

Belgian Advisory Committee on Bioethics

Opinion no. 9 of 22 February 1999 concerning active termination of the lives of persons incapable of expressing their wishes

*Request for an opinion of April 9th 1996
by Mr R. Langendries, President of the Chamber;
Request for an opinion of May 7th 1996
by Mr F. Swaelen, President of the Senate*

In July 1997, a select committee 97/4 was set up within the Advisory Committee on Bioethics, with the task of preparing a draft opinion on active termination of the lives of persons incapable of expressing their wishes. The said committee 97/4 started off from the idea that its task should be seen as the continuation of the deliberations conducted by committee 96/3 in 1996-1997 "on the question of the advisability of a legal regulation on ending life at the request of patients with incurable illnesses ("euthanasia" and palliative care); on the statement of wishes concerning treatment and living wills and their ethical, social and legal aspects; and, more specifically, on bills currently tabled on this issue".

The scope of the deliberations carried out by committee 96/3 was limited to the question of the advisability of legislating on the subject of euthanasia and the problem of capable persons themselves requesting euthanasia. Committee 97/4 was given the task of addressing the problem of active termination of the lives of persons incapable of expressing their wishes.

In the first stage, the said committee discussed a number of notes prepared by the members on the question: "Do you consider it appropriate for the legislator to intervene in the active termination of the lives of incapable persons?". These notes had the following titles: "Categorization of situations legitimizing the intervention of third parties in end-of-life medical decisions", "Ethical positions", "Putting an end to life or allowing to die", etc. Experts were then heard on the question of "advance directives" (replacing the term "living wills"), the problem of active termination of life in intensive care departments and the same problem with newborn children.

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Chapter 1 - Presentation of the problem

I. Medical end-of-life decisions

1. When the end of a patient's life is approaching, the medical decision takes on a special dimension. From now on, the doctor will see his task differently. Indeed, since there is now no prospect of any recovery, the curative objective of his practice disappears. The approach to the patient is then focused on minimizing pain, controlling symptoms and providing care and psychological and moral support, generally accompanied by a gradual reduction in curative care. The aura of medical technology disappears and the doctor is reminded that his department and its efforts to protect life come to an end in dramatic fashion in an unavoidable confrontation with suffering and death. The medical act then becomes one of "accompanying the process of death".
It should be noted, however, that the meaning of the concept of "end of life" is not unambiguous. Everyone understands it to mean in all cases the last hours or days of the terminal stage of a fatal illness or the last hours or days following a medical decision gradually to reduce or to stop medical treatment that has become absurd. For some, however, "end of life" also means a "hopeless situation", i.e. the few years of life left to a newborn child suffering from an incurable disease that will shorten its life, people in a persistent vegetative state (PVS), or the more numerous years left to live for a demented person who nevertheless still has well-preserved vital functions.
2. Whilst for some, from the medico-technical point of view, the practice of medicine loses a lot of its glamour and prestige in this context, the decisions that the doctor has to take from that moment on are usually extremely important from the ethical point of view. They tend towards keeping the patient comfortable in the terminal stage and making a dignified death possible. Any decision gives rise to actions which, whilst they can no longer have any curative effect, can be decisive: indeed, a good many of these decisions can result in life being prolonged or shortened.
3. Given their implications, these decisions are difficult for the doctor. How can he be sure of his judgment and know what the best solution is for the patient whose life he has the power to shorten or prolong? How to determine when it really is time to stop the treatment because the situation is hopeless?
4. Furthermore, a good many decisions taken within the context of the "medical accompaniment of death" have an important *symbolic* significance, for both the doctor and the patient. Switching off the equipment or administering a lytic cocktail to hasten death are not routine actions. Nobody is unaware of their symbolism, even if the interpretation and experience of the symbolic meaning of these medical acts can certainly vary from one person to another.
5. Is there a place in all this experience for a *rational* approach, for an objective analysis? In the ethical judgment that goes with these decisions, the distinction remains, from the point of view of intentions, between "not *wanting* to let a hopeless situation continue", "wanting to prevent intolerable suffering right to the end, by all possible means" and "wanting actively to terminate life". But many doctors point out that the intuitive perception of the actions that put these intentions into practice often gives rise to a mixture of these intentions or objectives, with the result that the distinction is less clear than in the rational analysis.

In ethical deliberations, the different ways of interpreting and experiencing the symbolic significance of medical end-of-life actions form part of the debate on "active termination of life" or "allowing to die".

- Some consider that there is an ethical difference between the two attitudes of "stopping or not beginning treatment" or "actively terminating life". Certainly, in both cases the end result is the same in principle, i.e. the death of the patient. In the first attitude, however, the doctor forgoes direct control over the life of the person, a seriously ill person in this instance, and lets that life expire. In the second attitude, he takes direct control over the person by actively hastening his death.
- Other members of the Committee challenge the relevance of this distinction which, in certain cases, is founded primarily in their view on subjective bases since, in either of the two cases (treating or refraining from treating or not beginning any new treatment), not only the result but also the intention, i.e. hastening death, remain the same. In both cases, doctors can start off from the same conception of humanity or base themselves on the same advance directive.

In some situations, however, when the patient's disability is limited to the irreversible loss of his mental faculties and there is no physical deterioration allowing a quick death to be expected, this distinction is relevant, even in the view of members who did not accept the principle. For some members of the Committee, whatever the patient's advance directives, there can be no question of inducing death (only refraining from treatment - in the case of concurrent diseases presumed to be fatal - can be envisaged), whilst other members consider that it is ethically questionable, even unacceptable, to keep alive a person who has expressly requested that his life be actively terminated in the case of dementia.

6. For some members of the Committee, the conditions in which medical end-of-life activity is practised are characterized by a lack of transparency, sometimes unfortunately open to abuse, negligence or bad decisions. As important moral values are concerned (life, dignity, physical integrity, autonomy), the question arises of whether, in these circumstances, the legislator ought not to intervene in order to reduce this lack of transparency.
7. Finally, certain members of the Committee consider that in the current state of insufficient training for nursing staff in dealing with patients coming to the end of their lives - with more particular reference to controlling pain and other symptoms, counselling patients and their families and taking ethical decisions -, allowing euthanasia or active termination of life with or without conditions could only lead to inappropriate and premature decisions. In their view, priority must be given to the training and supervision of nursing staff to enable them, as calmly as possible, to recognize and accept the imminent death of a patient, to provide him with the treatment, care and psychological support to which he is entitled and to refrain from any practice intended to shorten or prolong life.
For other members of the Committee, it is indeed important for doctors and nurses to be trained to take into consideration quite transparently the end-of-life requests made beforehand in writing by the patient and/or expressed by persons of trust previously designated by the patient, so that decisions as regards forgoing new treatment or actively terminating a life can be taken calmly on a consensual basis rather than through hasty decisions by one or other member of the nursing team.

II. Should the legislature intervene within the framework medical end-of-life decisions for persons incapable of expressing their wishes?

1. **The general interest** implies that people can live together, work together and manage society in concert, peacefully, safely, with mutual trust and with respect for the dignity and freedom of others (personal fulfilment and self-determination). When it appears, in a particular field of human activity (health care, for instance), that there is a real danger of uncertainty, lack of foresight or negligent behaviour, violation of rights (of incapable persons in this case), abuse, lack of transparency in decision-making, etc., it is then the State's responsibility to design appropriate legislation creating a normative framework for that activity which at the same time protects and develops the rights and liberties of those concerned. It should however be acknowledged in this respect that the general interest depends not only on a well-conceived legislative activity but also on the financial resources provided to institutions by the authorities and on the measures taken by them as regards educating and training nursing staff. In creating the most favourable "social space" for a particular human activity in each case, the law can contribute specifically towards protecting, encouraging and fully applying the values that belong to these activities.

2. **Specific values underlying medical treatment**

The specific values generally acknowledged concerning medical treatment are: life, physical integrity, health (and therefore recovery), quality of life, well-being (and therefore the easing of pain), comfort, autonomy (freedom) and dignity.

How does the law contribute towards protecting, encouraging and applying *these values in end-of-life situations*?

- 1) by *the legal protection* of life and physical integrity;
- 2) by recognizing and guaranteeing certain *patient's rights*:
 - a) *Basic social rights* such as the right to "health protection" and "medical assistance" (Art. 23 of the Constitution), together with, in the field of medical end-of-life assistance, the "right to alleviation of their suffering in the current state of knowledge" and the "right to receive palliative care and die in dignity" (cf. Declaration of Patients' Rights in Europe, Amsterdam 1994).
 - b) *Basic individual rights* such as the right to informed consent concerning the most important end-of life medical decisions such as "continuation or discontinuation of treatment", "administration of large doses of analgesics", with the decision tending towards "taking the request for euthanasia into consideration".
- 3) by protecting and encouraging the *legitimate interests* of which the persons concerned may avail themselves as regards the above-mentioned values and by settling disputes arising on this subject.

3. The above-mentioned values, interests and rights may already be threatened during the **decision-making process**, particularly when it concerns incapable patients. That is why end-of-life medical decision-making calls for special attention from the legislator.

III. Persons incapable of expressing their wishes. Definitions and classifications.

1) Persons incapable in law and in fact

In this opinion, the term incapable persons refers to not only persons who are incapable *de jure* (e.g. minors, persons with the status of extended legal incapacity) but also legally capable persons who *de facto*, because of illness, accident, old age, dementia, are not (or no longer) capable of making their wishes known as regards the decisions concerning their own person (health, medical treatment, physical integrity, quality of life, dying in dignity).

The concepts of “persons capable in fact” and “legally capable persons”, on the one hand, and “persons incapable in fact” and “legally incapable persons”, on the other hand, do not match entirely. Legally incapable persons are not always incapable in fact: for example, minors who have reached the age of reason are often quite capable of expressing their wishes as regards decisions concerning their person. It would seem that ethically this fact should be taken into account. The same can be said of some mentally handicapped persons with the status of extended legal incapacity. On the other hand, some legally capable persons, due to circumstances of various kinds, can become incapable *de facto*, which raises another problem.

Moreover, the most difficult problem often lies in the doctor’s assessment of the effective capability of the patient. What is the person’s degree of incapacity? Is this incapacity irreversible, etc.? Ultimately, the doctor is responsible for this assessment. However, when it is neither purely medical nor purely legal, some members fear that the expertise concerned may turn into undue assumption of power. Some members of the Committee suggest that only a collegial decision-making process (based on “the ethics of discussion”) can prevent such a risk.

2) The advance directive

We are talking here about “advance directive” and not “living will” - an expression unanimously rejected because it is equivocal. For some members of the Committee, the question of whether or not an advance directive has been written is important for the ethical and legal approach to active termination of the lives of incapable persons.

By “advance directive” is to be understood a written document in which a person, prior to his possible state of incapacity, gives precise instructions as regards the medical decisions that he wants or does not want to be taken and possibly designates a person of trust (doctor or otherwise) whom the doctor must consult at the time of taking medical end-of-life decisions concerning the person who has in the meantime become incapable.

3) The person of trust

It may happen that no advance directive is written before the person becomes incapable, but the patient, before incapacity sets in, has however designated a person of trust who must therefore intervene in his stead. This person must make his wishes known as regards the medical decision.

Some members consider that it may be justified, in exceptional circumstances, at the request of the person of trust, for the doctor to go ahead with the active termination of life. They consider in fact that the express designation of a person of trust implies that the patient has entrusted this person with expressing

his wishes and defending his interests vis-à-vis the doctor, including aspects relating to the request for active termination of life.

For other members, however, it is unacceptable for one to be able to designate a person of trust empowered to take an end-of-life decision.

4) Classifications

It should be specified first of all that some members of the Committee have serious reservations as regards the way in which to approach the subject of active termination by any kind of classification of the lives of incapable persons. Before undertaking such a classification of incapable persons according to their physical or legal status, in order to establish for them a legal system allowing their lives to be brought to an end on certain conditions, these members underline that their conception of the intangible and inalienable right to life of all human beings - whatever their physical state or their legal position - prevents them from accepting such classifications. In their view, the real ethical issue is not the way in which society is to put an end to the lives of these beings that it considers to be suffering or deficient but the way in which to implement the solidarity that is their due.

Other members of the Committee, on the other hand, consider that an “inalienable right to life” does indeed imply that one cannot take someone’s life without his will but does not necessarily imply a duty to live; they then think that freedom (the right to self-determinism) , the right to the safeguarding of one’s dignity, the right to the pursuit of happiness (and avoiding absurd suffering) are inalienable rights which, in certain circumstances, must be balanced against this “right” to live. According to the same members, a distinction should be made between those who have written an advance directive and those who have not. Among the latter, there are also those who had the capability to do so but did not and those who were never capable of writing such an advance directive. The last-mentioned category includes all newborn and young children, for whom medical decisions of whatever kind must be taken, and the seriously mentally handicapped. The same applies to children and adolescents who cannot be expected to have written an advance directive.

CHAPTER II - ETHICAL POSITIONS

I. Ethical legitimacy of the act of putting an end to the life of a patient incapable of expressing his wishes

Faced with the question of the ethical legitimacy of the act of putting an end to the life of a patient incapable of expressing his wishes, insurmountable *differences of opinion* emerge:

1. Of those who *reject this legitimacy*, some refer to the intangible respect for life. According to them, the illegitimacy of ending the life of an incurable patient can already be seen when the patient himself requests such a homicidal act *there and then*; this is even more evident when the act is committed on a patient who is not capable of expressing his present wishes. For others, however, it is the patient's incapability of expressing his wishes, and therefore his extreme vulnerability, his absolute dependence on others, that demand that the doctor refrain from any act aimed at intentionally putting an end to his life. The situation of an unconscious or demented patient, a child, etc., obliges the doctor, and with him society as a whole, to accept a heightened duty of solidarity and attention so that the patient's dignity as a human being is preserved right to the end. Faced with a patient at the end of his life and incapable of expressing his wishes, the doctor must deploy all available means with a view to ensuring the best possible quality of life, without transgressing the two limits constituted by, on the one hand, prolongation of life by medical means and, on the other hand, active termination of life.

2. For those who *recognize the legitimacy in certain cases* of actively terminating the life of an incurable patient incapable of expressing his wishes, the primary assertion is that the absence of current wishes on the part of the patient can be replaced, in the vast majority of cases, by an "advance directive" previously written by him and/or the designation of a "person of trust" empowered to dialogue with the doctor. They even consider that, exceptionally, in some cases in which it has not been possible to record any wishes, the active termination of life may still be justified, especially when forgoing or stopping treatment is not enough to put an end to an inhuman situation. The principle of compassion then obliges the doctor to ease the patient's intense suffering and/or to spare an individual the prospect of a painful and meaningless existence and his family a dramatic situation. According to these members, a distinction must then be made between two types of situations.

In the case of persons who were capable in the past of writing an advance directive and/or designating a person of trust and failed to make use of this possibility, the active termination of life is generally not justified, except for certain completely exceptional circumstances arising from a situation of sudden and urgent necessity. In actual fact, it must be supposed that those who did not designate a person of trust or express in writing their desire for possible termination of life when they were able to do so do not want their lives to be brought to an end prematurely,

- On the other hand, as far as newborn babies that are severely physically and/or mentally handicapped are concerned, the active termination of life could be envisaged exceptionally at the express request of the parents and in agreement with the nursing team, with a view to sparing them a painful or meaningless existence. A similar intervention could be ethically justified in the case of children or severely mentally handicapped individuals who, following a serious illness or an accident, are suddenly in a hopeless situation.

3. Among the members of the Committee who *recognize the legitimacy* of the act of putting an end to a patient's life in accordance with his advance directive, there is disagreement on the primary prerequisite for this legitimacy.

- For some, this legitimization implies that the patient has reached the terminal stage, that it is a question of a patient for whom the "end of life" is imminent. According to this point of view, the concept of end of life, which is the primary prerequisite, has a more objective significance: it implies that the process of death has really begun, that the patient is actually dying;

- For others, it is the existence of a "hopeless situation" that constitutes the primary prerequisite. This does not necessarily mean that the patient is really in the terminal stage. For the supporters of this second opinion, the concept of "end of life" has a more subjective significance: some people can regard as "hopeless" a situation of incurable illness or dementia¹.

Two other questions were also raised from the ethical viewpoint.

1. The discussion revealed that the doctor, through his actions and his attitude towards those diminished by illness or handicap, helps shape the image that society has of human dignity. This responsibility is even greater when it is a question of patients at the end of their lives. *Consequently, there is a consensus condemning any action or attitude that may seem to be a form of discrimination against the most vulnerable.* However, what is considered to be a form of discrimination is assessed in different ways. For some members of the Committee, this responsibility must remain limited to the medical decision, in so far as the doctor does not make a value judgment as regards someone else's life. When it comes to incapable persons in an end-of-life situation, the doctor must content himself with avoiding the prolongation of life by medical means and providing care and comfort. For other members of the Committee, on the other hand, this responsibility implies that the doctor, taking account of the wishes previously expressed by the patient and/or the opinion of the person of trust, questions himself, when the patient is in a hopeless situation, about whether or not active termination of life should then be regarded as a profoundly ethical act of compassion, solidarity and respect for human dignity.

2. *On the other hand, there is unanimous agreement in condemning any form of prolongation of life by medical means and/or pointless ("futile") treatment and in a good many cases there is a very broad consensus in favour of "letting the patient die" (even if he is incapable of expressing his wishes) when his situation becomes hopeless.* However, "letting someone die" can be viewed in different ways. The supporters of active termination of life doubt that in practice there is often a real difference between therapeutic "downgrading" (refraining from administering treatment, withdrawal of treatment, etc.) and active termination of life. According to them, the latter is even humanly more acceptable than the former. The opponents of this view retort that active termination of life is even more illegitimate (and even more pointless) when the possibility of "allowing to die" is recognized by common medical ethics and that a whole series of procedures and directives now exist to enable the doctor to act in a relevant manner in extreme situations without resorting to active termination of life.

II. Analysis of different situations

When it comes to patients incapable of expressing their wishes, a distinction must be made between (A) the situation in which a patient is incapable of expressing his wishes, for example by writing an *ad hoc* directive and/or designating a person of trust, (B) the situation in which no wishes have been expressed by

¹ Cf. above, Chap. I, 1: unequivocal definition of end of life.

the incapable person or there is no person of trust either because the patient did not write a directive when he could or because he did not designate a person of trust when he was able to do so, and (C) patients who have always been incapable of making their wishes known, i.e. newborn babies, young children and severely handicapped persons.

A. Situation in which the incapable person has communicated his wishes in an advance directive

It will be recalled that an “*advance directive*” is a written document in which a person, prior to his possible state of incapability, gives precise instructions as regards the medical decisions that he wishes or does not wish to be taken, and possibly designates a person of trust (doctor or otherwise) whom the doctor will consult when it comes to taking the most important end-of-life decisions.

Opinions differ on the principle and the practical details of such a directive.

1) For some members, an “advance directive” is *inappropriate in principle from an ethical viewpoint* because either it requires active termination of life on the part of the doctor, in which case it transgresses what they consider to be the prohibition of murder, or it requires prolongation of life by medical means, an excess that is prohibited in any case by the codes of medical ethics. Moreover, they continue, this directive does not refer to the precise present situation in which it has to be decided whether or not to continue with medical treatment. Wishes expressed when in good health, in the pure imagination of the writer, cannot apply in a situation in which this person is, so to say, “no longer the same”. Finally, the relationship established through such a directive between the patient and his doctor cannot be anything other than a “paper relationship”, a simple administrative document replacing the concrete living relationship that the doctor is bound to have with his patient, even now that he is incapable of expressing his wishes.

2) For other members, on the other hand, the “advance directive”, even though it can never be given the same weight as a present request, nevertheless constitutes a solid basis for the decision that the doctor will have to take. They reject the argument of the expression of wishes no longer being up to date: the incapable person is the same as when he was capable and his wishes and cannot have changed, since in the event of incapability these wishes no longer exist and the directive was written to replace them. They also think that such a directive would allow the patient to define his position as regards prolongation of life by medical means, resuscitation, unusual treatment, state of indignity, etc., thus providing the doctor with important indications as to the decision that he must take in his respect. Consequently, according to its supporters, the “advance directive” must be legally and ethically recognized in the doctor’s decision-making process.

There is a ***broad consensus considering that:***

1. such a directive, if legally recognized, has to be accompanied as far as possible by the *designation of a “person of trust”* empowered to hold a dialogue with the doctor on the subject of the decisive therapeutic choices that we are talking about here. The existence of such a mediator would have the advantage of: a) completing the directive, which cannot be expected to give precise instructions for all the situations that the patient is liable to experience; b) prolonging, albeit imperfectly but in a real sense nevertheless, the doctor/patient dialogue which is at the heart of all medical practice of quality;

2. such a directive cannot be legally binding on the doctor, who is ultimately responsible for the decision to be taken. It is therefore information that the doctor must take into account, that he must include in a *broad decision-making process* in which any designated “person of trust” plays an essential role.

Two differences of opinion remain among those arguing in favour of social and legal recognition of the advance directive.

The first concerns the nature of the decision-making process of which this directive is to form part. It will be recalled in this connection that in the first Opinion issued by the Committee (on the subject of euthanasia) positions 1 and 2 advocated confidential consultation and an *ex post facto* procedure, whereas position 3 was in favour of broader consultation in accordance with an *a priori* procedure. Here, *mutatis mutandis*, we find the same difference if we replace the patient’s current wishes (case of euthanasia) by the advance directive of the person incapable of expressing himself (case of active termination of life). For some members of the Committee, therefore, the advance directive, regarded as an integral part of the confidential consultation between the doctor and the person of trust, is in accordance with the ethical requirements laid down in the *ex post facto* procedure proposed in positions 1 and 2 of the 1st Opinion. On the other hand, among those who support position 3 of the 1st Opinion, some would like to include the advance directive in the consultation that must be established with the patient’s relatives and the nursing team before a decision is taken. Other supporters of this position 3, however, consider that - in an ethical dialogue with the patient’s relatives and the nursing team - the doctor must do everything possible to procure a dignified death for the patient, without transgressing the two limits (prolongation of life by medical means and active termination of life) rather than base himself on the advance directive.

The second is between the defenders of positions 1 and 2, on the one hand, and of position 3 of the 1st Opinion, on the other. For some supporters of proposal 3 of the same Opinion, the advance directive can only express the wish for abstention from or withdrawal of treatment, thus excluding any act intentionally putting an end to life. For the supporters of positions 1 and 2 of the 1st Opinion, the advance directive can leave the patient with the possibility of demanding (and therefore, possibly, obtaining) of the doctor an act that they consider to be profoundly ethical.

B. Situation in which the patient has expressed no prior wish (neither advance directive nor designation of a person of trust)

For certain members of the Committee, it is quite unacceptable, from an ethical point of view, to envisage actively terminating the lives of patients who have not requested it or who are incapable of expressing their wishes. The only ethical criterion by which the doctor must be guided is then the best possible quality of life for the patient, a criterion that itself derives from the principle of intangible respect for life.

It should be noted, however, that the argument against active termination of life can be understood in two ways, even though they both express the same sensitivity to the suffering of someone else and the love of one’s fellow man. For some (coming together overall within position 4 of the 1st Opinion), the act of putting an end to a patient’s life is still illegitimate regardless of whether or not he has expressed that wish. For the supporters of position 3 of the 1st Opinion, it is the absence of an expressed wish, and therefore the absence of any possible ethical dialogue, that makes the act illicit from a moral and legal point of view. They consider, however, that the interests of incapable individuals, even though they are outside the situation governed by the “euthanasia procedure”, must be protected by procedures relating to medical decisions concerning the end of life.

For the defenders of positions 1 and 2 of the 1st Opinion, active termination of the life of a person is ethically acceptable when this person has written an advance directive to this effect, or this is requested by the person of trust that he has designated. Active termination of the life of a patient having expressed no prior wishes and/or not having designated a person of trust, when he was able to do so, is not justified. However, in exceptional circumstances, when the doctor considers that, through compassion and/or human solidarity, active termination of the life is desirable, he may, with the consent of the family and the nursing team, go ahead with active termination of life.

C. Situation in which the patient has never been in a state to write an advance directive

Some members of the Committee consider that in the case of a hopeless medical situation affecting newborn babies, (young) children and severely mentally handicapped persons, when a medical complication sets in or they suffer a serious accident painfully aggravating their condition, then and then only, at the express request of the parents or the guardian and in agreement with the nursing team, may it be decided to forgo any further therapeutic treatment or even to proceed with active termination of life. This is justified from the ethical point of view by the fact that it is acknowledged that the parents and/or guardian have the right to request, on behalf of their seriously handicapped baby or their child suffering absurdly, that this inhuman life be brought to an end.

CHAPTER III. LEGISLATOR'S RESPONSE TO THE QUESTION

The debates on the question of “*Is it appropriate to legislate on active termination of the lives of incapable persons?*” elicited three separate proposals:

Proposal 1. Legal recognition of the active termination of life (brings together the supporters of positions 1 and 2 of the 1st Opinion)

In a democratic and pluralist society, the State cannot favour any particular approach to life and death to the detriment of others that are just as valid from the moral viewpoint. Since for many citizens it is not ethically defensible to be kept alive in physical or mental conditions not corresponding to their definition of a life worthy of that name, the State must provide the legislative framework in which the active termination of their lives may be decided on and implemented in complete transparency.

A distinction must be made between two situations in this respect:

- ◆ the first is that in which the doctor has an advance directive from the patient or the opinion of the person whom the patient has declared that he trusts or, in the absence of such a declaration or person of trust, the wishes of the patient's legal representatives;
- ◆ the second is that in which the doctor must envisage active termination of life without any statement from the patient or his legal representatives and with no possibility of consulting a person of trust.

In all these hypotheses, the doctor must examine the patient's *situation* by conducting a broad dialogue encompassing, apart from the person of trust or the legal representatives, his relatives and the nursing team (the doctor faced with an end-of-life situation at home and who is not in a position to establish the conditions for such a dialogue will discuss the situation with at least two other doctors). However, responsibility for the *decision* whereby this dialogue is completed lies solely with the doctor and can in no case be incumbent upon the relatives and the nursing staff.

In the case of a patient in a hopeless situation² who has neither written an advance directive nor designated a “person of trust” beforehand, whereas he could have done, the active termination of life may be justified from a medical and ethical point of view in exceptional cases in which discontinuing and forgoing treatment do not allow an escape from an inhuman situation. However, it does not seem desirable for such an act to be given legal recognition, due to the risk of abuse and slippage. The active termination of life will then be justified by way of a “situation of sudden and urgent necessity”.

In cases in which the patient in a hopeless situation is no longer capable of communicating his desire to die but has expressed his wishes in an advance directive or designated a person of trust expressing the same desire, the doctor will closely involve the person of trust in his decision properly speaking; he will endeavour to decide by basing himself as carefully as possible on the advance directive. He must also consult another doctor and make his decision known, when he judges it to be psychologically opportune (possibly afterwards), to the relatives and the nursing staff.

² On the concept of “hopeless situation”, see under Chap. 1, I,1
Final version

In the case of a patient who has never at any stage in his life been capable of writing an advance directive or designating a person of trust, the legal representatives may ask the doctor actively to terminate his life. The doctor may not proceed without being certain of the consensus of the family and the nursing team and of the advisability of such an act.

Moreover, whatever the situation of active termination of life with which the doctor has been faced, the doctor will be bound to inform the legal authorities subsequently, with the support of the medical file, that the death of his patient was a medically induced death. To this effect, the procedure for issuing death certificates and burial certificates will take account of cases in which the doctor considers that he has brought forward the time of his patient's death (on the basis of what is currently practised in the Netherlands). In this way, in return for the confidence placed in the doctor faced with a difficult end-of-life situation, the latter must assume his responsibilities within the utmost transparency and be ready, if necessary, to account for his actions.

Proposal 2. Procedural regulation a priori of active termination of life requested by a patient in an advance directive

For the supporters of proposal 2, the active termination of life must retain its criminal classification as a transgression of the prohibition of murder. According to them, however, the transgression of this prohibition can be legitimized in exceptional cases, in the form of a derogation, when in an advance directive written by the patient active termination of life is clearly requested and the hopeless situation³ of a patient in the terminal stage⁴ and now incapable confronts the doctor with conflicting ethical values and duties. The defenders of this point of view therefore propose that, in such cases, an *a priori* procedure is made legally compulsory, guaranteeing that the doctor - who ultimately is still responsible for this act - is provided with all the necessary information on which to base his judgment and take a decision. This *a priori procedure would comprise the following requirements*: analysis of the justification, from the medical point of view, of the request for active termination of life as expressed in an advance directive; consultation with the nursing staff; consultation with relatives (or at least obtaining their opinion); opinion of a medical colleague from outside the nursing team; ethical assessment with a third party. Thus informed, the doctor will judge to what extent active termination of life can be justified in this case by a situation of sudden and urgent necessity⁵.

If the patient incapable of expressing his wishes has not written an advance directive, the supporters of this proposal oppose any act aimed at putting an end to his life. In this case, the doctor and the nursing staff will limit themselves to preventing pain, to scaling down therapeutic treatment and to administering care and comfort.

The supporters of this proposal reject any form of legal recognition of active termination of life. They are therefore opposed to the “symbolic transformation” of the words euthanasia and active termination of life into a simple “medical act”. They fear that such a transformation may lead to the act of euthanasia becoming commonplace. More fundamentally, they also consider that such decriminalization of euthanasia and active termination of life in the form of medical acts would put the doctor in the illegitimate position of being the judge of the value of the life and death of patients, particularly those who are too ill to be still capable of expressing their point of view on this subject. They are afraid that such a transformation may lead to euthanasia and the active termination of life

³ On the subject of this concept: see under Chap. 1, I,1

⁴ On the subject of this concept: *ibid.*

⁵ On the subject of the concept of “situation of sudden and urgent necessity”: see first Opinion, proposal 3, and critical comments in proposal 4 of the first Opinion.

becoming commonplace and opening the door to justification of this act by the easing of the psychological and financial burdens involved in caring for persons at the end of their lives, and may release the authorities from responsibility for the financing of palliative care.

Finally, the supporters of this position put forward the idea that the problem of the active termination of life cannot be taken out of the broader context of all the medical decisions reached concerning the patient at the end of his life. These are important decisions such as: stopping or forgoing therapeutic treatment, gradually scaling down curative treatment, administering large doses of analgesics, etc. All these decisions can have an influence on the duration of the death process. Furthermore, the intentions underlying these decisions can be very different: not allowing a hopeless situation to continue, preventing pain, allowing to die, actively putting an end to life, etc. Consequently, as was the case in *proposal 3* of the *1st Opinion*, emphasis is also placed here on the need for a legal regulation of *Medical End-of-Life Decisions*. A minimum requirement would be that a report must be included in the medical file on how the rights of the patient and his relatives (as regards information, consultation and consent) were observed in the decision-making process. If the advance directive was to be given legal recognition, the written report referred to above should in any case also explain the content of this advance directive.

Proposal 3. Maintenance pure and simple of the legal prohibition of active termination of the lives of incapable persons

The supporters of this position consider the prohibition of homicide to be an essential feature of the rule of law. They are of the opinion that, even if an advance directive exists requesting active termination of life, it is never permitted to accede to this request, also considering that an advance directive can never anticipate a concrete situation of distress.

This group includes some supporters of proposal 3 of the first Opinion on euthanasia. For them, this proposal 3 constitutes the extreme limit of medical practice in situations of sudden and urgent necessity. They also think that this proposal cannot under any circumstances lead to any active termination of life among incapable persons or to any other form of procedural regulation that could serve as a pretext for active termination of the lives of incapable persons.

Also in this group are the supporters of proposal 4 of the first Opinion on euthanasia. They consider that the eminent value of life constitutes the natural basis for all the other rights of the human person. That is why they refuse to accept that the Belgian legal system should in any way legitimize the active termination of life, even in the form of an *ex post facto* or *a priori* procedure.

Medical ethics has developed enough directives and procedures to provide an appropriate response to the hopeless situations of people in the terminal stage, including incapable patients. Classifications of the states of patients entailing the limitation of therapeutic treatments, together with directives relating to the discontinuation of artificial feeding and hydration, are firmly recognized at international level. A doctor is never forced to practise interventions that are meaningless from the medical point of view. This implies that medical practice has a vast arsenal of possibilities allowing an appropriate solution to be found to the problematical situations of incapable patients at the end of their lives. All this may occur within an open atmosphere of communication with the (possible) person of trust and the relatives, as well as with the nursing staff, for whom any wishes previously expressed by the patient are seriously taken into consideration. The final decision lies with the doctor, but it must always remain an expression of responsibility, care and assistance for the (incapable) patient in the terminal stage. Directives given in advance, however, can never comprehend the complexity of the “here and now” or constitute a binding code of behaviour concerning unforeseen situations. Creativity

in everyday medical practice is constantly being fine-tuned in keeping with the vicissitudes of existence.

The supporters of this position consider that it is not the doctor's responsibility to judge the quality of the lives of his fellow beings (especially when they are incapable of making their wishes known). Recognizing this role on the part of the doctor, as some would like, is tantamount in their view to allowing him to exercise an unacceptable practice. They also recall that actively terminating a life, called "compassion for the dying", contains an internal contradiction: compassion implies more of medical and moral counselling to help the patient to die. A real democracy implies that nobody can assume the right to judge the value of someone else's life. Active termination of the lives of incapable persons must remain prohibited in all circumstances. In actual fact, the general ban on active termination of the lives of incapable persons is a prerequisite guaranteeing respect for the rights of the weakest and also, therefore, in the final analysis, guaranteeing protection of basic democratic values.

Generally speaking, those in favour of maintaining the ban are convinced that it alone can ensure protection for the weakest members of society. No doubt the extremely ill - capable or incapable - should be allowed to die by letting them make their way unaccompanied to their death. But it is not permitted to confuse this reasonable acceptance of the destiny of every human being with the radical control represented by the homicide of any other person.

CHAPTER IV. SUMMARY OF THE TWO OPINIONS ON THE ADVISABILITY OF A LEGISLATIVE AMENDMENT AS REGARDS EUTHANASIA AND ACTIVE TERMINATION OF THE LIVES OF PERSONS INCAPABLE OF EXPRESSING THEIR WISHES

The two opinions of the Committee 1) on euthanasia and 2) on active termination of the lives of persons incapable of expressing their wishes reveal positions that do not match entirely. It is therefore necessary to summarize the two opinions so as to isolate the different positions that exist in the final analysis.

It will be recalled that the *first Opinion* concerned *euthanasia*, i.e. the act carried out by a doctor who intentionally puts an end to the life of a patient whose situation is hopeless, *at the request of the latter*. This opinion comprised four distinct proposals:

1. A legislative amendment decriminalizing euthanasia;
2. An *ex post facto* procedural regularization of euthanasia decided on in a confidential consultation;
3. An *a priori* procedural regularization of the most important medical decisions concerning the end of life, including euthanasia, after collegial consultation and in the case of a situation of sudden and urgent necessity;
4. Maintenance pure and simple of the legal prohibition of euthanasia.

The *second Opinion* concerns *active termination of the lives of incapable persons*, i.e. the act carried out by a doctor who intentionally puts an end to the life of a patient whose situation is hopeless and who is *incapable of expressing his wishes*. This opinion comprised three distinct proposals:

1. Legal recognition of the active termination of life, which brings together the supporters of positions 1 and 2 of the 1st Opinion;
2. An *a priori* procedural regularization of the most important medical decisions concerning the end of life, including the active termination of life as requested by the patient in an advance directive; this proposal is defended by some supporters of position 3 of the 1st Opinion;
3. Maintenance pure and simple of the legal prohibition of the active termination of life, which brings together some supporters of position 3 of the 1st Opinion (those refusing to recognize the ethical and judicial legitimacy of the “advance directive”) and the supporters of position 4 of the 1st Opinion.

It emerges from the debates on the different situations referred to in the two opinions that there is a consensus on the following points:

1. rejection of prolongation of life by medical means;
2. the wish to develop palliative care;
3. the problem of the inadequacy of current regulations on the death certificate and the statement of death. In these documents, statements concerning causes of death should be more reliable;
4. the problem of lack of transparency in the medical end-of-life decision-making process.

Four positions were finally formulated during these debates:

Position A. Position of those wanting legal recognition of euthanasia and active termination of life. They argue in favour of legislative intervention recognizing the decision-making autonomy of every person facing death, together with the ethical nature of the act of solidarity and respect for human dignity that consists in putting an end to the life of a patient in a hopeless situation. Such recognition could take various forms, but these members consider that they do not have to choose between them: amendment of criminal and civil legislation, judicial regulation along the lines of the “Dutch model” or even classification of euthanasia or the active termination of life as a medical act coming within the scope of the art of healing (for which, therefore, the doctor performing it could not be held criminally liable).

In the case of a patient who is incapable of expressing his wishes and has not written an advance directive or designated a person of trust even though he could have done so in the past, active termination of life can be justified from the medical and ethical point of view (as an act of compassion) in some exceptional cases, but must not however be given legal recognition, due to the risk of possible slippage. In this case, the doctor must be able to justify his act by way of a “situation of sudden and urgent necessity”.

In other cases, in which the doctor can take account of a wish expressed by the patient, active termination of life must be given legal recognition. If such a wish is expressed *in the confidential consultation* with the doctor, the latter is authorized to practise euthanasia (on the conditions set out in Opinion No. 1 (see position 2 in particular). If the patient has written an *advance directive* and/or designated a person of trust, the doctor will assess the advisability of active termination of life with this person of trust and/or in accordance with the advance directive. Finally, if a patient with an incurable disease has not written an advance directive and/or has not designated a person of trust because he has never been capable of doing so, the doctor may, at the request of the legal representatives, envisage active termination of life after consulting all the nursing team. In all cases, the doctor must inform the legal authorities *ex post facto*, backed up by the medical file, that the death of his patient was a medically induced death.

Position B. Position of those who think that euthanasia can be ethically justified in exceptional cases (situation of sudden and urgent necessity) but who cannot in any circumstances consider it to be justified actively to terminate the lives of incapable persons who have never made out an advance directive. Exceptionally, active termination of life may be decided upon if an incapable patient has written an advance directive in cases in which one can evoke the principle of “necessity knows no law”. When this decision is taken, it is necessary, as with euthanasia (proposal 3 of the first Opinion), to follow an *a priori* procedure.

Position C. Position of those who consider that the third proposal of the first Opinion on euthanasia constitutes the extreme limit of medical practice in a situation of sudden and urgent necessity but that this proposal must not lead in any circumstances to practising active termination of the lives of incapable persons.

Position D. Position of those who wish purely and simply to maintain the legal prohibition of both euthanasia and the active termination of life (cf. Position 4 of the 1st Opinion). The supporters of this position want the legal prohibition of homicide to be maintained as one of the essential features of the rule of law. For them, the eminent value of life is the natural vehicle for all the other rights of the human person. For this reason, they refuse to allow into the Belgian legal system in any form whatsoever, even through an *a priori* or *ex post facto* procedure, the legitimacy of euthanasia and the active termination of life requested by the patient.

Summary table⁶ of the different positions adopted in the two opinions on the question: is it ethically justifiable for the legal system to legitimize euthanasia (for persons capable of expressing their wishes) or the active termination of life (for persons incapable of expressing their wishes)?

	First Opinion: Euthanasia of capable persons	Second Opinion: Active termination of the lives of incapable persons with advance directive and/or person of trust	Second Opinion: Active termination of the lives of incapable persons without advance directive or person of trust
Position A	YES - decision of the doctor and the patient (proposals 1 and 2 of the first Opinion)	YES - decision of the doctor and/or the person of trust if there is one (proposal 1 and 2 of the second Opinion)	YES - at the request of the legal representatives (proposal 1 of the second Opinion) NO - when the person has been capable (proposal 1 of the second Opinion)
Position B	YES - subject to situation of sudden and urgent necessity and a priori procedures (proposal 3 of the first Opinion)	YES - subject to situation of sudden and urgent necessity and a priori procedures (proposal 2 of the first Opinion)	NO (proposal 3 of the second Opinion)
Position C	YES - subject to situation of sudden and urgent necessity and a priori procedures (proposal 3 of the first Opinion)	NO (proposal 3 of the second Opinion)	NO (proposal 3 of the second Opinion)
Position D	NO (proposal 4 of the first Opinion)	NO (proposal 3 of the second Opinion)	NO (proposal 3 of the second Opinion)

⁶ This table is only intended as a guide and must not be used without the descriptions of the positions that are set out above.

The opinion was prepared by select commission 97/4, consisting of:

Joint chairmen	Joint reporters	Members	Member of the Bureau
L. Cassiers	E. Delruelle	C. Aubry	Y. Englert
E. Vermeersch	F. Van Neste	X. Dijon	
		Y. Galloy	
		J.-L. Legat	
		J. Messinne	
		M. Roelandt	
		P. Schotsmans	
		G. Verdonk	
		J. Vermlyn	
		B. Wouters	

Member of the Secretariat: B. Orban

Consulted experts:

- Pr. Dr. P. De Coninck, President of the Association for Paediatric Surgery
- Pr. Dr H.Nys and E. Strubbe, K.U.L., Leuven
- Dr. M. Lamy, Head of the Intensive Care Department at the C.H.U. Liège

The working documents of select commission 97/4 – request for opinion, personal contributions of the members, minutes of meetings, documents consulted - are stored as Annexes 97/4 at the Committee's documentation centre, where they may be consulted and copied.
