity and our ingenuity in seeking ways and means to express true compassion and act appropriately.

Several people have become household names as part of the debate on the end of life. Whether we like it or not, they have become part of our collective memory: Karen Ann Quinlan and Terri Schiavo from the United States, Ramón Sampedro and Immaculada Echevarría from Spain, Vincent Humbert and Chantal Sébire from France, Piergiorgio Welby and Eluana Englaro from Italy, Hugo Claus from Belgium, and many others.

The media has focussed on extreme cases which have been brought to public attention because of their particularly dramatic nature. Thus, the discussion has largely been based around certain "unusual" situations with high emotional stakes. Because of this, the complex and sensitive public debate surrounding the end of life is all too often reduced to a few paltry clichés and stereotypes built on feelings rather than an exchange of rational arguments. There is no end to specialised publications on this topic; however, their distribution often remains limited to the narrow circles of legal expertise, philosophy and medicine. Meanwhile, public opinion oscillates between knowledge, misunderstandings and approximations, and rigorous examination often gives way to the feelings, spectres and fears surrounding death.

Paradoxically, although reason is prized in the scientific and technological fields, the heart and sentiments are usually prioritised in issues relating to life and death, flesh and blood, meaning and values. This human tendency is understandable because ethical and legal principles, as sophisticated as they are, still seem abstract and far removed from the complex reality of tragic situations. Clearly, we are not trying to ignore the distress of such situations, but it is vital to inject a degree of reason into the debate. The emphasis placed on a few particularly tragic situations, at least from the perspective of the general public, has overshadowed many of the other facets in the end-of-life debate. It seems to have concentrated too strongly on granting the right to euthanasia to the detriment of other concerns, such as pain and symptom management, general support for the patient, and the development of palliative care. This document will use a summary-based, question and response approach in order to clarify certain crucial and overriding conceptual distinctions and provide some ethical points of reference for accompanying people nearing the end of life.
Basic care and treatment

1. What care is due patients nearing the end of life?

According to traditional understanding, humans have fourteen fundamental needs: to breathe, eat and drink, excrete (urine and stools), move and maintain good posture, sleep and rest, be clothed, maintain a correct temperature, enjoy good hygiene, avoid danger, communicate, act according to their beliefs and values, occupy themselves, have fun and learn.

"Basic care" means care which fulfils these basic human needs. This care must always be provided when a person cannot fulfil these needs independently. To deny a patient this basic care—which does not usually involve the use of disproportionate measures—would be considered a crime of negligence.

2. What is meant by “treatment”?

The word "treatment" describes the medical actions which aim to combat the progression of an illness and, if possible, restore health. It is perfectly legal to refuse medical treatment if treatment becomes disproportionate (see point 3 below). The difference between “abstention from disproportionate treatment” and “euthanasia via a lack of appropriate treatment” does not lie in the type of treatment which is renounced, but rather in the relationship between the action in question and the condition of the patient. Omitting a disproportionate treatment allows us to avoid overly aggressive therapy. Omitting a proportionate treatment constitutes euthanasia by omission.

3. What is meant by overly aggressive therapy?

Overly aggressive therapy describes an exaggeratedly stubborn struggle against inevitable death. A certain obstinacy in the fight against illness is legitimate and laudable. Nonetheless, such obstinacy is to be criticised if it leads to a use of disproportionate treatment, namely, when the anticipated benefit is not proportionate to the inconvenience it would cause (for example, if necessary, beginning or continuing chemotherapy or radiotherapy for a cancer patient nearing the end of life).

4. Is it often tempting to practise overly aggressive therapy?

It is an undeniable fact that at one time a certain branch of medicine, heady with knowledge, found it difficult to admit its powerlessness in the face of certain and inevitable death. The temptation to medically prolong life is a reversal of the extraordinary progress medicine has made, especially in the field of resuscitation. It compels some medical staff to employ medical treatment disproportionate to the condition of a patient which alters the quality of the end of their life, without being justified by any real hope of healing or even improvement. Overly aggressive therapy seems to be an attempt to reject limitations either on the art of healing or on human existence itself.

Fortunately, the abuse of overly aggressive therapy is now universally criticised. After exhausting all of the known reasonable resources in the medical arsenal and observed their failure, curative medicine, which aims to heal, is replaced by palliative medicine, which prioritises supporting the quality of life of the patient nearing the end of life.

Instead of attempting to delay an inevitable death by using equipment and treatments as ineffective as they are restrictive and painful, palliative care takes into account the psychological, social and human needs of the patient nearing the end of life. They focus not only on the illness but on the person’s global well-being (see below, point 14)
5. Overly aggressive therapy: the moral view

Doctors have never been under obligation in any medical, moral or legal codes of ethics to begin or extend futile or disproportionate treatments. The decision to end or not to introduce a disproportionate treatment is in line with the overarching mission of medicine, which must apply careful treatment based on scientific data. A wise decision of this kind should not be confused with euthanasia. In fact, this amounts to the acceptance of human mortality. Obeying the natural process which leads to death is also a means of respecting life.

6. What's the difference between “letting someone die” and “causing someone to die”?

It is one thing to help a patient die with dignity by trying to support them in their distress, relieve their pain and comfort them. To deliberately cause death is another matter altogether. The causes of death differ in every case. When a doctor decides not to begin, or to bring an end to, disproportionate treatment, the patient will die from the consequences of their terminal illness; however, if a lethal substance is administered to the patient, this will be the cause of death. There is also a difference in intention: in the first case, the doctor aims to spare the patient from pointless suffering, which could accelerate the onset of death despite there being no deliberate intention to induce it; whereas, in the second case, the intention is to bring about the death of the patient to prevent their suffering.

Pain treatment

7. Is it acceptable to relieve pain even if it could hasten the onset of death?

A doctor’s role is not only to restore health and save lives, but also to relieve a patient’s pain. It is his duty to administer pain-killers even if their indirect (and not in itself deliberate) effect is to shorten the patient’s life. A doctor trying to alleviate pain can legally assume the risk of hastening the onset of death, provided he respects the conditions outlined in the following point.

8. So can we use actions which may produce a negative effect?

It is acceptable to carry out a good action which we expect to produce a good effect, even if a negative effect (which is not the deliberate intention of the action) cannot be ruled out. This is commonly known as the principle of double effect. Otherwise, it would be impossible for us to act because there is always the possibility that a good action could indirectly have a negative effect. There are several conditions which must be in place for such an action to be morally acceptable:

1. The action carried out should not be bad in itself (in this case, the doctor is administering a painkiller);
2. The intention of the agent must be good (the doctor is simply seeking to relieve pain);
3. The negative effect can not be directly intended as a means to obtain the positive effect intended (the doctor does not want his patient to die but rather to deliver him from his pain);
4. Finally, there must be a reasonably proportionate relationship between the positive effect intended (in this case, pain relief) and the tolerated negative effect, namely, the potential shortening of life (the doctor administers a product in a dose proportional to the pain to be alleviated).

9. How can we identify sound medical practice for euthanasia?

If the doctor’s only intention is to relieve pain and the products and doses are chosen as a result, then his decision to administer strong doses of morphine or other analgesics cannot be considered an act of euthanasia. Euthanasia, on the other hand, intends to cause death and the choice of products and doses will be dependent on this intention. It is important to underline the subtle but unquestionable difference from a moral and legal perspective between taking a life to
eliminate pain and relieving pain in a way which runs the risk—albeit cautious and proportionate—of shortening life.

10. Are there any refractory symptoms?

According to specialists, in the current state of medicine, practically all physical ailments can be adequately relieved. It is extremely rare for symptoms to be refractory (resistant to any form of pain treatment). In these extreme cases, it is still possible to revert to controlled sedation. Nonetheless, in practice, despite progress in the field, some medical professionals remain unprepared for controlling symptoms and treating pain. Moreover, most requests for euthanasia arise due to inadequate pain treatment. There are multiple witness accounts and references in support of this argument. In this respect, training for health professionals must be improved as a matter of urgency.

11. What is meant by sedation?

Sedation means the administration of an appropriate substance to reduce the patient’s level of consciousness, in order to control certain difficult or refractory symptoms (such as extreme anxiety, panic attacks, haemorrhage, asthenia or dyspnoea).

12. Can we distinguish more clearly between different kinds of sedation?

The main distinction is between palliative and terminal sedation.

Palliative sedation describes the deliberate administration of various combinations and doses of medicinal substances to reduce the awareness of a patient in an advanced or terminal state of illness. Such action intends to adequately ease one or more refractory symptoms and is carried out with the patient’s explicit, implicit or delegated consent.

“Controlled” or intermittent sedation involves alternating periods of unconsciousness and consciousness for the patient.

Terminal sedation describes the deliberate administration of medicinal substances in order to provide the necessary pain relief for a physical and/or psychological ailment which has been impossible to obtain via other means. This involves a sufficiently deep and probably irreversible reduction of consciousness for a patient whose death is likely to be imminent and is carried out with their explicit, implicit or delegated consent. In basic terms, it is a specific type of palliative sedation, used in periods of agony.

13. What is the difference between terminal sedation and euthanasia?

Essentially, sedation has three differences to euthanasia: intention, the process implemented and the desired result. (1)

Intentionality. – With sedation, the doctor prescribes sedatives with the sole intention of relieving the patient who displays certain symptoms. The objective of euthanasia, on the other hand, is to deliberately cause the patient’s death in order to spare them from suffering. (see above, no.9)

Process: There must be a clear reason for the sedation, namely, the presence of a certain symptom. Furthermore, the products and doses employed are regularly adjusted depending on the patient’s response to the suffering brought on by the symptom. This requires continual assessment of both the symptom and the treatment. The process must be recorded on the patient’s medical files. However, in the case of euthanasia, the products and doses used guarantee a rapid death.

Result: With sedation, the response parameter (success) is the relief of suffering and an evaluation procedure is carried out to ascertain this result. However, with euthanasia, the response parameter (success) is death.

In summary, terminal sedation appears to be an indicator of imminent death and not the cause of premature death. The moral responsibility of the care team is linked to the decision-
making process on pain relief, not the result of the interventions in terms of life or death. In other words, euthanasia and terminal sedation both end in the death of the patient, but the decision-making process (including the intention which inspires the carers) reveals the ethical difference between these two forms of medical support for patients nearing death.

14. Who can benefit from palliative care?

When curative treatment is revealed to be fruitless or disproportionate, palliative care takes over. Its aim is to give the terminally ill person the best possible quality of life. Emphasis is placed not only on making the patient as comfortable as possible and managing pain and other uncomfortable symptoms, but also on caring for and assisting the patient's family and friends and supporting them as they grieve. In practical terms, this means providing material and moral comfort for the patient in order to make the last moments of his life easier for him, his family, and his friends.

Of course, death is a formidable test for all mortals. But by supporting the person nearing the end of life and his family in a human way, palliative care allows death to take place calmly and this reduces the temptation to cut brutally short the final moments of life. (2)

Vegetative state

15. What is meant by “vegetative state”?

A persistent vegetative state is the result of widespread and multiple lesions of the cerebral hemispheres, while the brain stem remains relatively intact. It is caused by anoxia (oxygen deprivation) which occurs after drowning, hanging, an attempt to commit suicide using medication or accidental skull trauma.

The person in a vegetative state shows no visible sign of awareness either of himself or of his surroundings, and seems incapable of interacting with others or reacting to appropriate stimulants. Such persons do, however, continue to display brain activity which regulates basic vital functions, such as spontaneous respiration, swallowing, and other metabolic functions. In particular, the person is awake and retains certain reflexes: he can groan, cry, shout, or even smile. (3)

This state is not comparable to a prolonged coma (which is characterised by an absence of alertness and a progressive loss of consciousness) (4), nor brain death (5), as the brain continues to guarantee vital functions.

A patient in a vegetative state is in a state of complete dependence: they need artificial nourishment and hydration as well as treatment to prevent illnesses and other complications, such as bedsores.

16. Is the vegetative state irreversible?

Based on current medical knowledge, it is not possible to affirm categorically that the vegetative state is persistent and irreversible. Although the probability is extremely low, recovery does sometimes occur.

17. Is the term “vegetative state” satisfactory?

The expression is negative. It suggests that people in this condition are reduced to the state of a "vegetable". A human being, even one whose capacity to exercise higher functions has been partially or completely restricted, is still a person and does not become/ can never be considered as? an animal or a plant.
18. Is the person in a vegetative state still a “person”?

Is a human being any less a member of the human race if he is incapable of reasoning, deprived of their self-awareness or unable even to communicate? If we define humanity by these functions alone, we are claiming that people are more or less human depending on their capacity to exercise certain skills or faculties. If we follow this logic, then more talented people would be more human than others, as they perform better in thought, desires or communication. This opinion is wrong and dangerous. The essential characteristics of a being, those which determine its essence, cannot be lessened or increased, nor be subject to variations. (6)

The essence of a person is to exist in a rational and free state. Attributes and functions which can increase, decrease or even disappear cannot be considered essential to a person, even if they are a result of the essence of a human. (7) For example, beings with the faculty of reason have the skill of speaking. However, a mute who cannot speak is no less a human being. The same is true of a person in a vegetative state who is deprived of the skill of communication, because they continue to be part of a free and rational state. In other words, a person is defined by what he is, not what he has or does, nor what may be considered “sufficient performance” of his essential attributes. This approach leads to a rediscovery of the dignity of each individual human being, without establishing criteria for exclusion which would open the door to arbitrary decisions and injustice.

19. Feeding and nourishing a person in a vegetative state: is this disproportionate treatment?

Administering water and food, even via artificial means, is a natural life support method. It is an ethical duty for as long as it continues to achieve its goal, namely, allowing nutrients to be assimilated correctly. It is a basic treatment- in principle, it is easy to implement, non-restrictive and manageable. In fact, feeding and hydration, similarly to bodily hygiene, is a fundamental energy need for all organisms, whether healthy or ill. The deprivation of such care would be considered an act of euthanasia via lack of basic treatment. Keep in mind the following principle: “to cure if possible, always to care”.

20. Is it ever acceptable to remove a feeding or hydration tube?

In certain rare circumstances, an exception can be made to the ethical demand outlined above, for example, if the artificial administration of food and water becomes either pointless (the patient is no longer able to assimilate), or excessively painful (complications linked to the use of instruments), or even impossible (in isolated and especially poor regions).

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Euthanasia

21. What is the definition of euthanasia?

According to the Belgian law of 28th May 2002 concerning euthanasia, “the term euthanasia describes the action of a third party who intentionally puts to an end the life of a person at their request” (article 2). It is clear that the doctor who conducts such an act is not committing a crime provided they respect the conditions and procedures set out in the law. More specifically, euthanasia means any action or omission which, in itself and intentionally, brings about the death of a patient with the aim of delivering him from suffering.

The active euthanasia is the administration, orally or by intravenous injection, of a lethal drug (barbiturate, such as pentothal, or an overdose of morphine) or a combination of toxic products (lethal cocktail), possibly in addition to the injection of a substance to induce neuromuscular paralysis.

Euthanasia by omission denotes the deprivation of ordinary and proportionate care and treatment.

The intention to cause death is essential. It matters little whether euthanasia was carried out at the request of the patient or not, by an overdose of analgesics or a lethal cocktail, or via the
omission or interruption of proportionate treatment: if the intention is clearly to end the life of the patient, this is euthanasia. (8)

Euthanasia can be distinguished from other perfectly legitimate medical actions such as the decision to refuse pointless or disproportionate treatments (see above, point 6) or the appropriate administration of analgesics intended to relieve pain (see above, point 9). It is therefore wrong to describe the refusal to prolong life artificially as "passive euthanasia", and appropriate pain relief as "indirect euthanasia". These negative expressions generate more of the confusion which already pervades the debate on the end of life.

22. What is meant by medically-assisted suicide?

Medically-assisted suicide posits that the patient himself causes his own death, in the presence of and with the assistance of, a doctor. Practically, the doctor provides the patient with a tool which will allow him to start the process leading to death (for example, by swallowing a lethal dose of a barbiturate substance).

23. What are we to think of euthanasia?

Intentional death has always been considered murder, or even assassination, except- in certain circumstances- in cases of individual or collective self-defence against an unjustified attacker (but that is not the case here). Euthanasia, which deliberately causes a person to die, comes up against an ethical barrier. Is the above observation enough to denounce euthanasia? Some people object that this argument- of a moral, if not religious nature- is inadmissible in a secular and pluralist democracy. It would be unacceptable for legislators to favour the philosophical or religious opinion of one single part of the population.

However, we cannot help but notice that, independent of any moral or religious considerations, we are invited to reject euthanasia for multiple psychological, social, legal and political reasons. Medically-assisted suicide meets with similar objections as it involves doctors in deliberately cooperating in suicide.

24. Doesn’t the refusal of euthanasia stem from an attempt to impose a Christian point of view on everyone?

We must decide for ourselves on the basis of these brief remarks. Euthanasia and assisted suicide are criminal offences in most countries of the world. Only a few exceptions have decriminalised euthanasia and/or assisted suicide (the Netherlands, Belgium, Luxembourg, Oregon and Washington in the United States, and, in very specific situations, Switzerland).

In 2005, France, a republican and secular country, chose to adopt a law to clarify best medical practices for the end of life without having recourse to euthanasia. Remarkably, this “Leonetti” law of 22nd April 2005 was unanimously approved (apart from three abstentions) by the Assemblée Nationale (lower house), before being ratified by the Senate. This means that it was supported by MPs from across the political spectrum. This choice was confirmed at the end of 2008 following multiple hearings attended by experts from all professional, ideological and political standpoints during a process of assessment for the law, carried out under the direction of Senator Jean Leonetti.

Next, the World Medical Association, which represents over 80 national medical associations and includes almost 10 million doctors from across the range of cultural, ideological and religious traditions, issued several Declarations firmly condemning euthanasia. Clearly, unless we try to ignore this evidence, we cannot deny that there are people from all perspectives who reject euthanasia. They certainly have other reasons than religious ones for doing so. At the very least, we should listen to their views.

25. Shouldn’t we bow to the patient’s request?

We can understand why an invalid would want to end their life and request euthanasia. The despair revealed by such a request renders it understandable, but not necessarily any more reasonable: it appears deeply contradictory to authorise the suppression of a person in the name of respecting their autonomy. The issue here is not the individual demand, but the right provided by
society to satisfy it. With euthanasia, the issue is not recognising the right to dispose of one's own life, but giving medical professionals the right to dispose of the lives of other people, which has much bigger implications. In reality, a person's individual decision is not the only parameter to take into consideration. The issues of euthanasia and medically assisted suicide are still public matters, with undeniable social, legal and political dimensions. In this respect, euthanasia differs from suicide. The possibility of killing oneself is a result of the natural control a person has over his own body and which thus allows him to remove that life. In our legal system, suicide is not a subjective right. At most, it is a freedom. In this way we can be forgiven for thinking that suicide is de facto beyond reach of the law (because those who avail themselves of this "freedom" run no risk of prosecution).

At first sight, exercising this “freedom” to commit suicide, while raising serious questions for society, does not cause legal repercussions nor involve medical professionals. On the contrary, euthanasia and medically-assisted suicide directly involve medicine and the fundamentals of the rule of law. That is why it is perfectly legal to refuse euthanasia and medically-assisted suicide in a secular and pluralist democracy for social, legal and political reasons, in the name of greater public interests which the law is there to protect.

26. What are these greater interests that are compromised by decriminalising euthanasia?

Firstly, decriminalising euthanasia would mean granting professionals of the healing arts a new option: that of ending a life at the person's request. Given that this contradicts the caring professions code of ethics, to which health professionals have always adhered, this affects the moral structure of medicine. In other words, euthanasia is not simply a question of personal choice: legalising it would have a profound impact on society and on our understanding of medicine. Rejecting euthanasia is justified politically as a legitimate concern to safeguard the integrity of the medical profession. Moreover, there is a risk that fragile people could feel guilty for being a burden to others and a financial strain on society because of their stubborn survival. The potential power of suggestion exercised by a patient's family and friends is another undeniable factor. For many ill people who think they are a burden, there is a risk that the right to die could be interpreted as a moral obligation to die. Thus, requests for euthanasia or medically-assisted suicide would not be an expression of freedom, but the result of an accumulation (whether conscious or unconscious) of pressure. Consequently, rejecting euthanasia can also be justified by the intention to ensure protection for the most vulnerable people in society (elderly, ill or handicapped people, or those in a vegetative state) in harmony with the primary role of the law.

In summary: euthanasia is not simply a right which some people claim over their own lives, but the right granted to medical personnel to end the lives of other people. We are entitled to believe that a society cannot grant itself such a right without seriously affecting the social value of humanity. The refusal of euthanasia is also driven by the intention to protect the foundation of the law which states that no man can take the life of another. (9)

27. How can we urge that a ban be reinstated?

By simply stating what cannot be done, without stating or indicating what must be done, a ban is a "fundamental thorn in the side of moral creativity." If a ban is removed, moral consideration loses its edge, and with it “the tireless search for the best, most appropriate, finest and most protective solutions…” (10) A ban helps health professionals to respect their limits, creates an environment of unconditional respect, and obliges them to perform well in controlling pain and symptoms as well as in continuing all forms of medical treatment; it encourages them to draw on their faculties of patience, intelligence, imagination, moral subtlety, and doing their very best to support ill people as humanely as possible until the end. A ban would help patients nearing the end of life by comforting them and providing inalienable dignity, despite their reduced physical or psychological capabilities. Finally, the ban protects the patient's friends and family from seeking death, encouraging them to draw on their resources of humanity and solidarity to support the patient devotedly to the very end.
There is abundant literature on this subject: the following few titles will help you deepen your knowledge.


Footnotes


(2) For more information, see EIB document n° 12, « Les palliative care, un accompagnement personnalisé en fin de vie », compiled jointly with L. DE LAMINNE, February 2008.

(3) For further information, see EIB document n° 6 «Les personnes en état végétatif persistant sont-elles des 'légumes' ?», compiled jointly with V. DELANNOY, October 2006.

(4) For further information, see S. LAUREYS, M.-E. FAYMONVILLE and P. MAQUAND, « Quelle conscience durant le coma ? », Pour la science, n° 302, December 2002, pp. 122-128, also available on EIB’s website (« Study » tab).

(5) For this topic see the study by P. REQUENA, « À propos de la mort cérébrale », also available on EIB’s website ("Study" tab).

(6) Cf. Thomas D’AQUIN, S. th., I, q. 76, art. 1 : illud quod inest alicui rei secundum se, semper inest ei (« ce qui appartient par essence à une réalité s’y trouve toujours »).

(7) For further information on this approach, see V. POSSENTI, « ¿Es el embrión persona ? Sobre el estatuto ontológico del embrión humano », in C.I. MASSINI and P. SERNA (eds), El derecho a la vida, Eunsa, 1998, pp.111-146.

(8) In the same vein, see e.g. P.-O. ARDUIN, « L’intention morale au cœur du questionnement éthique concernant les pratiques médicales en fin de vie », Ethique & Santé, 2006, n° 3, p. 193.

(9) Several eminent personalities have spoken about this issue during hearings which are part of the process to assess the so-called “Léonetti law”. See e.g. the hearing of R. BADINTER, as part of the assessment mission for the law of 22nd April 2005, Rapport d’information n° 1287 – Solidaires devant la vie, volume 2, December 2008, p. 569 and beyond.

(10) See hearing by Professor Suzanne RAMEIX, as part of the assessment procedure for the law of 22nd April 2005, Rapport d’information n° 1287 – Solidaires devant la vie, volume 2, December 2008, p. 73.