BELGIAN ADVISORY COMMITTEE ON
Bioethics

# Opinion no. 41 of 16 April 2007 on informed consent and "D.N.R." Codes

*Request for an opinion of 10 May 2004*
*from Dr M. Bogaert, Chairman of the Ethics Committee*
*at Sint-Lucas Hospital in Gent*

## Question put to Committee

(free translation)

*"As you are aware, on 27 September 2003 the National Council of the Order of Doctors expressed an opinion on the issue of DNR (Do not reanimate) codes.*

*This means, in relation to the law on patient's rights, that such decisions cannot be taken or acted upon without the prior informed consent of the patient, their family or their representative.*

*Word has come back to me from the anaesthetics department at Sint-Lucas Hospital in Ghent that difficulties are arising further to this opinion. In fact, it is not clear how to react so as to avoid relentlessly prolonging life by technological means, when the patient or family does not agree.*

*Could the Advisory Committee please consider this issue?*

# CONTENT OF THE OPINION

## 1. Reformulating the question

So as to cover all aspects of the issue raised, the Advisory Committee has decided to reformulate the question as follows:

> "Under what conditions can a patient be allocated a code indicating a limit on the care to be provided? What are the ethical precautions that need to precede such a decision? How, in ethical terms, should objections which may be raised on this subject between the nursing team on the one hand and the patient, his legal representative, his authorised representatives, his confidant or his family on the other be dealt with?"

Posed in these terms, and in order to arrive at a satisfactory response, the question presupposes an examination of the legal, deontological and finally ethical difficulties raised below.

## 2. Semantic difficulties

In this opinion, a number of expressions will be used frequently to designate the people to whom the doctors will refer to take their decision should the patient be unable to express himself in person:

- legal representative
- representative
- authorised representative
- relatives

These expressions have not been clearly defined by law, and their content is interpreted differently in medical practice.
However, it should be noted that the law of 22 August 2002 on patients' rights attributes different effects in law to the concept of the confidant and the concept of authorised representative; when these two terms are used in this opinion, this is in the specific sense given to them by the aforementioned law, it being understood that the expression "confidant" has a different meaning in the law on euthanasia.

## 3. Description of the concept

### *3.1. Historical development of the "Do not reanimate" (DNR) concept*

Progress in diagnosis and treatment, along with changes in the conditions of hygiene and the socio-cultural level in which people live, have resulted in a remarkable lengthening of life expectancy. At the same time, the increasing medicalisation of individuals has pushed back the traditional frontiers between health and illness, between normal and pathological, with the sick gradually dissociating themselves from their own death. Whereas before the Second World war, most patients died at home, surrounded by their relatives, today 75% of people die in hospital or in an institution[1].

Many of these deaths occur in intensive care units, and most of them have involved a medical decision to stop or reduce care or even, under more exceptional circumstances, to actively intervene to hasten death[2].

Very early on in fact, in the period from 1940 to 1960, the medical corps was confronted with patients who, having been resuscitated, retained satisfactory vital functions, but no longer showed any signs of brain activity. These patients, who were brain dead, or in a permanent vegetative state, were the first to be the subject of "DNR" decisions, in the first meaning of the term, that is the decision to refrain from resuscitating the patient in the event of cardio-respiratory failure. This attitude was ethically accepted, even in certain circles, as is borne out by the "Discourse for Doctors" delivered by Pope Pie XII in 1957[3].

However, it did not resolve all the situations, and numerous patients in a permanent vegetative state "survived", at the cost of intensive care, great discomfort to themselves and considerable moral suffering on their part of their relatives[4].
The Karen Ann Quinlan case in 1976 was to mark a development in this field. The Supreme Court of New Jersey in fact had to grant the father of this young patient, who had been in a permanent vegetative state for several years, the right to have the mechanical ventilation that was keeping her "alive" switched off.
Several US States were to rule along the same lines. In that same year, 1976, Massachusetts General Hospital published an article in the *New England Journal of Medicine* entitled "Optimum care for hopelessly ill patients[5], which recommended classifying patients in four categories, a classification which was very similar to that used today in intensive care units. Category A patients were given unlimited therapeutic and diagnostic care; Category B patients were given the same unlimited care, but were assessed daily as their prognosis was fairly poor; Category C patients were not – were this to prove necessary – given cardio-pulmonary resuscitation or further major treatment; finally, the care given to Category D patients was limited to that necessary to ensure their comfort.

The approach to patients in an irreversible coma has been modified along with the definition of brain death, and possible recourse to these patients as organ donors.

---

[1] CCNE (National Ethics Advisory Committee for life sciences and health), Opinion No 63 of 27 January 2000, "Fin de vie, arrêt de vie, euthanasie".

[2] Sprung C.L. Cohen S., Sjokvist P. et al: "End of life Practices in European Intensive Care Units", *Jama*, 2003, 290, p. 790-797.

[3] Pie XII, "Discourse for doctors", 24 November 1957, in: *La Documentation catholique*, No 1267, col. 1065-1610, referred to in *La revue générale de droit medical* No 17, 2005, p. 339.

[4] In 1974, the American Medical Association declared that the purpose of cardiopulmonary resuscitation was to avoid sudden death. Cardiopulmonary resuscitation is not appropriate in the case of irreversible terminal illnesses, where the death is not unexpected.

[5] The Society of Critical Committee of the Massachusetts General Hospital, "Optimum Care for hopelessly ill patients", in the *New England Journal of Medicine*, 1976, 295, 362-364.

Developments in reanimation and intensive care techniques were gradually to demonstrate that the purely passive attitude recommended by the Massachusetts General Hospital did not address every situation. Consequently, alongside refraining from applying major therapeutic techniques and treatment of causes (withholding), it proved necessary, to avoid excessively deferring the death of a patient in a desperate position and having exhausted every possible therapeutic option, to cease to provide a vital support (withdrawing), or even stop providing food and water. While the literature agrees on the ethical nature of refraining from using diagnostic and therapeutic techniques which can no longer be of benefit to the patient in terms of survival or comfort, the discussion on when to stop giving treatment that has become futile remains animated. In fact, to avoid such measures causing pain, discomfort and anxiety for the patient, it is sometimes justified to administer strong analgesics which, in addition to their effect on pain, may hasten death. No longer providing food and water is clearly intended to shorten the process of death.

For many years, DNR processes remained confined to intensive care units and, more recently, to the related neonatology units, although this poses particular problems given the substantial affective burden and the lack of opinion on the part of the patient in question. Today these protocols are also found in commonplace units such as geriatric departments, rest and care homes, particularly those that take care of patients suffering from dementia, oncology and neurology departments. Their application in such areas raises new questions. In these units, the patients affected by these protocols do, admittedly, suffer from irreversible ailments for which either there is no effective treatment or for which the existing means have been exhausted. However, they are not all in the final phase of their life. The date of death cannot be forecast in terms of days, sometimes even weeks or months. The attitude of the patient, of those around him and, ultimately of the doctor is then based essentially on their assessment of the quality of life or survival and the therapeutic resources required for this. These data are even more subjective than the prognosis in terms of the expected survival time and this opens up the debate on the concept of futile treatment and the resultant relentless prolonging of life by technological means.

### *3.2. Definitions*

Technological developments in medicine are constantly opening up new treatment possibilities that are likely to prolong the patient's life. It is appropriate to break off or not to start a course of treatment if it can be scientifically established that there is no further hope that this will offer the patient a reasonable benefit to his health and will not improve his comfort. The treatment does not provide any further benefit or therapeutic benefit for the patient and consequently will not contribute towards maintaining or improving the quality of his life or ensure him a dignified end to his life.

The variety of terms used in various different languages express different aspects of the same concept of relentlessly prolonging life by technological means:

- In Dutch: "therapeutische verbetenheid"
- In French: French-speakers in Belgium often talk about "acharnement thérapeutique", and in France the term used is "obstination déraisonnable". These terms have just been established by French law.
- In English the terms are "futile treatment" or "non-beneficial treatment".

The literature available has frequently attempted to define the concept of relentlessly prolonging life by technological means. For instance, the Swiss dictionary of social policy, V° "Acharnement thérapeutique", states that this "consists of using all medical means made available to keep a patient alive, irrespective of his or her condition", adding "The concept has taken on a qualitative dimension by attributing this term to treatments which, if administered, prolong the life of a patient whose quality of life proves extremely mediocre; in other words, futile treatment. Two basic concepts are involved in the definition of futility: the lack of effect or qualitative futility and the lack of benefit or quantitative futility. The effect is measured by the response of an organ to the administration of a treatment, for instance controlling an infection using antibiotics. The probability of achieving the expected effect is based on scientific work. The benefit is more difficult to assess as this involves subjectivity on two levels: individual, i.e. that of the patient, his relatives and the nursing staff, and collective, i.e. the socio-cultural or even economic aspect. In short, relentlessly prolonging life by technological means is a complex concept created in a context of huge variability in medical practice, for which a consensus is often difficult to obtain"[6]. Recalling the Venice declaration from the World Medical Association on the terminal phase of life (1983), the National Ethics Advisory Committee on Life Sciences and Health of the Grand Duchy of Luxembourg[7] defines relentlessly prolonging life by technological means in its opinion No 1996.1 in the following terms: "extraordinary treatment from which no-one can expect any benefit whatsoever for the patient". It stresses the term "*acharnement*" (relentlessness) which, according to the Robert dictionary of the French language, means "*ardeur furieuse et opinâtre dans la lutte, la poursuite, l'effort*" (furious and persistent or stubborn ardour in a struggle, continuation, effort"", and quotes Yvon Kenis[8], for whom the expression in question describes "the attitude of doctors who systematically use all medical means to keep someone alive", and in particular "the use of intensive means [...] with the aim of prolonging life [...] at the terminal stage". According to the *Dictionnaire permanent de bioéthique*[9], "it is an attitude that consists of continuing major treatment for curative purposes even though there is no real hope of obtaining any improvement in the condition of the patient and which results in simply prolonging life". Mylène Baum, having recalled this definition, notes that "the very word '*acharnement*' indicates a certain amount of violence done to the patient" and says that "*acharnement thérapeutique*" is a negative term that has come to censure something that was increasingly perceived as a medical technique that gave priority to an abstract perception of the value of life in itself, rather than the interests of the patient and his individual perception

---

[6] The article is signed André Laszio and refers to other works.

[7] Luxembourg university centre, 1996

[8] in: *Nouvelle Encyclopédie de Bioéthique*, v° "Acharnement thérapeutique" Gilbert Hottois and Jean-Noël Missa, De Boeck University, Brussels, 2001.

[9] *Rapport sur les sciences de la vie et les droits de l'homme*, Parliamentary office of development of scientific choices, fasc. No 7

of a good life"[10]. Other authors, including English-speaking writers, give similar definitions of the expression in question.

The Bioethics Advisory Committee of Belgium upholds these considerations and notes that, in medical circles, it is generally admitted that such forms of treatment are not appropriate[11] but observes, on the one hand, that the boundary between useful and futile treatment varies as it evolves over time in line with the progress made in medicine and, on the other hand, that practice shows that in the presence of a given patient displaying serious symptoms, a nursing team called upon to deal with the emergency sometimes thinks about doing the most they can rather than that which is reasonable.

Moreover, the Advisory Committee feels that the concept of relentlessly prolonging life by technological means is not confined to the care itself, but also covers invasive diagnostic acts.

However, it does not apply in the following situations:

- diagnostic treatments and interventions as long as the prognosis is uncertain;
- diagnostic treatments and possible interventions required to provide palliative care for the patient;
- resuscitation with a view to removing organs for transplantation.

The medically *futile* or *pointless* nature of the treatment for the patient is an essential aspect of the concept of relentlessly prolonging life by technological means. The medical approach places the emphasis on the lack of therapeutic utility or benefit for the health of the patient, based as far as possible on scientific data. Treatment is described as futile if the chances of achieving the desired effect are extremely slight, or even non-existent.

The probability of a positive effect must be so small that the treatment cannot be justified. One of the problems posed here lies in determining a threshold value. What must be the probability of obtaining a positive effect: 1 in 1000, 1 in 100 or 1 in 10? Moreover, given an actual case, it is often very difficult to reliably assess the objective chances that a treatment will succeed.

For this reason, views may differ between treatment teams and within such teams, when 'objective' scientific probability has to be applied to an actual case. Even in the context of consultation between the professional team and the patient or his relatives, diverging points of view cannot be ruled out when it comes to deciding whether or not there is any point, in medical terms, in administering a treatment.

A distinction has to be made between treatment that is 'medically futile' and treatment *that has no point;* Although the adjectives "futile" or "having no point" are sometimes used as

---

[10] "Acharnement thérapeutique", March 1998, text available on: http://www.md.ucl.ac.be/ebim/scientif/Recherche/Fin Vie/MB_Euth1.htm

[11] For example, the Medical Ethics Manual of the World Medical Association states: "the physician has no obligation to offer a patient futile or non-beneficial treatment" (2005, p. 48); and the new Article 97 of the Belgian Code of Medical Ethics, adopted by the National Council of the Order of Doctors on 18 March 2006, states in paragraph 2: "Relentlessly prolonging life by technological means should be avoided" (National Council Bulletin, No 112, June 2006).

synonyms when talking about a treatment, the Advisory Committee feels that a distinction should be made between the two: the fact that the treatment does or does not have a point refers more to the point of view of the patient and his scheme of values. It is up to him or his legal representative to determine whether a treatment has any point or not, and whether it contributes towards a better quality of life or makes life more acceptable. In this opinion, we will look in more detail at situations in which the perspective of the carer does not correspond to that of the patient or his representative.

The concept of relentlessly prolonging life by technological means also refers to *the disproportionate nature of the means and costs* compared with the result: the patient's life is prolonged without any qualitative benefit for him and death is simply deferred, thanks to the administration of excessively costly treatments, which could at the very most represent a very limited gain for the patient.

In the context of the treatment of terminally ill patients, a distinction must be made between a futile treatment and the disproportionate nature of the means used. It may be that in the latter case, there is still a limited benefit for the patient, but that this benefit does not offset the disadvantages that weigh in the given medical context.

### *3.3. Implementation via codes*

Most hospitals and care institutions have drawn up 'codes', on the basis of internal, multidisciplinary consultation, to decide on the interruption or non-administration of a treatment that makes no sense from a medical point of view and hence to avoid relentlessly prolonging life by technological means. These codes on the limitation of the treatment provided are often known as 'DNR' ("do not reanimate" or "do not resuscitate"). They are applied in a wide range of health care sectors, in which they do not always have the same meaning, but mainly in intensive care units, intensive neonatology units, psycho-geriatric units, palliative care units and rest and nursing homes.

Both conscious and unconscious patients in the final phase of their life or close to this can in theory be the subject of a "DNR" decision. The application of these codes does not under any circumstances involve any interruption in the care provided to ensure the patient's comfort, which on the contrary must be continued and even increased.

Witnesses from various heath-care sectors have explained how they use the "DNR" codes in the context of their clinical practice (see point 5). The terminology used varies considerably and does not always cover the same actual situation. However, as regards content, there is always a usually gradual limitation of treatment. The decision is noted on a standard form and kept in the patient's file.

The gradual limitation may be as follows[12]:

---

[12] Subject to specific local elements, including in rest and nursing homes

- **Code 0**: No limit on treatment. The use of Code 0 permits the start of early discussion of the ethical position, even before there is any question of gradually stopping the treatment[13];
- **Code 1**: "Do not resuscitate"
- **Code 2**: "Do not extend treatment", expressly indicating the types of treatment that should not be started (no further escalation of treatment);
- **Code 3**: "Reduce treatment", again indicating the forms of treatment that should be stopped. Reducing treatment is particularly sensitive as it can hasten the death of the patient, particularly if 'sedation' is added to ensure the patient's comfort. Of course, this same limitation applies to the use of diagnostic means that are no longer appropriate, unless they are for the purpose of making the patient comfortable.

The standard form identifies the attending physician, specifies the date and time of the decision, gives the reason for the decision, the level of information provided for the patient, the family, relatives and the family doctor, and provides for the possibility of immediate adjustment of the existing "DNR" measure. In practice, "DNR" codes are initiated by doctors, in consultation with the nursing team, and in principle they follow the logic of medical health.

Here are a number of terms and abbreviations that are not necessarily synonymous:

| | |
|---|---|
| DNR | Do Not Reanimate; Do Not Resuscitate |
| NTBR | Not to be Reanimated |
| NTR | Niet Te Reanimeren |
| PME | Pas Moyens Extraordinaires |
| ACP | Advanced Care Planning |
| NCPR | No Cardiopulmonary Resuscitation |
| AND | Allowed Natural Death |
| NTGIT | Not to be Intensively Treated |
| BPC | Best Palliative Care |

The "DNR" form has a number of objectives:

- to ensure respect for the wishes expressed by the patient
- to avoid relentlessly prolonging life by technological means
- to contribute towards an end of life in accordance with human dignity among terminally ill patients and patients whose condition is hopeless
- to adapt the care provided to the way in which patients see the end of their life
- to inform other care providers working outside normal working hours about measures taken in terms of treatment they have to observe;
- to clarify the situation within the team as regards the measures taken.

---

[13] Read amongst others in the Opinion from the ad hoc working group on "Ethics" of the federal platform of experts set up in accordance with the protocol of 24 May 2004 on "The policy to be adopted with regard to patients with acquired cerebral lesions and in particular with regard to patients in a vegetative state or a state of minimum responsiveness", version of 29 June 1996, p. 15.

# 4. The legal framework

Without wishing to engage in a study of comparative law[14], we feel it would be useful to refer to the work of the Council of Europe. Paragraph 49 of the report from the Committee on Social, Health and Family Affairs to the Parliamentary Assembly of the Council of Europe on 21 May 1999 states that:

> "Wishes concerning a given treatment must, however, be assessed from the point of view of their medical validity, as the patient may not expect a doctor to start a treatment that does not comply with the standards of his profession. A patient cannot oblige a doctor to undertake a treatment that is contrary to the rules of medical science or the ethics of the medical profession. Doctors who, for professional reasons, are convinced that they have to go against the written wishes of a patients, must provide a written explanation clarifying the decision, addressed to the patient, his lawyer and/or his family", and paragraph 28 points out that "the purpose of medical intervention is to cure the illness and relieve pain, and not to prolong life at all costs"[15]. Further to this report, on 25 June 1999 the Parliamentary Assembly adopted Recommendation No 1418 (1999) on the protection of human rights and the dignity of the incurably ill and the dying, paragraph 7, iii, of which reads "artificially prolonging the process of death, either by the use of medical means out of proportion to the condition of the patient or by continuing treatment without his consent" and paragraph 8 of which asks the member states "to establish provisions in their internal law assuring the incurably ill and the dying the necessary legal and social protection against the specific dangers and fears with which they may be confronted in the context of this law, and in particular against [...] ii; the risk of having their existence prolonged against their will; [...] v. the risk of having artificial means of survival limited for economic reasons"[16].

In Belgium, the law of 22 August 2002 on patient's rights is therefore in line with a general movement in Europe.

Before this law came into force, doctors had to consider the problem of refraining from providing care for a patient displaying very serious symptoms under the terms of Article 422bis of the Code of Criminal Law, which punishes by a term of imprisonment of between eight days and one year and a fine of between EUR 50 and EUR 500, or just one of these penalties, "anyone who refrains from coming to the assistance of or procuring assistance for a person in grave danger, whether he has observed the situation of this person himself, or this situation is described to him by those requesting his intervention".

---

[14] Such a study would in fact necessarily be incomplete. Let us confine ourselves here to referring, for France and purely as an example, to law No 2005-370 of 22 April 2005 on patients' rights and the end of life and amending the public health code, and to Decree No 2006-119 of 6 February 2006 on the anticipated guidelines provided for by the aforementioned law No 2005-370.

[15] Doc. 8421, 21 May 1999 – Protecting human rights and the dignity of the incurably ill and the dying – Report – Committee on Social, Health and Family Affairs.

[16] Recommendation No 1418 (1999) Official Gazette of the Council of Europe, June 1999

What should be understood by “assistance” in this provision? Jurisprudence and doctrine have often stated in this respect that assistance is due even if it is ineffective[17]; in this sense, a ruling from the Court of Appeal in Brussels on 14 May 1974[18] decided "that all the legal conditions for prevention are met, even if it was demonstrated that the assistance provided for the patient would have proved ineffective, the diagnosis being uncertain and the progress of illness already irreversible”[19].

Under Article 422bis of the Code of Criminal Law, doctors who, even with the consent of their patient or their patient’s family[20] decide not to resuscitate him therefore apparently commit a criminal offence, particularly if the decision has been taken before the heart stops.

Since the law of 22 August 2002 on patient’s rights came into force, the situation has been presented in very different terms: Article 5 of this law in fact states that:

> “The patient is entitled to receive high quality services from the professional practitioner in response to his needs, in respect of his human dignity and his autonomy and without any distinction of any kind whatsoever being made”.

Commenting on this article, Yves-Henri Leleu[21] says that it must be read together with Article 8, § 4 of the same law, which states that “the patient has the right to refuse or withdraw his consent [...] to an intervention”, and stipulates that this “provision is general and refers to all interventions which the patient does not wish to undergo, however vital” and “therefore takes precedence over the legal (and ethical) duty of the doctor to provide assistance (Article 422 bis, Code of Criminal Law)”[22], but immediately qualifies this conclusion:

“Such refusal or withdrawal of consent does not, according to the law, entail the forfeiture of the right to high-quality services in respect of the professional practitioner, as referred to in Article 5. Legal relations between the professional practitioner and the patient do not automatically cease to exist in these circumstances, nor may the practitioner terminate these relations as a matter of course, abandoning the patient to his fate.

In practical terms, this implies, on the one hand an obligation for the practitioner to offer the patient an alternative solution or a transfer to another care institution and, on the other hand, the continuation of the necessary hygiene care”[23].

---

[17] E.g. Philippe Quarré and Pierre Lambeau, “*Homicides et lésions corporelles involontaires*”, in: *Novelles*, Criminal Law, t. IV No 6940: “The offence is established even if the extent of the injuries was such that it was no longer possible, in medical terms, to prevent death”. The length of the period of survival is likewise irrelevant. It suffices “that an intervention appears or must appear to be reasonably necessary, if need be to verify the impossibility of usefully providing assistance” (Brussels, 20 April 1966, Pas. 1967, II, 77)

[18] J.T. 1975, 191

[19] This involved the case of a duty doctor who had not responded to a telephone call from the parents of a sick child calling for an immediate visit at around 6.00 am, but who had promised to visit in the afternoon; the child died before the doctor arrived.

[20] Generally speaking, the consent of the victim does not exclude an offence.

[21] Yves-Henri Leleu, “La loi du 22 août 2002 relative aux droits du patient”, J.T. 2003, p. 649 ff. No 13.

[22] Yves-Henri Leleu, *op.cit.* No 30.

[23] *Ibidem*, No 31

However, it will be noted that this comment does not consider the case where the patient has not expressed any wish either to be resuscitated or not to be resuscitated.

The preparation work relating to the law is a little more explicit: in the comments on Article 8, §1, paragraph 1, the preamble in fact includes the following regarding the term "intervention": "Let us imagine that a professional practitioner wishes to put an end to the course of treatment started. Without the patient's consent, he cannot do this, unless this treatment no longer has any point for the patient"[24]. During the committee stages, the minister often stressed what seems to be a major axis in the law: the primacy of the patient's wishes over those of the practitioner. As regards Article 8, §4, paragraph 4[25], in response to a member of parliament who was proposing an amendment, he stressed the need to respect a clearly expressed wish not to undergo a course of treatment, citing the example "of a women who had decided to end her life and had left a note earnestly requesting not to be resuscitated in the event of failure"[26]; replying to a question from another member of parliament who was upset by this response and who pointed out "that the doctor's obligation to provide the necessary care runs counter to the right to refuse consent. Does the patient's refusal to undergo a particular intervention relieve the doctor of this obligation?", the minister retorted that the text "offers the patient the right to refuse his consent to any intervention which, in all conscience, he does not feel able to undergo"[27]. As regards Article 5, he further declared: "Moreover, the doctor retains his therapeutic freedom: he can decide not to continue a course of medical treatment which he considers futile. It is up to the patient to consult another practitioner if appropriate"[28].

Concluding this examination, it may be admitted that the law on patients' rights and the preparatory work involved indicate:

1. that a patient has the right to refuse any care and that this decision is binding on the doctor, in legal terms;
2. that a doctor has the right not to continue a course of treatment which he considers futile - this implies the possibility, for this doctor, of allocating the patient a "DNR" code – but that he must obtain the consent of the patient or his representative to this. Legal problems will arise if this consent is not obtained.

The second conclusion is not unanimously accepted. According to some members, the outcome of the parliamentary work referred to on page 12, lines 11-12 is that no consent from the patient or his legal representative is required to apply a "DNR" code. However, these same members do feel that consultation with the patient or his legal representative is necessary.

---

[24] *Doc.Parl.* Chamber, 2002, DOC 50-1642/001, p. 24; our underlining. The comment on paragraph 4, first indent (p. 27 of the same preamble) does not repeat this, but is expressed in the terms used by Yves-Henri Leleu.

[25] This paragraph refers to the possibility for the patient to express his wishes in a written document drawn up when he "was still in a position to exercise the rights as established in this law"; this wish, which may be revoked, is therefore expressed in advance and in the event that, when the time comes, the patient is no longer able to express himself; the same line of reasoning must *a fortiori* be applied when the patient expresses his wishes.

[26] *Doc.Parl.* Chamber, 2002, Committee Report, DOC 50-1642/012, p. 80

[27] *Ibidem*, p. 81

[28] *Ibidem*, p. 64

## 5. The deontological framework

The Code of Medical Ethics drawn up by the National Council of the Order of Doctors[29] comprises five provisions on this subject:

**Article 29**, paragraph 2:

> "If the patient refuses an examination or treatment that has been suggested, the doctor may withdraw from his mission under the conditions set out in Article 28, paragraph 2"[30].

**Article 33**:

> "The doctor informs the patient of the diagnosis and the prognosis in time; this also applies in the case of a serious or even fatal prognosis. When the information is provided, the doctor takes account of the patient's aptitude to receive this information and the extent of the information he wishes to receive.
>
> In any case, the doctor ensures that the patient receives adequate subsequent treatment and support. The doctor involves the patient's relatives in this, unless the patient objects to this. At the patient's request, he contacts the people the patient has named."

**Article 95**:

> "Following on from Article 33, the attending physician informs the patient in good time that his life is drawing to a close and of the support that can be provided.
>
> In this context, the doctor takes account of the patient's clinical situation his ability to take the information, his philosophical and religious convictions and the extent of the information he wishes to receive.
>
> When any questions are asked about the end of life, the doctor explains the initiatives that can be taken, such as appointing an authorised representative, filing a refusal to consent to a given intervention and drafting an advance statement on euthanasia.
>
> The doctor draws the attention of his patient to the fact that he is still entitled to palliative care.
>
> The doctor informs the patient, clearly and in good time, of the medical support he is prepared to provide in the final stages of life. The patient must have the time to obtain a second medical opinion.
>
> The attending physician and the patient agree on who should be informed and what they should be told."

**Article 96**:

> "For any intervention in the final stages of life, the doctor must obtain the patient's consent.
>
> He must ensure that this consent is informed, free and independent.
>
> If the doctor feels that a patient is not capable of consenting, he consults the legal representative.

---

[29] This is the version updated on 18 March 2006.

[30] That is "provided that the patient or those around him are warned, care is continued, and all useful information is provided for the doctor succeeding him".

> The attending physician involves under-age patients in decisions concerning the end of life on the basis of the age and maturity of the patient and the nature of the intervention in question. It is advisable to obtain the opinion of a colleague and the nursing team."

**Article 97**:

> "In addition to the duty to provide information and the obligation to obtain consent, the doctor provides the patient with full medical and moral assistance in the final stages of life.
>
> If the doctor does not have sufficient knowledge of how to support a patient in the final stages of life, he obtains the necessary advice and/or calls in a competent colleague for consultation.
>
> Relentlessly prolonging life by technological means should be avoided.
>
> The doctor helps the patient to draw up and keep the declarations referred to in Article 95, paragraph 2.
>
> The doctor abides by commitments made in respect of the patient.
>
> When applying the provisions of this chapter of the Code of Medical Ethics, the doctor ensures that the legal provisions are observed both by him and by the patient."

All these provisions should henceforth be read together with Article 8, § 4, paragraph 1 of the law of 22 August 2002 on patient's rights, since from now on it is the patient who decides, and no longer the doctor.

The National Council of the Order of Doctors has itself adopted a position on this issue. In its opinion of 22 March 2003 on palliative care, euthanasia and other medical decisions concerning the end of life[31] it felt that "stopping or not providing treatment is ethically appropriate if it is scientifically established that there is no longer any hope of any reasonable improvement and that the treatments prolonging life do not increase the comfort of the patient and only cause discomfort and suffering", that "DNR" protocols "are appropriate in all places where these situations regularly occur", but that "the aforementioned protocols cannot be implemented without the prior consent of the duly informed patient or his representative as appointed in accordance with the law of 22 August 2002; if this representative "does not agree that the treatment should be stopped or not administered and asks the doctor to prolong life by technological means", Article 15, § 2 of the law[32] means that "the interests of the patient take precedence over the opinion of the representative" and that "this principle must apply not only for interventions but also as regards stopping or not administering treatment". On this same issue, the National Council in its opinion of 26 July 2003 on the law on patients' rights[33], pointed out that "if the professional practitioner and the representative do not agree on the treatment, the professional practitioner is then free, provided the necessary provisions are

---

[31] National Council Bulletin No 100, June 2003

[32] Article 15, §2: "In the interests of the patient and in order to avoid any threat to his life or any serious effect on his health, the professional practitioner may, if appropriate in the context of a multi-disciplinary consultation, deviate from the decision taken by the person referred to in Articles 12, 13 and 14, § 2. If the decision has been taken by a person referred to in Article 14, § 1, the professional practitioners my only deviate from it to the extent that this person cannot invoke the express wish of the patient.

[33] National Council Bulletin No 101, September 2003

taken to ensure the continuity of care, to stop looking after the patient, just as can be done if the doctor and patient do not agree on this subject".

These positions were expressly confirmed in the opinion of 27 September 2003 on the indication “DNR” in the hospital medical file[34], which repeats that “both medical ethics and the law on patients' rights state that such a decision may not be taken or implemented without the prior consent of the patient duly informed in good time”, adding that “it may be useful to have this consent put down in writing and included in the file”, but that “given that this consent results from a dialogue with the doctor, it offers more guarantees than the written refusal of consent to a given intervention, as defined by Article 8, § 4, paragraph 4 of the law on patients’ rights (as) the text of the law does not state that the written refusal of consent must be established with sufficient knowledge of the facts and in consultation with a doctor”; the National Council adds:

“If the patient or his authorised representative does not agree with the planned treatment strategy and it is not possible to reach an arrangement concerning quality care, the doctor, having consulted with his team and a colleague competent in the field, will advise the patient or his representatives to obtain the opinion of another doctor and meanwhile will provide the care he deems medically and ethically justified. In this respect, it should be noted that it has always been recommended; from the point of view of medical ethics, to include close relatives of a patient who is unable to express his wishes himself as closely as possible in the decision-making process. Settling this representation by law does not in any way alter this ethical precedence. However, it should be remembered that, like the patient himself, the authorised representative may object to consultation with close relatives.”

## 6. Clinical practice

When preparing this opinion, the select commission heard witnesses from four different health care sectors: intensive care units, rest and geriatric care homes, intensive neonatology units and palliative care units. They explained their practices and, more specifically, their usual attitude in the event of a disagreement between the nursing team and the patient or his representative regarding the strategy to be followed.

Despite a very wide variety of situations affecting both the clinical picture (imminent death in an unforeseeable situation, such as a road traffic accident or a birth, death foreseeable for a long time in the case of terminally ill patients, progressive degeneration or degeneration due to age, or permanent vegetative state[35], etc.) and the way in which the patient himself, his relatives or his representative experience them, it is possible to draw common lessons from these testimonies which are summarised below.

---

[34] National Council Bulletin No 102, December 2003.

[35] “ A patient is considered to be in a permanent vegetative state after three months of non-traumatic cerebral lesion and after 12 months of traumatic cerebral lesion, when the probability of an improvement is reduced to a minimum” in: Opinion of the ad hoc working group on “Ethics” of the federal platform of experts set up in accordance with the protocol of 24 May 2004 on “The policy to be adopted with regard to patients suffering from acquired cerebral lesion and in particular with regard to patients in a vegetative state or a state of minimum responsiveness", version of 29 June 2006.

a) Decisions to limit or reduce treatment are not taken by one doctor alone, but following consultation, which may or may not be multidisciplinary, of all members of the nursing team. The treatment strategy and the content of the "DNR" codes are discussed, if possible, with the patient himself, and if the patient is unable to express himself, with his relatives, the purpose of the discussion being to reach agreement. Only if the patient demonstrates by his attitude that he would prefer not to know or if no discussion partner is available will a "DNR" code be applied without the team seeking such agreement.

b) Virtually all disagreements can be resolved if the team takes the time to explain and answer questions. Such explanations call for wide-ranging communication skills and a considerable investment in time in the part of the nursing team. It may also take time for the relatives to admit that the situation is irreversible and that there is no longer any point in administering major treatment; care is continued throughout the period when these talks are taking place.

c) The mission of palliative care units is to make patients for whom no cure or significant improvement in their medical condition may reasonably be hoped for as comfortable as possible. The patient and his family are well informed and know that the situation is hopeless.

The practices implemented in the various palliative care units are not always comparable. Intercurrent disorders (a pulmonary infection, for instance) are treated in certain units, but not in others. The members of the Bioethics Advisory Committee do not feel it is necessary to start an ethical debate on this subject. However, they believe that the patient and his family must be informed of the usual practices in the unit, before the admission of the patient.

Admitting that a member of the family is terminally ill and is to be transferred to a palliative care unit does not mean that their death is considered imminent. When a person dies further to another medical disorder, for which there is usually a treatment, but this treatment has not been administered owing to the hopelessness of the situation, the family may have the impression that the patient has been abandoned to his fate (culpable abstention) if clear agreements have not been reached beforehand, and this can also make the grieving process more difficult.

The Committee stresses how important it is to provide explanations, for the family and the patient, about the time when and reasons why a palliative care unit administers certain treatments, and also to specify why such treatment was not administered at a given time. In the case in point, a frank and open dialogue seems to be the best approach to prevent those around the patient from feeling guilty and reacting negatively to the nursing team.

## 7. Ethical discussion

In principle, medical treatment aims to obtain a therapeutic benefit. However, in certain specific situations, in the lack of any therapeutic benefit for the patient, does such treatment lose its legitimacy and can it be interrupted or not started? Is such treatment synonymous with relentlessly prolonging life by technological means and can it be imposed upon the doctor?

The medical futility of a treatment is a matter for medical assessment, whereas whether or not there is any point to such treatment should in principle be assessed by the patient. In this situation, the doctor is the expert as regards the possibilities offered by medical science and the patient is the expert as regards the situation in which he finds himself[36].

The ethical discussion covers the following aspects: the information provided for the patient or his relatives, the expression of and compliance with their wishes, the professional autonomy of the doctor and the nursing team, the economic point of view. This chapter should be read in the context of a situation or a threat of relentlessly prolonging life by technological means.

### *7.1. Providing information for patient and relatives*

This is settled both by the law on patients' rights[37] and by Article 33 of the code of medical ethics. The diagnosis of a situation of inevitable death often causes despair among patients and their relatives and must be dealt with by the nursing team, who must be trained to do this. The content of the information concerns mainly the diagnosis, the prognosis, the extent of the injuries or the failure of organs and the treatments started or proposed.

To avoid relentlessly prolonging life by technological means, it is important to provide realistic information about what may be expected or not from any treatment administered. The possibilities of improvement in the short term are often overly stressed and too little care is taken to provide accurate information about the expected development in the longer term. It is often not made sufficiently clear to the patient and the family that the treatment proposed can only offer a temporary solution to each of the problems that occur within the short term. This gives rise to false hopes that 'something can be done after all'.

Information meetings about the long-term prognosis are more difficult for doctors because the patient and relatives concentrate on what is happening here and now. Doctors, whether general practitioners or specialists, have to dare to take the initiative to discuss the possibilities for care in the final phase of the illness with the patients in due course and as soon as possible. This presupposes a discussion of the prognosis and possible long-term development, at a time when the patient is still able to express his wishes. The patient will be encouraged to draft or informed of the interest of drafting an advance declaration and appointing a representative.

---

[36] M. Keirse, "Therapeutische verbetenheid en patientenrechten", Tijdschr. voor Geneeskunde, 62, No 12, 2006, p. 883.

[37] Law of 22 August 2002 on patients' rights, Article 8 § 4.

### *7.2. Expressing and respecting the wishes of the patient and relatives*

The right of consent of a patient capable of expressing his wishes, or that of his relatives if this is not the case, must be respected. The legislator[38] has clearly decided that patients capable of expressing their wishes have the final say as regards the consultation on treatment.

The principle of patient autonomy takes the place of the unilateral decision by the doctor.

On the other hand, although many people consider that, ethically speaking, there is no difference between the fact of not starting treatment and that of stopping it if it has already started, experience shows that it is usually far more difficult to explain to a patient or his relatives that there is no point, from a medical point of view, in continuing a treatment and consequently suggesting that it be stopped, than to get them to accept that it will not be started.

In reality, it is no doubt rate for an attending physician to provide practical information on a possible alternative treatment which has not yet been administered, if he feels that this treatment is futile, medically speaking.

Any new proposal put forward by the doctor may maintain the illusion that it is still possible to try something and arouse vain hopes.

However, many of the patients referred to in this opinion are incapable of expressing their wishes. This is the case, in particular of newborn babies, but also for most of those who are legally incapable, who have never had the chance to express their choice regarding the quality of life they would like or the care they are prepared to accept. In clinical terms, the capacity to express one's wishes is a gradual concept and the degree of this capacity has to be assessed with the greatest care. In cases like these, the nursing team will take account of the wishes, preferences and values of the patient as expressed by his relatives or as laid down in an advance statement. In the latter case, a meeting with the confidant appointed by the patient is necessary to ensure that the advance statement is properly interpreted. Consultation with the family doctor is also advisable, given that he is familiar with the patient’s past.

Situations in which decisions about the limitations of treatment have to be taken are characterised by intensive and regular consultation between the nursing team and the patient’s relatives or, more rarely, the patient himself. The literature argues unanimously in favour of a model for consultation or participation in which the relatives are intensively involved in the “DNR” decisions to be taken. An additional objective clearly aims to prepare relatives for the process of grieving and the medical team will make it clear to the relatives that, although partners in the decision-making process, they are in no way responsible for the life or death of the patient and it is the doctor who assumes the final responsibility.

---

[38] *Idem*

### *7.3. Professional autonomy of the doctor and the nursing team*

A doctor cannot be obliged to start or continue futile treatment[39]. For treatment to be medically justified, it must imply a potential therapeutic benefit for the patient. In several medical disciplines, there are practical guidelines for *appropriate* treatment. Where this is possible, these guidelines are underpinned by scientific proof, if not by a consensus (which may be national or international) within the professional group. These practical guidelines are dynamic and are constantly being adapted in line with scientific progress. A nursing team usually develops treatment models or protocols for their practical work situation which they have to follow and from which they may only deviate after consultation and on serious grounds.

Patients or their relatives can ask for all forms of treatment that prolong life without the prospect of therapeutic benefit to be started or continued in spite of everything. Such a request is often formulated because they find it difficult to accept the limits of medicine or they can no longer tolerate their feeling of powerlessness, either due to religious imperatives or because the patient or his relatives have a different assessment of the quality or value of the life remaining to him. The nursing team has to take the time to deal with and be capable of dealing with such reactions in patients or relatives. In most cases, the nursing team will be able to reach agreement with the relatives (or with the patient himself if he is still able to express his wishes) regarding therapeutic acts that may or may not be undertaken, after having provided sufficient explanations about the gravity of the situation and the futility of continuing the treatment. If necessary, it may be acceptable to continue the treatment for some time, even though it makes no medical sense, so as to enable the patient or his relatives to develop a more realistic view of the gravity of the situation and to draw the necessary conclusions.

The initiative of a “DNR” protocol in a particular case is taken by the attending physician, in consultation with various disciplines in the nursing team. Consultation with the relatives provides an opportunity to discuss the decisions to be taken or possible alternatives. In the event of a persistent disagreement between the attending physician and the relatives, the latter will be encouraged to seek the opinion of another doctor in whom they have confidence. The attending physician is obliged to place the entire dossier at the disposal of this third party and to discuss the treatment strategy in detail. If the opinion of the doctor consulted differs from that of the attending physician, it is a good idea to transfer the patient to an identical unit in another hospital.

If the disagreement persists and transfer is impossible, the attending physician can in principle decide to stop the treatment. In the Anglo-Saxon culture, the dispute is brought before the courts. This is not the case in Belgium, and we do not consider it desirable. In the extremely rare cases where it is impossible to reach agreement or the treatment demanded serves no medical purpose, the doctor cannot be obliged to administer it.

---

[39] Eric Gampel, “ Does professional autonomy protect medical futility judgments?”, Bioethics, Vol. 20, No 2, 2006, pp. 92-104; Article 29, paragraph 2 of the code of medical ethics, see above.

### *7.4. Economic point of view*

New treatments that are likely to prolong the patient's life briefly are constantly being proposed, sometimes at a high cost.

Although the doctor has a responsibility towards society and must use the financial resources made available by the community with circumspection, his main duty is that of loyalty to his patient. He cannot therefore decide that a particular treatment does not serve any medical purpose in a given situation because he feels that the treatment in question is too costly.
If patients (present and future) were to have the impression that "DNR" decisions are taken on the basis of economic considerations, this would have a negative impact on the relationship of trust that binds the doctor and the patient. If the State deems that certain treatments are too expensive given the potential therapeutic benefit, then it is up to it to intervene in the first place and explain to the people. This decision cannot be passed along to the level of the personal relationship between doctor and patient.

## 8. Conclusions

In the case of patients suffering from serious chronic illnesses which must be expected to develop unfavourably in a near future, it is advisable to draw a realistic picture of the situation, presenting the possibilities and the difficulties that will arise in the short and the long term. These patients therefore have the possibility of telling their doctor or their confidant of their specific wishes for the end of their life. Certain aspects relating to the limitation or treatment or a "DNR" decision can also be covered.

A decision on limiting treatment or on non-resuscitation must be taken when cardiopulmonary resuscitation or another specific intervention, whether therapeutic or diagnostic, no longer offers any therapeutic benefit for the patient. The concept of the "lack of therapeutic benefit" may refer to the total futility of the treatment from a medical point of view (because there is no reasonable chance of achieving a given physiological objective), or to the fact that the goal in question is pointless for the patient.

The current law and the rules of ethics require that the patient (or his relatives if he is incapable of expressing his wishes) be informed of the medical decision on limiting treatment or allocating a "DNR" code and that his wishes on this matter be respected. From an ethical point of view, the doctor and the nursing team have a duty to try and ensure that this decision is accepted.
In most cases, it is possible to achieve this.

In the extremely rare cases where it is impossible to reach agreement and where the medical act demanded serves no medical purpose, the doctor cannot be obliged to undertake it but has a duty to ensure that the patient continues to receive care.

* * *

**The opinion was prepared by the select commission 2005/2-Bis consisting of:**

| Joint chairpersons | Joint reporters | Members | Member of the Bureau |
|---|---|---|---|
| P. Cosyns | P. Cosyns | P. Beke | P. Schotsmans |
| J. Messinne | J. Messinne | P. Cras | |
| | | M. Dumont | |
| | | E. De Groot | |
| | | E. Eggermont | |
| | | Y. Englert | |
| | | M. Hiele | |
| | | G. Lebeer | |
| | | L. Leunen | |
| | | Th. Locoge | |
| | | H. NyS | |
| | | M.-G. Pinsart | |
| | | R. Rega | |
| | | M. Roelandt | |
| | | G. Rorive | |
| | | | |

| Member of the secretariat |
|---|
| B. Orban |
| |

| Experts interviewed |
|---|
| • Dr Marc De Smet, Head of the palliative care unit at the Virga Jesse Hospital, Hasselt |
| • Pr. Hugo Devlieger, neonatologist, UZ Gasthuisberg, Leuven |
| • Dr Gert Ghijsbrechts, coordinating doctor in a rest and nursing home, member of the "Crataegus" working group at KU Leuven |
| • Dr Jean-Michel Thomas, coordinating doctor in a rest and nursing home and Professor in the department of general medicine at the ULB |
| • Pr Jean-Louis Vincent, head of intensive care unit at Erasme Hospital |
| |

**The working documents of the select commission 2005/2-bis** - the question, personal contributions of the members, minutes of the meetings, documents consulted - are kept on file at the Committee’s Documentation Centre where they are available to be consulted and copied.

The opinion is available to be consulted at www.health.belgium.be/bioeth

* * *