

**Opinion no. 59 of 27 January 2014 on
ethical aspects of the application of the
Law of 28 May 2002 on euthanasia**

Content of the opinion

- The question put to the Committee..... 4
- I. The legal framework – The Law of 28 May 2002 on euthanasia..... 6**
 - 1. Definition of euthanasia and basic principles 6
 - 2. Essential conditions (Article 3, § 1) 7
 - 3. Formal and procedural conditions (Article 3, § 2) 8
 - 4. Advance directive on euthanasia (Article 4) 10
 - 5. Social control of the law: procedure and composition of the Federal Commission for the Control and Evaluation of Euthanasia (CFCE)..... 11
 - 6. Role of pharmacists (Article 3bis) 11
 - 7. Freedom of conscience (Article 14)..... 11
 - 8. Death from natural causes..... 12
- II. Ethical and legal considerations..... 13**
 - A. Institutional ethical policies on the end of life and euthanasia, as defined by the law 13**
 - A.1. **First position:** arguments against institutional policies15
 - a. The purpose and content of the Law of 28 May 2002..... 15
 - b. The conscience clause in (bio)medical law 19
 - c. Therapeutic freedom recognised and guaranteed by the law 22
 - d. Therapeutic freedom as an ethical condition 26
 - e. A duty to refer? 29
 - f. The nature and fundamental meaning of a request for euthanasia, and the appropriate response to it 30
 - g. Conclusion of the first position 31
 - A.2. **Second position:** arguments in favour of institutional policies34
 - a. Ethics, law and conscience..... 34
 - b. Good medical practice, the culture of care and institutional ethics 35
 - c. Human solidarity as a support for patient autonomy 38
 - d. What is the view of these members about the duty of referral? 38
 - e. Conclusion of the second position 40
 - B. “End-of-life clinics”, specialist organisations within or outside institutions42**
- III. Conclusions and recommendations..... 47**
 - A. Points of agreement 47**
 - A.1. Respect for the patient47
 - A.2. Respect for the Law of 28 May 200248
 - A.3. Respect for the doctor’s professional autonomy48
 - A.4. The duty to refer48
 - A.5. Continuity of care.....49

A.6. End-of-life “clinics”	49
B. Points of disagreement	50
B.1. On the first question.....	50
B.2. On the second question	51
[NOT TRANSLATED]	
Annexe 1	53
Synthèse des rapports de la Commission fédérale de contrôle et d'évaluation de l'euthanasie (CFCE).....	53
1. Nombre et répartition des euthanasies.....	54
2. L'euthanasie en pratique	55
3. Diagnostics à l'origine de l'euthanasie.....	55
4. Cas de loin le plus fréquent : demande consciente et décès prévisible à brève échéance.....	56
5. Souffrance constante, insupportable et inapaisable	57
6. Décisions de la CFCE.....	57
7. Résumés et conclusions des cinq premiers rapports de la CFCE.....	58
Annexe 2	60
Clinique de fin de vie ('Levenseindekliniek') aux Pays-Bas.....	60
Annexe 3	63
Exemples de politiques éthiques institutionnelles.....	63
Annexe 4	66
Référence à quelques études concernant la pratique de l'euthanasie	66

The question put to the Committee

On 3 February 2011, Ms Laurette Onkelinx, Federal Minister for Social Affairs and Public Health, addressed a letter to the Advisory Committee on Bioethics, asking two questions:

“Could the Committee therefore consider the following two points from the ethical, social and legal viewpoints:

1. The principle of such a clinic [‘whose sole purpose would be to assist patients at the end of their lives’], which would be intended in particular to enable any patient satisfying the legal requirements to gain access to a medical environment that is not ideologically opposed to the principle of euthanasia?
2. The prohibition by a care institution of any form of euthanasia on its premises, or the setting of conditions for euthanasia in addition to those laid down by the law, in particular in light of the principle of therapeutic freedom?”

On 14 February 2011, Mr Jo Vandeurzen, Flemish Minister for Welfare, Public Health and Family likewise sought the Committee’s opinion: “I therefore wish to ask the Belgian Advisory Committee on Bioethics to issue an opinion on the outlines of a policy on end-of-life practices in care institutions (hospitals and nursing and care homes), in light of the provisions of the law. This opinion should propose solutions to care facilities to help them address this delicate issue in the interaction between patient/user, doctor and institution in a manner that is consistent with patients’ rights, freedom of conscience, quality policy, self-determination and respect for the end of life.”

On 14 April 2011, the Committee then received a new request from Ms Onkelinx, the Federal Minister, “concerning euthanasia for patients who are not terminally ill”. This was prompted by a parliamentary question that had been put to her, and related to “whether it is necessary or desirable to extend the scope of the law”.

The Advisory Committee on Bioethics, at its plenary session on 9 May 2011, found the request admissible and formed a select commission to examine “the ethical aspects of the implementation of the law on euthanasia”. In this context, the questions were formulated by the select commission as follows:

- May a care facility (hospital, nursing and care home, nursing home) **prohibit the practice of euthanasia** (as defined by the Law of 28 May 2002) **on its premises, or add conditions for euthanasia to its regulations in addition to those laid down by the said law?**
- Should **competent clinics or specialist organisations** be created (whose sole purpose would be to assist patients at the end of their lives), which would be intended in particular to enable any patient satisfying the legal requirements to gain access to a medical environment that is not ideologically opposed to the principle of euthanasia?

The members of the Committee decided to respond in a first opinion to the questions directly relating to the ethical problems raised by the application of existing law. The question of 14

April 2011, which looks more to the future, will be the subject of a latter opinion, as the Committee members felt that this issue relates primarily to whether it is appropriate to expand the scope of the law. This involves a wider debate on a different level.

After a presentation of the legal framework established by the Law of 28 May 2002 on euthanasia **(I)**, this Opinion will discuss the ethical and legal considerations concerning, firstly, the institutional policies sometimes developed on access to euthanasia **(II.A)** and secondly, the possibility of creating specialist facilities capable of supporting end-of-life patients **(II.B)**; finally recommendations will be made on the two questions to which this Opinion relates **(III)**.

I. The legal framework – The Law of 28 May 2002 on euthanasia

Euthanasia is the act by which a doctor intentionally puts an end to the life of a patient at the latter's request. The Law of 28 May 2002 allows adult patients who are capable and conscious to make a voluntary, considered and repeated request for euthanasia if they are in a hopeless medical situation and report constant and unbearable physical or psychological suffering that cannot be alleviated and that results from a serious and incurable condition due to accident or illness. The law thus decriminalises the administration of euthanasia, under strict conditions, and describes the procedure to be followed by the doctor who receives such a request.

The most important aspects of the law relate to the definition of euthanasia and its underlying principles, the listed obligations and their implications, advance directives for patients who have lost consciousness, societal supervision of the law, the role of pharmacists, freedom of conscience, the treatment of euthanasia as death from natural causes and the issue of assisted suicide¹.

1. Definition of euthanasia and basic principles

Article 2 of the law contains the definition proposed by the Advisory Committee on Bioethics: euthanasia should be understood as meaning the act performed by a third party who intentionally puts an end to a person's life at the request of that person². The withholding or withdrawal of treatment and the administration of analgesics for pain are not regarded as euthanasia: such actions fall within the scope of medical practice.

The law on euthanasia has hybrid characteristics: though incorporated into the legislative codes in the civil section, in the chapter on medical law, it also has criminal aspects, since it removes euthanasia from the scope of criminal law when it is practised by a doctor in accordance with the specified conditions and procedures. Rather than legalising euthanasia, the law should rather be described as conditionally decriminalising it.

1 The following passages are largely taken from Herremans J., "Mourir dans la dignité. La loi belge relative à l'euthanasie, une réponse légale", *Frontières*, vol. 24, n^{os} 1-2, 2011-2012, pp. 76-79 (section "Eléments fondamentaux de la loi du 28 mai 2002").

For a description of the Law of 28 May 2002, see also Bussche F. and Distelmans W. (edd.), *Een goede dood. 2002-2012: tien jaar 'controversiële' euthanasiewet?*, VUB Press, 2012; Genicot G., *Droit médical et biomédical*, Larcier, 2010, pp. 649-674; Adams M. and Nys H., "Euthanasia in the Low Countries: Comparative Reflections on the Belgian and Dutch Euthanasia Act", in Schotsmans P. and Meulenbergs T. (edd.), *Euthanasia and Palliative Care in the Low Countries*, Leuven, Peeters, 2005, pp. 5-33.

See also *De euthanasie doorgelicht*, Kluwer, 2003; Nys H., *Recht en bio-ethiek. Wegwijs voor mensen in de gezondheidszorg*, Lannoo Campus, 2010, pp. 118-132; Nys H., *De wet op de euthanasie*, Kluwer, 2004; Schamps G. and Van Overstraeten M., "La loi belge relative à l'euthanasie et ses développements", in *Loyauté, justice et vérité. Liber amicorum Henri-D. Bosly*, La Charte, 2009, pp. 337-355; Schamps G., "La fin de vie – soins palliatifs et euthanasie – en droit belge. Situation actuelle et perspectives", Actes du colloque Jacques Cartier, *Fin de vie et mort au XXI^{ème} siècle, Revue générale de droit médical*, 2013, n^o 48, pp. 117-144.

For a detailed discussion predating the introduction of the law, but still just as relevant, see Velaers J., "Het leven, de dood en de grondrechten. Juridische beschouwingen over zelfdoding en euthanasie", in *Over zichzelf beschikken? Juridische en ethische bijdragen over het leven, het lichaam en de dood*, Maklu, 1996, pp. 469-574.

2 See Opinion No. 1 of 12 May 1997 of the Consultative Committee on Bioethics, on the advisability of a legal regulation on euthanasia, point I. (see www.health.belgium.be/bioeth)

Although the Law of 28 May 2002 is founded on respect for the autonomy of the human person, it should be noted that the principle of human autonomy is not absolute in this case. It is not enough for the patient to make a request for euthanasia: it is also necessary for the doctor to conclude, with the patient, that the conditions laid down by the law are satisfied.

2. Essential conditions (Article 3, § 1)

The act of euthanasia must be performed by a doctor: the doctor may not under any circumstances delegate this responsibility, for example to a nurse. The doctor must ensure that the following three essential conditions are all satisfied:

1. the request must be voluntary, considered and repeated, and made independently of any outside pressure; it must come from a patient who is competent, i.e. adult and lucid;
2. the patient must report unbearable physical or psychological suffering;
3. the patient must be in a hopeless medical situation, as a result of a serious and incurable condition due to accident or illness.

First condition: the patient's request

The patient's request is at the heart of the law: euthanasia cannot be said to take place without it. In the law's view, it is therefore incorrect to describe as euthanasia a request that comes from, for example, a family member or anyone other than the patient.

In 2002, the Belgian legislators rejected the possibility of agreeing to a request for euthanasia in the case of minors, other than emancipated minors, a very marginal category. In addition to the lack of consensus on this point during the parliamentary debates, as the law on euthanasia is based on the principle of patient autonomy, the legislators decided in 2002 to confine themselves to the issue of adults. However, it should be noted that the Law of 22 August 2002 on patients' rights has introduced a different notion of "medical majority": a minor who is deemed capable of reasonably evaluating his or her own interests may refuse treatment, even if this refusal leads to the shortening of her or her life (Article 12, § 2).

The law on euthanasia stresses the need for the patient's request to be voluntary and considered in character:

Article 3, § 1: "the request is voluntary, considered and repeated" and "it does not result from external pressure";

Article 3, § 2: "ensure [...] his or her repeated wish";

Article 3, § 3: "... voluntary, considered and repeated character of the request".

Parliament's concern is very clear: euthanasia must not under any circumstances be left open to requests arising from temporary depression, or induced by external considerations.

Patients must also be capable and conscious when they make their request. The question of capacity must be examined, not in the strict legal sense of the concept but as regards patients' ability to understand their medical situation and its implications: this is not just a question of suffering but also and essentially of life and death.

It should be noted that the law confers a right to request euthanasia, not a right to euthanasia.

Second condition: unbearable physical or psychological suffering

This condition is highly subjective: who could be better placed than the patient to judge whether his or her suffering is unbearable? However, that suffering is assessed in dialogue with the doctor, whose primary role, after listening to the patient, is to try to respond to his or her complaints.

Parliament was divided regarding the inclusion of psychological suffering as well as physical suffering. The law resolved this point by recognising that suffering can be analysed from the point of view of both physical pain and psychological suffering. It is sometimes possible to control physical pain while remaining powerless with regard to psychological suffering such as despair, loss of dignity or the sense of having lost all autonomy of movement. The legislators have taken account of this scenario, in which it is impossible to respond adequately to psychological suffering even when physical pain is controlled.

Third condition: a serious and incurable condition

The legislators did not draw up a list of serious and incurable diseases that may give rise to a request for euthanasia. Each case is unique: a person suffering from such a condition may be willing to travel to the very end of the road without wishing the journey to be cut short. Drawing up a list might have created pressure and would have been inconsistent with the legislators' intention of respecting individual choice.

The law refers to a "hopeless medical situation". This cannot be equated with the terminal phase. The debate on this point was thorough. Right up to the final moment, amendments were proposed to introduce the concept of the terminal phase. However, additional conditions were provided for the situation where the doctor believes that death is not foreseeable in the short term (see below). The medical condition may result either from an accident or from illness.

3. Formal and procedural conditions (Article 3, § 2)

To ensure compliance with the essential requirements of the law, the legislators have specified a series of steps that have to be taken: a written request, the attending doctor's duty of information, the consultation of a second or even a third doctor, additional conditions to be satisfied if death is not expected in the short term, an interview with the care team, a possible interview with relatives, and the noting of all information in the patient's medical record.

Written request from the patient

The request must be made in writing. If the patient is not capable of doing this him- or herself, it must be written, in the presence of the doctor, by a third party who may not have a material interest in the patient's death.

The attending doctor's duty of information

The doctor to whom the request is made must first have informed the patient about his or her state of health and life expectancy, and about the treatment possibilities and forms of palliative care available. There is thus an obligation to provide information about palliative care, but not to use it. The law on patients' rights also allows the patient to refuse any offer of care. The same law likewise requires clear, intelligible information to be provided to the patient.

The law on euthanasia also requires the doctor to hold several meetings with the patient to ensure that he or she has persisted in his or her intentions; the patient may withdraw the request at any time. Moreover, the request must result from a choice, made after receiving all the necessary information.

The role of medical consultants

The involvement of a medical consultant, who takes a fresh look at the case, is particularly useful where there is excessive emotional involvement on the part of the attending doctor, who may have been monitoring the patient for years, once a serious and incurable disease has been diagnosed. The consultant must be independent of the therapeutic relationship that has developed between the patient and the doctor to whom the request for euthanasia is made; he or she must also be competent with regard to the medical condition concerned. The consultant must not only read the medical report but also examine the patient, in order to verify firstly the serious and incurable nature of the disease and, secondly, the intolerable and unrelievable character of the physical or psychological suffering.

It has been pointed out that physical or psychological suffering is an element that is highly subjective in nature: in principle, the patient is best placed to assess whether it is unbearable. However, this subjective judgement must be corroborated by an assessment, on the basis of their knowledge and experience, by the professionals, i.e. the attending doctor and the medical consultant, who must answer this question: is it not possible to alleviate the suffering by providing treatment that will combat the pain or address the psychological suffering?

Death not foreseeable in the near future

More stringent requirements are set in the event that the doctor believes that death is not foreseeable in the near future. This situation requires the involvement of a third doctor, i.e. a second medical consultant. The legislators mention this scenario with two objectives in mind:

firstly, to avoid the pitfall of a definition that refers to a terminal phase or terminal patient, and secondly, to gain more time and put in place further safeguards when death can be regarded as remote. The Federal Commission for the Control and Evaluation of Euthanasia believes that if death is expected within days, weeks or months, it can be regarded as foreseeable in the near future³.

If death is not foreseeable in the near future, a period of at least one month must elapse between the written request and euthanasia. A third doctor must be consulted, who must be a specialist in the condition concerned or a psychiatrist; this doctor's role will be to examine in particular the voluntary nature of the request and the presence of suffering that cannot be alleviated.

Meeting with the care team

If there is a healthcare team, the doctor must meet with it or some of its members in order to hear their views. However, the team has no decision-making power.

Meeting with close relatives

The law stipulates that the doctor will discuss the request with the patient's relatives if the patient so desires.

Medical record

All information relating to the euthanasia process must be included in the medical record.

4. Advance directive on euthanasia (Article 4)

The legislation is very restrictive and formalistic regarding the advance directive that any adult or emancipated minor can draw up. This directive must be signed by two witnesses, at least one of whom must not have any material interest in the death of the directive's author. It must have been written within the five years before the patient becomes unable to express his or her wishes. It may be withdrawn or amended at any time.

The doctor may not rely on such a directive unless its author is in a state of irreversible unconsciousness as far as is known to medical science in its current state.

The directive's author may designate one or more trusted individuals who will act as his or her spokesperson(s) when he or she is no longer able to express him- or herself. Such persons are not agents: like the request of a conscious patient, the advance directive has no binding force

³ The Federal Commission for the Control and Evaluation of Euthanasia (CFCE) has produced a brochure for the medical profession: see www.health.belgium.be/euthanasie (publications). Biennial reports to the Legislative Chambers are available on this website; a summary appears in Appendix 1 of this Opinion.

and the doctor may refuse to perform euthanasia (see below: “Freedom of conscience”).

The doctor must also adhere to the following formal and procedural conditions: a second doctor must be consulted, who will examine the medical record and the patient and reach an opinion on whether unconsciousness is irreversible, meet the care team, if any, meet any confidant, and meet any relatives designated by any confidant.

5. Social control of the law: procedure and composition of the Federal Commission for the Control and Evaluation of Euthanasia (CFCE)

Within four working days of the administration of euthanasia, the doctor must make a declaration to the Federal Commission for the Control and Evaluation (henceforth referred to as the CFCE⁴) of the implementation of the law on the euthanasia.

The primary purpose of the CFCE is to ensure that society maintains control of acts of euthanasia. It is therefore required to examine, on the basis of declarations, doctors’ compliance with the conditions laid down by the law. *A priori*, the anonymity of all participants is preserved. Only in the event of doubts and after a simple majority vote in favour of doing so, may the CFCE decide to lift anonymity. Should the CFCE take the view that the essential requirements of the law have not been satisfied, by a vote with a two-thirds majority, the case is referred to the King’s prosecutor. The CFCE also has an evaluatory role, and compiles a report to Parliament on the application of the law every two years.

6. Role of pharmacists (Article 3bis)

Since the introduction of the law in 2002, only one amendment has been made to the original text, at the express request of the pharmacists. By the Law of 10 November 2005, Article 3bis has been inserted into the Law of 28 May 2002. This states that pharmacists are not guilty of an offence if they supply the drugs indicated for euthanasia. It is up to the doctor to specify on the prescription that the drugs will be used in the context of euthanasia. The drugs must be issued by the pharmacist to the doctor in person. It is up to the public authorities to take the necessary measures to ensure the availability of the necessary substances, including in pharmacies outside hospital.

7. Freedom of conscience (Article 14)

The law, which is based on respect for the autonomy and physical integrity of the person wishing to gain access to euthanasia, has stipulated that the same respect must be displayed by the doctor and any other person involved in any way in the euthanasia process.

4 The CFCE is composed of 16 members: eight doctors, four lawyers and four members of the groups affected by the issues of patients with incurable disease. Linguistic parity must be respected, and a pluralist representation: CFCE includes members who do not necessarily favour the decriminalisation of euthanasia.

Article 14 of the law states that no doctor is required to perform euthanasia and no one is required to participate in euthanasia. However, if the consulted doctor refuses for a personal reason arising from his or her personal convictions or for any other reason, he or she is required to inform the patient or confidant in good time, specifying the reasons, and at the request of the patient or confidant must pass on the medical record to another doctor designated by the patient or confidant.

8. Death from natural causes

A person who dies following legal euthanasia is deemed to have died from natural causes, particularly for the purposes of life assurance contracts and the death certificate.

The Committee thought it useful to reproduce (1) a summary of the official figures on declarations recorded since 22 September 2002, the date when the law came into effect (Appendix 1) and (2) references to some studies regarding the practice of euthanasia and the application of the law on euthanasia (Appendix 4).

II. Ethical and legal considerations

A. Institutional ethical policies on the end of life and euthanasia, as defined by the law

May a care facility (hospital, nursing and care home, residential home) prohibit the practice of euthanasia (as defined by the Law of 28 May 2002) on its premises, or add conditions for euthanasia to its regulations in addition to those laid down by the said law?

The legal basis for the issues addressed by this Opinion is created by the *conscience clause* as provided by Article 14 of the Law of 28 May 2002. Under this provision:

"The request and the advance directive as provided for in Articles 3 and 4 of this law are not binding.

***No doctor** is required to perform euthanasia.*

***No other person** is required to participate in euthanasia.*

If the doctor consulted refuses to perform euthanasia, he or she is required to inform the patient or confidant in good time, specifying the reasons. In cases where the refusal is on medical grounds, these must be noted in the patient's medical record.

A doctor who refuses to comply with a request for euthanasia is required, at the request of the patient or confidant, to pass on the patient's medical record to another doctor designated by the patient or confidant." (Emphasis added)

There are several comments to be made on this text. First, it is clear that neither the current request nor the advance directive can be binding. The law does not create a *right to euthanasia* and, in general, the patient cannot compel the doctor to perform acts which are not medically appropriate in his or her case (therapeutic freedom), or are inconsistent with the doctor's personal convictions in the case of actions with significant ethical implications.

This is what the law confirms when it stipulates that no doctor *is required* to perform euthanasia, and that no other person is required to participate in it⁵. This formally expresses the fact that the conditional decriminalisation of euthanasia is accompanied by the granting, to the doctor and other care providers, of a *conscience clause* whereby the law permits them to act in accordance with their own moral or religious convictions. Given that they are entitled to refuse to practise euthanasia, it follows that doctors are authorised, as we have seen, to subject the request to (medical) conditions beyond those stipulated by the law (cf. Art. 3, § 2, first sentence), provided that these conditions do not amount to obfuscation or delaying tactics and that the patient is informed in time.

5 The "other persons" in question are primarily nurses and pharmacists. On the latter, see De Groot E., "Euthanasie en de rol van de apotheker. Heeft een gewetensclausule een absoluut karakter?", *Tijdschrift voor Gezondheidsrecht*, 2006-2007, pp. 324-346, esp. pp. 335-337.

The law seeks to address the *consequences* of the doctor's use of the conscience clause⁶. It firstly states that if the doctor refuses to perform euthanasia, he or she is required to *inform* the patient or confidant *in good time*, specifying the reasons. In cases where the refusal is on medical grounds, these must be noted in the patient's medical record, insofar as they may affect the care subsequently provided. The law then states that a doctor who refuses to comply with a request for euthanasia is required, *at the request of the patient or confidant*, to pass on the patient's medical record *to another doctor designated by the patient or confidant*.

Thus, it seems vital to define more closely the duty with regard to timing imposed on the doctor by the legislation, i.e. the duty to inform the patient *in good time*.

The Committee takes the view that a patient has not been informed in time if he or she meets with a refusal on the part of a doctor – whether based on the policy of the institution to which the doctor is attached or not – when the request for euthanasia is actually made to the practitioner, and at a time when his or her physical condition is such that he or she is no longer able to find another practitioner or institution. The patient should be informed at a point when he or she is still able to make a choice.

A patient who meets with a refusal on the part of the doctor or a prolongation of the procedure could hold both the practitioner and the institution liable for any harm suffered as a consequence⁷. This harm may include a material component (e.g. the cost of subsequent treatment), but more importantly it will have a psychological component: the patient may feel let down if he or she wants euthanasia and is convinced that he or she satisfies the conditions laid down by the law, yet fails to satisfy the stricter conditions set by the institution.

This duty of information is based on the patient's autonomy, right to information and right to a free choice of care provider; these rights may be invoked against both doctor and institution.

When an institution has a corporate policy of not allowing euthanasia or clearly making it difficult, it must – as far as possible, and other than in emergency situations – tell patients this before giving them care. Otherwise, patients who come up against a policy which *de facto* prevents them from obtaining euthanasia or clearly makes the procedure for doing so more onerous are being treated in an improper and harmful manner, which engages the institution's liability.

Two viewpoints have been expressed about whether it is possible for an institution to develop a policy – more or less open and transparent – with regard to euthanasia.

6 See Delbeke E., *Juridische aspecten van zorgverlening aan het levenseinde*, Intersentia, 2012, pp. 208-212, n° 383-389.

7 See also Tack S. and Balthazar T., "Wettelijk kader voor instellingsbeleid in België" in *Palliatieve zorg en euthanasie in België. Evaluatie van de praktijk en de wetten*, Melc Consortium, Brussels, ASP 2011, p. 79.

A.1. First position: arguments against institutional policies

a. The purpose and content of the Law of 28 May 2002

This law does not compel anyone to request, practise or collaborate in euthanasia. It creates a margin of freedom in which the doctor and the patient must confer together, within the privacy of the one-to-one consultation (accompanied by the insights of the care team and family and the vital report of the medical consultant) with a view to reaching, as stipulated by the law (Art. 3, § 2, 1), “the conviction that there is no reasonable alternative in (the) circumstances” for the patient and that his or her request “is entirely voluntary”.

This law, which was introduced by democratic means and which applies to everyone since it is the substantive law in force in our country, was preceded by a thorough and high-quality parliamentary debate. Two years of sustained parliamentary work, mainly in the Senate (hearings, enquiries, consultations, deliberations and amendments, *Doc. Parl.*, Senate sessions 1999-2000 and 2000-2001, no. 2-244), stirred consciences and shed light on grey areas. Belgian legislators introduced an innovative, structural and binding framework to an area previously governed purely by the interpretation of criminal law. Belgium’s openness to euthanasia is rooted in a culture of political pragmatism and relatively high tolerance with regard to bioethical issues. The partial and conditional decriminalisation of the act of euthanasia is in the interests of both patients, whose autonomy is thus recognised, and the medical profession, which is reassured by the change of status of an act previously regarded as criminal into a *medical procedure* – in other words, an act performed by a doctor.

This act, which involves responding to a suffering patient’s request to help him or her to progress with serenity and humanity towards the inevitable end which he or she freely chooses to face, requires one-to-one consultation between patient and doctor – supported, where appropriate, by input from third parties – and is subject to effective *social control*, justified by the seriousness of the act. Nevertheless, euthanasia remains a *medical procedure*, which arises from a free encounter between confidentiality and conscience, to borrow a famous phrase⁸, and which is intended to meet the needs of the patient and dictated by his or her medical condition and by the primacy of his or her decision-making autonomy⁹.

The Law of 28 May 2002 is essentially a *criminal law* text which, as such, deals with a *specifically identified physical person*, namely the doctor faced with a request from a patient. It states that “the doctor who performs euthanasia does not commit an offence”, provided he or she complies with the set conditions and procedure; this is the case whether the doctor is acting on the basis of a current request (Article 3, § 1) or an advance directive (Art. 4, § 2). It is

8 Portes L., *A la recherche d'une éthique médicale*, Paris, Masson, 1964, pp. 159 and 168 : “Every medical act is only, can only be and must only be the free conjunction of trust and conscience” (spoken by the author, then President of the Order of French Physicians, at a conference in 1950).

9 On this see Delbeke E., *Juridische aspecten van zorgverlening aan het levenseinde*, Intersentia, 2012, pp. 204-207, n° 378-380.

essential to keep this point in mind in order to provide a coherent response to questions relating to the role assigned to *care institutions*, at which the legislation is not directed. It is worth recalling that the law has deliberately not amended the Criminal Code, mainly for symbolic reasons, and that the suggestion that euthanasia should be restricted to *cases of necessity* – which would involve an evaluation by a judge on a case-by-case basis of the relevant facts – was also expressly rejected, as was the idea that patients' requests should be submitted for *a priori* approval by a “panel of experts”. These were political and philosophical choices, which were enshrined in the text of the law and hence are now legal requirements.

The aim of the Belgian legislators was to help resolve an acute debate by increasing individuals' power to control the way they bring their life to an end, while at the same time responding to a real social need resulting from the paradoxical situation whereby medical progress enables life to be prolonged without always guaranteeing its *quality*. Since quality of life is essentially a subjective matter, there is virtually no other conceivable solution than to act in accordance with the *wishes of the individual* who is finding life a struggle during his or her last days. Modern medical law was unable to steer the debate on the end of life in a direction different from that taken on patients' rights, as enshrined in the Law of 22 August 2002.

The legal definition of euthanasia (“an act performed by a third party who intentionally puts an end to a person's life at the request of the said person”, Art. 2 of the Law), is narrow, clear and logical, and restates the definition on which consensus was reached within the Advisory Committee on Bioethics from the time of its first Opinion¹⁰. It is immediately added (Art. 3, § 1) that the third party in question must be a *doctor*, as the performance of euthanasia is legally restricted to doctors, which helps to classify it as a medical procedure. For the doctor in question it is therefore a matter of intentionally administering death to another person *at that person's request*. Unlike other attitudes which may be adopted at the end of life, euthanasia involves a *deliberate* act. It is not appropriate to make a distinction between euthanasia and assisted suicide, at least not if the latter takes place in a medical context governed by the same safeguards. Assisted suicide is not formally covered by the law. In practice, cases of assisted suicide are subject to the same prudential rules as euthanasia and are recorded by the CFCE as euthanasia. It could be argued that assisted suicide carries the same moral burden as euthanasia (with the doctor remaining in both cases at the patient's side until his or her death), with the difference that in assisted suicide the doctor makes the medicines available to the patient and does not personally administer them.

It is also important to emphasise the crucial distinction between euthanasia as defined above, and related concepts such as refusal of treatment, discontinuing (or deciding not to commence) medically ineffective treatment and use of continuous deep sedation. Regarding *palliative care*, it should be remembered that there is a broad consensus on the use of narcotics to suppress

¹⁰ In its Opinion no. 1 of 12 May 1997 concerning the advisability of a legal regulation on euthanasia (*Les avis du Comité Consultatif de Bioéthique de Belgique 1996-2000*, De Boeck, 2001, p. 11), the Committee agreed upon the existence of four positions on the advisability of legislating, without selecting one in particular; see also, by extension, Opinion no. 9 of 22 February 1999 concerning active termination of the lives of person unable to express their wishes and Opinion no. 41 of 16 April 2007 on informed consent and “D.N.R.” codes.

pain, and simultaneously consciousness, even if this is expected to shorten the patient's life, provided that there is no intention to end his or her life¹¹. This is moreover a legal and ethical obligation for doctors. Respect for the patient's autonomy means that he or she must be offered *genuine freedom of choice* regarding the treatment to be undertaken or not; if he or she no longer wishes to keep struggling, even to the extent required for palliative care, it is not right to compel him or her to do so¹². The Federal Commission for the Control and Evaluation of Euthanasia has also reached the same conclusion¹³. Ultimately, the "almost simultaneous adoption" of the Laws of 28 May 2002 and 14 June 2002 reveal "the legislators' intention to offer both possibilities in Belgium"¹⁴.

The law on euthanasia allows *the doctor* to subject the request or the decision-making process to additional conditions that he or she deems appropriate¹⁵, which confirms that the doctor has an *individual* freedom and latitude here. This option is a corollary (*a fortiori*) of the conscience clause accorded by the law. It is, according to the terms of the law, a personal matter for the doctor. If the doctor wishes to set additional conditions, he or she must "be transparent to the patient about his or her personal attitude and above all ensure the continuity of the patient's medical care", on the understanding that "if the reason for refusing euthanasia is medical, it must be noted in the patient's medical record, due to the possible future impact that the practitioner's opinion could have".¹⁶

In consequence, members opposed to institutional policies believe that it is out of the question for an institution to simply apply an outright ban on euthanasia, whether by prohibiting the performance of euthanasia on its premises, or by forbidding the doctors and staff it employs to perform or assist in euthanasia, or by banning patients from mentioning or requesting

11 Article 2,2° of the Law of 22 August 2002 on patients' rights defines "healthcare" as "services provided by a professional practitioner with the aim of promoting, determining, conserving, restoring or improving a patient's state of health, or of supporting that patient at the end of life", while Article 11 *bis* states that "every individual should receive from health professionals the most appropriate care aimed at *preventing, listening to, evaluating, taking account of, treating and relieving pain.*" The third major law adopted in 2002 (Law of 14 June 2002 on palliative care) reinforced the legal framework in this regard.

12 On the need to distinguish, on both a theoretical and a practical level, between the approach of euthanasia and that of palliative care, as well as the need for their coexistence, see F. Damas, *La mort choisie. Comprendre l'euthanasie et ses enjeux*, éditions Mardaga, collection Santé en Soi, 2013, p. 117-126. See also the conclusions of Distelmans W., *Euthanasie et soins palliatifs: le modèle belge. Pour le droit à une fin de vie digne*, Le Bord de l'Eau / La Muette, 2012, pp. 219-224.

13 In the "brochure for medical personnel" annexed to the assessment reports, "*the Commission considers that, (...) with regard to the unrelievable character of suffering, it should be borne in mind that the patient has the right to refuse pain relief, or even palliative treatment, for example if such treatment has side effects or involves methods of administration which he or she regards as intolerable. However, the Commission considers that in such cases a thorough discussion between doctor and patient is necessary.*" The Federal Commission for the Control and Evaluation of Euthanasia therefore does not consider it appropriate "to include in the law an obligatory 'palliative filter' whenever euthanasia is requested, or additional consultations if death is not expected in the short term", as "nothing in the declarations examined suggested that it is necessary or desirable to impose on doctors and patients additional constraints to those currently in place, which are already substantial" (first report in 2004 of the Federal Commission for the Control and Evaluation of Euthanasia, covering the period 22/9/2002-31/12/2003, p. 24).

14 Delfosse M.-L., "Euthanasie et intégrité. Enjeux de la loi belge et relation médecin-patient: une réflexion éthique", *Frontières*, 2012, vol. 24, n° 1-2, pp. 105-112, *in casu* p. 111.

15 Article 3, § 2, of the law: "Without prejudice to any additional conditions that the doctor may wish to set for his or her intervention, he or she must, in advance and in all cases (...)" On this point, see Delbeke E., *Juridische aspecten van zorgverlening aan het levenseinde*, *op. cit.*, pp. 168-171, n° 303-305.

16 Leleu Y.-H. and Genicot G., "L'euthanasie en Belgique et aux Pays-Bas. Variations sur le thème de l'autodétermination", *op. cit.*, pp. 30-31, n° 31; and on the same subject, Vansweevelt T., "De euthanasiewet: de ultieme bevestiging van het zelfbeschikkingsrecht of een gecontroleerde keuzevrijheid?", *T. Gez.*, 2003, p. 255.

euthanasia. By “institution” is meant a hospital, residential home or nursing home where a patient is staying who is likely to meet the strict requirements of the Law of 28 May 2002. As has already been pointed out, this law does not create a *right* to euthanasia: it creates a *space for dialogue* in which the suffering patient, who has no prospect of recovery, must be allowed to express his or her request, which must be heard and evaluated by the medical and care personnel, in consultation with the family. Euthanasia is only one of many possible end-of-life options, and remains statistically of marginal significance¹⁷. What is distinctive about it is that, along with assisted suicide, it is the only “medical end-of-life decision” which is initiated by the *patient* and not by the doctor: it means facing death *consciously*, “with open eyes”, and involves an *intentional* and clearly non-trivial act on the part of the practitioner¹⁸. In this respect, euthanasia is clearly distinguishable, for example, from terminal sedation¹⁹.

An institutional policy may consist of dissuading medical personnel as far as possible from performing euthanasia, sometimes under threat of direct or indirect sanctions or even by introducing clauses in employment contracts which require doctors and care workers to comply with the principles and beliefs of the institution; or it may consist of censoring patient demands or making them subject to conditions or “filters” not stipulated by the law, such as mandatory prior palliative care, which is not required by the law²⁰. Studies show that some institutions which set conditions, often in the form of written instructions, in addition to those provided for by the law, *do not (systematically) communicate these* to patients and their families when admitting them. Although doctors who practise at such institutions are often familiar with these guidelines, patients and their families are left in ignorance, and only become aware of them at the point when a request for euthanasia is spontaneously made. Even were such an institutional policy admissible, it would nevertheless be unacceptable for it not to be communicated to the

17 On end-of-life decisions (including euthanasia), see in particular Distelmans W., *Euthanasie et soins palliatifs: le modèle belge. Pour le droit à une fin de vie digne*, Le Bord de l'Eau / La Murette, 2012, pp. 155-165. On the fact that the Law of 28 May 2002 does not introduce a right to euthanasia, but rather a right to *request* but not to insist that it be carried out, see Delbeke E., *Juridische aspecten van zorgverlening aan het levenseinde*, Intersentia, 2012, pp. 207-208, n° 381; Schamps G. and Van Overstraeten M., “La loi relative à l'euthanasie et ses développements”, in *Liber amicorum Henri-D. Bosly*, La Chartre, 2009, p. 345.

18 For a philosophical analysis based around the concepts of (critical) care, patient integrity *and doctor integrity*, and of availability and existential coherence, see Delfosse M.-L., “Euthanasie et intégrité. Enjeux de la loi belge et relation médecin-patient: une réflexion éthique”, *Frontières*, 2012, vol. 24, n° 1-2, pp. 105-112. The author concludes as follows: “The doctor, just like the family members, can only trust the word of the patient who, despite his or her fear of death, seeks it out of a strong and freely forged inner conviction. In such circumstances, respect goes beyond respect for the person’s physical life and becomes respect for the unfathomable mystery of the other person, which is an element in that person’s integrity. Under certain conditions, the law gives this moral duty a binding force which is further accentuated by being turned into a social norm.” (p. 111).

19 On this subject, see in particular Raus K., Sterckx S. and Mortier F., “Continuous Deep Sedation at the End of Life and the ‘Natural Death’ Hypothesis” *Bioethics*, 2012, 26(6):329-36; Sterckx S., Raus K. and Mortier F., *Continuous Sedation at the End of Life. Ethical, Clinical and Legal Perspectives*, Cambridge, 2013.

20 We will be discussing the “institutional policy” here, not the “institutional conscience clause.” The former expression, which corresponds to the Dutch term “*instellingsbeleid*” seems more appropriate, since citing a conscientious objection to the law is an *individual* and not an institutional prerogative, as seems to be widely recognised (see below). For a description of what these policies consist of exactly, see in particular Mortier F., “Ethische aspecten van euthanasie en de toepassing van de wet”, in Bussche F. and Distelmans W. (edd.), *Een goede dood. 2002-2012: tien jaar ‘controversiële’ euthanasiewet?*, VUB Press, 2012, pp. 76-79; Tack S. (2009), “Legal aspects of end-of-life decision policies in healthcare institutions”, *Med. & Law* 28(4):725-738. A team led by J. Lemiengre carried out an in-depth analysis of euthanasia policies in Flemish care institutions: see in particular Lemiengre J. et al. (2008), “How do hospitals deal with euthanasia requests in Flanders (Belgium)? A content analysis of policy documents”, *Patient Education and Counseling* 71 (2008) 293-301; Lemiengre J. et al. (2010), “Impact of Written Ethics Policy on Euthanasia From the Perspective of Physicians and Nurses: A Multiple Case Study in Hospitals”, *AJOB Primary Research*, 1:2, 49-60.

public, in view of the need for *transparency* in connection with a patient's admission to a hospital, residential home or nursing home, in order to fully safeguard the patient's rights²¹.

There are several arguments in support of this position:

b. The conscience clause in (bio)medical law

The existence of a *conscience clause, elevated into an individual right*, is perfectly conceivable. Although the law's philosophical neutrality requires tolerance and kindness to be shown towards patients who are suffering, it also insists that health professionals should be protected by not forcing them to commit an act which goes against their conscience. It is always with reference to the *individual conscience* that this right not to perform – or participate in – a particular act regarded as immoral is presented. The difficulty of placing institutional policies on the same footing is immediately obvious: "a person has a conscience, but not an institution"²².

During the parliamentary debates which preceded the adoption of the Law of 28 May 2002, several amendments were introduced to *extend* the conscience clause provided by Article 14 to include care institutions, but they were all rejected. These debates reveal the lack of political will for such an extension, which is further evidence that Article 14 of the law must be interpreted in the sense advocated here. Parliamentary discussion since the introduction of the law has confirmed this position²³.

Sylvie Tack, who has studied this issue especially closely²⁴, particularly with regard to human rights as guaranteed at the European level²⁵, also considers that institutional policies can only be valid if they do not impede the patient's fundamental right to self-determination, if they are sufficiently transparent and if they are accompanied by reasonable alternatives, such as the patient's transfer to another hospital. Ultimately, there are many arguments to suggest "*that an institutional ban imposed a priori on doctors is contrary to their professional autonomy. From this point of view, care institutions may not impose restrictions on doctors with regard to carrying out these acts, contractual stipulations to this effect are null and void, and doctors*

21 Mortier F., *op. cit.*, p. 78.

22 Bussche F. and Distelmans W., "Waarheen? Naar een netwerk voor een 'waardig levenseinde" in Bussche F. and Distelmans W. (edd.), *Een goede dood. 2002-2012: tien jaar 'controversiële' euthanasiewet?*, VUB Press, 2012, p. 344. These authors make a strong case (pp. 344-346) against institutional policies which are restrictive and disregard patient autonomy.

23 Tack S., "Recht op (uitvoering van) euthanasie? Instellingsbeleid en de professionele autonomie van de arts", *Rev. dr. santé*, 2012-2013, pp. 14-17. The author goes on to comment on the various "doctrinal interpretations" of Article 14, Paragraph 3 of the Law, and in particular that of Tom Goffin (pp. 17-19). See also Delbeke E., *Juridische aspecten van zorgverlening aan het levenseinde*, Intersentia, 2012, p. 216, n° 398.

24 See esp. Tack S., "Recht op (uitvoering van) euthanasie? Instellingsbeleid en de professionele autonomie van de arts", *Rev. dr. santé*, 2012-2013, pp. 7-22 (also published, in an abridged version, in Bussche F. and Distelmans W. (edd.), *Een goede dood. 2002-2012: tien jaar 'controversiële' euthanasiewet?*, *op. cit.*, pp. 125-149). Sylvie Tack's thesis, defended at the University of Ghent on 28 September 2012, relates to *Het ethisch beleid in zorginstellingen: een juridische analyse met focus op levenseindezorg* (for more on this thesis, see also Backx P., "Les hôpitaux n'ont pas le droit d'interdire l'euthanasie", *Le Journal du Médecin*, 9 November 2012, p. 31). See also, previously, Tack S. (2009), "Legal aspects of end-of-life decision policies in healthcare institutions", *Med. & Law* 28(4), pp. 725-738.

25 Tack S. (2011), "Can hospitals prohibit euthanasia? An analysis from a European human rights perspective", *Med & Law* 30(2), pp. 295-306.

have the de facto right to carry out euthanasia within the legal framework"²⁶.

Relatively little attention has been paid to the notion of conscience in law²⁷. Studies focusing on the conscience clause as such are also rare²⁸. Freedom of conscience is based on moral pluralism and the principles of neutrality and secularism²⁹. It is an integral part of positive law, with conscience being understood "*as the value judgment made by the person's practical intelligence. It is not conscience understood as immediate knowledge of internal states or external things, nor the ability of an individual to perceive that he or she exists, thinks or experiences sensations. It is not speculative knowledge or power, but intelligence itself in its function of guiding action. (...) The moral conscience is the value judgement made by the person's practical intelligence about the rights and wrongs of a concrete act. In other words, conscience does not consider what is good or bad in general, but makes a particular judgement, here and now, about a planned action or one that has already been performed*"³⁰.

In positive (bio)medical law, the conscience clause is found in the case of acts (1) *requested by the patient* – as distinct from the usual situation where the patient consents to what the caregivers *propose* – and (2) with a strong ethical component: euthanasia, but also termination of pregnancy and assisted reproduction (and embryo research). The fact that the law expressly provides for such a clause – although it also has far wider applications – for interventions *where the initiative comes from the patient and not the doctor*, is obviously no coincidence. The consequence that necessarily follows from this is that any reference to “an act which is legally required” or “a legal duty” is contradicted here by the texts themselves: none of the above acts is “obligatory” as far as the doctor is concerned. The laws that authorise and regulate these acts do not create a “personal right” for patients that can be invoked against medical personnel³¹. Consequently, the argument that a conscience clause only makes sense as a means of avoiding performing an obligatory act is irrelevant here³².

26 Tack S., "Recht op (uitvoering van) euthanasie? Instellingsbeleid en de professionele autonomie van de arts", *op. cit.*, p. 22.

Original version: "*dat een a priori aan artsen opgelegd instellingsverbod inzake euthanasie strijdig is met hun professionele autonomie. In die redenering mogen zorginstellingen voor de uitvoering van deze handelingen geen beperkingen opleggen aan artsen, zijn contractuele afspraken hierover nietig en bestaat voor artsen hierdoor de facto een recht op uitvoering van euthanasie binnen het wettelijk kader*".

27 With the notable exception of the doctoral thesis of Dominique Lazlo-Fenouillet, *La conscience*, Paris, L.G.D.J., Bibliothèque de droit privé, 1993, vol. 235, 550 pp.

28 See e.g. Montero E., "La loi contre la conscience : réflexions autour de l'objection de conscience", in *Jérusalem, Athènes, Rome. Liber amicorum Xavier Dijon*, Bruylant, 2012, pp. 163-198; Rousset G., "La clause de conscience dans le domaine de la santé, une notion à la croisée des chemins", in Fortier V. and Violla F. (edd.), *La religion dans les établissements de santé*, Bordeaux, Les Etudes Hospitalières, 2013, pp. 289-317; Hiez D., "La clause de conscience ou la conscience source du droit?", in *Libres propos sur les sources du droit. Mélanges en l'honneur de Philippe Jestaz*, Paris, Dalloz, 2006, pp. 209-224.

29 For a general overview including the legal duty of reasonable accommodation, the impact of religious beliefs and the status of convictions of conscience, and comparison of these with the principles of neutrality and secularism and their terms and variations, especially in the public arena, see Maclure J. and Taylor C., *Laïcité & liberté de conscience*, Paris, La Découverte, 2010.

30 Montero E., *op. cit.*, pp. 163-165.

31 This point is clear regarding euthanasia, if only on the basis of Article 14, Paragraph 1 of the Law of 28 May 2002, but it also applies with regard to assisted reproduction, as governed by the Law of 6 July 2007. This position has to be qualified somewhat in relation to abortion, at least during the first twelve weeks of pregnancy, where there is a largely discretionary prerogative on the part of the pregnant woman, who are not asked to *justify* a state of distress which cannot in any case be objectified (see Genicot G., *Droit médical et biomédical*, Larcier, 2010, pp. 546-553).

32 In this sense, and emphasising the usefulness of retaining the conscience clause here, Delbeke E., *Juridische aspecten van zorgverlening aan het levenseinde*, Intersentia, 2012, p. 208, n° 382.

Comparison, from this point of view, between the laws on euthanasia, termination of pregnancy and medically assisted reproduction

Where it is expressly stated, the conscience clause differs in the various legal texts. Under Article 350, Paragraph 2, 6°, of the Criminal Code, derived from the Law of 3 April 1990 on the termination of pregnancy, “no doctor, nurse or medical aid is required to be involved in a termination of pregnancy. The doctor to whom the request is made must inform the person concerned, on the first visit, of his or her refusal to take such action”. This wording clearly refers to an *individual* position on the part of the caregiver to whom the request is made. Furthermore it may be assumed, with regard to the termination of pregnancy, that it would no longer be acceptable in our society for the *possibility of having an abortion* not to be guaranteed. It should be noted that in many respects, the structure of the conditional decriminalisation of abortion has been used as a technical model for that of euthanasia³³.

The situation is different with regard to medically assisted reproduction. Article 5 of the Law of 6 July 2007 is particularly explicit on this point:

“Fertility clinics shall display the utmost transparency about their options regarding access to treatment; they are free to invoke the conscience clause with respect to requests made to them.

Fertility clinics must notify the requesting party or parties of their refusal to comply with the request within a month of the decision of the consulted doctor.

This refusal must be expressed in writing and must indicate:

- 1. either the medical grounds for the refusal;*
- 2. or the fact that the conscience clause for which provision is made in Paragraph 1 of this article is being invoked;*
- 3. and, where the requesting party or parties have expressed interest, the contact details of another fertility clinic that they can contact.”*

It can immediately be seen that here – the only place where the expression “conscience clause” is actually used in the law, at least in the (bio)medical field – this clause is granted to *fertility clinics*. They clearly derive from it the freedom to develop an “institutional policy” which must be transparent and respectful of the prospective parents, but which in other respects may therefore be the product of *the institution* and not just of one doctor in particular. This should not be seen as recognition of the concept of “institutional conscience”, but rather a kind of linguistic shortcut which indicates that, under this law, it is the *fertility clinic itself* with which the prospective parents enter into an agreement, from the start of the process of medically assisted reproduction through to embryo transfer or insemination of gametes (Art. 7, 13 and 42 of the Law of 6 July 2007). In any case, the conclusion seems clear: where the legislators intend to give *a health institution* the right to invoke the “conscience clause”, they do so expressly.

³³ Genicot G., *op. cit.*, p. 650.

They do not do so in the Law of 28 May 2002 on euthanasia, and it follows that “things should not be read into Article 14, Paragraph 3 of (this law) which are not there. Healthcare institutions cannot therefore derive a right to conscientious objection from the law on euthanasia”³⁴.

c. Therapeutic freedom recognised and guaranteed by the law

Doctors in Belgium enjoy legal recognition of their therapeutic freedom. Under Article 11, Paragraph 1 of Royal Decree no. 78 of 10 November 1967 on the exercise of the healthcare professions³⁵, practitioners – starting of course with doctors – may not be subject to regulatory limitations on their choice of means of implementation, whether for making a diagnosis or for initiating and carrying out a treatment³⁶.

The scope of this provision relates to the professional status of the people concerned, i.e. the practitioners, and not to the acts they perform. Practitioners have freedom not only of thought in their work (i.e. the freedom to engage in intellectual reasoning of a medical nature arising from the case of their patient), but also and above all freedom from limitations as to the means they use, especially in making a diagnosis and implementing treatment, in order to ensure the patient optimal care³⁷.

In terms of professional practice, this right is upheld by Article 36 of the Code of Medical Ethics, which states: “*The doctor has diagnostic and therapeutic freedom*”.

Granting this freedom to doctors allows – but also compels – them to give the best care to their patients, because as Article 3 of the Code of Medical Ethics stresses, “*The exercise of the medical profession is an eminently humanitarian mission; the doctor cares, in all circumstances, for the health of individuals and of the community. To accomplish this mission, the doctor must, whatever the branch of medical practice that he or she practises, be fully qualified and remain respectful of the human person.*”

The Law of 22 August 2002 on patients’ rights enshrines this obligation for doctors to deliver quality care (Article 5). A doctor who is accountable to the patient in this way, on pain of liability for negligence, cannot therefore be forced by his or her employer (the hospital or one of its medical bodies) to adopt an approach which conflicts with this obligation³⁸.

It may also be asked whether, in such a situation, the hospital’s own personal liability would not

34 Tack S., “Recht op (uitvoering van) euthanasie? Instellingsbeleid en de professionele autonomie van de arts”, *Rev. dr. santé*, 2012-2013, p. 19.

35 A numbered Royal Decree has the same value as a law and can only be modified or repealed by a law.

36 See Goffin T., *De professionele autonomie van de arts*, Die Keure, 2011, no. 276 ff.; Genicot G., *Droit médical et biomédical*, Larcier, 2010, pp. 380 ff, not. p. 385; Nys H. and Goffin T., “Recente ontwikkelingen met betrekking tot de autonomie van arts en patiënt”, in *Medisch recht*, Nys H. and Callens S. (edd.), Die Keure, Themis, 2011, vol. 63, pp. 41 ff.

37 Leurquin X. and Kaiser M., “La liberté diagnostique et thérapeutique : un principe juridique à soigner...”, in *Liber amicorum Michel Melchior*, Anthemis, 2010, p. 819.

38 Tack S., “Recht op (uitvoering van) euthanasie ? Instellingsbeleid en de professionele autonomie van de arts”, *Rev. dr. santé*, 2012-2013, not. p. 10, n° 16.

be engaged, not only towards the doctor, but also towards the patient to whom access to optimal care – in this case to the procedure for euthanasia – has been wrongfully restricted or prohibited³⁹.

This important principle is also recalled in the Coordinated Law of 14 July 1994 on health insurance and benefits (the INAMI law), Article 73, § 1 of which states that “*The doctor (...) shall assess the treatment given to the patient according to his or her conscience and in full liberty.*”

Compliance with the principle of therapeutic freedom is ensured by the fact that any provision in an agreement or regulation that is inconsistent with it is null and void. Article 12 of Royal Decree no. 78 states that “*In agreements entered into by practitioners, clauses that undermine the freedom of choice bestowed by Article 11 shall be deemed to be non-existent*”. The hospitals that employ doctors are also bound to respect this freedom held by doctors by the law on hospitals and on other care institutions, coordinated on 10 July 2008; see Article 144 § 1: “*(...) the general regulations may not contain provisions that would undermine the professional autonomy of the individual hospital doctor in terms of making a diagnosis or carrying out treatment.*”

The obligation to uphold therapeutic freedom is restated in Articles 169 and 174 of the Code of Medical Ethics.

Finally, while hospitals cannot restrict this individual right of the doctor, medical organisations cannot do so either. French jurisprudence has shown this with regard to the voluntary termination of pregnancy: a head of a service may invoke his or her conscience clause, but may not require the same attitude on the part of his or her colleagues, on pain of liability for undermining their professional autonomy⁴⁰.

The above provisions apply to all end-of-life medical decisions: initiation of pain relief treatment which may shorten the patient’s life, continuous deep sedation and euthanasia. Thus a care institution may not impose limitations on doctors in this regard, since these are options covered by their *therapeutic freedom*⁴¹. It is also not allowed to seek the prior opinion of the hospital ethics committee on an end-of-life course of treatment; however, such an opinion, which is in any case not binding, may be sought by the doctor. In the absence of any exception in this regard in the Law of 28 May 2002, the principle must be adhered to that is established in Article 11 of Royal Decree no. 78 of 10 November 1967 on the exercise of the healthcare professions, which enshrines the doctor’s right to therapeutic freedom with respect to *all medical procedures*, including euthanasia, especially as the Law of 28 May 2002 does not

39 Leurquin X. and Kaiser M., *op. cit.*, p. 912.

40 See the jurisprudence cited by Haoulia N., “La clause de conscience des professionnels de santé : étude comparée des jurisprudences constitutionnelles américaines et françaises”, in *Santé, Religion et Laïcité* n° 13, Les Etudes Hospitalières, September 2011, pp. 280-281.

41 Delbeke E., *op. cit.*, p. 545, n° 981. As Tom Goffin explained, particularly during his appearance before the select commission, if euthanasia is regarded as a *medical treatment* – which is obviously the case in the eyes of members supporting the position developed here – this implies that institutions *cannot* impose binding instructions in this regard, since to do so would limit doctors’ therapeutic freedom.

contain any provision concerning institutions, for whom the text is not intended, and no legal standard authorises them to ban or set conditions for euthanasia.⁴²

The recognition of this therapeutic freedom with regard to euthanasia is challenged by two types of argument: firstly, that euthanasia is not a medical act, and thus that therapeutic freedom does not apply to it; and secondly, that the terms used in Article 11 of Royal Decree no. 78, which refer to Article 2, § 1, Paragraph 2 of the same decree, when taken together can be seen to exclude euthanasia.

The authors who support this position describe euthanasia as a medical act *sui generis* or *in extenso*⁴³. This is because, in their view, such an act has no therapeutic purpose or is not a therapy, and the legal framework for it established by the Law of 28 May 2002 makes it a distinctive type of act.

This position is disputed, in particular on the grounds that the legislators' decision to issue a specific law setting out the conditions for decriminalising this act is neither new nor innovative. A similar approach had already been used to deal with other medical acts implying societal choices, such as the Law of 3 April 1990 on the voluntary termination of pregnancy, the Law of 13 June 1986 on the removal and transplantation of organs, the Law of 6 July 2007 on medically assisted reproduction, and finally the Law of 7 May 2004 on experiments on the human person. At the very least, euthanasia is an act which belongs to the healing arts, and this is sufficient to ensure that doctors' therapeutic freedom should be recognised⁴⁴.

Other arguments also support the classification of euthanasia as a medical act: thus the law entrusts this act – which is decriminalised – to doctors only; it was regarded as such during the parliamentary preparatory work, and may be thought of as a treatment given at the request of the patient; and finally, the doctor assumes responsibility for it under the same legal conditions as for all other acts that he or she performs.⁴⁵

Moreover, euthanasia should not be reduced to the mere performance of the lethal act: it must be preceded by a diagnosis by the doctor relating in particular to the patient's medical condition, i.e. an assessment of the patient's health, which belongs exclusively to the medical domain. The doctor must also note everything which he or she has done in the patient's record.

Finally, the choice of the terms used in Articles 11 and 2, § 1 of Royal Decree no. 78 is not decisive: in addition to the fact that this Royal Decree indicates in general terms the "means" to

42 Tack S., "Recht op (uitvoering van) euthanasie? Instellingsbeleid en de professionele autonomie van de arts", *Rev. dr. santé*, 2012-2013, p. 19. Analysing the legitimacy of institutional policies in light of possible justifications for limiting doctors' professional autonomy (pp. 10-14), the author concludes that at the very least an absolute ban on euthanasia violates the principle of professional autonomy and is therefore inadmissible.

43 Nys H., "Euthanasie en therapeutische vrijheid", *Acta Hosp.*, 2002-2, pp. 58-60; Nys H., "Euthanasie is geen medische handeling", *Acta Hosp.*, 1999-4, pp. 71-72; Goffin T., *De professionele autonomie van de arts*, Die Keure, 2011, pp. 27 ff, esp. nos 81 and 203.

44 Goffin T., *op. cit.*, n° 70 and n° 87.

45 Delbeke E., *op. cit.*, pp. 265-288, n° 479-518; Genicot, G., *Droit médical et biomédical*, Larcier, 2010, p. 672.

be used, which is not incompatible with the euthanasia procedure, the term “treatment” which is also used is one that long predates the law on euthanasia and therefore cannot be reinterpreted. On the other hand, the legislators have not modified Article 11 since 2002 in order to exclude euthanasia from its scope of application, despite having the powers to do so.

In any case, euthanasia falls at least *de facto* within what is normally regarded as “medical activity”. The National Council of the College of Physicians also gave several recommendations in an important and argued opinion of 22 March 2003 (on palliative care, euthanasia and other medical decisions relating to the end of life)⁴⁶.

Finally, in order to override doctors’ therapeutic freedom, some institutions argue that they are not obliged to include euthanasia in the care they offer⁴⁷. They rely on the fact that no accreditation standard is applicable to euthanasia. This position, though correct in the sense that the Law of 28 May 2002 does not allow patients to claim a right to euthanasia, wrongly disregards the legal recognition of euthanasia. Euthanasia may be performed either in a hospital or in a care home, and may not be prohibited there⁴⁸.

Even institutions that claim a particular philosophical orientation (known in anti-discrimination legislation as *institutions de tendance*), they may not penalise a doctor (e.g. by sacking him or her) for exercising his or her right to therapeutic freedom. The doctor may not be regarded as showing disloyalty to the institution for performing an act carried out *within the legal conditions* and covered by professional secrecy. The institution may not use its philosophical orientation as grounds for infringing the legal rights of the patient and doctor; in the final analysis, it is the *doctor’s conscience* that must guide the decision that he or she makes about the care provided to the patient.

The legislators have therefore shown balance, preserving the dynamic of the patient-doctor partnership by respecting both the patient’s decision about his or her own life and the doctor’s conscience. If we seek (as an institution, colleague or third party) to force a doctor to perform this act, the doctor can invoke the conscience clause; if we wish to ban a doctor from performing it, the doctor may invoke his or her therapeutic freedom.

Allowing an institution, and moreover one which is an employer, to interfere in this relationship could severely upset the acknowledged autonomy of the care relationship between doctor and patient, with all the risks of abuses that this entails. An institution would thus be able to impose the manner of care provision on its practitioners, for example on economic grounds.

This is also the conclusion of Evelien Delbeke, who argues that an institution may not prohibit a doctor from performing euthanasia if the material and procedural requirements of the law are

46 Available at <http://www.ordomedic.be/fr/avis>.

47 Goffin T., *op. cit.*, n° 83 ff. and n° 95 ff.

48 Vansweevelt T., “De euthanasie : de ultieme bevestiging van het zelfbeschikkingsrecht of een gecontroleerde keuzevrijheid?”, *Rev. dr. santé*, 2003, pp. 268 ff.; Tack S., *op. cit.*, n° 53; Goffin T., *op. cit.*, n° 116, who criticises this argument which is also put forward by J. Ter Heerdt.

satisfied: euthanasia, although it has its own normative social framework within which the doctor must act according to the usual standards of professional diligence, and although it is subject to more stringent requirements than other treatments, remains a medical procedure, since its execution is *restricted to doctors*, who alone are able to assess whether the conditions are satisfied. Euthanasia therefore falls within the doctor's therapeutic freedom, which is protected by law. This implies that restrictive guidelines may not be imposed on doctors in this regard, and that doctors cannot be penalised in any way for taking a legally justified end-of-life decision. These principles also hold true for all end-of-life medical decisions⁴⁹.

d. Therapeutic freedom as an ethical condition

The process of euthanasia is governed by the *one-to-one relationship* between doctor and patient, and the fact that other people can or should be consulted, starting with a second doctor, does not alter the strictly *interpersonal* nature of the euthanasia process. It is the *doctor* who must ensure that the patient's request is made voluntarily, after due reflection, and repeatedly, and is not the result of external pressure; who must establish the existence of a medical situation which is hopeless, and of constant physical or psychological suffering which is unbearable and unrelievable; who must inform the patient about his or her state of health and life expectancy, and engage in dialogue with him or her about the request for euthanasia and discuss the treatment options which are still possible, as well as the possibilities and consequences of palliative care; and who must verify that the patient is continuing to suffer physically or psychologically, and that his or her wish for euthanasia is repeated. In short, it is the *doctor* who is required to conduct "several conversations with the patient, at intervals of a reasonable length bearing in mind developments in the patient's state of health" in order to "arrive, with the patient, at the conviction that there is no reasonable alternative solution in the circumstances, and that the patient's request is entirely voluntary" (Art. 3, § 2, 1° and 2° of the Law of 28 May 2002).

The institutional policies which are under discussion here threaten the freedom (if not the right) of self-determination with regard to one's life. This freedom can be seen as comparable with the freedom of expression, the fundamental importance of which is attested to in our democratic and pluralistic legal system by the number of provisions – at both national and supranational level – that guarantee and protect it against all forms of threat from any kind of institutionalised power.

The possibility for the practitioner of invoking a conscience clause against the patient's wish for his or her suffering to be ended by bringing his or her life to an end represents a theoretical threat to the effective exercise of each person's right of self-determination with regard to his or her life. It is theoretical, as this threat would only be insurmountable if all medical practitioners were to invoke such a clause. Such an outcome can only be imagined in practice if the State

49 Delbeke E., *Juridische aspecten van zorgverlening aan het levenseinde*, Intersentia, 2012, pp. 204-207, n° 378-380, and pp. 216-217, n° 398. For a presentation in summary form, see Delbeke E., "Juridische aspecten van zorgverlening aan het levenseinde", *Rev. dr. santé*, 2011-2012, pp. 345-355.

were to prohibit all doctors from exercising their free will and use all possible means to curb resistance. This theoretical impasse resulting from the possibility of universal adoption of the conscience clause by the entire medical profession – which would, incidentally, be similar to an “institutional conscience clause” – is highly problematic on an ethical level; it could even be argued that it would be completely unethical. From an ethical point of view, even a practitioner who refuses euthanasia and refuses at the same time to refer the patient to a colleague, for fear that he or she will be more amenable to the request, can be seen as desiring a social world that is ideologically monolithic and devoid of democracy and ethics. Such a position is obviously based on a definition of ethics as a collective response to moral dilemmas or to a practical impasse (to use the phrase of Ricoeur⁵⁰); a response which potentially – and this word is important, because of course more or less immediate agreement may be reached – involves differing views on the situation. Ethics presupposes this unavoidable possibility of a disagreement in principle.

The medical relationship is one governed by ethics, where two consciences meet and potentially enter into conflict: those of the patient and the doctor. The principle of the individual conscience clause can be accepted essentially because its exercise is never a foregone conclusion, and because the patient’s right can hence theoretically be satisfied “somewhere”. The doctor’s decision results in principle from his or her desire to understand the patient’s motives and to compare them with his or her own, and from the act of weighing up the different motives brought into play. This is definitely a situation of ethical reasoning. In the course of the discussion, it is possible that the practitioner may revise his or her initial judgement; one of the doctors who appeared before the select commission testified to having gone through such a process. No doctor would be likely to reject such a conception of the profession and of the relationship, understood in this light, between doctor and patient.

A prohibitive institutional policy would contradict this conception. The doctor confronted with such a policy loses his or her therapeutic freedom, the medical relationship loses its ethical character and its humane foundation of trust, and the patient loses the opportunity to be heard by an interlocutor with whom he or she seeks to understand and determine his or her own destiny in a meaningful fashion and in an atmosphere of trust.

In principle, the idea that a conscientious objection could be imposed on a doctor externally by any institution with which he or she was unable to reach a compromise, is frankly fairly disturbing. It amounts to placing the doctor in a position diametrically opposed to the situation described above, a position of submission that is incompatible with the very notion of conscience. This is where the parallel with freedom of expression seems quite telling. When dominated by institutional policies, the medical relationship is no longer and can no longer be one governed by ethical considerations: thoughtfulness, debate and deliberation no longer have any part to play in it. It is now inevitably one-way only; the patient’s point of view becomes irrelevant, the power of the doctor – or rather of the institution of which he or she is now

50 Ricoeur P., *Soi-même comme un autre*, Ed. du Seuil, Paris, 1990, p 201.

merely a tool – is exercised without opposition. This could undermine efforts to establish a participatory democracy within healthcare institutions that includes caregivers and patients. It is also clear that in such a model, it is futile for the patient to set up a dialogue between his or her reasons and those behind the conscience with which he is dealing, and whose sympathy he seeks. And in this case, his or her right is no longer guaranteed because with the end of the possibility of ethical exploration, the spectre of an uncompromising obligation arises. To put it another way, if an institutional conscience clause were to be approved, the individual clause would immediately be called into question: the latter is only possible if the former is rejected.

Some contend that the medical relationship can no longer be reduced to the one-to-one patient-doctor consultation, suggesting that when therapeutic decisions are no longer taken at this level but at a collective level, then the same goes for the response to a request for euthanasia, and that in the final analysis, the institutional level is acceptable as it is no different in nature from any other form of community.

This line of argument is based on a serious confusion of meaning and moral consequences between “institution” and “ethical community”. In the social and technical conditions under which it takes place, the practice of hospital medicine is certainly collective, and the ethical reflection that accompanies it is so too. The practice of medicine is usually shaped by collective deliberation, and demonstrates the strength of ethical culture in care institutions. Ultimately, though, doctors retain their independence of thought and action and full responsibility. And if various motivations, especially economic ones, impede autonomy and responsibility, doctors generally complain, citing these very principles. The ethical approach described above to the medical relationship, in the theoretical form of the one-to-one patient-doctor consultation, is therefore fully transposable to an ethical community, while the latter can never replace the individual practitioner in the relationship that the practitioner ultimately forms with the patient, especially in areas such as those at issue here. This argument forms the basis for the advisory character of any clinical ethics committee. It has been agreed ever since such committees – institutional bodies – were first set up, that their role is to issue non-binding opinions, leaving the individual practitioner his or her full responsibility in daily clinical practice.

The clinical institution, with its power of imposing its policies as an employer, cannot be equated to an ethical community, lest roles be confused. It is ultimately up to the individual doctor to decide whether to perform euthanasia or not. Bodies such as healthcare institutions are certainly supposed to be a *crucible* where questions are asked and ethical discussion takes place, but they are not supposed to *produce their own* ethical standards, which would complicate or indeed paralyse the exercise of legally acknowledged rights. Besides the fact that the very notion of “conscience” refers to personal judgement and values, and thus *by definition* to an individual, not an institution, it is essential for doctors not to be subservient to an institutional culture that is not subject to ethical and legal rules (particularly in terms of medical liability), and which can therefore interfere with the practitioner’s moral intuition. Doctors must be able to defend the legitimacy of the therapeutic choices which are allowed them by their *therapeutic freedom* within the rules of their profession, as this freedom guarantees the bond

of trust between them and their patients.

e. A duty to refer?

It will be recalled that the law is intended to govern the *consequences* of the doctor's invocation of the conscience clause⁵¹. It first of all states that if the doctor refuses to perform euthanasia, he or she is required to inform the patient or confidant *in good time*, stating the grounds for refusal. If the refusal is on medical grounds, this must be noted in the patient's medical record, insofar as it might affect his or her subsequent treatment. It then states that a doctor who refuses to comply with a request for euthanasia is required, *at the request of the patient or confidant*, to pass on the patient's medical record *to the doctor designated by the latter or by the confidant*. It is thus up to the patient and his or her family to seek out another doctor who is likely to listen to the request and travel down this road with him or her. This is an onerous process for a patient who is already seriously weakened and an exhausted family.

To ensure that patients are listened to more attentively and to optimise the care they receive, an extension of Article 14 seems desirable: a doctor who invokes the conscience clause should be under an *obligation* to refer the patient to a colleague, without waiting for another doctor to be designated by the patient. This addition, which is quite widely supported, has recently formed the basis of two legislative proposals. The first proposal⁵² is to replace the last paragraph of Article 14 of the Law of 28 May 2002 with the following wording: "*If the consulted doctor refuses to comply with a request for euthanasia for non-medical reasons, or has ethical objections to euthanasia, the social service of the institution shall communicate to the patient or confidant the name of a doctor in the institution or, if necessary, a doctor from outside it, who will comply with the request or advance directive. A doctor who refuses to comply with a request for euthanasia shall pass on the patient's medical record to the doctor mentioned in the preceding paragraph.*" Another proposal⁵³ suggests that Article 14 should be left unchanged, but that an extra paragraph should be added to it as follows: "*If no doctor has been designated by the patient or his/her confidant, the doctor who refuses to comply with a request for euthanasia shall transfer the medical record to another doctor in order to ensure continuity of care*".

It is not necessary to comment on these proposals here. However, we can observe that, according to the members who support the position outlined here, the obligation to refer the patient should be approved and enshrined in law. They believe it is perfectly compatible with the conscience clause that the individual practitioner is free to invoke, and represents an application of the well-established principle of *continuity of care*. It should be recalled that Article 5 of the Law of 22 August 2002 on the rights of the patient requires patients to receive

51 See Delbeke E., *Juridische aspecten van zorgverlening aan het levenseinde*, Intersentia, 2012, pp. 208-212, n° 383-389.

52 Bill amending the Law of 28 May 2002 on euthanasia, introducing an obligation for doctors who refuse to perform euthanasia to refer the patient to a colleague, *Doc. parl.*, Sénat, 2011-2012, 5 October 2012, n° 5-1798/1.

53 *Doc. parl.*, Sénat, 2011-2012, 9 May 2012, n° 5-1611/1. Other bills with the same purpose have been introduced recently.

from all care personnel “quality services that answer to their needs and respect their human dignity and autonomy, and without any discrimination whatsoever,” and that Article 8 § 1 of Royal Decree No. 78 of 10 November 1967 on the exercise of the healthcare professions states that practitioners “shall not knowingly and without lawful justification break off current treatment without first taking all steps to ensure continuity of care by another practitioner with the same legal qualification. Continuity of care also includes palliative care and pain relief.”

The obligation to refer the patient in distress to a colleague willing to take consider the request for euthanasia, and to follow up on it if the legal requirements are satisfied, is likely to diminish the desire expressed by some for “end-of-life clinics” to be introduced, a suggestion concerning which some reservations have been raised (see below, II.B). Properly formulated, it avoids the pitfall of “moral complicity” that would be faced by the doctor who, on grounds of conscience, rejects the idea of euthanasia but is legally obliged to refer the patient to one of his or her colleagues whom he or she knows does not share the same objections, and will carry out the act if the legal conditions are satisfied. Moreover, in light of the principle of proportionality, the idea of “moral complicity is of little account compared with a distressed patient; the first concern should be to reassure and relieve the latter, which involves first listening properly to the request for euthanasia.

Such a referral obligation, though certainly desirable, will in any case need to be applied with caution, since the purpose of euthanasia is to allow the person who requests it to die in peace. The referral obligation should help ensure the achievement of this goal.

f. The nature and fundamental meaning of a request for euthanasia, and the appropriate response to it

In the view many expert observers of the Law of 28 May 2002, its advent and its implementation, institutional policies should definitely not be defined, whereas the need for an individual conscience clause is obvious to everyone⁵⁴. The foundation of the Law of 28 May

54 This is explained by the desire not to tarnish the “beautiful area of freedom” opened up in our country by the Law of 28 May 2002, on whose “essential principles” it is not “accept(able) to go back” as “this would be an insult to the men and women who have opted for this chosen death, to the relatives who have accompanied them up to the final moment, and to the doctors and care teams who have performed this ultimate act of humanity.” “The fact that this law does not compel anyone to request euthanasia or to participate in it (...) does not seem important” in the eyes of those who continue to oppose it, who appear to demonstrate a desire to “return to the time when a particular ethical position was imposed on those who did not share it, and when a doctor who agreed to listen to a request for euthanasia and to perform this ultimate act of fraternity might be prosecuted for murder.” It is important to state emphatically that “freed from the taboo on euthanasia, the doctor-patient dialogue has gained in clarity and authenticity. Provided, of course, that caregivers do not turn a deaf ear when patients express a request to die” and “that a society that permits and oversees euthanasia strengthens the ties that make it beautiful and grows by promoting respect and freedom, without imposing in any way” (Collectif, “Loi sur l’euthanasie : heureux anniversaire!”, *La Libre*, 16-17 June 2012, pp. 60-61).

In his work *La mort choisie. Comprendre l’euthanasie et ses enjeux*, François Damas, an intensive care doctor, writes with particular reference to the Law of 28 May 2002 and end-of-life support: “Euthanasia is (...) a prepared and planned event, but also one that is shared. This is what is so different from an ordinary suicide, which is carried out alone and in necessary concealment. After euthanasia, the pain of separation is bound to remain significant for those left behind. But it is perfectly plausible to suggest that the business of mourning is facilitated by the nature of the departure. These meetings of families, friends and caregivers at a selected time were unimaginable before this law. Death now becomes a shared experience. It can be talked about, feelings can be shared, a common experience can be discussed. Death ceases to be a taboo subject. In reality it had been shrouded in obscurity by the medical world and the hospitals without any deliberate intention to conceal it. Giving patients autonomy thus also means

2002 is the control of one's own body reflected in the principle of self-determination which is firmly anchored in our law⁵⁵. The conscience clause granted to the doctor is the corollary of this: what could be more understandable in a country that promotes the neutrality of the law with regard to individual moral conceptions than to explicitly allow the potential subjects of a law to remove themselves from its scope if it is not consistent with their convictions? Individual freedom seems to be preserved in this way, since no ethical orientation is legally binding⁵⁶. Supporters and opponents of the law agree on this point.

g. Conclusion of the first position

The Act of 28 May 2002 does not create a right to *euthanasia*, but the right for the subject to be discussed if the patient so desires. It aims to promote a culture of transparency and openness, avoiding obfuscation and putting the patient at the centre of the process. Unfortunately, in reality this is far from always being the case, and a real effort still needs to be made to promote a "new culture" concerning end-of-life issues among caregivers – and among patients too. Some networks, such as LEIF and EOL, are already doing an excellent job in this regard. By introducing the three "great laws" of 2002 (on euthanasia, palliative care and patients' rights), our country has given the words "autonomy", "freedom", "respect" and "dignity" their full meaning. Our law has had the intelligence to put tolerance, humanism, trust and respect for privacy ahead of the various abstract forms of morality, which are by definition relative since they are not shared by all. It has restored an essential prerogative to the individual by enabling the individual to regain control of his or her destiny as a free and responsible person until the very end of the road. At the same time, it has carefully designed a legal framework and conditions for the taking of highly significant medical decisions. The great merit of these laws is to have understood, affirmed and systematised these things.

Does this make it a solid foundation? In this context, the tendency of some institutions (hospitals, residential homes and nursing homes) to categorically reject the practice of euthanasia, or to impose additional conditions not stipulated by the law on euthanasia and not authorised by the law on patients' rights, is disturbing. This practice is contrary to the professional autonomy of doctors with regard to medical procedures. It is contrary to patients' self-determination, despite this being firmly guaranteed by our law and central to ethical considerations. Thus, imposing a "palliative filter" is in direct contradiction not only with the law

enabling them to reclaim their own death. (...) A significant cultural shift made possible by the law which has released death from its confines." (Damas F., *La mort choisie. Comprendre l'euthanasie et ses enjeux*, éditions Mardaga, collection Santé en soi, 2013, pp. 110-111).

55 This is the intention of the European Court of Human Rights when, in the important judgment *Haas v. Switzerland* of 20 January 2011, it considers (§ 51) that "an individual's right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention." This laudable statement builds on the remarkable doctrine of *Pretty v. United Kingdom* of 29 April 2002, whereby (§§ 61-67), "the notion of personal autonomy is an important principle underlying the interpretation of the guarantees of Article 8 of the Convention", a principle which can be understood "in the sense of the right to make choices about one's own body." The Court reiterated these principles in its judgment *Koch v. Germany* of 19 July 2012.

56 Genicot G., "Tour d'horizon de quelques acquis et enjeux actuels du droit médical et biomédical", in *Nouveaux dialogues en droit médical*, Genicot G. (ed.), Anthemis, 2012, p. 57, n° 39.

of 28 May 2002 – which deliberately abstains from any such requirement – but also and above all with the patient’s absolute right to refuse any treatment, even palliative treatment; this right stands alongside the patient’s right to have his or her request for euthanasia listened to properly and examined in light of the criteria set by the law. Such guidelines hamper the therapeutic freedom of doctors and undermine the relationship of trust between doctors and patients, which is particularly important at the end of life. They lead to painful and unacceptable situations on the human level: at best, the patient will be referred to an institution where the request will be listened to more seriously, if euthanasia is feasible; at worst, the request will simply not be heard, will be ignored, which is the opposite of what the legislators intended in 2002.

In a democracy, it is hardly conceivable for one private actor (the care institution) to prohibit another private actor (the doctor) from using the possibilities offered by a law, in his or her relations with a third private actor (the patient), thereby preventing the latter from enjoying a legally enshrined right. It is not lawful for health facilities to block the application of a law “on their territory”; and the possible transfer of the patient to another institution, even if this is practicable, should not be seen as an acceptable solution, given the discomfort and stress it generates.

The need for a conscience clause to be accorded *individually* to each practitioner or caregiver is self-evident in the context of a serious act with heavy moral implications. But the object of this clause *is the doctor, not the institution*: only a natural person has a conscience, and the extension of Article 14 of the Law of 28 May 2002 to institutions was *deliberately ruled out by the legislators*. The direction of treatment must be a matter for patient and doctor to decide on freely, protected against institutional dictates. Whether one likes it or not, the Law of 28 May 2002 is part of our body of law: each of us has the individual freedom to agree with it or not, but on the part of institutions, such obstacles to the application of a democratically introduced law seem shocking, as they amount to imposing on others (patients and health professionals) a moral choice which, while respectable, is not shared by everyone. Performing a legal act may mean offending the convictions of others (on an abstract level, as those opposed to euthanasia need never be personally involved if they decline to do so); to forbid the performance of that act is to interfere *directly* with the rights and freedoms of others, and thus to set oneself up as a censor... or even as a legislator “after the event”.

It would be desirable in this respect, as on other issues left unsettled by the Law of 28 May 2002, for the legislators to return to the text of the law and clarify their intentions. This would satisfy the desire expressed by the European Court of Human Rights for States “to organise the health services system in such a way as to ensure that an effective exercise of the freedom of conscience of health professionals in the professional context *does not prevent patients from obtaining access to services to which they are entitled under the applicable legislation*”⁵⁷.

This is because it is essential that, in a manner consistent with the ethical choices of each

57 E.C.H.R., judgment *R.R. v. Poland* of 26 May 2011, § 206.

caregiver, the patient's request should at least be *heard*, and that his or her right to benefit from a possibility expressly created by the law, provided the required conditions are met, should not be violated⁵⁸. The question is important, and the practical difficulties are real. If care facilities were to be allowed to prohibit euthanasia under "institutional guidelines", or to add regulatory or contractual conditions beyond those provided by the law in situations where the required criteria were met, this would mean either recognising that a legal entity has a conscience⁵⁹ – which would be a surprising position – or allowing a right that was recognised and affirmed by the law to become a dead letter on the basis of an institutional policy *rather than a personal position*, which would be disturbing to say the least. Bear in mind that the right in question is the right for a patient who is in the throes of an incurable condition causing unbearable and unrelievable suffering – not to receive euthanasia, but to have his or her request for euthanasia *genuinely heard*, with attentiveness, empathy and serenity, in the place where he or she lives or is being cared for, in order to ascertain whether all the requirements are met and to travel together towards the best – or least bad – possible outcome.

Finally, members who support the first position point out that Article 23 of the Constitution declares, in the name of human dignity, the right to the protection of health and to medical assistance. More specifically, Article 5 of the Law of 22 August 2002 on patients' rights states that the patient "has the right to quality services that meet his or her needs and respect his or her human dignity and autonomy, without any discrimination of any kind being practised". By allowing non-transparent institutional policies in the field of medical end-of-life care, does one not run the risk of responding inconsistently to patients' requests for euthanasia, and hence of inequality of access to possibilities offered by the law? In the light of social justice, which is one of the ethical paradigms that should govern the optimal organisation of healthcare⁶⁰, this certainly raises issues. This is especially the case given that this issue concerns particularly vulnerable patients, who are often in the terminal phase of an illness that causes great suffering, and who, as a result, no longer have the time and the energy to engage in a gruelling battle with the hospital and caregivers. The additional criteria improperly imposed by certain institutions lead in practice to the simple denial of legal requests for euthanasia, and are sometimes accompanied by futile palliative care. This reinforces social inequality in access to healthcare: there is no real equality at the end of life, and many patients' requests are met with a wall of incomprehension. It follows that the argument concerning the protection of vulnerable patients can be turned against itself, as it is precisely their requests which are the most

58 Despite this it is still difficult in practice to find "doctors who are willing to cooperate". On the reasons for this unfortunate situation, see Distelmans W., *Euthanasie et soins palliatifs : le modèle belge. Pour le droit à une fin de vie digne*, Le Bord de l'Eau / La Muette, 2012, pp. 171-174.

59 Cf. the opinion of Professor Nys, who seems to admit the possibility of institutional policies on the grounds that a hospital or a nursing home is a "legal entity" (Nys H., *Recht en bio-ethiek. Wegwijs voor mensen in de gezondheidszorg*, Lannoo Campus, 2010, p. 123), despite the fact that in Article 14 of the Law, the words "any other person" come immediately after "any doctor" and must thus refer, like the concept of "participation", to a natural person (on this point, see Dierickx A., "Als sterven 'leven' is... Is helpen sterven dan 'doden'? Een commentaar bij de Wet van 28 mei 2002 betreffende de euthanasie", *T. Strafr.*, 2003/2, p. 33).

60 On this concept, see Dupuis M., "La justice : une valeur-phare ? Quelques considérations personnelles", in Pinsart M.-G. and Schotsmans P. (edd.), *Les 15 ans du Comité consultatif de Bioéthique. Bilans & perspectives*, Racine / Lannoo Campus, 2012, pp. 179-203.

disregarded⁶¹.

A.2. Second position: arguments in favour of institutional policies

a. Ethics, law and conscience

The 2002 law decriminalises euthanasia, i.e. provides for a dispensation or exception, under very strict conditions, from the prohibition on killing. It has created a legal framework in which the doctor, provided he or she adheres to certain precautions, do not commit an offence. This legal framework does not imply a right to euthanasia, even in cases where all the conditions are satisfied. A well-founded current request for euthanasia is not legally binding. In this sense, the request for euthanasia and the actions taken by the doctor who may or may not administer euthanasia differ, by their nature, from healthcare to which the patient is entitled⁶². Nobody can force an institution to perform euthanasia on its premises⁶³.

This law does not legalise, oblige, or even invite. The members who support this position hope that as little use will be made of it as possible. They believe that there is nothing to prevent an institution from putting in place precautionary ethical measures in addition to those provided by the law, especially for an act which is so unusual for a doctor, and contrary to everything that he or she has been taught: putting an end to the life of a patient. The fact that an institutional ethics policy is not included in the law does not preclude its existence⁶⁴. The law serves as a safeguard to prevent unregulated or ill-considered euthanasia, and not to encourage euthanasia. It sums up fairly effectively what constituted a state of necessity prior to its introduction, i.e. the circumstances in which it is permitted to make an exception to the rule (in this case the prohibition on killing) for an ethical reason higher than that prohibition: the patient's autonomy, his or her suffering, and the duty to assist him or her.

For some members who support this position, ethics stands above the law. Ethics is the quest for the good. Ethics is constructed *a priori*, not *a posteriori*. Conversely, laws are a consecration of moral values (ethos, mores). They reflect the minimum ethical standard of a society at any given time in its history. They are used to protect the autonomy of a society's most vulnerable members against the unethical actions of those who are stronger. They are also, in a

61 Mortier F., "Ethische aspecten van euthanasie en de toepassing van de wet", in Bussche F. and Distelmans W. (edd.), *Een goede dood. 2002-2012: tien jaar 'controversiële' euthanasiewet?*, VUB Press, 2012, pp. 78-79.

62 Nys H., *De Standaard*, 28 March 2008, quoted at www.paulschotsmans.be (> opinies > bijdragen tot het euthanasiedebat). See also Nys H., *Recht en bio-ethiek. Wegwijs voor mensen in de gezondheidszorg*, Lannoo Campus, 2010, pp. 122-123.

63 "Not every objection of conscience is admissible, but no objection may be overruled purely on the grounds that no provision is made for it in law" (*Clauses de conscience au profit des professionnels de la santé*, brochure issued by the European Institute of Bioethics, 2011, p. 25).

64 Resolution 1763 of the Parliamentary Assembly of the Council of Europe, adopted on 7 October 2010, "The right to conscientious objection in lawful medical care": "No person, hospital or institution shall be coerced, held liable or discriminated against in any manner because of a refusal to perform, accommodate, assist or submit to an abortion, the performance of a human miscarriage, or euthanasia or any act which could cause the death of a human foetus or embryo, for any reason".

democracy, the expression of a consensus. What is ethical is not automatically legal; conversely, what is legal is not necessarily ethical. Ethical reflection cannot be replaced by compliance with legal requirements. For these members, this difference between ethics and the law is the foundation of the conscience clause contained in the law. This conscience clause can therefore be invoked by any caregiver or any group of caregivers, as is the case with the 2007 law on medically assisted procreation. In areas that touch closely on life, love and death, it makes sense to leave some space for ethical reflection beyond the legal rules.

b. Good medical practice, the culture of care and institutional ethics

Care institutions are obliged to justify the care they provide, to conduct a policy that focuses on quality and to aim for quality control. Many institutions seek accreditation by international organisations. Among other things, this accreditation requires there to be an institutional policy on interventions, and that policy must be translated into detailed procedures. Areas such as oncology, transplantation, in vitro fertilisation (IVF) and many others use international guidelines, which are translated into an institutional policy applicable at local level. An institutional policy is therefore regarded not as a binding framework imposed on doctors by a higher authority, but rather as an organisational culture within which doctors faced with difficult decisions can turn to other care providers, to medical ethics committees, to practical guidelines and to evidence-based medicine, with the sole aim of providing the best possible care. An institutional policy may not have the objective of curbing therapeutic freedom, but must help ensure the achievement of comprehensive, high-quality care.

The complexity of the ethical decision relating to requests for euthanasia requires the legal provisions to be translated into the concrete organisation of care for patients who request euthanasia. The development of a written institutional ethics policy⁶⁵ is one possible way of making this responsibility concrete. A written institutional ethics policy is defined in written agreements (procedures, guidelines, vision notes, etc.) which are approved at the institutional level and whose objective is to guide caregivers in ethical decision-making. This institutional policy outlines missions defined by the management, often after collective dialogue, based on norms, values and beliefs present in the institution. A mission text refers to the philosophical, moral and religious principles that drive the institution. These principles are implicitly or explicitly accepted by the workers, who enter into a contract within the institution and form a corporate culture represented by the workers.

A care institution that works correctly and completely ethically takes a broad view of quality care and seeks to provide care consistent with the human dignity of its patients, residents and customers. The vision of the institution is known to all; it is clear, transparent, and developed through a consultation process, and it provides care staff with assistance on ethical issues. It might be called the “institutional conscience” of a healthcare institution.

The ethical vision of care is reflected in all the organisation’s activities. The way in which

⁶⁵ For example, see Appendix 3.

hospitals recruit new employees on the employment market is often a good reflection of the values with which the hospital identifies. Some institutions specify the characteristics required of a new employee, while others express their vision of care in a text.

Institutions that work together on their identity and unite their staff around chosen ethical values in this way avoid weakening ethical standards. In this way, the institution becomes the project of all caregivers – a project that is collectively supported by a community that identifies with the values upheld. The institution thus acquires a moral identity⁶⁶.

An institution's ethics policy can be expressed in texts, but also through the dynamic processes that take place within an ethics committee or through regular multidisciplinary consultations. A sincere process of ethical reflection is both a journey and a dialogue, in which the employees are stakeholders as far as possible. Within the hospital, it goes without saying that a doctor does not exercise his or her profession as an individual only, but as a member of a healthcare team. This also means that the doctor's actions have an impact on the reputation and functioning of the team as a whole, and by extension on the entire hospital.

The general and medical management, the medical board, the ethics committee and the board of directors have the task of putting in place the combination of conditions that will help ensure the establishment of a culture of care based on ethics.

These conditions are as follows:

1. the definition of a mission and vision clearly based on values (as part of a process of horizontal and vertical dialogue);
2. the facilitation and encouragement of open and transparent dialogue;
3. the promotion of discussion of ethical issues through the provision of training, reflection evenings, discussion sessions, etc.

It is thus specifically through a process of consultation and dialogue that an institutional ethics policy will be developed around euthanasia that (1) is not a simple copy of the law (legalism), (2) is not a purely clinical procedure as part of the care practice (proceduralism), and finally, (3) is not a mere list of values (moralism), but is instead a policy that integrates the law, care practice and ethics.

With regard to end of life, such an ethics policy may involve not doing certain things (e.g. "euthanasia on demand") and applying certain prudential criteria (e.g. palliative deliberation – a consultation of a multidisciplinary nature or conducted with the ethics committee).

The question of whether an institution should offer euthanasia is fundamentally different from the question of whether it may refuse or restrict it in some way, because it has to be related to the notion of "minimum care provision". Every hospital provides healthcare, but euthanasia is not yet part of the minimum care provision required for an institution to be recognised. Nor does the law on euthanasia contain any obligation for institutions to practise euthanasia.

66 Herranz G. and Thomas H., "Das Krankenhaus als moralisches Subjekt", "L'hôpital en tant que sujet moral" in Burre A., Ketterer B. (ed.), *Katholisches Krankenhaus heute? Zur Zukunft der Krankenhäuser in freigemeinnütziger Trägerschaft (De l'avenir des hôpitaux avec statut d'asbl)*, Paderborn, Bonifatius, 1994, pp. 58-80.

Sanctions may not be imposed on a hospital that has no stock of the products needed to perform euthanasia. Euthanasia is also not an integral legal element of palliative care or of quality care. The very most that can be suggested is that services which are regularly confronted with end-of-life situations should have a policy on how to behave if euthanasia is requested. There is also no consensus that euthanasia should be part of “good palliative care”. The question of whether institutions are required to offer euthanasia is related to whether euthanasia is a form of medical treatment. If the answer to this question is negative, then there is surely no obligation to offer euthanasia. If it is positive, then euthanasia should be one of the legal roles of the hospital.

For a number of forms of treatment with significant ethical connotations, relating to the beginning and the end of life, it is necessary for the institution to define a clear ethical care policy⁶⁷. For example, in many Catholic institutions, the policy requires requests for euthanasia to be examined by a doctor or team specialising in palliative care. This so-called “palliative filter procedure” originated after consultation with numerous care providers and decision makers. Its purpose is to detect inappropriate euthanasia requests as far as possible⁶⁸.

Caritas Vlaanderen has developed a guideline of this kind, which was published in 2004⁶⁹. The development of this guideline began when the bill was introduced in parliament that would lead to the law on euthanasia. The guideline goes beyond the law in its adoption of precautionary criteria, and in particular in the attention it pays to the patient and the immediate family. It lays stress on encouraging a culture of palliative care and anticipating situations in which the request for euthanasia may arise. In this context, conferring with the palliative support team is essential, as the care provided is never purely medical, but is also psychological, relational, existential and spiritual. When it becomes clear that the patient’s suffering cannot be relieved by the conventional palliative means of symptom control, palliative sedation can also be considered. The patient is thus informed about the palliative care options available to him or her. It is assumed that the palliative filter procedure should eliminate a considerable number of requests for euthanasia, given the expectation that if the request is maintained despite the application of this filter, the doctor may end up in a situation in which euthanasia may be the only possible solution for this patient in these circumstances. The palliative filter is regarded as a “preventive measure”⁷⁰. In this context, the doctor is not only required to observe the legal safeguards, but to discuss the request for euthanasia with several members of the care team and with the family. The decision to perform euthanasia should be regarded in this context as a joint decision of the patient, doctor, family and palliative support team.

67 Herranz G. and Thomas H., *op. cit.*

68 *Palliatieve zorg en euthanasie in België. Evaluatie van praktijk en wetten*, MELC Consortium, ASP, 2011, p. 71.

69 Gastmans C., Van Neste F., Schotsmans P. "Facing requests for euthanasia: a clinical practice guideline", *Journal of Medical Ethics*, 2004, Apr, 30(2), pp. 212-7.

70 Gastmans C. et al., 2004, *op. cit.*

c. Human solidarity as a support for patient autonomy

For some members who support the second position, this prudent ethical approach seems especially necessary as it is rooted in very considerable misgivings about the act of euthanasia itself. Thus, as Xavier Dijon states, “rights necessarily presuppose relations with others, and their essence consists of governing this relationship. (...) How then could relations (a human right) be taken as the basis for giving oneself the right to end life and hence relations, without any contradiction?”⁷¹. According to Xavier Dijon, “containing within itself nothing but the natural state of free and equal wills, democracy will entrust to the will alone of positive legislators the task of striking the necessary balance between freedom and equality, at the risk of allowing infringements of individuals’ human dignity or identity”.⁷² Such questions about how we relate with others are common to all religions.

To quote Michela Marzano’s analysis: “Behind a request for death is suffering that can find no other form of expression. In any request of this kind, there is an element of doubt, of the unfathomable, of ambivalence and ambiguity. (...) In these people, the desire to live and the wish to die fluctuate constantly (...), in particular in response to the quality of care, guidance or the availability of family. This is perhaps why Françoise Dolto used to say that if death was requested and given, this represented a failure of communication.”⁷³

d. What is the view of these members about the duty of referral?

A practitioner who does not think he or she can accede to a request for euthanasia due to conscientious objection is subject to three obligations: the doctor must inform the patient of his or her refusal clearly and in good time, explain his or her reasons and, in accordance with the law on patients’ rights, refer the case to a colleague if the patient so requests. The question is whether a duty of referral exists when the practitioner does not think he or she can accede to the request for euthanasia.

Referrals are common practice in the case of treatments that lie outside the competence of the referring doctor. The practitioner must be aware of the limits of his or her competence and, if necessary, seek the help of a qualified consultant. Articles 140 to 145 of the Code of Medical Ethics indicate that good collegial relationships involve intense collaboration. Article 97 of the same code states that “if the doctor lacks sufficient knowledge on providing the patient with end-of-life support, he or she should seek the necessary advice and/or consult a competent colleague”. However, this does not necessarily imply a duty to refer in the case of a request for euthanasia.

71 Dijon X., *La raison du corps*, Brussels, Bruylant, 2012, p. 197.

72 Dijon X., S. J., Séminaire de droit naturel : Dignité, identité, laïcité, au Palais de Justice de Bruxelles ; séance 2 du 30 avril 2013 : “L’égalité menace-t-elle l’identité?”, p. 23.

73 Marzano M., *L’éthique appliquée*, PUF, coll. “Que sais-je ?” n° 3823, 2nd ed., 2010, p. 56.

When a doctor decides not to perform euthanasia, several reasons may be invoked: the professional belief that the patient's state of health does not satisfy the medical and legal conditions for administering euthanasia, the practitioner's objections of personal conscience, or the policy of the institution to which the doctor is attached. In each case, the question arises of what attitude the practitioner should take, and in particular whether he or she is required to refer the patient to a colleague. He or she has three options: perform euthanasia despite his or her conscientious objection, do not perform euthanasia, but refer the patient to a colleague who can, or do not perform euthanasia and do not refer the patient.

Members defending a position in favour of an institutional policy are divided as to the obligation to refer. Some members believe that a doctor who refuses to perform euthanasia for reasons of personal conscience nevertheless has a duty to refer the patient to a colleague who will perform euthanasia. However, other members believe instead that if a doctor him- or herself has conscientious objections vis-à-vis euthanasia or considers it inappropriate in a particular situation, he or she will probably choose the third option: he or she will not perform euthanasia and will not be tempted to refer the patient. They argue that a referral makes no sense unless it is to a colleague whom the referring doctor thinks will be willing to participate in euthanasia. Requiring the doctor to refer would contradict the right to refuse to practise euthanasia, since referral means that the referring doctor will feel complicit, at least morally, in the euthanasia that will be performed by the colleague to whom the patient is referred. If the refusal is based on conscientious objection on the part of the doctor or on the policy of the institution to which he or she is attached, one may ask if the doctor can set his or her conscience or the institutional policy above the desire of the patient who asks for help. This question will be answered in the affirmative, as the right of any doctor (and any caregiver) is recognised to refuse to participate in euthanasia. Requiring the doctor, despite conscientious objection, to refer the patient to a doctor who does not share the objection would mean implicitly requiring the doctor to participate in euthanasia. All he or she would then have would be the right to refuse to perform the act him- or herself. A duty of referral would therefore be contrary to the law.

In addition to this point, there are other objections to arguments in favour of referring the patient.

A first argument in favour of a duty of referral is based on the weak position in which the requesting patient finds him- or herself. The patient is in a state of visible suffering, which he or she finds unbearable, is frequently in the terminal stage of the illness, and in most cases is very weak. He or she is largely dependent on the doctor: it is the doctor who, in agreement with the patient, decides which treatments are or are not given; the patient him- or herself only has a limited and non-medical knowledge of his or her own health. Unlike the referring doctor, he or she usually does not know any other doctor who could accede to the request for euthanasia, and is not in a fit state to find one him- or herself.

Reference is sometimes made in this context to the doctor's ethical duty to ensure continuity of care by referring the patient to a colleague willing to perform euthanasia (Royal Decree No. 78 and Code of Medical Ethics). However, this argument is not convincing, as the therapeutic

relationship does not come to an end if the doctor refuses to perform euthanasia. The practitioner may ensure continuity of care in some other way, through a referral to palliative care, the administration of pain relief, etc.

A second argument in favour of transferring the patient is based on the confidentiality of the medical relationship between patient and doctor. The importance of this in the context of euthanasia cannot be overstated. In practice, this confidential relationship is extended to the other care providers and doctors that are consulted.

There is no legal or regulatory requirement concerning the referral duty. The law on euthanasia merely requires the practitioner who refuses to perform euthanasia to inform the patient, not to make a referral. Still less is there any right to euthanasia such that a patient can demand it.

The Committee members who believe that there is no obligation to refer stress that the doctor who does not comply with the patient's request for euthanasia has other obligations towards the patient that he or she must satisfy. Firstly, of course, the patients' rights must be respected. Thus, the patient has, among other things, "the right to quality services that meet his or her needs and respect his or her human dignity and autonomy, without any discrimination of any kind being practised" (Article 5 of the Law of 22 August 2002 on the rights of the patient). Moreover, all doctors, especially those who refuse to perform euthanasia, have a duty of information. The doctor has a legal duty to inform the patient of his or her refusal in a clear and timely fashion (Article 14 of the Law on euthanasia and Article 7 of the Law on patients' rights). Provided the patient is still capable of doing so, he or she can then consult another doctor or find another care institution. When the patient decides to use another practitioner who will respond favourably to his or her request for euthanasia, the doctor is obliged to transfer the patient's medical record to the new doctor (Art. 14 of the Law on euthanasia).

e. Conclusion of the second position

The Law of 28 May 2002 does not create a right to euthanasia. The law cannot compel any person, group of persons or institution to administer or arrange for the administration of euthanasia. Moreover, additional ethical safeguards are not against the law. Such safeguards are welcomed as a way of preventing what should be the exceptional administration of euthanasia from becoming widespread. Some members in favour of the second position believe that the palliative filter will be sufficient to meet the patient's needs without resorting to euthanasia; other members think that palliative care is a necessary filter but may, in some very specific cases, be followed by euthanasia.

Developing an ethical vision is essential in every care institution. A care institution is not just a building where care is provided. The people who work there treat their fellow-humans at a time when they are vulnerable, facing suffering and death. These workers need to reflect together in order to develop a culture of quality care based on respect for their patients in their dignity, vulnerability and autonomy. The institution's work must meet the patient's needs, the criteria of prudence and humanity, and the transparency necessary for its practical application.

In the view of some members defending this second position, there is a duty to refer; for other members, the duty of referral does not apply and the principle of continuity of care is confined in this context to the communication of medical records.

Performing an act of euthanasia is a question of conscience and not of competence. It is not an everyday, ordinary action, requiring only a certain technical ability, but rather an act of exceptional gravity, which violates a fundamental prohibition in our civilisation. Compelling a doctor to refer a patient because he or she responds negatively to the patient's request for euthanasia, would, according to these members, violate the doctor's conscience by forcing him or her to participate in an act which he or she finds intolerable.

The patient's vulnerability is viewed in a number of different ways by defenders of the second position. Some members feel that the patient's physical and/or psychological weakness at the end of life prevents him or her from finding another place or care provider that will respond positively to a request for euthanasia. This vulnerability therefore implies an obligation to refer on the part of the doctor who has indicated a conscientious objection to euthanasia.

Others believe that the doctor's role is to hear the distress of the patient and to bring relief with dedication and competence. If there are other ways to alleviate the patient's suffering and stay true to his or her convictions, the doctor should not disregard them, even though the law has decriminalised euthanasia. Euthanasia as defined by the law is not the only way to die with dignity. On the contrary, acceding too promptly to the patient's request seems to take no account of the patient's extreme vulnerability, especially at the end of life.

The members who believe that the doctor is not under an obligation to refer the patient hold that this is even less the case for an institution. However, information must be exchanged at all levels, and on a timely basis: between patient and doctor within the framework of their confidential therapeutic relationship, between these two and the patient's friends and family, and between all these parties and the care team, as well as, on a broader scale, between the general public and the institutions. The latter must provide a transparent and detailed explanation of their care policy regarding the management of the end of life.

Other members who take a more nuanced position on the institutional policy focus primarily on the development of a culture of ethical care in care establishments. The definition of an ethically grounded and phased plan will ensure that every effort is made to develop a culture of palliative care, but at the same time to accept that euthanasia is consistent with care if the patient persists in a request for his or her life to be ended.

Patients who request euthanasia must be listened to with empathy and treated with competence.

B. “End-of-life clinics”, specialist organisations within or outside institutions

Should competent specialised clinics or institutions be created with the sole purpose of assisting patients at the end of life, and aiming in particular to enable any patient satisfying the legal requirements to gain access to a medical environment that is not ideologically opposed to the principle of euthanasia?

A partial response has already been given to this question in Part II.A, where the advocates of the two positions explained their arguments in favour of or against the duty to refer. This is a matter currently under debate⁷⁴. At issue is not just euthanasia, as this is *only one of the possibilities* offered at the end of life and is applied only to a small percentage of deaths (1 to 2% of deaths, according to studies, although none of them is able to certify with any reliability the exact figures or percentages for the incidence of euthanasia in Belgium)⁷⁵. Pain relief treatments that can shorten life, withdrawing or withholding futile treatment, therapeutic de-escalation, “do not resuscitate” decisions, and palliative care, including palliative sedation, are other end-of-life decisions that could be taken in this specific type of context.

The debate about the practical application of the law on euthanasia is conducted in many institutions, and, as society evolves, attitudes have gradually changed. The law on euthanasia has made discussion possible about the active termination of life, and the number of declarations (which increases every year) demonstrates that both in institutions and at home,

74 See Delbeke E., *Juridische aspecten van zorgverlening aan het levenseinde*, Intersentia, 2012, pp. 218-222, n° 399-405, who concludes that such an option is not particularly subject to any objections of a strictly legal nature, but that it hardly seems desirable at the societal level in view of its potential consequences. The situation in the Netherlands (proposal issued by the Nederlandse Vereniging voor een Vrijwillig Levenseinde) was explained at Petra de Jong’s appearance before the Select Commission (see Appendix 2); see also de Jong P., “Levenseindekliniek is noodzaak in Nederland”, in Bussche F. and Distelmans W. (edd.), *Een goede dood. 2002-2012: tien jaar ‘controversiële’ euthanasiewet?*, VUB Press, 2012, pp. 311-317; den Hartogh G.A., “Levenseindekliniek binnen de grenzen van de wet?”, *Tijdschrift voor Gezondheidsrecht*, 2011 (35) 212-216; Soumois F., “Une clinique de l’euthanasie en Belgique?”, *Le Soir*, 3-4 November 2012.

75 These percentages are derived, firstly, from the fifth report of the Federal Commission for the Control and Evaluation of Euthanasia (CFCE), which covers the period 2010-2011 and which reveals that the number of deaths due to euthanasia reported to the Commission during this period represents an average of 1% of all deaths in Belgium (see Appendix 1). However, the CFCE obviously only knows about those cases of euthanasia which are declared to it, leaving unanswered the question of how frequently euthanasia is practised but not declared. The survey conducted by the Consortium MELC on the basis of a sample of medicalised deaths in Flanders resulted in several publications. Thus it appears from Smets T., Bilsen J., Cohen J., Rurup M.L., Mortier F. and Deliëns L., “Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases”, *BMJ* 2010 (341:c5174, doi:10.1136/bmj.c5174), that this survey, carried out in 2007 on the basis of death certificates in Flanders, shows a rate of 1.9%. To this end, a stratified random sample was obtained from people who had died between 1 June 2007 and 30 November 2007. All deaths in this period were grouped into four strata according to the cause of death mentioned on the death certificate: stratum 1 related to deaths for which euthanasia was the *direct cause* of death; stratum 2 related to deaths where medical assistance at the time of death was *probably* the cause; stratum 3 related to deaths where medical assistance at the time of death *may have been* the cause; and stratum 4 related to deaths where medical assistance was *unlikely* to have been the cause. Next, all deaths in stratum 1, half of the deaths in stratum 2, a quarter of stratum 3 and 12.5% of stratum 4 were included in the sample. The data were then weighted to correct for this disproportionate stratification. The doctors who had drawn up the death certificates for deaths included in the sample received a questionnaire concerning the end-of-life decision-making process. The response rate to the questionnaire was 58.4%. The most notable findings of this study were that the incidence of euthanasia in Flanders in 2007 was estimated at 1.9% of all deaths, that around half of the cases of euthanasia evaluated were reported to the Federal Commission for the Control and Evaluation of Euthanasia, and that doctors who regarded an end-of-life decision as euthanasia reported it to the Commission in 93.1% of cases. By way of comparison, a similar study of deaths conducted in 1998 resulted in an estimated incidence of euthanasia in Flanders of 1.1%.

euthanasia is actually being applied. The procedure and precautions that the law provides appear to represent a robust framework, as can be seen from an analysis of declarations. Despite the development of specific guidelines, the support of doctors at the LEIF, EOL⁷⁶ and other initiatives⁷⁷, patients and caregivers continue to confront certain questions. Some Committee members believe that some institutions refuse to discuss euthanasia or set additional conditions that are so hard to meet that euthanasia seems impossible. There are also institutions which, while open to requests, do not accede to them, but systematically refer patients to institutions where the procedure is applied. Some caregivers feel under pressure to initiate treatments that are morally problematic for them.

It is for these reasons that a process of reflection has been initiated in Belgium about the usefulness of what are called “end-of-life clinics” (as opposed to euthanasia clinics). Such an initiative has been taken in the Netherlands by the *Nederlandse Vereniging voor een Vrijwillig Levenseinde* (NVVE), and such clinics now operate as support structures for patients who were not receiving a positive response to their request for euthanasia despite satisfying the criteria set by the Dutch law (see Appendix 2).

This debate is thus not just about euthanasia. In 2002, the euthanasia law was issued at the same time as two other laws governing end of life: the law of 14 June 2002 on palliative care and the law of 22 August 2002 on the rights of the patient. It is important to set euthanasia in the context of all end-of-life decisions, which require additional training for professionals in various disciplines in order to promote good medical practice.

One may also wonder if it is not also necessary to give the public more information. This is important, because a gradual shift has taken place in society regarding the perception of pain and a decreasing acceptance of it, along with the expression of an increased desire for control (or in some cases the illusion of control). In the view of some members of the Committee, there is thus a risk that a less strict view will be taken as to whether the conditions for euthanasia are satisfied. The pain is evaluated by the patient, but the doctor who receives the request needs to understand how severe the pain is. This happens during a personal conversation within the confidential doctor-patient relationship, which is obviously characterised by inter-individual subjectivity.

76 See www.leif.be: (translation) “LEIF (LevensEinde InformatieForum/Forum for End of Life Information) was founded in early 2003 on the initiative of the non-profit organisation Recht op Waardig Sterven (Right to Die with Dignity) (www.leif.be), in response to the laws concerning patients’ rights, palliative care and euthanasia which came into force in 2002. LEIF was created as an open forum for care providers, patients and their families, as it quickly became apparent that few were familiar with the content of these laws. LEIF organises the training of LEIF doctors, LEIF nurses and other care providers, and offers telephone support regarding end-of-life issues (‘LEIFlijn’ or LEIF line.”

See www.admd.be/medecins.html: “The EOL Forum was established in the French Community in November 2003 with the logistical support of the ADMD. It currently consists of around a hundred doctors who are particularly interested in the question of end-of-life management and who have attended a brief but specific information session on this issue. [...] The EOL Forum doctors, who are available to their colleagues, guarantee a consultation with an independent doctor who is knowledgeable about these issues, on the subject of the palliative care networks available locally as well as on the conditions and procedures for euthanasia requests. EOL doctors are expected to regard euthanasia as a perfectly valid ethical end-of-life option.”

77 ULteam, a multidisciplinary team (palliative care doctor, psychiatrist, psychologist, social and psychiatric nurse philosophical companion, oncologist, lawyer, LEIF doctor, paediatrician, etc.), aims to clarify end-of-life issues and to answer questions from patients (and their families) on everything related to this topic (www.ulteam.be).

A recent study showed that about 50% of current euthanasia requests are honoured⁷⁸. We do not know the reasons why the procedure is not initiated in the case of some requests. However, these reasons are probably to be found in the characteristics of patients, doctors and possibly institutions. Many care institutions apply a so-called palliative filter, which involves exhausting all the possibilities offered by palliative care before acceding to a request for euthanasia. The study that led to these findings is based on a questionnaire sent to 3,006 doctors potentially involved in end-of-life care. Doctors were only included in the survey if they had been qualified in their specialist field for at least 12 months and were on of a list of specialists who could potentially receive requests for euthanasia. The response rate was 36%. Out of the whole group, 48% of the doctors had already dealt with a request for euthanasia. A doctor may refuse to accede to the patient's request for various reasons. Among other things, he or she may refuse for moral reasons. Van Wesemael *et al.* have shown that doctors working in palliative care are more likely to receive requests for euthanasia. The number of requests that the doctors received was not affected by their moral and religious convictions, but doctors who did not report any religious beliefs were much more likely to comply with a request for euthanasia.

Doctors may also refuse for professional reasons. Patients who do not satisfy the legal requirements cannot receive euthanasia. Depression or a diminished ability to decide on the part of the patient are strong reasons for many doctors to turn down a request for euthanasia. In addition, in the cited study, the consulted doctors who had responded negatively to a request for euthanasia believed in the case of a quarter of the patients that their suffering could not be regarded as intolerable. In the case of a quarter of the patients, the doctors turned to alternatives such as palliative care, and for one-third of them they did not regard the situation as hopeless. In the case of 10% of patients to whom a negative response was given, the request was regarded as groundless.

Some Committee members regret the fact that in practice, some hospitals construct a procedure of examinations and reflection that is complicated and prolonged, and engage in communicate about the procedure with the family that is similarly complicated and prolonged, so that the patient ends up dying of his or her illness, or a palliative solution is preferred to the euthanasia procedure. In any case, the threshold for regarding a request for euthanasia as justified differs according to the practitioner, just as there are differences in the assessment of the medical conditions to be met.

In this context, **some members** of the Committee are opposed to the creation of specialist care institutions, or specialist care services in existing institutions, whose purpose is to accede to requests for euthanasia from patients who, although they meet the statutory decriminalisation criteria, would have been refused elsewhere. The following arguments were used:

1. Such an attitude is likely to lead to the formal and ethical trivialisation of euthanasia, which

78 Van Wesemael Y., Cohen J., Bilsen J., Smets T., Onwuteaka-Philipsen B., Deliens L., "Process and outcomes of euthanasia requests under the Belgian act on euthanasia: a nationwide survey", *Journal of Pain and Symptom Management*, Elsevier, 10 February 2011.

should remain a last resort – a response to an exceptional situation and not a normal practice. Whenever euthanasia is performed, it is hoped that the patient concerned travels down a road of discernment together with his or her loved ones and practitioner. Merely completing a checklist of legal criteria would be a very reductivist way of interpreting the law.

2. In another vein, the subsidies used to create these clinics could be used to improve end-of-life care, which, **some members** argue, would in practice reduce the number of requests for euthanasia.

End-of-life clinics, simply by existing, are likely to put pressure on the most vulnerable and/or least affluent members of our society to move towards a decision to request euthanasia. According to some authors, the “right to die”, by putting too much pressure on vulnerable groups such as the elderly or those suffering from dementia, could become a “duty to die”⁷⁹. The unbearability of the condition from which the patient suffers depends, according to these authors, on personal values. The availability of a social network and individual differences in the way different people respond to the same situation play an important role in whether a request for euthanasia is made. The fear of dependency and the unbearable nature of institutional life for older people with dementia can influence the request for euthanasia when the patient concerned attaches great value to autonomy and self-determination⁸⁰.

3. The very existence of such services, it is argued, would provide practitioners who do not work there themselves with a means of getting rid of the problem (and the patient), instead of engaging with the patient, within the framework of the one-to-one consultation, in a dialogue about what the patient is experiencing, what he or she wants, what is possible, and what would probably be best for him or her. To some degree, such institutions would practise euthanasia on demand, rather than at the end of a process of reflection. This is contrary to the spirit of the Law of 28 May 2002, which seeks to encourage a culture of listening and compassionate end-of-life treatment throughout the medical profession, and not to make this form of treatment the preserve of a small body of professionals for whom it is their main activity.

4. In the view of **some members**, end-of-life clinics would be in danger of becoming – whether or not euthanasia is regarded as a medical procedure – an ‘on demand’ medical practice, rather than one guided by the doctor’s concern for the patient. This is contrary to general and medical ethics, in relation to treatments, diagnostic tests or even just medical certificates of any kind.

5. Our society is moving towards a situation where people are classified and put into boxes: end-of-life clinics, substance abuse centres, centres for refugees and illegal immigrants, retirement and care homes, closed institutions for juvenile delinquents, mental institutions⁸¹

79 Gastmans C., Van Laere L., "De plicht tot zorgen", *De Standaard*, 26 March 2008, pp. 1-3.

80 Gastmans C., Van Laere L., *op. cit.*

81 "This is the new order for Westerners, which reached a climax during the Second World War. I still believe that the concentration camps, for example, were neither an innovation nor an accident (...). They were largely foreshadowed by several centuries of leper colonies in remote areas or on deserted islands, isolated villages where people with cholera were sent to die in the Middle Ages, native reserves in North America, and so on." (Pierre A., *Toxicomanie, entre justice et médecine*, 2002, p. 22).

and so on. In recent decades, the taboo on death has grown stronger in Western societies⁸². A place specialising in euthanasia would encourage this tendency to efface.

6. The arguments put forward by **certain members** depend on their answer to the first question, about the legitimacy of institutional policies:

- **Committee members who do not accept the existence of institutional policies** argue that they are unacceptable whether they are in favour of or against euthanasia. They cannot imagine an institution or service which automatically or by definition adopted a single approach, ignoring the caregivers' conscience clause⁸³.
- **Members who are not opposed to institutional policies** see euthanasia not as a treatment, but as the end of all treatment and of the patient's life. Services should not be set up to provide anything other than patient cure or patient care. **Still others** believe that, as the law does not license but merely decriminalises, end-of-life clinics would be contrary to the law.

7. Who would agree to work in such services? On this point, it is relevant to recall the (understandable) extreme reluctance of caregivers to end their patients' lives. Euthanasia is perceived by caregivers as an unusual act of exceptional gravity which is both psychologically and emotionally challenging.

Other members of the Committee would not be formally opposed to the principle of organisations specialising in the management of end of life, and especially in the practice of euthanasia. These members draw a comparison between such organisations and, for example, family planning centres where, since the Law of 3 April 1990 decriminalising abortion, voluntary terminations of pregnancy under medical and psychological supervision have been among the services offered to women in distress. These members believe that Belgian society no longer accepts a situation where the possibilities offered by the law are not actually available.

Some members believe that the creation of **mobile teams** practising euthanasia, as is done in the Netherlands, could be a helpful development to propose in Belgium. The term "clinic" should be explained: these are not clinics in the sense of buildings in particular locations, but support teams who assist and guide doctors who receive euthanasia requests. The role of these teams is to ensure that the end-of-life issue is addressed in the best possible way. Hospitals and family doctors do not always have the required expertise, or such expertise is limited to a small number of people.

82 Ariès Ph., *Essais sur l'histoire de la mort en Occident du Moyen Âge à nos jours*, Paris, Seuil, Points Histoire, 1977.

83 The scenario is evoked of an institution that imposes the practice of euthanasia, which is in any case "legal", on all doctors, or forbids them to refuse to perform euthanasia: "There is, to our knowledge, no instance in which this has actually happened, and this is very fortunate. It would be the other side of the same coin of the institutional conscience clause which would be 'brutal' and hence equally reprehensible" (Lossignol D., *Clause de conscience, liberté individuelle et laïcité*, p. 14).

III. Conclusions and recommendations

A. Points of agreement

A.1. Respect for the patient

The patient must remain at the heart of the debate. Ethical reflection must be centred on the patient, and on respect for the patient's humanity and vulnerability, and must take account of the quality care to which the patient is entitled. The patient must retain freedom of choice as to medical care.

The doctor and every member of the healthcare team has a **duty to listen** attentively and with professionalism and care to the requests of people at the end of life who place their trust in them (whether for therapeutic de-escalation, palliative care, refusal of treatment, or euthanasia), and respond to them in accurate, honest and understandable terms.

Information is crucial in this context. It must be exchanged between doctor and patient with sincerity and clarity, within the framework of their confidential relationship, and between doctor and patient and the care team in the multidisciplinary consultation. Dialogue should always be preferred to silence. A patient's request for euthanasia must be open to expression and discussed. The patient should be informed, in good time and in a transparent and explicit manner, of all the possibilities for end-of-life care. Such transparency also involves institutions explaining their care policy regarding end-of-life management. Institutions are also under an obligation to provide such explanations to doctors when they are recruited, so that they are familiar with the institution's medical approach and underlying philosophy. Finally, information must also be provided by the public and academic authorities and from bodies such as the Order of Physicians, each within its own field of expertise, in order to promote a proper understanding of the law and good medical practices in this area.

The patient's **informed consent** is required for any treatment or withholding of treatment. Particularly at the end of life, patients are vulnerable and dependent on the care provided by their loved ones and the care team. They must be listened to with empathy and treated according to their own understanding of human dignity, and not according to the desires or projections of the people around them and caring for them. Where there are advance directives, these must be taken into account, depending on the legal framework that must be respected. It is therefore desirable for health professionals to inform patients at the end of life about the existence and scope of such advance directives, the possibility of using a designated person or confidant and the fact that these possibilities, which are a reflection of the patient's own wishes which should be respected, are never final and may be revoked at any time.

A.2. Respect for the Law of 28 May 2002

All members welcome the measured and thoughtful wording of the law on euthanasia. In particular, the law still allows the doctor to make the patient's request subject to additional conditions that the doctor deems appropriate, in order to arrive at a correct and accurate medical assessment. The doctor may seek advice from any quarter, provided he or she informs the patient of such initiatives and provided these complementary approaches do not disguise a personal or institutional position of rejection of euthanasia. Any institutional policy along the lines of a quality care policy must comply with the Law of 28 May 2002 on euthanasia and the Law of 22 August 2002 on the rights of the patient.

A.3. Respect for the doctor's professional autonomy

All members of the Committee note that euthanasia is an act that must be performed by a doctor. This act is by no means trivial and requires the utmost care. It must meet the standards of good medical practice. Thus, an assessment by health professionals of their practices may be conducted within an institution by its competent bodies, for example through the establishment of protocols or a reflection on the care provided to patients who are admitted, but the doctor's professional conscience must be the final arbiter.

A.4. The duty to refer

All members agree that a doctor must inform his or her patient explicitly and in good time of the rejection of a request for euthanasia and of the reasons for the decision, either because the doctor believes that the legal conditions are not satisfied, or because of a conscientious objection. Proper compliance with this duty will enable the patient to find another doctor to whom the request can be submitted, and thus ensures the patient's freedom from dependency on the doctor's decision whether or not to refer him or her to a colleague. If this duty is neglected, it is to be feared that the patient, especially given his or her condition of great vulnerability, will feel that his or her trust has been betrayed when he or she ends up without any alternative solution.

In addition, the Committee considers it necessary to clarify the different approaches to the duty to refer: the first, widely practised approach allows the doctor to refer the patient to a more specialised or experienced colleague. The referring doctor considers the medical procedure to be necessary or useful, but asks a colleague to perform it. All members approve of this approach, including in end-of-life situations and for euthanasia in particular. The second approach – and there is no consensus about its consequences, which are discussed in point B – reflects the attitude of a doctor who, on the contrary, does not want euthanasia to be practised and is subject to a duty to refer the patient to a colleague who has no objection in principle to performing euthanasia.

A.5. Continuity of care

In accordance with legal and ethical requirements, a patient cannot be abandoned. Care provision is sufficiently diverse to satisfy the needs of end-of-life patients. Three laws, on euthanasia, palliative care and patients' rights, were introduced in 2002 in order to support this attitude of respect, empathy and mutual collaboration.

Even in the event of a disagreement between the patient and the doctor or care team, or between health professionals, about how the end-of-life patient should be treated, even if a particular solution is rejected, the patient must continue to receive the best care for his or her condition. Though beyond hope of recovery or survival, he or she must be treated with the utmost concern and responsibility by everyone at the bedside, in respect for his or her dignity and autonomy.

A.6. End-of-life “clinics”

With regard to end-of-life clinics, all members feel that their introduction must not lead to the disappearance of confidential dialogue between patient and doctor about the patient's end-of-life situation. It must not lead to a situation where such requests are responded to mechanically and systematically. Such a clinic must not be an institution that imposes the “mandatory” practice of euthanasia in a routine and disengaged fashion. Nor must it be a place to which patients are automatically referred, under a “protocol”, from institutions which apply institutional policies prohibiting or restricting euthanasia. The law highlights the unique relationship between patient and doctor, and in no way endorses the establishment between institutions of practices involving the systematic referral of a particular category of patients.

B. Points of disagreement

B.1. On the first question

May a care facility (hospital, nursing and care home, residential home) prohibit the practice of euthanasia (as defined by the Act of 28 May 2002) on its premises, or add conditions for euthanasia to its regulations in addition to those laid down by the said law?

Beyond these unanimous recommendations, some members believe that it is neither legal nor ethically legitimate for an institution to develop and enforce compliance by its doctors with an institutional policy imposing conditions additional to those already set by the Law of 28 May 2002, or systematically providing for additional investigations which are presented as precautionary measures but which in fact excessively delay or prevent all euthanasia. This law has created a margin of freedom between the patient and his or her doctor which would be undermined by the automatic application of this type of policy. Such required compliance would deny the doctor the ability to listen and make a personal response to the patient, in accordance with the provisions of the law. These members argue that an institution may not prohibit a doctor who complies with the legal criteria from practising euthanasia on its premises, or punish him or her for having done so. For more details on this viewpoint, see the conclusions of the first position, which describes it in depth and detail; see above, Part II, A.2., g).

Other members feel that an institutional policy may be developed if it reflects an endeavour to come up with a high-quality medical response to the patient's request and is then incorporated into a compulsory care path with regard to the patient.

A further group of members contends that it is in itself ethically legitimate for an institution to construct and defend its personal identity – including its religious or philosophical orientation – as patient autonomy can only be exercised in an institutionally defined care culture.

Various different views are taken by the members of the “**duty to refer**”, whether or not they are in favour of an institutional policy.

Some members argue that if the consulted doctor believes that the medical conditions are not satisfied, the only duty incumbent upon him or her, as indicated by the law, is to mention this in the patient's medical record and ensure that the record is passed on to a colleague chosen by the patient. The obligation to refer to which the doctor is subject is only appropriate if he or she is objecting on grounds of conscience. Otherwise, this obligation would amount to a kind of appeal procedure, but one initiated by the doctor rather than the patient, which would be meaningless.

Other members, however, believe that precisely because the doctor objects on grounds of conscience, he or she should not be obliged to refer the patient, as this would be contrary to his or her convictions. A doctor should have the freedom to refuse not only to perform euthanasia, but also to perform any action that would make its performance possible by another doctor. Employee recruitment procedures should be characterised by greater

transparency as regards both the organisational culture and the origin and content of the institutional policy, to avoid having to resort to repressive measures due to non-compliance with the policy.

Finally, a further group of members defends the doctor's obligation to refer, whatever the grounds for his or her refusal to administer euthanasia, in order to ensure continuity of care and to respond to the vulnerability of the patient, to enable his or her care provision to be brought to an end in calmer conditions.

B.2. On the second question

Should competent specialised clinics or institutions be created (whose sole purpose would be to assist patients at the end of their lives), which would be intended in particular to enable any patient satisfying the legal requirements to gain access to a medical environment that is not ideologically opposed to the principle of euthanasia?

Some members are not opposed to this, by analogy with other specialist organisations such as family planning centres. The creation of such institutions would allow euthanasia to be organised, where the legal requirements were satisfied, when it had been requested by patients but not carried out.

Others argue instead in favour of teams that would provide support to the doctors consulted and would be external to the institutions; these would be able to stand in for the doctor if, after examining the request, the latter refused to perform euthanasia.

Still others are opposed to end-of-life clinics for various reasons. The first is that the existence of such "clinics" would put too much pressure on the most vulnerable people to accept a "duty to die". It would also reinforce the categorisation of people and their treatment according to those categories: centres for drug addicts, for the mentally ill, for refugees, for the homeless, for old people – and for people who wish to die.

The second reason is that any institution must provide defined care in all its different forms, and not exist for the sole purpose of performing a medical act of euthanasia.

Finally, the third reason is that the public funds invested in such clinics would be better used for the benefit of end-of-life treatment and campaigns to inform the public about the practical application of the Law of 28 May 2002.

The opinion was prepared by the select commission 2011/1, consisting of:

Joint chairpersons	Joint reporters	Members	Member of the Bureau
P. Cras	P. Cras	C. Bolly	M.-G. Pinsart
M.-G. Pinsart (from 27 May 2013)	G. Genicot	Y. Denier	
	Th. Locoge	M. Dumont	
		M. Eisenhuth	
		G. Evers-Kiebooms	
		J. Frühling	
		J. Herremans	
		R. Kramp	
		G. Lebeer	
		Th. Locoge	
		Y. Oschinsky	
		A. Pierre	
		R. Rega	
		R. Rubens	
		B. Spitz	

Member of the secretariat

V. Weltens

Experts interviewed

Prof. Luc Deliens, Director End-of-life-care Research Group Ghent University & Vrije Universiteit Brussel

Prof. Wim Distelmans, Co-President of the Federal Commission for the Control and Evaluation of Euthanasia

Dr Antonino Spoto, Head of the Palliative Care Service at the Grand Hôpital de Charleroi (Loverval)

Sylvie Tack, Researcher at the University of Ghent (UGent), Lawyer

Evelien Delbeke, Researcher at the University of Antwerp (UA), Lawyer

Prof. Chris Gastmans, Centre for Biomedical Ethics and Law, KU Leuven

Peter Degadt, Manager Director of Zorgnet Vlaanderen

Dr Petra de Jong, Director of the Vereniging voor een Vrijwillig Levenseinde (NVVE, the Netherlands)

Tom Goffin, Legal expert to the National Council of the Order of Physicians, Centre for Biomedical Ethics and Law, KU Leuven

The working documents of the select commission 2011/1 – request for opinion, personal contributions of the members, minutes of the meetings, documents consulted – are stored as Appendixes 2011/1 at the Committee’s documentation centre, where they may be consulted and copied.

This opinion is available at www.health.belgium.be/bioeth, under the heading ‘Opinions’.

[NOT TRANSLATED]

Annexe 1

Synthèse des rapports de la Commission fédérale de contrôle et d'évaluation de l'euthanasie (CFCE)

La synthèse ci-après reproduit les chiffres officiels des déclarations enregistrées depuis le 22 septembre 2002, date de l'entrée en vigueur de la loi. Ces rapports sont basés sur les déclarations des médecins et donnent une information forcément limitée aux euthanasies déclarées.

En vertu de l'article 9 de la loi du 28 mai 2002, l'une des missions légales de la Commission fédérale de contrôle et d'évaluation de l'euthanasie, appelée ci-dessous la CFCE, est d'établir, à l'intention des Chambres législatives, tous les deux ans, un rapport composé :

- a) d'un rapport statistique basé sur les informations recueillies dans le second volet du document d'enregistrement transmis par les médecins;
- b) d'une description et d'une évaluation de l'application de la loi;
- c) le cas échéant, de recommandations susceptibles de déboucher sur une initiative législative et/ou d'autres mesures concernant l'exécution de la loi.

Ces rapports sont disponibles sur le portail du SPF Santé publique (<http://www.health.belgium.be/euthanasie>).

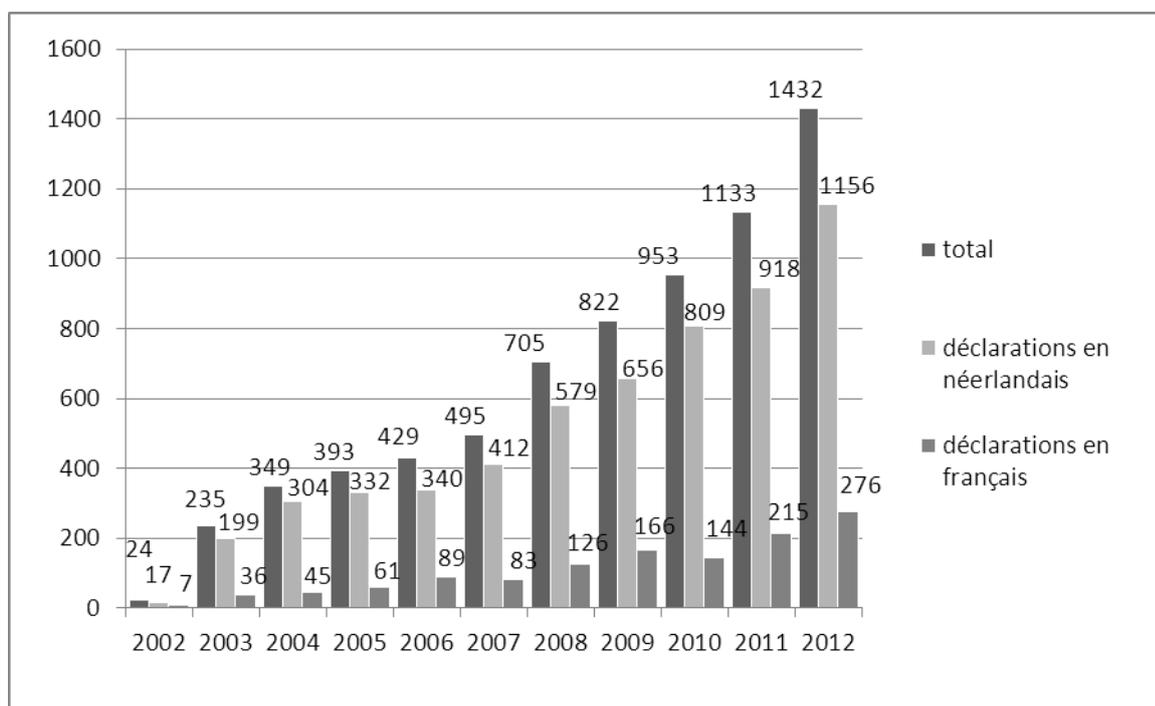
La présente synthèse tient compte des dernières données statistiques relatives aux années 2010 et 2011, qui sont reprises dans le cinquième rapport. Les données sont pour l'essentiel assez stables. Pour en juger, le parti a été pris d'indiquer, lorsque cela est pertinent, les pourcentages de chaque couple d'années couvert par un rapport.

Il a également été tenu compte dans cette synthèse de la "brochure à l'intention du corps médical", figurant en annexe des rapports, que la CFCE a pris l'initiative de rédiger après avoir constaté que "*ses délibérations et les discussions qui ont eu lieu en son sein (...) pourraient être utiles pour lever (...) quelques difficultés rencontrées par des médecins dans l'interprétation de certains termes de la loi*". En revanche, par souci de synthèse, on n'a pas - à ce stade - tenté de résumer les considérations contenues dans la section 2 des rapports ("*Description et évaluation de l'application de la loi*"), qui consistent en une explication détaillée et des commentaires à propos des statistiques reprises ici. Les "*Recommandations de la Commission [CFCE] concernant l'exécution de la loi*" ont en revanche été prises en compte, de même que les conclusions des cinq rapports, qui se rejoignent et qui sont reproduites et résumées *in fine*.

Dans ses cinq premiers rapports, la CFCE a estimé que l'application de la loi n'a pas donné lieu à des difficultés majeures. Il n'est ni de sa mission ni de sa compétence de prendre position sur les débats éthiques et philosophiques portant sur une éventuelle extension de son domaine d'application.

1. Nombre et répartition des euthanasies

La CFCE reçoit de plus en plus de déclarations, signe sans doute que la loi du 28 mai 2002 entre de plus en plus dans les mœurs des patients et des médecins : 235 en 2003, 349 en 2004, 393 en 2005, 429 en 2006, 495 en 2007, 704 en 2008, 822 en 2009, 953 en 2010, 1133 en 2011 et 1432 en 2012.



Source: J. Herremans, sur base des chiffres CFCE

Les déclarations sont très majoritairement néerlandophones (82% en 2010-2011, 80% en 2008-2009, 81% en 2006-2007 et 86% en 2004-2005). Depuis le début, la CFCE s'interroge sur les raisons de cette disproportion marquante; dès son premier rapport (pp. 13-14), elle n'a pu qu'émettre des conjectures, sans pouvoir conclure. Il est probable que ceci soit dû à la conjugaison de plusieurs facteurs.

En 2006-2007, la **proportion du nombre de décès par euthanasies déclarées** fut en moyenne de 0,44% de l'ensemble des décès; en 2008-2009, 0,7%; en 2010-2011, environ 1%.

En ce qui concerne **l'âge des patients**, la majorité des euthanasies concernent des patients âgés de 40 à 79 ans (77% en 2004-2005, 80% en 2006-2007, 73% en 2008-2009, 69% en 2010-2011). L'euthanasie est très rare avant 40 ans (2%, chiffre stable sur les six dernières années) et peu fréquente après 80 ans (18% en 2006-2007, 25% en 2008-2009 et 27% en 2010-2011). Le grand âge n'apparaît dès lors pas être un facteur favorisant l'euthanasie : la plupart des patients (52%, chiffre stable sur les quatre dernières années) étaient âgés de 60 à 79 ans. Il s'agit un peu plus souvent d'hommes (54% en 2006-2007, 51% en 2008-2009, 52% en 2010-2011).

Lieu du décès: actuellement, 52% des euthanasies sont pratiquées à la résidence du patient (soit à son domicile – en général par le médecin généraliste –, soit dans une maison de repos ou de repos et de soins : respectivement 44 à 45% et 7 à 8% des cas). 45% des euthanasies sont effectuées en milieu hospitalier et 3% dans des lieux divers (chiffres stables ces quatre dernières années). La proportion des décès hospitaliers était un peu plus grande auparavant (54% en 2004-2005 et 50% en 2006-2007).

2. L'euthanasie en pratique

Sur le plan technique, à l'heure actuelle, dans la quasi-totalité des cas (96% en 2006-2007, 98% en 2008-2009, 99% en 2010-2011), le décès est obtenu en induisant d'abord une inconscience profonde par injection intraveineuse (en général de Pentothal ou Thiopental) et – sauf si le décès se produit en quelques minutes dès cette injection – en injectant ensuite un paralysant neuromusculaire qui provoque le décès par arrêt respiratoire. La CFCE a noté que, d'après les données disponibles de la littérature médicale, une telle manière d'agir est effectivement la plus adéquate pour remplir les conditions requises pour une euthanasie correcte: décès rapide et calme, sans souffrance ni effets secondaires. Une légère sédation préalable par Benzodiazépine en intraveineux est fréquente.

Dans de rares cas (1 à 2%), l'inconscience a été obtenue par administration d'une dose létale d'un barbiturique en potion que le malade a avalé lui-même. Dans la majorité de ces cas, le décès s'est produit rapidement sans autre intervention; parfois, un paralysant neuromusculaire a été injecté après la perte de conscience. Quand c'est le malade lui-même qui ingère le produit, il s'agit d'un acte qui peut être qualifié de "suicide médicalement assisté". La CFCE a très tôt considéré (brochure précitée) que *"cette manière de procéder est autorisée par la loi, pour autant que les conditions et les procédures légales pour que l'euthanasie soit autorisée aient été respectées et que l'acte se soit déroulé sous la responsabilité du médecin présent et prêt à intervenir"*. Elle a également indiqué (premier rapport, p. 24) que *"lorsque le geste létal est posé par le patient, ce n'est souvent qu'en partie : le patient qui absorbe une potion le fait avec l'aide du médecin, le patient peut actionner lui-même le robinet de la perfusion mais celle-ci a été mise en place par le médecin, l'absorption par la bouche peut être suivie d'une injection I.V., etc. Ces circonstances entrent dans le cadre de la loi dans sa rédaction actuelle, qui implique que le médecin ait le contrôle du processus de décès jusqu'à son terme, quelles qu'en soient les modalités"*. La loi ne prévoit en effet pas la technique à utiliser pour pratiquer l'euthanasie, elle n'impose pas une manière plutôt qu'une autre. Il faut noter que cette interprétation est conforme à celle du Conseil National de l'Ordre des médecins dans son avis du 22 mars 2003.

3. Diagnostics à l'origine de l'euthanasie

La grande majorité des affections qui ont donné lieu à une euthanasie (83% en 2004-2005, 81% en 2006-2007, 79% en 2008-2009, 75% en 2010-2011; on note donc une tendance à une légère diminution) étaient des *cancers généralisés ou gravement mutilants*, sous leurs diverses formes (ceci inclut les tumeurs malignes et les affections sanguines malignes). La plupart des patients

avaient subi de multiples traitements à visée curative et/ou palliative; ils étaient souvent suivis par des équipes de soins palliatifs et leur décès était prévisible dans les jours ou semaines à venir.

Les *affections neuromusculaires évolutives mortelles* et, dans une moindre mesure, les séquelles neurologiques dues à une maladie ou un accident (séquelles pathologiques ou traumatiques) viennent en second lieu (de 6 à 8%). Les autres affections, plus rares, qui ont été à l'origine d'une euthanasie étaient, respectivement en 2008-2009 et 2010-2011 : affections neuromusculaires non évolutives, 1% et 0%; affections pulmonaires non cancéreuses, 3%; affections cardio-vasculaires, 4% et 5%; affections rénales, 1% et 0%; affections neuropsychiques, 2% et 3%; pathologies multiples, 2%; autres diagnostics, 2% et 4%.

Dans l'hypothèse où le décès n'est pas prévu à brève échéance, les diagnostics sont les suivants, respectivement en 2008-2009 et 2010-2011 : cancers, 10% et 9%; affections neuromusculaires évolutives, 19% et 20%; affections neuromusculaires non évolutives, 0% et 5%; affections pulmonaires non cancéreuses, 0% et 5%; affections cardio-vasculaires, 0% et 10%; affections neuropsychiques, 24% (stable); pathologies multiples, 12% et 9%; autres diagnostics, 12% et 16%.

4. Cas de loin le plus fréquent : demande consciente et décès prévisible à brève échéance

La très grande majorité des euthanasies (97% de 2006 à 2009, 98% en 2010-2011) sont consécutives à une *demande consciente* du malade, souvent antérieure de plusieurs semaines, voire de plusieurs mois à l'acte. Seuls 2 à 3% des euthanasies portent donc sur des patients irréversiblement inconscients qui avaient rédigé une *déclaration anticipée* moins de cinq ans avant le début de l'impossibilité de manifester leur volonté.

Dans la brochure dont question ci-dessus, la CFCE a souligné que la demande actuelle, exprimée par un patient capable et conscient qui se trouve dans une situation médicale où les conditions mises par la loi pour pratiquer une euthanasie sont réunies, est le cas habituel et que cette "*demande reste valable pendant tout le temps nécessaire à la mise en œuvre de l'euthanasie, même si le patient devient inconscient pendant cette période*". Par contraste, l'euthanasie pratiquée sur base d'une déclaration anticipée est une éventualité qui ne concerne *que les patients irréversiblement inconscients*.

L'échéance du décès était brève dans 94% des cas en 2006-2007, 92% en 2008-2009 et 91% en 2010-2011. Dans les autres cas, le décès n'était prévisible qu'à une échéance plus lointaine. Lorsque l'euthanasie a été pratiquée chez un patient irréversiblement inconscient sur la base d'une déclaration anticipée, l'échéance du décès, si elle était indéterminée, a été classée brève.

Dans la brochure précitée, "*la Commission [CFCE] a considéré que l'échéance du décès doit être estimée "non brève" si la mort n'est pas attendue dans les mois qui viennent. En pratique, ceci*

signifie que seules les affections non évolutives ou très lentement évolutives doivent être considérées comme exigeant la procédure renforcée" (deux consultants, dont l'un est psychiatre ou spécialiste de l'affection en cause, et délai d'attente d'un mois après la demande écrite; article 3, § 3, de la loi). "Quand le décès est attendu dans les jours, semaines ou mois qui viennent, il peut être considéré comme prévisible à brève échéance. Lors des discussions qui ont eu lieu au sein de la Commission [CFCE] concernant l'estimation faite par le médecin de la prévision du décès, il est apparu qu'en dehors de cas évidents, le médecin qui a le patient en charge est seul à même de juger de l'échéance plus ou moins proche du décès".

5. Souffrance constante, insupportable et inapaisable

Pour pouvoir accéder à l'euthanasie, le patient doit se trouver "dans une situation médicale sans issue" et faire état "d'une souffrance physique ou psychique constante et insupportable qui ne peut être apaisée et qui résulte d'une affection accidentelle ou pathologique grave et incurable" (article 3, § 1^{er}, de la loi). Les souffrances physiques le plus souvent mentionnées sont : suffocation, obstruction digestive, vomissements, douleurs diverses, cachexie, dyspnée, dysphagie, épuisement, hémorragies, paralysies, plaies, transfusions répétées, etc. Quant aux souffrances psychiques, les plus fréquentes sont « la dépendance, la perte de dignité et le désespoir ou la désespérance ». Chez la plupart des malades, plusieurs types de souffrances, tant physiques que psychiques, étaient présents simultanément. Les souffrances sont toujours décrites comme constantes, insupportables et inapaisables.

Dans la brochure dont question ci-dessus, *"la Commission [CFCE] a considéré que, si certains facteurs objectifs peuvent contribuer à estimer le caractère insupportable de la souffrance, celui-ci est en grande partie d'ordre subjectif et dépend de la personnalité du patient, des conceptions et des valeurs qui lui sont propres. Quant au caractère inapaisable de la souffrance, il faut tenir compte du fait que le patient a le droit de refuser un traitement de la souffrance, ou même un traitement palliatif, par exemple lorsque ce traitement comporte des effets secondaires ou des modalités d'application qu'il juge insupportables. La Commission [CFCE] a toutefois estimé que dans ces cas, une discussion approfondie entre le médecin et le patient est nécessaire".* Elle note également par ailleurs que, dans certains cas, le caractère insupportable des souffrances doit être estimé en tenant compte de l'âge.

6. Décisions de la CFCE

Les décisions prises par la CFCE sont, le plus souvent, l'acceptation simple de la déclaration (80% en 2006-2007, 85% en 2008-2009, 86% en 2010-2011). Le volet I, mentionnant l'identité des personnes impliquées, fut ouvert pour adresser une simple remarque "didactique" au médecin (détail manquant, anonymat du volet II non respecté) respectivement dans 7%, 4% et 2% des cas. Dans 11% à 13% des situations, ce volet nominatif fut ouvert afin de solliciter des précisions qui ont toujours permis l'acceptation de la déclaration dans un second temps. Depuis l'entrée en vigueur de la loi, aucune déclaration n'a comporté d'éléments faisant douter du respect des conditions essentielles de la loi, et aucun dossier n'a donc été transmis à la

justice.

7. Résumés et conclusions des cinq premiers rapports de la CFCE

Il faut souligner qu'un certain nombre de déclarations mentionnent que le décès est survenu rapidement, paisiblement et sereinement, en quelques minutes, souvent en présence de la famille ou de certains proches précisés, parfois d'une infirmière, d'un autre médecin ou de l'équipe de soins palliatifs. Il arrive aussi qu'il soit simplement indiqué que la procédure s'est déroulée très correctement, rapidement et calmement. Lorsque cela est précisé dans la déclaration, l'atmosphère est toujours décrite comme sereine, avec un soulagement du malade, un accompagnement par ses proches pendant l'acte et des remerciements adressés au médecin.

Dans ses trois premiers rapports, la CFCE a tenu "*à souligner qu'[elle a] apprécié l'attitude des médecins qui, en complétant le document d'enregistrement, ont tenu, tout en respectant la volonté de leur patient, à se conformer à la loi*". Dans le quatrième rapport, elle ajoute que ses membres "*insistent sur l'obligation de compléter ce document qui, dans un état de droit, doit permettre de vérifier que l'acte, autorisé par la loi, de mettre intentionnellement fin à la vie a été accompli dans le strict respect des obligations légales*".

Selon la CFCE, l'augmentation constante du nombre d'euthanasies "*était prévisible et s'explique vraisemblablement par la diffusion progressive de l'information relative aux décisions en fin de vie auprès du public et des médecins*".

Elle constate que "*les affections à l'origine des euthanasies ont toutes été, comme l'exige la loi, incurables et graves, sans issue médicale possible. Dans la très large majorité des cas, il s'agit de cancers généralisés ou gravement mutilants chez des patients dont le décès est attendu à brève échéance et, dans une moindre mesure, d'affections neuromusculaires évolutives mortelles. D'autres pathologies sont rarement en cause*", et que "*les souffrances insupportables et inapaisables dont font état les patients sont souvent multiples et concernent généralement à la fois les sphères physique et psychique*". Dans le quatrième rapport, il est ajouté que, "*parfois, la gravité de la pathologie ou le caractère insupportable des souffrances résultent de la coexistence de plusieurs pathologies incurables. Chez les patients d'âge avancé, la distinction qui doit être faite entre les souffrances liées à ces pathologies et celles qui sont propres à l'âge a parfois donné lieu à des divergences de vues entre la majorité de la Commission [CFCE] et certains de ses membres*".

Les euthanasies pratiquées alors que le décès n'est pas attendu à brève échéance sont relativement rares et concernent essentiellement des affections neuromusculaires évolutives mortelles avec tétraplégies ou paralysies graves multiples, et exceptionnellement des séquelles neurologiques graves consécutives à une affection pathologique ou à un accident. Les cas de pathologies neuropsychiatriques donnent lieu à un examen particulièrement minutieux pour s'assurer qu'ils entrent effectivement dans le cadre de la loi et que les conditions légales ont été

respectées.

Le nombre d'euthanasies pratiquées chez des patients inconscients sur la base d'une déclaration anticipée reste faible, en raison du champ d'application limité de cette déclaration puisqu'elle ne concerne que les patients irréversiblement inconscients. La CFCE estime que la pratique de la déclaration anticipée devrait être encouragée, étant donné la difficulté et la gravité des décisions médicales dans les situations d'inconscience irréversible. Certains membres de la CFCE estiment que les procédures de rédaction, de renouvellement et d'enregistrement de la déclaration sont inutilement lourdes et devraient être simplifiées.

Dans la très grande majorité des cas, l'euthanasie est pratiquée correctement et en accord avec les données disponibles de la littérature médicale, en induisant d'abord une inconscience profonde; dans tous les cas où un commentaire accompagne la technique utilisée, il signale que le décès survient paisiblement en quelques minutes, fréquemment en présence de proches.

Il faut relever qu'en plus des consultations imposées par la loi, de nombreux médecins et équipes palliatives sont volontairement consultés, ce qui confirme le sérieux des décisions prises. Certains membres de la CFCE estiment cependant qu'il convient de veiller à éviter que des consultations médicales supplémentaires n'aboutissent en fait à créer des conditions non prévues par la loi, au détriment du respect de la volonté du patient.

Dans le cadre de ses compétences et de sa mission, la CFCE n'a à aucun moment recueilli d'éléments qui justifieraient des initiatives législatives nouvelles. Dans son premier rapport, elle a estimé *"nécessaire un effort d'information dirigé tant vers le corps médical que vers les citoyens. L'information des médecins devrait, en particulier, viser à leur donner les éléments permettant d'intervenir efficacement comme consultants dans le domaine de la fin de la vie"* et suggéré *"que des enquêtes concernant l'ensemble des décisions médicales en fin de vie soient régulièrement organisées dans notre pays, comme elles le sont depuis 1990 aux Pays-Bas"*.

Enfin, la CFCE se satisfait de ce qu'aucune déclaration n'a mis en évidence de violation des conditions de fond de la loi. Les erreurs d'interprétation, qui portent uniquement sur des points de procédure, sont rares et ont été résolues sans difficulté majeure.

Annexe 2

Clinique de fin de vie ('Levenseindekliniek') aux Pays-Bas

La Levenseindekliniek⁸⁴ (*Clinique de fin de vie*) est un institut auquel peuvent s'adresser les personnes qui satisfont aux critères de la loi néerlandaise *Toetsing Levensbeëindiging op verzoek en hulp bij zelfdoding* (*contrôle de l'euthanasie et de l'assistance au suicide*) et qui ont fait une demande effective d'euthanasie à laquelle leur propre médecin n'accède pas. La clinique de fin de vie intervient donc uniquement lorsque la demande du patient n'est pas prise en compte par son propre médecin. Les critères de prudence de la loi sur l'euthanasie sont de nouveau examinés par cet institut et, pour la plupart des demandes examinées, l'euthanasie est finalement pratiquée à domicile et par le médecin propre du patient. Pour l'examen de la demande, la clinique de fin de vie dispose du dossier médical et envoie une équipe composée d'un médecin et d'un infirmier afin d'avoir un ou plusieurs entretiens au domicile du patient et, de préférence, des proches également. La clinique n'intervient que pour les patients néerlandais. La clinique de fin de vie se compose donc d'équipes ambulantes, financées par des dons pour la plupart, bien que des négociations soient en cours avec les assurances maladie.

Au cours du congrès du 1^{er} novembre 2012 à La Haye, la "Nederlandse Vereniging voor een Vrijwillig Levenseinde" (NVVE) a dressé le tableau des 7 premiers mois de l'existence de cette clinique de fin de vie⁸⁵. Ont pris la parole les acteurs de cette expérience, la veuve d'un patient atteint de la sclérose en plaques qui s'était heurté à divers refus successifs, un représentant de la KNMG, académie royale de médecine dont l'avis était réservé quant à cette initiative, un membre des commissions régionales de contrôle afin d'évoquer la manière dont les commissions entendent analyser les déclarations d'euthanasie pour ces cas spécifiques. A noter aussi l'intervention du président d'une compagnie d'assurance intervenant pour le coût des prestations médicales annonçant la conclusion d'un accord pour couvrir les frais engendrés par l'intervention de l'équipe de cette clinique.

La question posée à l'entame de ce congrès était : clinique de fin de vie : une solution d'urgence ou LA solution ? De nombreux intervenants penchaient pour la première option : la clinique de fin de vie ne pourrait représenter qu'une solution transitoire permettant de répondre au problème des patients qui ne reçoivent pas une écoute positive à leur demande d'aide médicale à mourir. Même aux Pays-Bas, pays pionnier en matière de dépénalisation de l'euthanasie, il faut constater que des patients qui répondent pourtant aux critères prévus par la loi se heurtent à des refus de la part de leur médecin, soit parce que celui-ci pense que la personne n'entre pas dans les conditions, soit parce qu'il ne peut ou ne veut pratiquer l'acte. Il est important de souligner que cette initiative s'inscrit dans le cadre de la loi et qu'il n'est nullement question de répondre à d'autres problématiques, telles que celle d'une personne qui ne ferait état que d'une lassitude de vivre. Tout est mis en place pour que les critères de minutie soient respectés et cela dans la plus grande transparence.

84 www.NVVE.nl consulté le 19/4/2013.

85 J. Herremans, communication personnelle.

Le siège de cette clinique est établi dans une maison bourgeoise de La Haye. L'équipe présente est réduite : il s'agit essentiellement d'examiner les demandes qui doivent être introduites par écrit, sur un formulaire qui permet d'avoir une première idée de la situation. Les questions portent tant sur des points extrêmement administratifs (domicile, police d'assurance, etc.) que sur les aspects propres à une demande d'euthanasie : nature de la souffrance, éléments concernant la demande (durée, motivation, etc.) et la pathologie et enfin les coordonnées du ou des médecins traitants.

Après un premier examen de cette demande, il peut être demandé de compléter l'une ou l'autre information faisant défaut. Mais dans tous les cas, contact est pris avec le médecin traitant pour recueillir les éléments médicaux nécessaires.

Par la suite, si la demande apparaît comme entrant dans le cadre de la loi, une équipe composée d'un médecin et d'une infirmière prend contact avec le patient. En novembre 2012, 15 équipes opérationnelles tentaient de couvrir le territoire des Pays-Bas.

Du 1^{er} mars au 31 octobre 2012, 456 demandes avaient été enregistrées (62,7 % femmes versus 37,3 % hommes). Par rapport aux euthanasies «classiques », d'autres différences apparaissent : 31 % d'affections psychiatriques, un plus grand nombre de personnes âgées de moins de 60 ans. 27 % des dossiers ont tout de suite été classés sans suite, soit par ce que les personnes ne répondaient pas aux critères, soit parce qu'elles n'ont pas voulu poursuivre leur demande. Pour 6 %, l'euthanasie a été accomplie par le médecin traitant, qui s'est senti soutenu par l'équipe ambulatoire. Pour 4 %, c'est le médecin de l'équipe qui, au terme de la procédure, a posé l'acte : comme il s'agit en général de situation que l'on pourrait qualifier de non terminale, le médecin a l'occasion de nouer cette relation profonde qui est un des fondements de la loi. Près d'un tiers des patients a opté pour l'absorption d'une potion létale.

En conclusion, la population qui fait appel à cette clinique de fin de vie est en général plus jeune que celle qui apparaît dans les statistiques des euthanasies, atteinte de manière plus importante de maladies psychiatriques et préférant de manière également plus importante la méthode du suicide médicalement assisté.

La clinique de fin de vie selon le modèle néerlandais connaît un parallèle avec les centres d'interruption de grossesse. L'institut répond à un certain besoin étant donné qu'il existe des demandes effectives d'euthanasie qui ne sont pas prises en compte ou à l'égard desquelles le médecin a des doutes concernant les dispositions légales. Il a donc essentiellement une fonction de clarification et de soutien. La clinique de fin de vie soutient le « colloque singulier » et l'élargit à une équipe spécialisée. En Belgique, cette fonction est surtout assurée par les médecins LEIF qui proposent non seulement des consultations mais aussi une assistance pratique lors de la pratique de l'euthanasie. Cependant, l'initiative d'une clinique de fin de vie recèle également des dangers. Pourquoi y aurait-il encore des instituts qui pratiquent l'euthanasie lorsqu'il y a des cliniques de fin de vie qui mènent une pratique libérale. À terme, la clinique de fin de vie disposera également des espaces nécessaires pour exécuter elle-même

les procédures d'euthanasie. Des questions se posent alors sur la pratique qui serait menée dans un tel institut. Comment les critères de prudence garantissant que la loi est respectée dans un tel institut doivent-ils être surveillés? Quels prestataires de soins seraient-ils désireux de travailler dans un tel environnement, en étant constamment confrontés à des personnes qui demandent une fin de vie choisie par elles-mêmes?

Annexe 3

Exemples de politiques éthiques institutionnelles

1) Avis n° 1 de Zorgnet Vlaanderen

www.zorgnetvlaanderen.be/Documents/VISIETEKST_advies1.pdf

Il s'agit d'un texte de vision concernant « Zorg voor een menswaardig levenseinde ».

2) Plan par étapes dans une demande d'euthanasie d'un groupe de maisons de repos et de soins du Limbourg [Traduction libre]

ÉTAPE 1 : une politique éthique prévenante en cas de demande d'euthanasie

Exploration de la demande : s'agit-il d'une véritable demande d'euthanasie?

- ◆ Ce que demande le résident est-ce clair ? Est-ce bien une demande d'euthanasie, ou une demande d'accompagnement prévenant en fin de vie ? La clarification et l'exploration approfondies de la demande constituent un processus qui prend du temps et est d'une importance cruciale.
- ◆ Soyez clairs et définissez l'euthanasie pour que chacun soit sur la même longueur d'onde.
- ◆ Notez mot à mot la demande du résident dans le dossier médical et infirmier, et datez-la.
- ◆ Écoutez la demande du résident et vérifiez :
 - Pourquoi pose-t-il la question ? Quelle est sa motivation ?
 - A qui a-t-il exprimé sa demande en premier lieu ? Et à qui a-t-il réitéré sa demande depuis lors ?
 - Depuis combien de temps est-il en demande ? Et combien de fois a-t-il déjà exprimé la demande ?
 - A-t-il déjà fait la demande au médecin traitant et quelle a été la réponse ?
 - Sa demande découle-t-elle de la peur des douleurs et souffrances à venir ? Sa demande est-elle le fruit d'une impulsion ou est-on en présence de sentiments dépressifs ?
 - A-t-il suffisamment d'informations au sujet du diagnostic, du pronostic et des possibilités de traitement ? A-t-il été informé de tous les aspects de son état de santé ?
 - A-t-il suffisamment d'informations sur les possibilités existantes des soins palliatifs ?
 - Est-il en état d'exprimer sa volonté au moment de la demande ? Est-on en présence de diminution de la conscience ou de diminution de la capacité de raisonnement ?
 - Fait-il sa demande de manière entièrement volontaire ? Une quelconque pression s'exerce-t-elle ?
 - Qu'attend le résident qui m'adresse la demande ?
- ◆ Demandez au résident avec quels membres de sa famille il a déjà parlé de sa demande d'euthanasie, et avec lesquels les discussions ultérieures peuvent être menées.

- ◆ Dans tous les cas, expliquez clairement au résident à qui il peut s'adresser, quels soins il peut escompter, et ce qui arrivera lorsqu'il ne sera plus en mesure de prendre une décision par lui-même.

Notez tous ces éléments dans le dossier du résident.

Intégration d'un filtre palliatif.

- ◆ Mise en place d'un responsable ou d'une équipe de soutien palliatif.
 - Fourniture d'informations sur toutes les possibilités en matière de soins palliatifs (contrôle des symptômes, alternatives de traitement)
 - Avis palliatif (au besoin, optimisation du contrôle de la douleur et des symptômes, soutien psychosocial et spirituel)

ÉTAPE 2 : si la demande persiste

- ◆ Vérifiez si la loi s'applique à ce résident. Vous pouvez consulter la loi dans le Moniteur Belge (publication 22/06/2002) ou sur le site internet www.just.fgov.be.

Les conditions de base sont les suivantes :

- Le résident doit être majeur, être capable dans le sens juridique du terme, et être conscient au moment de sa demande.
- La demande est formulée de manière volontaire, réfléchie et répétée, et elle ne résulte pas d'une pression extérieure.
- Le résident se trouve dans une situation médicale sans issue et fait état d'une souffrance physique ou psychique constante et insupportable qui ne peut être apaisée, et qui résulte d'une affection accidentelle ou pathologique grave et incurable.
- ◆ Discutez de la demande avec le médecin traitant, demandez-lui son point de vue et s'il est disposé à pratiquer l'euthanasie.
- ◆ Si l'on décide de donner suite à la demande, informez-vous qui peut être contacté comme médecin consultant.
- ◆ Si l'on décide de ne **pas** donner suite à la demande d'euthanasie pour un problème de principe (p.ex. la demande ne répond pas aux conditions légales ou à la procédure, le médecin ne souhaite pas procéder à l'euthanasie),
 - Évaluez les autres options, notamment :
 - poursuite du contrôle de la douleur et des symptômes
 - sédation palliative
 - le résident souhaite prendre un deuxième avis auprès d'un médecin de son choix
 - Organisez une concertation avec le résident, sa famille et ses soignants. Le médecin traitant explique les raisons du refus.
 - En concertation avec toutes les parties concernées, le médecin traitant s'efforce de référer correctement le résident.

ÉTAPE 3 : procédure

- ◆ Organisation d'un entretien avec les proches du résident.
 - Quel est leur état d'esprit vis-à-vis de la situation de cette personne qui leur est

chère ?

- Comment vivent-ils sa maladie ?
- De quelles informations les proches ont-ils besoin concernant la maladie et le pronostic ?
- Que doivent-ils savoir concernant les possibilités palliatives ?
- Quelles attitudes les proches adoptent-ils vis-à-vis de la demande d'euthanasie ?
- ◆ Prévoyez une requête écrite de demande d'euthanasie conformément à la législation.
- ◆ Évaluation par un médecin autre que le médecin traitant du résident.
- ◆ Évaluation par un deuxième médecin pour un résident non terminal.
- ◆ Organisation d'une concertation interdisciplinaire par le chef de service et le responsable palliatif.
- ◆ Préparation concrète de l'euthanasie
 - Accompagnement du résident et de sa famille (adieux...).
 - Fixer la date et l'heure avec le résident et sa famille.
 - Commander les médicaments en pharmacie (le médecin traitant prend contact avec le pharmacien).
 - Prévoir le document d'enregistrement.
 - Vérifier la présence d'une bonne voie d'accès veineuse chez le résident.
- ◆ Euthanasie
 - Le médecin va chercher le médicament en temps voulu à la pharmacie (au moins la veille).
 - Passer encore une fois les gestes en revue.
 - L'euthanasie a lieu à la date et à l'heure convenues.
 - La présence d'un témoin auprès du médecin dans la chambre du résident pendant toute la procédure est obligatoire (définir au préalable qui veut le faire : famille, infirmière...)
 - Les soignants ont le droit de refuser de participer!

ÉTAPE 4 : évaluation et soins de suivi

- ◆ Soins de suivi concernant les émotions de la famille et des soignants.
- ◆ Organiser une discussion de suivi dans l'équipe de soins.
- ◆ Document d'enregistrement à compléter par le médecin traitant et à retourner dans les quatre jours ouvrables par recommandé postal à la Commission fédérale de Contrôle et d'Évaluation.

Annexe 4

Référence à quelques études concernant la pratique de l'euthanasie

- Gastmans C., Lemiengre J., van der Wal G., Schotsmans P., Dierckx de Casterlé B. "Prevalence and content of written ethics policies on euthanasia in Catholic healthcare institutions in Belgium (Flanders)", *Health Policy*, 2006, 76(2): 169-178.
- Gastmans C., Lemiengre J., Dierckx de Casterlé B. "Development and communication of written ethics policies on euthanasia in Catholic hospitals and nursing homes in Belgium (Flanders)", *Patient Education and Counseling*, 2006, 63(1-2):188-195.
- Lemiengre J., Dierckx de Casterlé B., Van Craen K., Schotsmans P., Gastmans C. "Institutional ethics policies on medical end-of-life decisions: A literature review", *Health Policy*, 2007a, 83: 131-143.
- Lemiengre J., Dierckx de Casterlé B., Verbeke G., Guisson C., Schotsmans P., Gastmans C. "Ethics policies on euthanasia in hospitals: A survey in Flanders (Belgium)", *Health Policy*, 2007b, 84, 170-180.
- Lemiengre J., Dierckx de Casterlé B., Denier Y., Schotsmans P., Gastmans C. "How do hospitals deal with euthanasia requests in Flanders (Belgium)? A content analysis of policy documents", *Patient Education and Counseling*, 2008, 71: 293-301.
- Lemiengre J., Gastmans C., Schotsmans P., Dierckx de Casterlé B., "Impact of Written Ethics Policy on Euthanasia From the Perspective of Physicians and Nurses: A Multiple Case Study in Hospitals", *AJOB Primary research*, 2010, 1(2): 49-60.
- MELC consortium, *Palliatieve zorg en euthanasie in België. Evaluatie van de praktijk en de wetten*, ASP, 2011, 334 p.
- Smets T., Bilsen J., Cohen J., Rurup M.L., Mortier F., Deliens L., "Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported Cases", *BMJ*, 2010 (341:c5174, doi:10.1136/bmj.c5174)
- Smets T., Bilsen J., Cohen J., Rurup M.L., Deliens L., "Legal euthanasia in Belgium. Characteristics of all reported euthanasia cases", *Medical Care*, 2009, 47(12).
- Van Wesemael Y., Cohen J., Bilsen J., Smets T., Onwuteaka-Philipsen B., Deliens L. "Process and outcomes of euthanasia requests under the Belgian act on euthanasia: a nationwide survey", *Journal of pain and symptom management*, 2011.