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Progress in hygiene and medical techniques achieved in recent decades has brought about a remarkable extension of life. Simultaneously, the borderline between life and death has become somewhat blurred and to a certain extent, the dying are dispossessed of their own death. As a result, many unprecedented ethical and human problems arise. This is demonstrated by recent hesitation and fluctuation of legislation, repeated debate with frequently a high impact on the media, and significant literary production on the issue.

In France, in particular, strict enforcement of the law leads to euthanasia being described as wilful homicide, murder, or failure of duty to rescue (Article 63 of the French Criminal Code "*non assistance à personne en danger*" -failure to assist a person in danger- ). However, such cases are rarely brought to trial, and when they are, and a verdict is pronounced, they are judged with great leniency. Furthermore, various schools of opinion press for a modification of existing legislation.

CCNE has already expressed itself on the subject (7), but written under the pressure of time, the opinion simply stated a few major principles on the basis of which it voiced its disapproval "of legislation or regulations that legitimise the act of taking the life of a patient". Eight years later, in 1998, in a report entitled *Informed consent of and information provided to persons accepting care or research procedures* (9), the same CCNE declared itself in favour of a serene public discussion on the subject of end of life care, including inter alia the issue of euthanasia. It speculated whether its position in 1991 had not been overtaken by events and emphasised the importance of "collective reflection" on the "circumstances before death".

This report attempts to make some contribution to consideration of the issue, which is indeed necessary.

## 1. Living and dying today

No one would deny, even less deplore, progress in hygiene and medicine which has been one of the outstanding and consequential characteristics of our time. Abundant proof is provided by the quality of life in general, and its spectacular extension in the Western world. In these countries for instance, approximately one little girl out of every two born today will live to be a hundred years old.

Such progress however comes at the expense of some constraints such as the medicalisation of the end of life. Seventy percent of the population now dies in a hospital or an institution. The fact in itself which is the result of beneficial health care, should not in any way give rise to criticism. But hospitalisation has its drawbacks : it uproots from a familiar human environment people made more vulnerable by disease and delivers them to usually highly sophisticated technical systems which by their very logic treat them dispassionately. Technique is characterised by performance, but in the face of inevitable death, what kind of performance should one hope for ? By its very essence, technique is efficient but impersonal. Furthermore, it evolves by fragmentation, and tends to fragment all it touches upon; it multiplies incessantly the web of its power into specialities, instruments, and products which never cease to diversify and grow more sophisticated so that the unity of

people under treatment is shattered and they become more than ever **patients**. Medical extension of life sometimes leads to consequences not really compatible with quality of life. Of course, such methods are necessary to ensure survival and cure and are justified generally by the fact that they are temporary and transient, but they become rather more questionable when as the end draws near, they are the last environment of a life.

The pervasive technicality which marks our time follows on the quest for immortality which has always driven mankind, so that many are led to believe and hope that scientific progress will one day give us the power to elude death itself. Fantasies regarding cryogenic methods for preserving corpses at  $-196^{\circ}$  whilst awaiting some future technical progress which could effectuate a cure, or about cloning, are evidence in a way of this tendency. However, even without indulging in such beliefs, it is clear that death is disappearing from our everyday environment. Rites of death, including mourning, are fading and death is becoming a kind of taboo. To mention or think about death is almost an obscenity or depravity.

Just over three centuries ago, Jean de la Fontaine could write on the subject of a peasant wishing to give his children the benefit of his views on the virtues of work :

"A wealthy peasant, aware that death was upon him,  
Called his children to gather around him and spoke to them in private..."

At the time, death was a family or a public affair – which is no rarity today in our country and in many other countries world wide. But the truly striking words in that verse are those which seem totally natural to the author, that the peasant is aware of **his impending death** ... and prepares himself for that event. Could that be said now ?

In fact, the indisputable advances of medicine and technology and fantasies about immortality have frequently led **to depriving the dying of their death**, to taking away from them, in some cases when it would still be possible to do otherwise, the possibility of retaining control over, and living out the last moments of their lives.

It is true that death in a way is still a part of life. It brings it to an end and puts a final stop to life so that it can achieve a form of unity. A person's identity is never finally defined until life is over. And the mysterious power of death is due to the fact that by putting an end to life (by obliterating it, leaving faith out of the equation) death confers value and meaning to life. Scansion and sanction by death condition the existence of human time.

Would not medical practices solely confined to the impersonal and depersonalising principles of technique, or to the utopia of life without end, come into conflict with those other fundamental values of human existence, vulnerability, autonomy, dignity, and the knowledge that all comes to an end ?

This is the context in which, to some minds, arises the question of euthanasia or "the good death.

## 2. A better death today

Believing that to die and that improvement of the conditions surrounding death can ever be a "good thing" to which one should aspire triumphantly, would be an illusion. Dying will remain a painful and testing time even for the most spiritually inspired, and all that can be done is to try and attenuate the pain and distress involved while steering clear of the other utopia of believing that a "good death" or "harmonious death" could be at hand or provided by technique. In fact, that is one of the difficulties involved in the position which gives credence to the belief that life and death – one's own or in general – can be fully controlled. That being said, the question of the conditions in which people face their death must not be eluded.

Some actions and attitudes are today the subject of a very broad consensus and should indeed be encouraged. They firmly commit the responsibility of carers and call for a review of the actual mission of the medical profession. They correspond to awareness that those who have reached the end of their lives, however frail and vulnerable, because indeed they are frail and vulnerable, must be entitled to respect of their autonomy and dignity. These actions and attitudes are in particular related to the development of palliative care, support and care of the dying, and rejection of futile and aggressive treatment. Strict observance of conditions related to the demands implied by these principles will very certainly lead to situating the issue of euthanasia as such in a more appropriate place.

## **2.1. Development of palliative care**

The concept of palliative care as advocated in the 1970s by pioneers in Saint Christopher's Hospice in London, aimed mainly at improving the end of life of cancer patients. Progressively, it was extended to the terminal phase of other ailments and diversified according to the type of pathology and age groups, in particular younger AIDS patients. In France, palliative care started in the 80s in geriatric wards. There is notable progress in its development, but there is still room for improvement.

Palliative care is described as being "active care in a holistic perspective for a patient suffering from severe progressive or terminal illness. It aims to relieve physical pain and other symptoms and to take into account psychological and spiritual distress" Such care can be given either in an institution or at the patient's home.

The objective is simple : allow the natural end of life process to take place in the most favourable conditions, for patients, their families, and hospital carers. Therefore palliative care seeks to control pain and other uncomfortable symptoms whilst maintaining patients' alertness as far as possible and their capacity to relate to those attending them; it seeks to ensure nutrition and hydration in a way which is appropriate to end of life, avoid the unnecessary use of instrumentation; it guarantees nursing and care with due regard for quality – which is the basis of comfort, and an essential component of solace – and seeks to maintain communication with patients by contributing appropriate relational support for as long as verbal communication is possible, or when that becomes impossible, by resorting to non-verbal communication.

Beyond the attention given to those whose life is ending, the entire team involved in palliative care takes care to maintain or re-establish family ties, by giving families the material assistance and psychological support required for them to experience the attendance of their dying relative in satisfactory circumstances of material and moral comfort. After death, the mission continues in the form of support for the family so as to prevent the somatic and psychological sequelae of bereavement, suicide in particular, to which elderly spouses are prone, men especially.

In France, the importance of palliative care was recognised in 1986 by a ministerial circular on the subject of the organisation of care for terminal patients (6). The circular defined palliative care and gave official recognition to the creation of appropriate specialised units. Since 1991, such care is part of a hospital's mission and access to it is on the list of Patient's Rights (17). A survey in 1993 took stock of the dissemination of palliative care, obstacles to its development and how to overcome them. The ensuing report (15) made a large number of proposals and recommendations regarding the organisation of palliative care, pain control, training and support for carers, the role of voluntary workers in the process of attending and caring for the dying and their families, and on caring and attending the dying at home or in hospitals.

Since 1993, several efforts to regulate have been made. The most recent of them sets up a three-year plan of action to fight pain in public and private health care establishments. Finally, a law dated June 9, 1999 (18) aims to guarantee access to palliative care and attendance for anyone "whose state of ill health requires it". The effectiveness of this law however remains subordinated to its financing. When they voted on it, French parliamentarians complied with the spirit of the draft recommendation by the Council of Europe which was published in May, 1999, and which aims to give incurable and dying patients the right to palliative care (13).

In terms of deontology, the 1995 Code of Medical Deontology (19) states that "in all circumstances, a physician must seek to relieve his patient's suffering and give him moral solace..." (article 37); it goes on to say that "a dying person must be attended until the last, given appropriate care and suitable support to preserve the quality of the life which is ending, safeguarding the dignity of patients, and comforting their entourage" (article 38). The comment attached to this article highlights the curative to palliative continuity of the medical act, and underlines the importance of specific care in a situation when "a life has irremediably reached its extremity".

## **2.2. Care for the dying**

Since the Laroque circular in 1986, care and support for the dying is recognised as an essential part of palliative care aimed at reinserting the end of life into the ordinary framework of social relationships. The object is to re-situate those who have reached the end of their lives into their family and their social context and, in doing this, to re-situate death within the framework of family events from which it had been all too frequently excluded. Care for the dying is a commitment which is not exclusive to health care providers - it also commits family members and volunteer workers.

The 1994 Delbecque report underlined the main components of care for the dying philosophy : respect of privacy, considering the patient and the patient's family as a unit "which is in need of help to ... adapt to a distressing and destabilising situation, ...(and to) express itself and actively participate in the care providing process".

A recent Opinion by the Economic and Social Council on the subject of "*Caring for people at the end of their lives*" (14) insists on the positive role that volunteers can play to support health care providers and families. "Since they are neither health care providers, nor relatives, they are the interface – and sometimes the only interface – between the patient and the outside world. They represent the moving world and society in the sealed chamber into which end of life tends to confine a patient. A volunteer can be told everything and can listen to everything, including silence".

The articles written into the recent law on palliative care are on the same lines and include leave for end of life caring which allows employees to take the time required to be with someone at the end of life, either as a relative or as a volunteer. It is stated in the law that such volunteers must be trained in caring for the dying and belong to associations whose charter defines principles to be followed. It is to be noted however that these articles of law will exist in theory only, until such time as arrangements have been made for their financing.

## **2.3. Rejection of aggressive and futile therapy**

Aggressive and futile therapy can be defined as irrational obstinacy, "stubbornly refusing to recognise that a human being is on the way to death and cannot be cured". There is now widespread agreement by representatives of all religious faiths and ethical authorities that it should be rejected. As early as 1957, Pope Pius XII recognised that the duty to dispense health care did not imply "using pointless and disproportionate therapy or therapy which carries with it a burden that he (the patient) judges to be excessive either for himself or for others (21). This point is emphasised in 1980 in the Declaration on Euthanasia of the Congregation for the Doctrine of the Faith (point 4, (12)), and generally speaking, is shared by the various religious and spiritual authorities. In the same way, all ethics committees who have given consideration to the subject of euthanasia in recent years speak against "...aggressive, futile, and unreasonable therapy, continued beyond any hope of success. (Therapy) must give way to relieving suffering which remains a physician's duty" (7).

*The Code of Medical Deontology* of 1995 (19) also mentions in its article 37 that "in all circumstances, a physician must strive to relieve the sufferings of his patients, give them moral assistance, and avoid any unreasonable obstinacy in pursuing clinical investigations". The comments regarding the Code add that "exorbitant regard to prolonging life may lead to excess..."

It is worth noting in this respect that in certain countries, such as Denmark for example, rejection of futile and aggressive therapy goes as far as recognising a patient's right to refuse treatment. The recent French law (18) which aims to guarantee the right to obtain palliative care contains an article to that effect which states that "a sick person may refuse to submit to investigation or therapy of whatever kind".

Situations in which intrusive medical interventions arise are very dissimilar, and their boundaries are sometimes difficult to delineate. They arise in particular at the two extremities of life and concern both those newly born and extreme old age. In the first case, the newborn in question may have a illusive life expectancy. In the second, very old patients may be in an acute poly pathological state which is in fact incurable.

Rejecting aggressive and futile therapy may certainly bring closer the moment of death, but it implies – by definition – acceptance of mortal risk consecutive to pain control and/or abstention from, or limitation of treatment. Battling pain – irrespective of how and why – is not only not a crime but in fact the duty of any health carer. Managing pain is not the same as seeking to kill, and although death comes peacefully, it comes when it chooses. To act in this way is simply to fight pain and suffering, responsibly and effectively. This attitude may also be the expression of the rejection of inhumane situations, for instance in cases where the aims of therapy and the actual situation are out of proportion, or if pursuing active therapy leads to suffering which is disproportionate to an unrealistic objective. Ceasing to provide respiratory or cardiac assistance simply means that the futility of such assistance – and thereby the imminence of death – is acknowledged. Therefore, refraining from pointless action may be the a true mark of respect for the individual.

It cannot be denied that in these various cases, medical decision to abstain from resuscitation, to refrain from prolonging or initiating deep sedation –on occasion described by some as being passive euthanasia – may bring death closer. This is not a deliberate ending of life ; it is simply recognising that ensuing death is the consequence of the disease or of certain therapeutic decisions which it may have prompted. In fact, these situations when therapeutic procedures are curtailed are consistent with a rejection of futile and aggressive therapy and should not be criticised on ethical grounds. Without going as far as supporting participation in assisted suicide or active euthanasia, accepting a request for curtailment or withdrawal of active therapy from a fully conscious, and correctly informed adult patient, seems compatible with the ethical principle of autonomy. When a patient becomes incapable of decision, communication between health professionals and an agent for decisions and/or the patient's relatives is essential as an aid to decision making, with due consideration inter alia for the values and aims subscribed to by each patient, and proper balance between benefits which may accrue from treatment and its constraints or servitudes. For a hospitalised patient, this duty of communication must extend to the medical institution which is encouraged to draft in a multidisciplinary approach, "management protocols" which strive to define in particular the circumstances and situations which may be disquieting, and to set out in writing objective elements guiding the options adopted.

It is true that implementing such principles is fraught with difficulty in everyday practice. There is in particular the difficulty of identifying with precision the ultimate moments of life. One cannot deny that it is troubling for health professionals to abandon curative treatment and move on to palliative care. There are also the difficult organisational problems (such as necessary coordination between personal physicians and hospital carers) regarding the follow-up of patients who may be subjected suddenly to resuscitation against their wishes, sometimes simply because communication between patient and carer has been faulty. But such indisputable difficulties should not be an obstacle to progress towards what must remain a decisive ethical objective : make sure that there is no entry into the vicious circle of overtreatment which gives priority to the operation of the health care system at the expense of respect for the human being.

**In conclusion** : CCNE states its total agreement with the evolutions which have just been mentioned. They move in the direction of integrating the last moments of an existence into life itself, of respecting patients up to the very end, of conforming with the vocation of health care providers. Resolute implementation of such principles should ensure, as far as is at all possible, that individuals **regain possession of their own death**, surrounded by the consolation of loved ones and relatives. Therefore, CCNE encourages those variously involved in these domains to pursue and intensify their efforts and invites political leaders to guarantee essential financial support for this purpose.

Although such a course may well reduce considerably the number of requests for euthanasia, it is not certain that general implementation of this way of managing end of life situations, including inter alia the development of palliative care and care for the dying, will totally solve the question of euthanasia and prevent it ever arising again. However, it might then be seen as unnecessary recourse rather than impossible or prohibited succour.

But there is also the possibility that, somewhere between these two extremities, could emerge an ultimate plea in certain extreme or borderline cases which continued to be perplexing. They should therefore be discussed openly.

## 3. Borderline cases : the debate on euthanasia

### 3.1. *The scope of the debate*

Certain situations can be considered extreme or exceptional and appear from the outset as not fitting into the "standard". "Standard" in this case means that a health care provider provides health care, come what may, and that the patient has the will to survive. But that will may not just be missing, it may in fact be reversed and replaced by a will to end it all and die.

This is the point where euthanasia as such becomes the issue.

Euthanasia is the action of a third party deliberately putting an end to someone's life with the intention of terminating a situation which is considered to be unendurable. **CCNE is unanimous in condemning such action which is planned and executed without any request being made or consent being given by individuals concerned or their "representatives"**. But even supposing such a request for assisted suicide to be sincere, determined, and repeated, and that it is not a call for help in disguise, there is the ethical issue which arises because of the difficulty of satisfying two legitimate but contradictory requirements :

- Heed the wishes of individuals, their choices as regards their liberty, independence, and autonomy.
- Assume and ensure on behalf of society, which the medical profession is, in its own way, the representative of at the side of any patient, the defence and the preservation of values without which there could be neither groups nor societies. This demand is all the more potent as regards members of the medical profession whose vocation it is to give health care to people, to help them live, and never to betray the trust that patients grant them. This is emphasised vigorously in the last sentence of article 38 of the Code of Deontology : "a physician cannot deliberately bring about death".

CCNE was itself faced with this dilemma in its report on informed consent (9). It did not feel it could provide an easy answer and therefore tried to find middle-of-the-road compromise solutions, satisfying in varying degrees as regards purely rational considerations.

This fundamental difficulty is emphasised further by scientific and technical progress, which without any doubt is of service to the medical profession and patients, and emerges as a powerful, legitimate, and valuable tool, which can in no way be disputed. However, in a significant number of cases, scientific and technical progress raises novel human and ethical problems which are difficult to solve. In that category, there is the particularly delicate problem of patients unable to voice their wishes, such as new-born babies, the very old, or younger people who have fallen victim to serious accidents or disease depriving them of the means to communicate.

Such are some of these new dramatic problems, which are the price to be paid for technical effectiveness, and which confront society.

### 3.2. *Existing positions*

Two positions are commonly held concerning these issues :

1. The first is based on the way in which many people see **the respect that is owed to human life**. Life is a transcendental reality and cannot be left to the sole disposition of man . Those in favour of this view **decry the abuse** which would be bound to follow on the heels of recognition of the right to euthanasia. They consider that to authorise euthanasia would open a sizeable moral and social breach the consequences of which would be difficult to evaluate. Furthermore, the following points are made :

- the principle of respect for life whatever the cost could not be ignored by whoever halts a life, and the ambiguous wording "assisted suicide" does nothing to alter the fact that it is a third party who does away with another's life ;
- the dignity of a person can of course be appreciated differently depending on whether it is viewed from the outside or as experienced by the person concerned, but dignity remains an intrinsic character of any person ;
- healthy individuals, stating what their wishes would be in given circumstances regarding ending their lives, do not know what their reactions would be in the event of severe illness and imminent death, nor how constant such reactions might be. The will to end it all varies frequently according to relief from pain, information, or other external factors;
- at the end of life, the sick are very sensitive to feelings of anguish experienced by their loved ones, and may try to spare them by making a request which does not necessarily meet their innermost wishes ;
- individuals apparently deprived of the capacity to relate run the risk of becoming the victims of a "death wish" on the part of family or carers;
- the deontological duty of a doctor is to provide care. When he can no longer hold out any hope for a cure, there remains the possibility of relieving suffering, without therapeutic perseverance degenerating into obsessive technicality, or unreasonable medical obstinacy – relieving suffering may well take the form, in full compliance with medical ethics, of sedation ;
- legal justification of euthanasia, even if it was restricted to a very small number of cases, would be likely to limit recourse to palliative care, or at least retard its development, or to bring into play excessive reference to economic or hospital management parameters.

The legal implications of such a position are clear : present legislation according to which euthanasia is classified as wilful homicide, or assassination, or failure of duty to rescue, must be kept intact. There is no wish here to be excessively severe (which in any case is an incentive for concealment and hypocrisy), nor to be insensitive to distress. As a result, there is no rejection of the notion that courts could – when they are involved – be indulgent.

2. At the other extreme, there is also the belief that **to die with dignity implies a right** which must be acknowledged when it is claimed

**For those who subscribe to this position**, death being inevitable, most human beings in our Western societies wish to be reassured about conditions at the end of their lives. The great majority of them reject physical and mental decrepitude.

Human existence should not be viewed from a purely biological angle or in entirely quantitative terms. Life is essentially experience of living by reference to a symbolic order. Therefore, a request for assistance to achieve serene release is a fully cultural act.

Other points include :

- Individuals are the sole judge of the quality of their own life and dignity. No one else can make that judgement for them. It is how individuals see themselves which matters and not how someone else might view them. Dignity **is an understanding with oneself** that no one else can interpret. It is a component of each individual's personal freedom.
- Attempted suicide is no longer a punishable offence in France since 1792. And yet, although suicide is not punishable, assisted and accepted death is censured by the Criminal Code. This paradox would need to be eliminated by decriminalising euthanasia.
- Certainly no one is permitted to take away the life of someone who has not requested it, but nor is anyone entitled to force life on someone who no longer wishes it. Hence the claim that euthanasia is a right, which according to its advocates is in no way in opposition to the development of palliative care.
- Such a right is no obligation on anyone. No one is obliged to follow up a request, and the conscience clause is an absolute imperative.
- The right to die with dignity is no ordinary right. It is not a right given to others to kill. It is simply the possibility for a conscious and free individual to be **heard** and assisted when expressing an exceptional plea for his own life to be ended.
- The ethical imperative in a debate on euthanasia would be to never forget that a request for assistance for an accepted death, or a request for active euthanasia, are the ultimate liberty to which man is entitled. Confiscation of this right, which is retractable to the last, would only be justifiable when persisting in unreasonable therapeutic obstinacy, which as we have seen, is unanimously condemned.

In legal terms, **decriminalising** assisted dying should sufficiently protect liberties to which all are entitled while forestalling the present clandestine practices and their cortege of deviations.

However active euthanasia would remain an offence.

In certain circumstances, however, derogations and exemptions could be accepted as regards the guilt of the person who assists another in dying. Thus :

- When the existential, psychological, and sentimental sufferings of someone are unbearable and intractable and that person requests a termination, the act of interruption of life by a third party should not be punishable ;
- The intolerable nature of the suffering endured and the lack of other reasonable solutions to relieve that suffering would need corroborating by the attending physician and by another health care provider ;
- A request for the interruption of life is not a medical act; it is a cultural act and is a component of individual liberty. The request must be lucid, repeated, and freely given. It is expressed either in the form of a written document which may be handed for safekeeping to an agent capable of becoming a proxy for those who have lost consciousness or are unable to speak for themselves, or by any other explicit means. Third parties who intervene must have no personal or selfish interest of their own in satisfying this request.
- A request for assistance for an accepted death must be formulated freely, consciously, clearly, and repeatedly. It is retractable to the last so as to protect individual liberty and autonomy.

**Both the positions in this debate represent weighty values and are worthy of attention and respect. The Committee taken as a whole recognises and emphasises this. However, they appear to be irreconcilable and their opposition seems to lead to an impasse. Should that be accepted with resignation and any hope of further progress forsaken ?**

**Faced with this dilemma, the Committee proposes to approach the issue differently.**

## **4. Joint commitment, and plea of euthanasia**

The Committee puts aside the possibility that demanding an end to life from a third party is a right by entitlement. Prohibiting murder is still a founding value, as is the call to do all that is possible to improve the quality of life of individuals. Furthermore, the view that confines society to a sum of individual contracts is found to be wanting, particularly as regards health care when the provider is seen as no more than a provider of services.

However, what cannot be accepted at the level of principles and discursive reason, **human solidarity and compassion** may well adopt. Faced with such distress that all hope of alleviation is lost, and suffering becomes intolerable, there can be a need to take into consideration the fact that a human being transcends rules and that plain solicitude may sometimes appear as the only remaining route **to take to face the inevitable** in a spirit of solidarity. Such a position could be then designated by the expression : **joint commitment**.

Indeed, solidarity could be mobilised in cases – probably rare – when resolute attempts at the three courses outlined above (palliative care, care for the dying, and rejection of aggressive and futile therapy) have been powerless to provide a tolerable end of life.

One could mention as examples exceptional cases when pain cannot be alleviated by any existing method ; when an individual is totally and irreversibly dependent on life-support machines and asks for termination ; when someone is irremediably deprived of the capacity to relate and has asked that life should not be prolonged ; and the case of autonomous new-born infants suffering from extreme and incurable neurologic sequelae of which the parents have been informed.

Such distress demands compassion and solicitude. Of course, it is possible to give a paternalistic slant to these expressions and see them as pleas for pity and commiseration. But combined with respect and a sincere quest for authentic partnership, compassion and solicitude nourish humanity, sensitivity, and solidarity. Broader in scope than moral right and assertive claims, they open new paths justified by the sharing of a common lot.



Such **exceptional openings** are linked to the concept of **consent both given and accepted**.

The semantic ground opened by these expressions contain three decisive elements which structure the joint commitment - in which by definition there are several individuals engaged in a joint battle – in a specific and precise connotation :

- To consent obviously means to give or to have previously given one's consent. This is the case for those who can, or could previously, participate in an assessment of their condition and express their wishes : or those who are incapable of doing so at the end of their life, but had formally made their wishes known previously and handed them into the care of a third party. In this respect, CCNE recalls the position adopted in its Report on Informed Consent in which it proposed that "it would be possible for everyone to designate a "representative" (or "agent", or "spokesperson") empowered to dialogue with doctors when the person concerned is in no condition to express choices".

In the above mentioned cases of autonomous new-born infants suffering from extreme and incurable neurologic sequelae, consent by parents would be required.

**Without consent, no act of euthanasia could even be considered. Hence, in the absence of third parties (e.g. for homeless people) such action is simply unacceptable.**

- To consent is to acquiesce, accept that something must take place, not obstinately refuse to let it happen when in any event, the end seems inevitable. In the face of imminent death, at the end of life, when the battle is done, there is surely more dignity in facing up to inevitable fatality and thereby consenting to it, than in seeking to disguise it and run away from it.

- Finally, to consent is **to feel in unison**, to engage in a process whose ideal finality is **consensual**. Possible decisions regarding acts of euthanasia should not appear in the guise of **solitary** and variously **arbitrary acts**. On the contrary, they should be seen as the fruit of **joint** and hesitant exploration, products of as perfectly **con-sensual** thought as is possible within **a group of carers** or of loved ones, consenting to follow the least adverse course in an extreme situation.

If that is so, facing up to the diverse demands of consent, in a given situation, commits to solidarity and authorises action. The latter does not signify unthinking implementation of an impersonal and dis-empowering rule, but the carefully measured and thoughtful decision to take the risk of following **the least detrimental of various courses of action**.

**Furthermore, it is never healthy for a society to experience a situation where discrepancy between rules as they are laid down and real life is too glaring. The joint commitment is in fact already almost a reality, but is clandestine in varying degrees, and so "anarchy" and inequality prevail over its application. Because of this, there is a kind of ethical denial at two levels : hypocrisy and concealment on the one hand; unequal outcome depending on which procedures are followed and which jurisdictions consulted (if they are) on the other.**

As regards the law however, **these findings should not lead to decriminalisation** and the relevant texts in the Criminal Code should not be modified. Courts when they apply them, should be given the possibility of formulating their decisions without being obliged to resort to legal subterfuge for lack of the technical instruments required to support their judgement and rulings.

Criminal procedure could offer solutions which it is not in CCNE's purview to define. The most that it can do is to formulate a few suggestions to contribute to reflection on the subject.

The act of euthanasia should continue to be subject to judiciary authority. However, it should also be the subject of special consideration if its author presents it as euthanasia. A kind of **plea of defence of euthanasia**, which could be specifically provided for by law, would make it possible to assess both the exceptional circumstances which could lead to a life being ended and the conditions in which the act is committed. When the case begins to be investigated or debated, it should be the subject of examination by an interdisciplinary commission whose task would be to evaluate the probity of the claims made by those concerned, not so much regarding their guilt in fact and in law, but as regards their motivation, i.e. concern to end suffering, respect for a request made by the patient,

compassion in the face of the inevitable. The judge of course remains in control of the decision.

Other solutions might be considered but would converge towards the same ends, that is to give Courts and Tribunals the possibility of extricating themselves from the dilemma existing at present because of the discrepancy between the Law and human reality.

In any event, the following ethical requirements should be taken into account:

- Would only be eligible recognised borderline or extreme cases ;
- The patient's autonomy would require formal recognition and expression by authentic petition (free, repeated, expressed orally at the time, or previously in a document).

Regardless of how it is worded in legal language, the joint commitment must state that the necessity of confronting, in a spirit of solidarity, without the benefit of any certainty, what is and must remain in any event one of the frontiers and essential mysteries of any human existence, is set in an ethical endeavour.

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**In the presence of a trying and painful issue such as the end of life and ending life, CCNE states that the question of euthanasia as such cannot be isolated from the broader context of dying today in a world which is profoundly marked by medical technicality and its obvious advantages, but also its limitations. The true challenge with which society is faced is in fact how to allow everyone to live as best they can (or as harmlessly as possible) their own death and in so far as that is possible, not to be dispossessed of it. This should be achieved by implementing resolutely a policy of palliative care, care for the dying, and rejection of excessive and futile therapy. Furthermore, this same determined attitude should lead to reducing to rare and exceptional circumstances requests for euthanasia proper, but could not succeed in eliminating the issue altogether.**

**To face up to euthanasia in those cases means asserting values and principles which have a bearing on the freedom of individuals and the demands of respect for the life of the individual and of society. These values and principles deserve the highest consideration. But in fact they are in conflict with each other and turn out to be contradictory, thus generating a dilemma which could paralyse any effort to solve it. But the dilemma itself raises ethical issues ; ethics are born and thrive less through categorical certainties than through tension and refusals to settle once and for all questions which are recurrent and irksome and thereby express one of the fundamental aspects of the human condition.**

**CCNE feels therefore that a position based on commitment and solidarity is able to respond positively to the legitimate convictions of the various schools of thought, and also to lift the veil of hypocrisy and concealment which shrouds certain practices at the moment. This position of joint commitment, motivated by the various aspects of the reality of consent as a value (respect for a person's consent, refusal to deny the inevitable, need for collective debate and decision) is a call to establish a system of solidarity which cannot, however, totally escape the risk represented by an action which at best only aims at following the least harmful course. In legal terms, it might be expressed as "plea of euthanasia".**

**Death inflicted wilfully remains, whatever the circumstances and justification, a transgression. However, termination of life-supporting efforts and ending life sometimes lead to accepting the paradox of transgression of what must be seen as forbidden to transgression.**

**Although in a concrete situation, the decision to end a life may in borderline cases appear acceptable, this action cannot rest upon clear ethical evidence. Such a decision cannot, and never should become routine practice.**

**This practice, based on respect for unalienable personal rights, should only strive to contain firmly end of life, and possibly ending of life, within the embrace of life itself, so as not to exclude from a humane world the last moments of a given existence.**

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## Annex :

### **Euthanasia – Opinions expressed by Ethics Committees in other countries.**

There was some alarm when news broke of an initiative taken in 1991 by the European Parliament, aiming to authorise in certain circumstances the ending of a patient's life by his/her request. CCNE, in its Opinion n°26 of June 24, 1991, reacted very expeditiously to this proposal, which in fact was never put to the vote. However, from that time onwards, several Committees gave considered thought to the ethical issues of euthanasia. This study summarises the contents and presents the main conclusions of the Belgian, Canadian, Danish, Luxembourg, and Portuguese Committees All of the reports, with the exception of the Canadian Senate's, are the work of official ethical institutions. All of them, except the Portuguese report, raise the issue of a possible modification of legislation on euthanasia.

## **Subjects dealt with**

**Belgium** : active and voluntary euthanasia .

**Canada** : assisted suicide, palliative care, relieving pain (potentially life-threatening treatment, complete sedation) ; withholding and withdrawal of life-sustaining therapy ; advance directives; assisted suicide, non-voluntary euthanasia (performed in ignorance of the patient's wishes), voluntary euthanasia, involuntary euthanasia (performed against the patient's will).

**Denmark** : active voluntary euthanasia, controlling pain, supporting and nursing care at the end of life, palliative care.

**Luxembourg** : palliative care, aggressive and futile therapy, assisted suicide; voluntary euthanasia (several cases), non voluntary, involuntary, case of a seriously malformed baby.

**Portugal** : palliative care, aggressive and futile therapy, advance instructions, assisted suicide, withholding and withdrawing life-prolonging therapy, voluntary and non voluntary euthanasia.

## Definitions of euthanasia

**Canada** : action consisting in intentionally provoking someone's death to put an end to their suffering.

**Belgium** : action performed by a third party which intentionally ends the life of a person at that person's request.

**Luxembourg** : action of deliberately provoking the death of a patient, of a disabled person, or of a severely malformed new born baby, this being done at the express request of the person concerned, or without their express request, or even against that person's will ; the range of motivations for euthanasia may extend from inter alia respect for the patient's or disabled person's autonomy, to pity and, as we recall only too well, to eugenic considerations.

**Denmark** : medical assistance to relieve a life of unbearable suffering.

**Portugal** : intentional death given to a patient at the instigation of anyone, in particular following a medical decision, even though this may be done on "request" and/or "compassionate" grounds.

## Total consensus

There is **total consensus** on the subject of certain actions and attitudes, in particular :

- the need to encourage development of **palliative care** (by training doctors, creating palliative care units and generalising palliative care methods in all medical departments treating severely sick people); and the **necessity of pain control**, even at the risk of shortening life;
- involving **the family** in care of the dying;
- the acceptability, both from the medical and moral viewpoint, of **withholding or withdrawing treatment which has become pointless**, as long as everything possible is done to ensure the patient's comfort and well-being (what some people call passive euthanasia).

It is worth noting here that the **Danish** Parliament voted a law on passive euthanasia in 1992. According to that law, a patient is entitled to refuse treatment at any time, particularly treatment to sustain life artificially. If such treatment is futile, the physician must abstain from providing it. If a patient is inexorably dying (when death is expected within days or weeks), the doctor may authorise the withdrawal of treatment which only delays the onset of death, and use palliatives even if they accelerate the coming of death. The spirit of that law is revisited in the 1996 report of the Luxembourg Committee on aggressive and futile therapy : "any legally adult fully informed patient, who has given in depth consideration to the consequences of his decision, has the right to refuse proposed or already ongoing treatment". The **Luxembourg** Committee underlined that it is nevertheless necessary to create procedures so as to check that such conditions are satisfied.

In other countries, these decisions are regulated by codes of medical practice. However, there are "grey" areas where action becomes difficult, or even impossible, and for which no consensus has as yet been reached. **The Canadian and Luxembourg** reports raise the issue of how to act in the case of a legally incompetent patient, for example an unconscious adult, a child, a new born baby, or a patient who wants treatment which the doctors considers to be pointless.

The **Canadian** report raises the question of the usefulness of defining the acceptability of these actions in a specific article of law : "These powerful values – liberty and autonomy - , (...) have led the biomedical ethical and the legal communities to agree, almost unanimously, that what has been called "passive euthanasia" (withholding and withdrawing life-support treatment) is legitimate in moral terms and should therefore be allowed by law". The report suggests that the Canadian Code of Criminal Law should be modified to take that into account.

## Substantial but not total consensus

- A comparison of reports shows that there is a substantial but **not absolute consensus** as regards other attitudes and actions. There is frequently disagreement within the Committees.

- **assisted suicide** is condemned by all the members of the **Portuguese** Committee, and by the great majority of the members of the Canadian Committee, as well as by certain members of the **Luxembourg** Commission. The **Canadian** report would want to have explored the possibility of certain alternative solutions which might be found acceptable;
- **voluntary euthanasia** is condemned by the **Portuguese** Committee ("there is no ethical, social, moral, legal, or deontologic argument which can justify the theory of arriving at making possible by law intentional death of a patient by anyone whatsoever, in particular by medical decision, even if that is the result of a "request" and/or out of "compassion"), the very large majority in the **Canadian** Committee, a majority in the **Danish and Luxembourg** Committees. The **Belgian** Committee notes the existence of divergent opinions within society, but does not attempt to quantify.
- A majority of opinions in the Committees is hostile to a **modification of the law as regards euthanasia**. However, there is a minority in favour of modification noted in the **Belgian, Canadian, and Danish** reports.

## Divergence

The question of the mandatory nature of **advance directives** divides committees. Their attitude is naturally influenced by the legal status already granted or otherwise to such directives in their own country. In **Canada**, for instance, most provincial legislatures have adopted or are considering a vote on laws to that effect. The Senatorial Committee considers that they present major advantages. The **Luxembourg** report is in favour of "taking living wills into consideration to a certain extent (more so when the document is drafted by terminally ill patients asking for alleviation of suffering even at the expense of shortening life"). They recall that the Council of Europe's Convention on Bioethics confers legal status to "wishes previously expressed" which must be "taken into account". The **Portuguese** consider the case of patients who, while in normal circumstances and fully conscious, have drafted instructions prohibiting certain therapies in situations where they could not express themselves, even if such situations are a serious threat to their lives. In that case, "there is no obligation on the doctor to follow these advance instructions, particularly if there is a reasonable likelihood of saving a patient's life".

### Methods of work adopted by committees

It may be rather hazardous to draw conclusions on methods of work on the basis of the final reports. However, certain observations may be made concerning the method of work and the conclusions of each report. The **Canadian** Special Senatorial Committee tried to "prepare the ground in view of a broad national debate to take place in coming months or years". To report on public attitudes to the issue, it heard a large number of "witnesses" (on the principle of hearings on the North American continent in which anyone concerned may be heard) and it included many excerpts from these hearings into the presentation of its arguments. On the basis of these open hearings, the Committee asserts by way of conclusion that in the majority there is opposition to a change in the law. On the contrary, the **Portuguese** Committee started out by setting the normative and ethical framework of its considerations in the appropriate medical attitude. It then goes on to deduce the positions to be adopted in a certain number of specific cases, and since these positions are expressed affirmatively, any argument to the contrary is excluded from the outset. The **Danish** Committee presents the arguments in favour or against euthanasia. The **Belgian** Committee notes that there are "irremediable divergences" in opinions, but does not specify their respective weight in the public mind. However, it does discuss four proposals regarding a modification to the law and indicates a slight preference in favour of the one which recommends a priori "procedural" regulation of the more important medical decisions concerning end of life, including euthanasia, after collegial consultation. The **Luxembourg** Committee gives pride of place in the introduction to its report to terminology used in debates on euthanasia. It comments and complements the expressions proposed in the **Canadian** report and as does the latter, it includes in its discussion observations on the "societal background of the debate on euthanasia". It proposes to study the issue from three aspects : ethical, deontological, and legal. It presents arguments for and against euthanasia, and then goes on to discuss these as related to a number of cases. This Committee underlines that during the course of debate points of view converged and explains the contents of what it calls "a limited consensus obtained in spite of deep dissent".

## The problem of social dissensus

Committee reports amply demonstrate to what extent the question of euthanasia divides society. This finding was obvious at the outset of each body's task and led them to react to it. At the level of social ethics, the underlying question concerns the possibility of now getting beyond the expression in conflicting terms of divergent sympathies regarding euthanasia. Would the process of discussion particular to Ethics Committees make it possible to achieve a minimal consensus ? Three approaches can be mentioned :

- **refusal to recognise an adverse position.** The single position as reaffirmed in the **Portuguese** report is based on a reference to the vocation of medicine and on principles of deontology, from which stem individual and social obligations. There is no mention of any arguments put forward by adversaries of this classical standpoint.
- **refusal to arbitrate.** The **Belgian** report "deems itself unable to arbitrate in a debate in which ethical leanings and concepts of life and death diverge". Nevertheless, it considers that in the light of its own deliberations, it should be possible at some point in the future to reconcile positions which are neither blocked nor final.
- **Search for a minimum consensus.** The **Luxembourg** report presents arguments raised for and against assisted suicide and euthanasia, then reviews them in relation to several cases in point (voluntary euthanasia, unconscious patient who had written a living will, non voluntary euthanasia, new born baby, involuntary euthanasia). It points out deep seated disagreement within the Commission but notes that, thanks to the discussion, the group arrived at a limited consensus on the subject of euthanasia in spite of disagreement. Thus certain members of the Commission who condemn euthanasia in principle (...) "are nevertheless ready to recognise that in certain limited contexts and on certain very restrictive conditions, certain decisions and behaviours which they condemn are based on morally genuine and honourable evaluations of a situation. As a result, they are ready to make a morally pertinent distinction between certain acts of euthanasia and certain other acts, and to recognise that in all conscience and honesty, the authors of certain behaviours of which they disapprove, can regard themselves as morally blameless".

Gwen TERRENOIRE

CCNE gave the data and the issues arising out of the extension of life expectancy in its report on ageing (11). Life expectancy for men is slightly lower than for women.

According to Greek ethymology, the word means good (eu) death (thanatos).

Definition as given by the Société française d'accompagnement et de soins palliatifs, (French Society for attending the dying and palliative care) 1996. See (23) for full extract.

This circular gave the conclusions of a Commission chaired by Madame Geneviève Laroque.

5 Article L-711-4 of the Code of Public Health provides that "health care establishments give preventive, curative, or palliative care to patients as required by their state of health and ensure the continuity of such care once they are discharged".

Cf. in particular Circular DGS/DH n° 98-586 dated September 24, 1998.

See (18).

Louis René in his comments on the Code de déontologie médicale (Code of Medical Deontology) (19).

Cf. also "Religious and moral problems posed by analgesia", *Documentation catholique*, 1957, n° 1247, col. 337-340 [22].

See in particular various statements made by representatives of spiritual groups at the session of the Académie de Médecine, on May 18 1999, on the subject of "Caring for the dying". See (2).

Cf. for an analysis of factors which have led to a modification of medical attitudes in the face of the emergence of the striking phenomenon of care for the dying, *Ordre National des Médecins (Medical Association), Déontologie médicale et soins palliatifs*, 1996, 31 p.[20]

The subject of which attitude to adopt when dealing with distressed neonates has, in ethical terms, special characteristics which will be covered by CCNE in another separate report.

On this subject, see INSERM's *Grande prématurité, dépistage et prévention du risque*, (Very premature infants and risk prevention). *Rapport d'expertise collective*, Edition INSERM, 1997 (16), and CCNE's Opinion n° 42, *Opinion on the Evolution of Practices Concerning Medically Assisted Procreation*, March 30, 1994 (8).

On this subject, see the proposals made by the American Thoracic Society, « Withholding and withdrawing life-sustaining therapy », *American Review of Respiratory Diseases* 1991, vol 144, n° 3, p. 726-731 [3].

For further details, refer to : *British Medical Association, Withholding and Withdrawing Life-prolonging Medical Treatment –Guidance for Decision Making*, Londres, BMJ Books, 1999, p.10ss [4].

Thus, when after a stay in hospital, patients wish to return home to die, it is essential that they are looked after by a team of health care providers who must have immediate access to a summary version of a patient's medical file. If there is a family doctor, the latter must be

previously informed of the patient's release from hospital and health care needs. Otherwise, the hospital must itself organise the patient's return home and management by a team of health care providers. If such precautions are omitted, at the first alarm, the distraught family will call on emergency services whose doctors will be totally in the dark about the case and may send the patient back to hospital to an unsuitable ward or to resuscitation which is the only service accepting emergencies. This adds up to involuntary intrusive medical intervention. For identical reasons, it is important that emergency hospital teams should have permanent access to the patient's hospital files, and as far as possible, to the patient's wishes regarding health care advance directives.

See on this subject CCNE's report n° 57, dated May 25, 1998 Progrès technique, santé et modèle de société : la dimension éthique des choix collectifs (Technical Progress, Health And Societal Models : The Ethical Dimension Of Collective Choices) (10)

Cf. also the definitions and positions adopted by various institutions and committees, collected and presented by G. Terrenoire, annexed to this report.

Cf. (9).

Problems may be administrative and concern the organisation of health care, another form of technical development. See note 16.

Most religions state with emphasis the supreme and sacred value of human life. A very good outline of the positions adopted by the major faiths on this matter is given by M. Abiven, C. Chardot, R. Fresco, in *Euthanasie. Alternatives et controverses* (Euthanasia, Alternatives, and Controversies), Paris : Presses de la Renaissance, 2000, p. 85-108 [1].

Cf. on this subject Chochinov H.C. et al., Will to live in the terminally ill, *Lancet*, 1999, vol. 354, p. 816-819 [5].

This position is upheld in particular by the Association pour le Droit de Mourir dans la Dignité (ADMD), (Association for the Right to Die with Dignity).

A certain number of democratic countries, in particular the Netherlands and Switzerland, have already adopted legislation on euthanasia. As regards Switzerland, article 14 of the Criminal Code condemns euthanasia by request, whereas article 115 accepts the concept of assisted suicide, as long as there is no personal or selfish interest of the intervening third party concerned. A draft bill under discussion by the Federal Council would authorise active euthanasia pursuant to a request made by an incurable patient.

In its Report on Informed Consent (9), CCNE did not consider it desirable to choose between the concept of authoritarian paternalistic care (depriving the patient of autonomy) and the notion of a purely contractual relationship. The Committee declared at the time that the proper route (still remaining to be mapped to a large extent) should merge the demands of respect for individual autonomy and those due to the constraints of life in society.

Cf. (9), point 5.

In chronological order, the reports presented here are the following :

National Council for Bioethics (Portugal). (Avis sur les aspects éthiques des soins de santé ayant trait à la fin de la vie, 1995. (Opinion on ethical aspects of health care at the end of life). Special Committee of the Canadian Senate on Euthanasia and Assisted Suicide, *De la vie et de la mort - Rapport final*, 1995, (On Life and Death – Final Report, 1995). Danish Council of Ethics, *Euthanasia*, summary of a report for use in the public debate, 1996; Opinion n° 1 of the Belgian Consultative Committee on Bioethics concerning the (Possible need for legislation on euthanasia) *l'opportunité d'un règlement légal de l'euthanasie*, 1997. National Consultative Commission for Bioethics (Luxembourg), *Opinion on L'aide au suicide et l'euthanasie (Assisted Suicide and Euthanasia) Opinion 1*, 1998. Our lack of knowledge of the language prevented us from including in our study the report of the National Committee for bioethics of Italy, *Questioni bioetiche relative alla fine della vita umana*, 1995. All of these reports may be consulted at the Centre de Documentation en Ethique de l'INSERM, 71 rue Saint Dominique, 75007 Paris

This subject had already been given in depth consideration in Opinion 1/1996 of the C.N.E.

Countries not mentioned are those where the Committee did not broach the subject.



