# ALAIN CANNEEL

# EUTHANASIA: REFLECTIONS ON EXPERIENCE IN BELGIUM

**for Michèle**

This book was originally published in French with the title "*Pour une loi sur l'euthanasie et l'aide au suicide: l'exemple belge*" by **a**ssociation **B**iarritz **B**ilbao **B**ruxelles, **a**rt contemporain (ISBN: 978-2-9535174-2-2). This abridged version in English was prepared by Nicholas Argyris and Danielle Canneel and has been adapted, with the approval of the author, for publication on the internet.

*If one considers end of life issues in a coherent and constructive way, it is impossible not to see them as being principally a question of the self-determination of the patient rather than of the duties of the doctor. To permit euthanasia is to go beyond the (obvious) duty of the doctor to refrain from care or treatment which has no therapeutic benefit; it relies on a different logic, which goes beyond the strict framework of medical law to integrate legally the full autonomy of the individual. Belgian (bio)medical law thus respects one of the most noble achievements of the growing ratification of the primacy of self-determination, tolerance and trust over the various abstract forms of morality, which are by definition relative.*

(Gilles Génicot, *Droit médical et biomédical*, Collection de la Faculté de droit de l'Université de Liège, 2010)

# Contents

# TRANSLATORS' PREFACE

When we read this book as it was being completed in its original French version, we were deeply moved by Alain's description of Michèle's battle with cancer, of her suffering and, finally, of her release by euthanasia. We were impressed by the end of life possibilities available in Belgium and felt they should be more widely known, so that public debate can be fully informed, and public opinion can exercise pressure on the governments of other countries to follow the Belgian lead and show the same respect for human autonomy and dignity as now exists in the Benelux countries. We are grateful to Alain for agreeing to our proposal that we prepare a version in English and for his help with this project.

In our experience in Britain, many discussions between people over sixty (and we are both well past that age) turn at some point to end of life issues: concerns and fears about being confined to a nursing home, suffering from dementia or being in a permanent vegetative state or otherwise incapable... the indignity of losing control, of living through such an end to one's life. The best possibility for taking charge in advance is to make a living will, but, without legal backing, there is no guarantee that one's wishes will be respected; the decisions are left to a doctor, who may or may not follow one's directives, especially as he is himself subject to legal constraints.

The text which follows differs from the original French publication in a number of ways: the author has adapted his text for an English-speaking readership and for publication on the internet, in particular to abridge some passages which were particularly relevant to the current debate in France. The annexes, which contain the texts of the various laws and of a number of policy documents have also not been included here, as most are available on the web. Some quotations have been paraphrased and included in the text; others, at the beginning of some chapters have been deleted. The translations of the quotations which remain have been made by the translators, except for that on page 15, which was taken from the website of the European Court of Human Rights.

Finally, *he, him* or *his* includes *she* or *her.*

N.A. and D.C.
April 2013

# 1. WITNESS TO A DIGNIFIED DEATH

*I ask to die with dignity*
*by euthanasia,*
*as permitted by the law.*

Michèle B., 19 March 2009

## 1.1. AFTER FOUR YEARS BATTLING CANCER, PEACE AT LAST!

> *It has to be said that, after a certain time, one no longer knows how to reply to questions such as "How are you?" or "Are you well?" If you are accompanying a sick person, a better question would be: "How was your day, your night, your week?" These are neutral questions which do not force the person to "feel well" or "feel unwell". They allow him the freedom to say as much or as little as he wishes.*
>
> (Guy Corneau, *Revivre*)

Michèle B. died on 30 March 2009 in our house on the borders of the Belgian Ardennes after four years and three months of bitter struggle against a particularly aggressive cancer of the breast. She was 63 years old. In the month of January we had celebrated the 38th anniversary of our life together and the 20th anniversary of our marriage.

Michèle was treated in a large university hospital in Brussels, 75 miles (120 kilometres) from our home, until she no longer had the strength to make the journey. She underwent a mastectomy and two courses of radiation therapy (of which one, of the whole brain, was particularly taxing). She also received six chemotherapies (of which two were experimental), which sought to eliminate any secondary cancers, the first throughout the body and the rest specifically in the lymph system, in the lungs and especially in the liver.

By the mid-October 2008, Michèle was no longer able to make the journey to Brussels. Her oncologist concluded that the treatments were no longer justified and, from 19 October, Michèle was to receive palliative care at home under the supervision of her general practitioner. But she had not herself yet given up the struggle. Through her insistence and thanks to the energy which she had regained as a result of the palliative care, it was agreed that she should receive one more course of chemotherapy from 5 December 2008 to 6 March 2009 in a university hospital in Wallonia some 30 miles (50 kilometres) away. This would be the last chance for Michèle, who still wanted to believe in the possibility of remission. She could not imagine that there was no treatment which could save her, or at least delay her death. Her new oncologist felt that further chemotherapy would be futile and would not have considered it, were it not for the fact that Michèle was insistently requesting the treatment. Indeed, she only agreed to treat Michèle on three conditions: that Michèle maintained her request during the weekly treatments, that any side-effects were moderate and that the blood tests showed a favorable evolution of the tumour.

In the first weeks of 2009 Michèle's state seemed to improve. However, by mid-January, the third condition was no longer met: the blood tests showed sharp fluctuations in the tumour indicator, but with a clear upward trend. This was no doubt an advance warning of what was to come by late February-early March: the morphine patches and the pills used for palliative care, together with the cortisone (to ease the pain due to the growth of the secondary cancer in the liver), were no longer sufficient. This tumour, which the oncologists had been unable to overcome, already measured 8 cm by 6 or 7 cm on 21 November 2008. On 6 March, when we went to the hospital for another course of chemotherapy, we informed the oncologists of the persistence of the pain, and they immediately decided to stop the chemotherapy. While *we* had not given up hope, the oncologists clearly had; for them, the only issue remaining was to determine the correct morphine dosage to be administered to Michèle by morphine pump. She was sent home ten days later.

During the fifty months which had elapsed since her cancer was diagnosed in December 2004, Michèle endured the many serious side effects of the various treatments, in particular nausea and vomiting, diarrhoea and constipation, sharp muscle pains and exhaustion, which sleep did not ease, from the very moment of awakening. In reality, for more than three years she suffered more from the medical treatments than from the cancer. At least twice, as a result of the massive destruction of her white blood cells by the chemotherapy, she had to be taken urgently to hospital for intense antibiotic treatment in an isolation ward. She completely lost her hair three times, for 20 months in all, as a result of the chemotherapy and the radiation therapy of the brain.

Her hair was beginning to grow again when, on 30 March 2009 at 1.10 p.m., Michèle finally found peace, at home, having been "actively helped to depart".

Once she fully realised that the cocktail of morphine, cortisone and diazepam (trade name *Valium*), which she was receiving as palliative care, was not only demolishing her physical strength but also beginning to affect her reason and to undermine her intellectual capacity, Michèle demanded this legal euthanasia with the same insistence as she had the final chemotherapy.

## 1.2. HOW DID THE IDEA COME?

> *What a shame that we could not die like Philemon and Baucis...*
>
> Michèle B., 29 March 2009

From 4 to 13 October 2008, Michèle was treated in the oncology department of the Brussels university hospital, because of a sharp deterioration in her health: great physical weakness, stomach pains, vertigo and nausea preventing her from eating and, almost, from drinking...

On 26 November, just before requesting the final course of chemotherapy, Michèle wrote about this time in one of her many notebooks: *"In mid-October, we were seized by a great panic; I was so ill-prepared to pass on; today I have moved on"*.

During this period in hospital, Michèle had been visited, at her request, by a humanist (lay) counsellor, who was a member of the Belgian association for the right to die with dignity (*Association pour le droit de mourir dans la dignité* – ADMD). I was with her during this visit. Perhaps seeing matters more clearly than we did, the counsellor spoke in particular about the possibilities afforded by the Law of 28 May 2002 on euthanasia and the Law of 22 August 2002 on the rights of the patient. He gave us the forms required to request the application of some of these legal provisions. As atheists, we had no religious, ideological or moral reservations regarding active assistance to depart, i.e. legal euthanasia.

On 19 October 2008, Michèle signed a declaration of wishes as regards treatment, if her cancer should result in a state of extreme physical and mental collapse, in particular a total dependence on other people for her normal daily needs or a loss of essential mental capacity, both of which she regarded as totally unacceptable. For example, no nurse ever had to help her with her personal hygiene, nor would she have permitted it. Michèle accepted only my help, and then within limits which she set.

In her declaration, Michèle:
- refused to be kept alive by treatments whose only result would be to prolong her life without improving its quality, in particular forced or artificial feeding;
- refused to be resuscitated;
- requested that medication to combat pain should be given to her at dosages which would be effective, even if this would hasten her death; and
- asked to remain at home to the maximum extent possible.

On 27 October 2008, Michèle signed an advance declaration on euthanasia, i.e. an advance request for euthanasia, in case she should lose the ability to make her wishes clear.

On 6 December 2008, the day after the start of the “last chance” chemotherapy, Michèle wrote in a notebook: *“Yesterday, the chemo was OK, although very long. Today I am alright: I slept 14 hours on the trot. Now we must to see how things go. Otherwise, as soon as possible, OUT.”*

This note lacks her usual elegance and good cheer and was, as she herself said, “a spidery scribble” (whereas her neat and careful handwriting was known to all who read her letters): two effects among many of the anticancer treatment and the morphine.  However, the note clearly expressed Michèle’s firm resolve.

The previous month, on 13 November, she had written, with humour: *“My epitaph: ‘Michèle B. She lived for 30 years after a fatal diagnosis‘.  But, if that cannot be, my joie-de-vivre will light up the time which is left to me.  I do not deny my situation.  I face it with optimism, with the support of Alain.  With the support of the Universe, of Eternity.”*

## 1.3. WHAT HAPPENED

> *Requests for euthanasia often come from people who refuse to continue an existence which they know will only bring them physical collapse and indignity. The demand to manage their life to its very end is often the last chapter of a struggle which they have continuously fought for freedom of thought and self-determination.*
>
> (Dr Philippe Cobut, supplement to the May 2012 issue of "*Espace de libertés"*, the magazine of the "*Centre d'action laïque"*)

So, on 16 March 2009, Michèle returned home with a morphine pump. During her stay in hospital, a room in our house had been equipped with a hospital bed, which had a button to ring a bell near my bed in the adjacent room. She now required my help, and soon that of a wheelchair, in order to go from her room to the bathroom or the lavatory. However, on the first night, not wishing to awaken me, she tried to go on her own, but fell near her bed and hit her face on the floor. I was awakened by her calls and picked her up. Her face was covered in blood, but, fortunately, only from a nosebleed. But we had both been given a shock. Therefore, I placed near her bed, for my own use, a mattress which I would be able to fold up during the day; I also left a low light on at night.

Although the morphine, cortisone and diazepam given to her in palliative care were destroying her physical strength and undermining her intellectual faculties, Michèle was, nevertheless, fully aware of her situation: there was no more hope, no prospect other than to allow herself to be stupefied by increasing doses of these drugs and to end up a poor dying object, lying for weeks, or perhaps months, on a hospital bed, in a somnolent state somewhere between life and death, and relying on others in order to be able to move, to drink, to eat, to urinate, to defecate, to wash,...

Never!

This was not how she intended to end her life. Michèle wished to face death, still sufficiently independent, and especially aware and resolute. The following day, she told me that she wanted euthanasia as soon as possible. "*I don't want to end up as a vegetable,*" she added. Later that day, she also told one of her palliative care nurses, and two days later, on 19 March, she informed her general practitioner, and then wrote and signed the request.

While fully understanding her reasons, the doctor informed Michèle that she felt morally unable assume the responsibility for her death and said that she would consult her local colleagues to try to find a solution. We thus found ourselves confronting a gap in the law: it does not provide a patient meeting all the conditions for legal euthanasia with a solution, if his doctor has a conscientious objection.

We waited a few days, but we were ready, if necessary, to try to act alone. For Michèle, it was now an absolute imperative to die soon; for me, it was impossible not to help her. However, we were telephoned late one evening by the coordinator of the palliative care, who had managed to find a solution and, aware of our distress, wished to inform us without delay.

On 26 March, a Thursday, the general practitioner arrived at the beginning of the afternoon with a colleague who had agreed to perform the euthanasia which Michèle had requested a week earlier. It was agreed that this would be done four days later, on Monday 30 March at 1 p.m.

While I was showing the doctors out, Michèle called us back and asked: *“Couldn’t we do it right away?”* But it was still necessary to get the required drugs from a pharmacist, who would need some hours to obtain them. And then there was the week-end...

So began for Michèle a long wait – too long... but serene now that the date and the time of her death had been decided. We were busy, inter alia, with preparations for “afterwards”, for what would need to be done when she was no more.

On two occasions (for the morphine was affecting her memory), Michèle expressed a doubt: *“Do I have the right to do this, to leave you like that?”* Twice I responded: *“Of course you do. And all who love you will admire you for your determination and your courage.”*

Finally, a little after 1 p.m. on 30 March 2009, 160 days of palliative care, which had brought her to a point where the only choice was either insupportable suffering or to end as a *vegetable* stupefied by the drugs, came to an end. There were six of us around Michèle’s bed: the two doctors, two palliative care nurses, her brother and I. Michèle, who had slept for a large part of the morning as a result of the morphine whose dosage, at her request, I had increased to combat her increasing pain, wanted to kiss each one of us, starting with me and ending with the doctor who already had the syringe in his hand.

Then, it all happened very fast. The neuromuscular blocking agent was injected intravenously. It was vecuronium bromide (trade name *Norcuron*), a type of curare, which in large doses causes a sudden respiratory depression, i.e. an almost instantaneous reduction of ventilation to apnea. With her heart stopped, Michèle suffocated and, at the third breath, fell back onto her pillow. I had the impression that it had not even taken three seconds.

Michèle was free at last. Michèle was dead.

I feel very grateful to the two doctors, especially, of course, to the one who held the syringe, but also to the palliative care coordinator, who managed to solve the problem.

I regret that, at the time, I was not aware that the Law, as interpreted by the Federal Control and Evaluation Commission, authorises not only euthanasia, but also, subject to the same conditions, assisted suicide. I think that the latter, which involves the patient himself swallowing a lethal formula prepared by the doctor, would reduce the emotional stress on the physician. I also think that Michèle would have preferred this, since it would have allowed her for a little longer – a very little longer – to have control over her death, and thus over her life. Michèle had the *"fierce determination for autonomy and the exercise of individual freedom"* identified in the report of the Commission of Inquiry into the end of life in France (*Commission de réflexion sur la fin de vie en France*) as the motivation of the beneficiaries of the assisted suicide authorised in the State of Oregon (U.S.A.) for end of life cases linked to serious and incurable illness. *"This cultural characteristic is particularly evident among the people concerned. Few, if any, of these people are socially deprived; many, if not all, are highly educated and have occupied management positions."* (Report of the same Commission of Inquiry, December 2012).

For the same reason, I am convinced that, in the case of euthanasia, if she had been given the choice, Michèle would have opted for the form in which it was in fact administered to her, i.e. the immediate injection of the neuromuscular blocker, which leads almost instantaneously to death by respiratory failure. In Belgium, in 98% of cases of euthanasia, this injection is given after another intravenous injection to induce a prior deep unconsciousness or coma. Michèle was worried that this might not work; she was afraid she might wake up... In the moments between the injection of the curare and her death, Michèle must have understood that what was happening to her was indeed what she had so long demanded. And that it worked!

*“Michèle was the younger sister who was always big enough to manage on her own,”* said her brother on Saturday 4 April 2009, a beautiful spring day. We were assembled in the sunshine for a moving humanist funeral service to bury Michèle in the little cemetery of our village. “*She was strong and fought unreservedly for her ideas. She was also very sensitive and very generous. She had a big heart.”*

# 2. THE LAW: BELGIAN LEGISLATION ON EUTHANASIA AND ASSISTED SUICIDE

*The right to self-determination within the meaning of Article 8 § 1* [*of the Convention*] *includes the right of an individual to decide at what point and in what manner he or she will die, at least where he or she is capable of freely reaching a decision in that respect and of acting accordingly.*

(European Court of Human Rights, Case Haas v. Switzerland, 21 January 2011)

## 2.1. THE CONTEXT

Euthanasia was illegal in Belgium before 22 September 2002. It was classed as murder (homicide with premeditation). Assisted suicide could be considered as failure to assist a person in danger (or even as poisoning) and could also, therefore, be regarded as illegal. Decriminalisation faced the stubborn opposition of the christian political parties (*Christelijke Volkspartij* and *Parti social chrétien*), which had dominated coalition governments without interruption since June 1958. Except for a period of fifteen months in 1973-74, the post of prime minister had always been held by a member of one of these parties.

However, the elections of 13 June 1999 shattered that political status quo. The two christian parties, with only 32 members out of 150 in the House of Representatives (*Chambre des représentants*), were replaced as the most important political family by the two liberal parties (*Vlaamse Liberalen en Democraten* and *Parti réformateur libéral-Front des francophones*) with 41 seats. This was the first time since the beginning of the century that these parties had achieved such a position.

Within one month of the elections, a new government took power. It was led by the Flemish liberal Guy Verhofstadt and also included the socialist parties (*Parti socialiste* and *Socialistische Partij*), which had 33 seats in the House, as well as the green parties (*ECOLO* and *AGALEV*) with 20 seats. The christian parties thus found themselves in opposition (alongside the extremist *Vlaams Belang*, *Volksunie* and *Front national*), facing a government with a huge majority (94 seats out of 150 in the House and 25 seats out of 40 in the Senate).

The Government and Parliament were now able to take up a number of ethical issues and, after thorough deliberation, to legislate on the most important of these. The measures adopted included the law of 28 May 2002 on euthanasia (hereafter “the Law”), which was followed on 14 June 2002 by a law on palliative care, and then by a law of 22 August 2002 on the rights of the patient. Under the second government led by Guy Verhofstadt (July 2003 to December 2007), an amendment was made to the law of 28 May 2002 on the role of pharmacists and the use and availability of drugs for euthanasia.

### Legalisation of euthanasia and assisted suicide in other countries

In the **Netherlands** a law decriminalising euthanasia and assisted suicide was adopted in April 2001 and entered into force on 1 April 2002 (*wet van 12 april 2001, houdende toetsing van levensbeëindiging op verzoek en hulp by* *zelfdoding*). This law was the culmination of a long process of progressive alignment of the law to medical practices which were more and more widely known, recognised, socially approved and accepted by the courts on grounds of *force majeure* and public interest.

More recently, **Luxembourg** adopted a law on euthanasia and assisted suicide (*loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide*), which entered into force on 17 March 2009.

Thus, within the space of a few years, all three Benelux countries have decriminalised euthanasia and assisted suicide subject to the conditions laid down in the various laws. This is in sharp contrast with the dissimulation and the arbitrariness in which the practice of provoking death medically is all too often shrouded in other countries.

There are signs of change in **France**. In January 2012 in his "60 undertakings for France" (*"60 engagements pour la France"*), François Hollande, then a presidential candidate, included this 21st undertaking: "*I will propose that any adult in an advanced or terminal phase of an incurable illness, which is causing him unbearable physical or mental suffering which cannot be relieved, may request, subject to clear and strict conditions, medical help to end his life with dignity.*" Two days after being elected President on 15 May 2012, François Hollande asked Professor Didier Sicard, honorary president of the National Advisory Committee on Ethics (*"Comité consultatif national d'éthique"*), to examine and to report on this subject before the end of the year.

A commission on the end of life in France (*Commission de réflexion sur la fin de vie en France*), chaired by Professor Sicard, reported on 18 December 2012. An important conclusion in the report was the following: *"When a person at the end of life expressly, or on the basis of advance directives included in his medical file, requests the cessation of any treatment liable to prolong his life, or of all feeding and hydration, it would be cruel to leave him to live or die without offering him the possibility of having a doctor perform an act to accelerate death. The same applies:*

- *If such a request is made by close relatives of an unconscious patient, for whom advance directives are not included in the medical file, of which the Commission continues to underline the importance. Such a request must be submitted to a collegial discussion in order to ensure that it accords with the real wishes of the patient.*
- *If, after collegial discussion with the patient or his close relatives, the treatment itself is considered to be unreasonable as its only purpose would be an artificial survival."* (Sicard Report, p.93)

The Sicard Commission also accepted, albeit with considerable reticence, a form of assisted suicide *"for certain patients in the final stages of a degenerative and incurable disease"*, who requested it, provided that the lethal act was accomplished by the patient himself (otherwise it would not be suicide) and that the medical assistance was limited to the prescription of drugs to provoke death.

According to a press notice issued by the Elysée on the day the report was presented, President Hollande decided to request the opinion of the National Consultative Committee on Ethics *(Comité consultatif national d'Ethique)* on the possibilities for legislation suggested by the report. He asked the Committee to propose strict procedures and conditions for allowing a patient suffering from a serious and incurable illness, who is conscious and not subject to outside influence, to be accompanied and assisted in his desire himself to terminate his life. The President intended to propose a draft law to the French Parliament in June 2013.

Assisted suicide is already legal in **Switzerland**, where, however, euthanasia has not been decriminalised. This legalisation results from an interpretation of article 115 of the Swiss penal code, which prohibits assistance to suicide for personal advantage; since it does not prohibit disinterested assistance, it is concluded that this is lawful. On the other hand, the penal code (article 114) explicitly prohibits euthanasia, even for disinterested motives, and provides that it is punishable by up to three years in prison or a fine. Moreover, assistance to suicide in Switzerland is not a medical act and need not, therefore, be performed by a doctor, although the lethal drugs must in any event be prescribed by a doctor.

Since death has not resulted from natural causes, the judicial authorities must be informed. The procedures to be followed depend on the rules of each canton. Thus, for instance, in the canton of Geneva, the police and a doctor (*"médecin légiste"*) will visit the place of death to verify, by examination of the body and the medical file and by discussion with the accompanying person, that no legal action is required. The doctor may then sign a death certificate indicating that the death has been "violent" or "not natural". The police officer will then deliver a document entitled "*Nihil obstat*", which will allow the family to take charge of the body and make arrangements for a funeral.

Moreover, in June 2012, the canton of Vaud (the Lausanne region) modified its law of 29 May 1985 on public health ("*loi du 29 mai 1985 sur la santé publique*") to provide that public-interest health care establishments ("*établissements sanitaires reconnus d'intérêt public*") may not refuse an assisted suicide within their walls, if a patient or resident requests it, provided that:

- the establishment's responsible doctor has discussed with the care team, the general practitioner and with family members designated by the patient or resident and has verified that the latter is mentally competent, persists in his request for suicide and is suffering from an illness or the effects of an accident which are serious and incurable; and
- alternative treatments, in particular those linked to palliative care, have been discussed with the patient or resident.

This is the first legislative provision on assisted suicide in Switzerland.

In the **United States** assisted suicide is legal in three states, but only for patients at the end of life.

**Oregon** was the first, with the *Death with Dignity Act* adopted in October 1997. This law allows patients in the terminal phase of an illness considered incurable, who are over eighteen years of age, resident in the State and considered mentally competent to express their wish to terminate their life, to obtain from a doctor for this purpose a prescription of medicines to be self-administered in a lethal dose at the moment of their choice. The procedure to follow is similar to that prescribed by the Belgian Law. However, the presence of a doctor is not required, either at the moment of self-administration or at the moment of death. In most cases, in addition to the intervention of the patient's relatives, assistance during the preparation and the absorption of the lethal drugs is provided by members of *Compassion and Choices of Oregon*, a private association. While this is similar to the situation in Switzerland, there is no follow-up intervention by judicial authorities, but only the obligatory transmission to the State health authority of information concerning the death.

The State of **Washington** followed the example of Oregon when it adopted its own *Death with Dignity Act* which entered into force in March 2009.

In **Montana**, on the other hand, the law evolved as a result not of legislation but of judicial proceedings. In the case *Baxter v. Montana* brought by Robert Baxter (a 76-year-old man dying of leukemia) and four doctors, as well as the association *Compassion and Choices,* the plaintiffs sought judicial recognition of a constitutional right for patients in the terminal stage of an illness to obtain from a doctor the prescription of a lethal drug. In December 2008 the Helena district court ruled that the rights to self-determination and to human dignity guaranteed by the Montana constitution, taken together, include the right for a patient of sound mind and in the terminal phase of illness to die with dignity, including the right to medically assisted death. The State of Montana having appealed this ruling, the State Supreme Court gave its judgment on 31 December 2009. It ruled that, while it was not necessary to rule on the question of constitutionality, nothing in the State's legislation, including its penal code, or in the Court's jurisprudence, prevented medical assistance to the suicide of adult patients of sound mind and in the terminal phase of illness.

Finally, in **Québec**, following the report of a Special Parliamentary Committee (*Commission spéciale de l'Assemblée nationale du Québec, "Mourir dans la dignité", March 2012*), the provincial government plans to propose, by the summer of 2013, draft legislation establishing "*medically assisted death*" as a new type of medical care exclusively for mentally competent adults resident in Québec, who have a serious and incurable illness, whose medical condition entails a significant deterioration of their capabilities with no prospects of improvement and who are subjected to constant and unbearable physical or mental suffering, which cannot be alleviated in a manner which they consider acceptable. This would amount to a legalisation of euthanasia similar to that in Belgium, except that a doctor who, for reasons of conscience, refused to offer medical assistance for death (euthanasia) would be obliged to help his patient to find a willing doctor. The word "euthanasia" is avoided in these plans because there was no consensus for its use: on the one hand, it could have a negative connotation; on the other hand, it did not express the essential values of support and medical security at the end of life. For this reason, "*medically assisted death*" does not include assisted suicide, since the latter is regarded as an individual act which does not respect these values and cannot, therefore, be considered a form of medical care within the panoply of end of life care. Moreover, the report of the Special Parliamentary Committee recommends that an information guide be given to all patients diagnosed with an incurable illness to inform them of their legal rights and of the services available to them. In addition to providing the patient with useful information, this guide would allow the care team to discuss delicate end of life issues with him. The team should also inquire whether the patient has signed an advance request or directives concerning his end of life care.

## 2.2. THE PROVISIONS OF THE BELGIAN LAW ON EUTHANASIA

The Belgian law of 28 May 2002 decriminalised euthanasia **performed by a physician who intentionally terminates a person's life at his request**, provided that:

(1) the person concerned is an adult or an emancipated minor, legally competent and conscious at the moment of the request;

(2) the person's medical condition is irreversible and he is subjected to continuous and unbearable physical or mental suffering, which cannot be alleviated and which is the result of a serious and incurable illness, whether accidental or pathological, but which will not necessarily be fatal within a relatively short period;

> "*The absence of therapeutic prospects – incurability – is determined by the doctor. The unbearableness of the suffering – the absence of human prospects – is essentially defined by the patient. Nevertheless, the general practitioner must be able to attest to the patient's perspective on the situation*." (Dr Wim Distelmans, in "*Euthanasie et soins palliatifs: le modèle belge", 2012*)

(3) the person's request has been made voluntarily, consciously and repeatedly and does not result from any external pressure.

It follows that any act, even if performed by a doctor, which intentionally terminates the life of a person who has not **requested it clearly, consciously, persistently and autonomously** continues to be considered as murder by Belgian law.

The Law also requires that the patient's request be made in writing and be lodged in his medical file. This **written request** is an essential document for which no particular form is specified and which may be summary (*"I desire euthanasia"* or *"I request euthanasia"* are sufficient). It must be drafted, dated and signed by the patient himself or, if he is not able to do so, by an adult person of his choice who must not have any material interest in his death. Until the very last second, at the moment of receiving the lethal injection (or the possible prior injection of an anaesthetic) or at the moment of swallowing the lethal formula, the patient may revoke his request, in which case the document is removed from his medical file and returned to him.

The doctor, before agreeing to a request for euthanasia, must inform the patient of his state of health and of his life expectancy and discuss with him his request, the possibilities for further treatment and of palliative care, without there being any obligation on the patient to accept one or other of these treatments in order to benefit from euthanasia. The doctor, in discussion with the patient, must conclude that there is no other reasonable solution given the patient's situation and that the latter's request is entirely voluntary.

The Law further obliges the doctor to verify that the patient's physical or mental suffering, as well as his desire for euthanasia, are constant. For this purpose, the doctor must have several discussions with the patient at intervals which are reasonable having regard to the evolution of the patient's condition.

The Law also requires the **consultation of a second doctor** on the serious and incurable nature of the patient's condition. This doctor must be independent both of the patient and of the doctor who is consulting him and must be qualified as regards the illness concerned. The second doctor is required to examine the medical file and the patient and to verify that the physical or mental suffering is constant and unbearable and cannot be alleviated.

Moreover, his general practitioner is himself required to discuss, if the patient so wishes, the request for euthanasia with the nursing team or some of its members as well as with any close family members designated by the patient, and also to verify that the patient has been able to discuss his request in person with anyone he wished.

If the general practitioner considers that the serious and incurable illness which is the cause of the request for euthanasia is manifestly unlikely to lead to the death of the patient in the near future, he is further required **to consult a third doctor, a psychiatrist or a specialist in the pathology concerned**. This second consultation has the same format as the first. In this case at least one month must elapse between the patient's written request and the act of euthanasia.

All requests made by the patient, as well as all actions taken by the general practitioner and their results, including the reports of any doctors consulted, must be lodged in the patient's medical file. Neither the patient nor his general practitioner is required to follow the opinion of the second or third doctor consulted. Even if a doctor consulted considers that further palliative care is possible, the patient can refuse it and maintain his request for euthanasia. Thus, it is the general practitioner's responsibility to meet his patient's request.

An article added to the Law in November 2005 decriminalises **the delivery by a pharmacist of the lethal drugs required for euthanasia** against a prescription in which the doctor has specified that he is acting on the basis of this law. The pharmacist must personally hand over the substance to the prescribing doctor; and the latter must return to the pharmacist any unused substances for destruction in accordance with the normal rules for unused medicines or medicines past their validity date. The government is empowered to specify by Royal Decree the prudential criteria and the conditions which must be met by the prescription and in the supply of the substance, and also the measures to be taken to ensure the availability in pharmacies of the drugs required for euthanasia.

The Law has also established a system of **advance requests for euthanasia, in case the patient is no longer able to state his wishes** (for example, if he is in an irreversible coma). Adults and emancipated minors who are of sound mind can indicate in **a written declaration** that they wish a doctor to perform euthanasia if he finds that:

(1) the patient is suffering from a serious and incurable illness, whether accidental or pathological;
(2) he is unconscious; and
(3) this situation is irreversible in the current state of medical science.

The declaration can be made at any time, but it must be drafted in a form fixed by Royal Decree. The declaration may designate one or more trusted persons with the duty of informing the general practitioner of the patient's wishes. It must be drafted in the presence of two adult witnesses, at least one of whom has no material interest in the death of the patient, and it must be dated and signed by the declarer, the witnesses and any persons of trust.
If the declarer is physically and permanently unable to write his request, to date it and to sign it, he may, provided this physical impossibility is medically certified and subject to certain conditions specified in the law, entrust this task to an adult of his choice who has no material interest in his death.

The **advance declaration of wishes regarding euthanasia** is valid for five years and may be confirmed, adjusted or withdrawn at any moment. Whereas a revision or a withdrawal of the declaration requires no formalities, its confirmation (or renewal) is subject to the same conditions as the original declaration, which means that, in this case, an entirely new declaration has to be drafted, possibly with other witnesses or persons of trust.

Such declarations may be registered with the responsible public authorities, and this is recommended. The procedure is relatively simple: since 1 September 2008, the author of an **advance declaration of wishes concerning euthanasia** may register his declaration with the population department (*"service de la population"*) of the municipality in which he is domiciled. The responsible official will use an informatics application developed specifically for euthanasia to register the declaration directly, through a secure internet connection, in the specific data base of the federal public administration responsible for public health (Health Ministry). This data base may only be accessed by recognised doctors, who can thus check, as the law requires, whether a patient in their charge, who meets the legal criteria for euthanasia but who is not able to express his wishes, has registered an advance declaration. During the registration process the personal information is automatically checked against that in the national register of physical persons (*"Registre national des personnes physiques"*), without infringing the right to privacy. After registration the document is sent by the municipal administration, for safekeeping, to the federal public administration responsible for the organisation of health establishments.

Euthanasia performed on the basis of an advance declaration and respecting the conditions and procedures specified by the law is also decriminalised.

A person who has died by euthanasia in accordance with the Law is legally **considered as having died a natural death** for the purposes of the execution of contracts to which he was a party, and in particular of insurance contracts. The doctor will indicate on the death certificate that it is a case of natural death and will specify the illness which led to the request for euthanasia.

Neither the request for euthanasia nor the advance declaration of wishes is considered by the Law to be binding on others: **no doctor is obliged to perform euthanasia and no other person (for instance a pharmacist asked to supply drugs for euthanasia) is obliged to participate in a euthanasia**. A general practitioner unwilling to agree to a request for euthanasia is required by the Law to inform his patient accordingly and in good time and to give his reasons. At the request of the patient, he must transfer the medical file to another doctor, designated by the patient himself.

The Law of 28 May 2002 established a **Federal Control and Evaluation Commission** (*Commission fédérale de contrôle et d'évaluation*), comprising sixteen members nominated on the basis of their knowledge and experience. Eight of these members must be medical doctors, of whom at least four must be professors at a Belgian university; four other members must be professors of law at a Belgian university or practising lawyers and four members must have experience in handling the problems of patients suffering from incurable illness. On the basis of proposals by the Senate, the members of the Commission are appointed by the Government for a renewable period of four years, the composition of the Commission being also required to ensure that the principles of linguistic parity and a fair representation of all parties are also respected.

The doctor who has performed euthanasia is required to submit to this Commission, within four working days, a confidential **registration document**, of which the first part (which must be sealed by the doctor) contains identification data for the patient, the general practitioner, other persons consulted and any persons of trust who have been involved. A second part contains anonymous details of the case: sex, date and place of birth of the patient; place and time of death; the illness of the patient; the suffering endured by the patient; the reasons why this suffering could not be alleviated; how the doctor determined that the request was voluntary, considered and repeated and without external pressure; whether death was imminent; whether there had been **a declaration of wishes**; the procedure followed by the doctor; details of the consultations of other doctors; details of the consultations of any other persons; and how the euthanasia was carried out and the means used.

Using the information in the second part, the Commission checks whether each specific case of euthanasia has respected the conditions and procedures fixed by the Law. In case of doubt, the Commission may decide, by simple majority, to remove anonymity by unsealing the first part of the registration document. It may then ask the general practitioner to supply all the elements of the medical file concerning the euthanasia. The Commission is required to act within two months. If, by a two-thirds majority, it concludes that the legal conditions have not been respected, it will send the dossier to the Public Prosecutor ("*Procureur du Roi*") for the place of death of the patient.

Every two years the Commission reports to Parliament. The report contains statistics established on the basis of the information supplied in the second part of the registration document and a description and evaluation of the application of the law. The Commission may add recommendations designed to improve the law or its application. The Commission has power to obtain all useful information from relevant authorities and institutions, such information remaining confidential. The Commission may also hear experts.

As regards **the manner of performing euthanasia and the means used**, the Commission, in its fifth report (for the years 2010-2011), repeated an important observation which it had already made in earlier reports and documents and which concerned the fact that **the law does not lay down how euthanasia is to be performed**:

> *In virtually all cases of euthanasia (99% in 2010-2011), the doctor first induced deep unconsciousness by administering a general anaesthetic, in most cases by injection of 1 to 3 gr of thiopental, a rapid-onset quick-acting barbiturate, or more rarely by other general anaesthetics administered by intravenous injection or drip. Where death did not result spontaneously within a few minutes, an intravenous injection of a neuromuscular blocker such as vecuronium or atracurium was*

> *administered. Doctors frequently remark that this technique results in a calm and speedy death by respiratory failure within a few minutes.*
>
> *In only 12 cases (less than 1% of all euthanasias) unconsciousness was achieved by the oral administration of a barbiturate. In 8 of these cases death resulted in a few minutes without further intervention. In the other 4 cases a neuromuscular blocking agent was given once the patient had lost consciousness. In the first 8 cases, the procedure can be regarded as* ***"medically assisted suicide"****.*

Thus, although it does not explicitly apply to assisted suicide, the Belgian law on euthanasia is considered to permit **assisted suicide,** provided that the conditions and procedures which are required for euthanasia have been respected and provided that it is carried out in the presence and under the responsibility of a doctor.

Belgian practice as regards assisted suicide is similar to that of the association EXIT-ADMD in Switzerland. The lethal product is a high dose (10 to 15 grams) of sodium pentobarbitone ("pentobarbital" in the US), another barbiturate, taken by the patient himself as a powder dissolved in warm water. This gives the patient a gentle death. The absorption of pentobarbitone, which is particularly bitter and emetic, is preceded by an antiemetic. Drinking some alcohol first can be recommended, as this seems to have the effect of accelerating gastric absorption of the active ingredient. (See Sandra Burkhardt, *L'assistance au suicide: pratique et aspects légaux*.)

In June 2001, the State Council (*"Conseil d'Etat"*) had examined the issues raised by the decision of the legislator to exclude **assisted suicide** from the scope of the draft law on euthanasia and made two remarks:

(1) The State Council noted that there was uncertainty as to the criminal character of assisting a suicide. On the one hand, suicide not being illegal, someone assisting another's suicide could not be regarded as an accomplice in a crime and should not, therefore, be subject to legal pursuit. On the other hand, this behaviour could be considered in some cases as a failure to help a person in danger, which would infringe certain provisions of the penal code.

(2) More fundamentally, the Council pointed to the need for the legislator to respect the constitutional principles of equality and non-discrimination. It was felt acceptable that, when suicide is committed outside a medical context and when the assistance of a doctor is not provided in the same way as proposed in the draft law (or subject to conditions which are equivalent having regard to the objectives pursued), the Law should not apply. On the other hand, if the conditions prescribed by the draft law (or equivalent conditions) are respected, there is no difference in the nature of the behaviour or in the intentions of a person assisting another's suicide between euthanasia as

defined in the draft law and medically assisted suicide. The Council, therefore, wondered why the draft law did not explicitly apply to the behaviour of a doctor who made lethal drugs available to his patient at the latter's request, while leaving it to the patient to decide the moment of his death and abstaining from himself carrying out the lethal act, especially as such behaviour might leave the doctor open to a criminal charge of failure to assist a person in danger.

The Council observed that the only objective difference between these two situations is whether or not a doctor carries out the final act. This difference was not considered sufficient, on its own, to justify the failure to regulate assisted suicide in cases where all the other prior actions have been carried out by a doctor in the same way as for euthanasia. The Council concluded that the law should either apply to this aspect of assisted dying or should explain the objective reasons why, having regard to the principles of equality and non-discrimination, this distinction is maintained, especially as medically assisted suicide can be subject to medical controls comparable to those for euthanasia, such that there would be no risk of abuse.

*

The Belgian law of 22 August 2002 on the rights of the patient contains important provisions relative to the Law and, in particular to **advance requests for euthanasia**:

- **The patient may freely agree to any medical intervention of which he has been informed in advance**. This agreement must be given explicitly, unless the medical practitioner, having sufficiently informed the patient, can reasonably infer consent from the behaviour of the patient. Either the patient or the practitioner may, with the agreement of the other, request that consent be given in writing and added to the patient's medical file.

- **The patient has the right both to refuse a medical intervention and to withdraw any consent previously given**. At the request of the patient or the medical practitioner, this refusal or withdrawal of consent must be made in writing and added to the medical file.

- **If the patient is no longer able to indicate his wishes, any previous written refusal of consent to a specific medical intervention must be honoured by the medical practitioner** until the patient is able to indicate his wishes and decides to withdraw his refusal.

Thus, separately from the advance declaration of wishes as regards euthanasia, any patient (or potential patient) may draft, date and sign **a**

**declaration of wishes as regards treatment,** in case he should no longer be able to express his wishes. This is the Belgian equivalent of a “living will” or “advance directives”. The Belgian association for the right to die with dignity (*Association pour le droit de mourir dans la dignité - ADMD)* has prepared an example of such a declaration. It is important to note that the expression of wishes in such a declaration is **legally binding on the medical practitioner**.

Although legally binding and in contrast to the position for advance requests for euthanasia, there is no provision for registration of the declaration of wishes as regards treatment, so that it is left to the individual to ensure that his doctor has this on the medical file and perhaps to carry a copy on his person.

*

**NOTE**

The official Belgian website http://www.health.belgium.be contains the text of the laws and official documents mentioned in the text in the French, Dutch and German languages. Unofficial translations into English of some of these documents can be found on the web.

Further information on living wills and on forms for “DO NOT ATTEMPT RESUSCITATION” may be found on various websites, including that of FATE.

## 2.3. THE BELGIAN LAW IN PRACTICE

From the date of entry into force of the Belgian Law (22 September 2002) to 21 December 2011, the end of the period covered by the most recent report of the Federal Control and Evaluation Commission, 5537 cases of euthanasia were declared, an average over the period of about 600 per year, for a population of some 11 million. During this decade, year on year growth was rapid, from an average of 17 cases a month during the first 15 months to 87 per month in the period 2010-2011. Currently the number of euthanasias is just over 1% of deaths. The Commission did not bring any case to the attention of the judicial authorities, considering that there was no evidence of any violation of the conditions laid down by the Law.

### Statistical Breakdown of Cases

Of these 5537 cases of euthanasia:

- 98% followed a conscious request, and only 2% were based on an advance declaration of wishes;
- 98.8 % were performed directly by intravenous injection, and only 1.2% by oral ingestion, but in 12 of these cases the ingestion of the lethal drug had to be followed by an intravenous injection of a neuromuscular blocking agent, so that the number of assisted suicides in the strict sense was 54 (1%);
- 92% of the patients were expected to die in the very near future;
- the three illnesses most frequently diagnosed were, in decreasing order of importance, cancers (79%), neuromuscular diseases (8%) and cardiovascular disease (4%);
- 52% of the patients were men and 48% were women;
- the three age groups most frequently represented were, in decreasing order of importance, 60 to 79 years (52%), 80 years or more (23 %) and 40 to 59 years (22%);
- in 51% of these cases euthanasia was performed at the place of residence of the patient: either at his home (44%) or in a residential or nursing home (7%). In 47% of cases, euthanasia was performed in a hospital. The trend has been for euthanasia to be increasingly performed at home: in the most recent two-year period for which data is available (2010-2011), the number of cases performed at home (944) was, for the first time, greater than the number in hospital (935), a trend which is in line with the results of the many studies which have shown that most patients wish to end their life at home.

*

There are three official languages in Belgium: Dutch (spoken by 60% of the population), French (39%) and German (less than 1%). Declarations of euthanasia made to the Federal Control and Evaluation Commission may be made in any of the official languages and will normally be made in that of the patient. It is surprising, therefore, that, of the 5537 declarations, fully 82 % were in Dutch and only 18 % in French. There was no declaration in German.

The Commission noted that there might be a number of reasons for this disparity, including differences between the linguistic communities, in particular as regards the information given to the public or to doctors, in socio-cultural attitudes, in medical practices at the end of life, or in attitudes to the obligation to make a declaration. However, the Commission was unable to determine the relative importance of these various factors.

The ADMD considers that French-speaking doctors are insufficiently informed about the Law and the techniques to be used. Other commentators do not agree and have pointed out that, for end of life care in industrialised countries, doctors are accustomed, in order to alleviate pain, to have recourse to palliative drugs (sedatives, opiates, etc.) in dosages that may hasten the patient's death, while leaving the manner and the time of death to the development of the illness. Such practices are not euthanasia as allowed by the Law, and it seems that, for terminal cancers, these practices, which are outside the Law, may be substituted for lawful euthanasia more frequently in the French-speaking community. A Co-president of the Commission (Dr Wim Distelmans) has expressed concern that these techniques of palliative sedation can be used without any request from the patient and do not allow the latter a rapid and painless death, at the time of his choosing and in the company of any members of his family whom he wishes to be present. *"Too many doctors decide unilaterally to administer pain killers to the point where the patient loses consciousness, enters a coma and dies, which we call 'palliative sedation'.* [...] *On the basis of our inquiries, we estimate that such sedation is ten times as frequent as euthanasia and twice as frequent in Wallonia as in Flanders!* [...] *This practice, which may today be carried out without the patient's knowledge, should no longer be clandestine and should be declared to a commission, in the same way as is the case for euthanasia."* (interview of Dr Wim Distelmans in the newspaper *Le Soir*, 7 April 2012).

*

In all its reports to the Belgian Parliament the Federal Control and Evaluation Commission has underlined that the implementation of the Law has given rise to no major difficulties or abuses calling for legislative action. However, "*with regard to the issue of the possible extension of the scope of the law to minors and changes to the advance declaration of wishes, which are the subject of ethical and philosophical debates, the Commission considers that it is neither its mission nor its competence to pronounce on these matters, which do not concern the application of the law of 28 May 2002.*" On the other hand, the Commission has underlined that the correct practice of euthanasia, in conformity with the Law, requires above all an increase in the information available to the public and to doctors and that the medical curriculum, as well as postgraduate training and continuing professional development, should include training to prepare doctors to face the problems of end of life care, including palliative care and the correct practice of euthanasia.

## Issues for Reform

The implementation of the Law has raised a number of ethical and philosophical questions, the most important of which have led to proposals by parliamentarians for amending legislation. Examination of fifteen proposals began in the Senate in February 2013. These proposals mainly concern five issues:

### 1. Assisted suicide

The issue is whether, as discussed above, explicitly to legalise **medically assisted suicide**, subject to conditions and procedures comparable to those for euthanasia. Medically assisted suicide would be understood as deliberate assistance by a doctor to a patient by providing him with lethal substances which enable him to terminate his life, leaving it up to him to self-administer the drugs.

### 2. Conscience clause for doctors

The issue is whether to specify explicitly that euthanasia within the framework of the Law is **part of care** (*"un acte de soin"*) in the sense of the legislation on hospitals and other care establishments and accordingly falls within the doctor's freedom to choose his care program. Therefore, an objection of conscience has to be a matter for the doctor himself and no doctor should be obliged to perform or prevented from performing euthanasia within the Law, no matter where he practises. The conscience clause cannot apply to an institution as a whole and no medical institution should be able to prohibit a doctor from performing euthanasia within its walls.

## 3. Scope of the advance declaration of wishes

- One issue is whether to give this declaration an indefinite **validity** (as against the period of 5 years at present), while allowing its author to revoke or modify it at any time.

- The Law currently provides that the advance declaration of wishes only comes into play if the patient is irreversibly unconscious, i.e. in a coma. For **patients suffering from serious and incurable dementia** to benefit from euthanasia the Law at present only affords a relatively narrow window of opportunity: the period during which the disease is sufficiently advanced for the legal requirement of suffering which is insupportable and cannot be alleviated to be met, but not so advanced that a request for euthanasia cannot be expressed. Thus the Law, as it currently stands, would for instance encourage patients suffering from Alzheimer's disease to request euthanasia in the first phase of the disease, as did the author Hugo Claus in March 2008. The issue is, therefore, how far to extend the scope of the advance declaration of wishes to include a persistent vegetative state, or a state in which the patient is no longer conscious of his physical and mental state or of his social and physical environment, so that dementia sufferers would also be covered.

## 4. Persons eligible for euthanasia

- A first issue is whether and how to bring within the scope of the Law **minors who are considered able to judge their interests rationally** and who are conscious at the moment of their request for euthanasia. In the Netherlands, there is already a provision that, subject to conditions ensuring that the request is clear and conscious and with the agreement of those exercising parental authority, minors under 16 years old may benefit from euthanasia; for minors over 16, those in parental authority may give their opinion, but the final decision rests with the minor. Moreover, the Belgian Law of 22 August 2002 on the rights of the patient provides for a special medical majority lower than the legal age of majority: the rights established by this law are exercised by those in parental authority on behalf of the minor, but the latter is associated with the exercise of his rights in accordance with his age and his maturity; indeed, a minor who can be considered capable of rationally assessing his interests may exercise his rights autonomously. Thus, a minor may refuse a treatment which would affect the length of his life, for instance a medical, surgical or other treatment whose only effect would be to prolong his existence without improving its quality.

- A second issue is whether to bring within the scope of the law **minors who do not have the required mental competence**, including babies who are not viable; this would require the request for euthanasia to be made by the parents or legal representatives and the decision to be taken in agreement with an appropriate medical team, whose composition would be determined by the Law. According to Dr Yvon Englert, professor of medical ethics and head of the gynecological/obstetric service at the *Hôpital Erasme* (a leading university hospital in Brussels), *"the problem here is how to manage the end of life for patients who are unconscious and are incapable of discernment. It can happen that the standard acts of withdrawing or abstaining from care* [...] *do not allow the medical team to offer the patient 'a good death'. In such cases, 'a good death' may require the medical team to take active steps* [...] *To distinguish between a passive act and an active act is rather hypocritical, since in both cases the doctor is well aware that he is hastening death. In the Netherlands, the Groningen Protocol provides a code of good practice for managing the end of life of newborn babies, including the possibility of active intervention, where necessary."* (interview published in the newspaper *Le Soir*, 9 April 2009).

- There remains the question of the exclusion of persons suffering from the **handicaps of old age** (restricted movement, sensory loss, in particular of sight and hearing, incontinence, inability to cope independently with daily life, etc.), but not from a disease which meets the conditions required to benefit from euthanasia or from assisted suicide. Such persons may also wish to end their life with dignity. (It seems that of the 400 people whose suicide is assisted each year in Switzerland, one third are not so much ill as "tired of living".)

## 5. Replacement of a doctor who invokes the conscience clause.

As already noted, the procedures established by the Law have one **major lacuna**: **the patient whose request for euthanasia or assisted suicide is not accepted by his doctor is left to his own devices**, since no doctor is legally required to perform euthanasia or to assist a suicide; the doctor's only legal obligation is to inform his patient in sufficient time of his refusal and of the reasons for it and to make available the patient's file to another doctor designated by the patient. The patient, therefore, has himself to find a replacement doctor who will meet his wishes, which may not be easy for a patient who is on his own, seriously ill and confined to bed – precisely the state in which the terminally ill patient will frequently find himself.

How is a patient (or his family) to find a physician willing to accept a request for euthanasia or assisted suicide? There is no provision in the Law.

“*Medical ethics require the continuity of care, but, in our experience, many requests for euthanasia are not met or are unilaterally changed by the administration of increasing doses of tranquillizers and/or sedatives*” (Dr Wim Distelmans, *Euthanasie et soins palliatifs: le modèle belge,* p.183).

Anyone who has been in such a situation will understand that the patient and his family can be overwhelmed by feelings of revolt, not against the doctor who has exercised his legal right to refuse, but rather against what amounts to legislative bungling. This revolt may encourage the resolve, if one must act alone, to attempt or to assist suicide, which may be simpler and more rapid than searching for a consenting physician, without knowing how or where to find one.

The same problem has arisen in the Netherlands, where, according to Dr Petra de Jong, director of the NVVE (“*Nederlandse Vereniging voor een Vrijwilling levenseinde*” – the Dutch association for freedom of choice at the end of life), “*it is a tragedy that a certain number of people in this situation choose an awful suicide and others a less awful but a lonely one. Yet others find themselves obliged to await the natural end of the process of dying.*” (reported in the quarterly bulletin n°122 of the ADMD-Belgium). The NVVE has sought partially to address this problem by posting information on its website about the drugs available and how they may be obtained and used in order to commit suicide. This information is only accessible to members of the association. The association underlines, moreover, that additional information is often required, which will only be communicated to those of its members who are resident in the Netherlands. Such initiatives may enable those who wish to commit suicide to do so in greater tranquillity and with less unpleasantness than by, for example, throwing themselves off the top of a building, into a canal or in front of a train, or by hanging or shooting themselves.

Three solutions may be envisaged for this major problem:

- **An obligation on the doctor to find a replacement**

The Dutch Medical Association supports this solution: “*When a physician is unwilling to accept a request by his patient for euthanasia, he must not start the procedure. Instead, he must enable the patient to contact a colleague who has no objections of principle to the practice of euthanasia and assisted suicide. This is not in any sense a legal obligation, but rather his moral and professional duty to assist the patient in sufficient time to enable him to find a physician (for example within the same practice) who is not opposed in principle to euthanasia or assisted suicide.*” (reported in the quarterly bulletin n° 122 of the ADMD-Belgium).

In an opinion issued in 2003, the Belgian Medical Association (*Conseil national de l'Ordre des médecins*) argued: "*it is important that the patient should be informed in good time of his state of health; but it is equally important that he be informed in time of the convictions of his doctors as regards the different possibilities for the end of life. We must avoid a situation in which a patient is informed at a late stage of the conscientious objections of his doctor and thus constrained in the terminal phase of his illness to find a physician who is willing to meet his request for a specific end of life. However, the Law on euthanasia must not lead to the appearance of teams or centers for euthanasia.*"

In order to ensure continuity of care, as required both ethically and legally, four senators from the Flemish liberal party had, in the summer of 2010, proposed legislation to provide that, unless the patient or his representative had designated another doctor and in order to find a legal solution to this problem, "*a physician who is unwilling to accept a patient's request for euthanasia or for assisted suicide must transfer the patient's medical file to another physician in order to ensure continuity of care*".

However, a senator from the socialist party has recently opposed this approach, on the basis of a broad interpretation of the physician's conscience clause. On the one hand, he proposes that the doctor invoking the conscience clause must communicate his refusal to the patient within seven days of the latter's request for euthanasia and also sets a limit of four days for him to transfer the patient's file to a replacement doctor designated by the patient; but, although he accepts that it is difficult to imagine that a patient enfeebled by serious illness will have the means to find a consenting doctor, the senator, nevertheless, and rather surprisingly, argues that to oblige a doctor invoking the conscience clause to refer his patient to a consenting doctor could be considered to put in question this very conscience clause. Therefore, the senator proposes that the public be provided with more information on the rights of patients at the end of life and that the training of doctors and nursing staff to handle end of life situations should be increased – recommendations which have also been made by the Federal Control and Evaluation Commission. On the other hand, the senator recommends the establishment of multidisciplinary teams capable of providing palliative care throughout the country, and, in particular, of effectively controlling pain and able to meet a request for euthanasia. To this end, he suggests that it would be desirable, as a first step, to make use of the forums of doctors LEIF-EOL (*Levenseinde Informatieforum – Forum End of Life*) in order to support the development, in each Belgian province, of a centre of excellence and a contact point able to provide help to doctors, in particular to general practitioners who have received a request for euthanasia and to patients who have encountered difficulties in finding a willing doctor.

One wonders, however, how such provincial centres could concretely resolve the real difficulty for an enfeebled patient who is forced to rely on his own resources to find a consenting doctor, unless these provincial centers are in fact to become end of life clinics similar to the one that exists in the Netherlands.

- **Specialised end of life clinics**

Dr Petra de Jong, director of the NVVE, has examined this question in depth: "*An end of life clinic can be set up. The need exists, the personnel can be found, it is legally permitted and therefore politics should not come into it.* [...] *As a doctor, and I speak as a doctor, you may terminate someone's life because you recognise his right not to be obliged to live longer. For patients with a well-established and heavy medical history, who meet the legal criteria, you may, if their physician has refused, agree to honour their request, even quite rapidly.* [...] *I have asked various doctors whether they would be willing to be involved within such a framework and all have said 'yes'. This would not be a full time activity: to be dealing with death all day is a heavy emotional burden. I would rather suggest a team of five doctors, each of whom would spend one day a week at the clinic and practise elsewhere on the other days.* [...] *Only people who have chosen their end of life would approach the clinic.* [...] *I would expect an average stay of three days, which means that there would already have been a verification that the person met the legal criteria. If someone is eligible, a first appointment should be fixed as quickly as possible, because it is important that people are not left for too long in a state of uncertainty. These appointments would involve a meeting between a doctor and the patient, preferably accompanied by members of his family. These meetings are necessary for the doctor to get to know the patient and for the patient to explain his situation. As soon as possible thereafter, the patient would come in.* [...] *The number of beds should be eight, as, on the basis of experience in hospices, 6 to 8 is the ideal number of beds for providing optimum care. There should also be spaces for family members. An end of life clinic could be part of a hospital or a nursing home, but could also be a separate institution in its own building.* [...] *An end of life clinic should also be open to those who wish to end their life for other reasons. For instance, to those who have assembled the drugs and wish to take them within a safe environment, and not alone. This would be suicide rather than assisted suicide. The clinic must be able to judge in advance that nothing would go wrong.*" (interview of Dr Petra de Jong in the quarterly bulletin n°122 of the ADMD-Belgium, 2011).

The first end of life clinic (“*levenseindekliniek*”) in the Netherlands opened its doors in The Hague on 1 March 2012. It is intended for persons who wish to die and meet the legal conditions for euthanasia or assisted suicide, but whose doctor cannot or will not meet their request. Two months after opening, the clinic had already received 200 requests for euthanasia, of which two-thirds were from women and one third from men. Two-thirds of these patients were suffering from physical illnesses and one third from mental illnesses. Most of the patients came from the regions of Randstad and Utrecht but none from the region of Drenthe, where doctors have put in place arrangements which enable them to refer patients to another doctor if they are themselves unwilling or unable to meet a request for euthanasia or assisted suicide. As currently organised, however, this first initiative resembles an itinerant team.

- **Itinerant medical teams**

At present, it is not the patient who goes to the end of life clinic in The Hague, but a mobile team, comprising a specially trained doctor and nurse, which goes from the clinic to the patient. There are currently ten such teams. A patient who has had his request for euthanasia refused can contact the clinic by telephone and fill in and send back a detailed questionnaire (available on the internet). The patient will then be visited by the team which will handle his case and which he must authorise to have access to his medical file. Normally, the team will contact the patient’s doctor. They will first seek to persuade him to meet the patient’s request himself and will offer to help him with implementation. If the doctor continues to refuse, the team will take the case over and itself perform euthanasia. A doctor may himself pass to the clinic a request from a patient.

In the first eight months of its existence, 51 euthanasias were performed by the clinic, of which 21 by a doctor of one of the itinerant teams and 30 by the patient’s doctor with the help of one of the teams.

In **Belgium**, a similar approach seems to be taking form.

The doctors belonging to the LEIF (“*Levenseinde Informatieforum*” for the Dutch-speaking region) and to the EOL (“*Forum End of Live*”, for the French-speaking region), although trained for the purpose, initially only acted to provide support by giving advice and help to doctors confronted with difficult end of life problems or in receipt of a request for euthanasia, or by providing assistance with implementation in specific cases. The LEIF network, which has three times as many doctors as its French-speaking counterpart, has expanded the scope of its activities by creating, within the *Academisch Medisch Centrum Wemmel* in the Brussels suburbs, a medical center called

*ULteam* ("*Uitklaring Levenseindevragen Team*"), whose objective is to help patients eligible under the Law who are having difficulties resolving their end of life problems. This is a joint project of the *Flemish University of Brussels*, where Dr Wim Distelmans is professor of palliative care, and the University of Gent. The centre offers consultations to patients in various specialities (palliative care, end of life care, oncology, psychiatry, pediatrics, psychology, social and psychiatric nursing, philosophical support, legal assistance,...) and can arrange for admittance of its patients to the Flemish University Hospital in Jette in the Brussels region. (The oncologist Dr Wim Distelmans is head of the department of palliative care at this hospital.)

The *EOL Forum* is apparently studying the possibility of establishing one or two similar centers for French-speaking patients.

These initiatives, which are greatly to be welcomed, emanate directly from the medical profession and from the two Belgian associations for the right to die with dignity. They provide concrete support for the right of an individual to decide the manner and the time of the end of his life.

One must also recognise and salute the trail-blazing role, in the promotion of the right to freedom to choose one's death, first of the Netherlands and the NVVE and then, in Belgium, of Flemish physicians and members of Parliament and, in particular, of the Flemish liberal senators.

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Lesterny (Belgium)
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It goes without saying that I retain sole responsibility for the content of this work, including the use made of the texts I have quoted in support of my arguments.

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