

## DOES THE BELGIAN MODEL OF INTEGRATED PALLIATIVE CARE DISTORT PALLIATIVE CARE PRACTICE?

*The purpose of this report is to describe the Belgian model of end of life care that, since 2002, has aimed at developing "palliative care for all", while nonetheless authorizing the practice of euthanasia under certain conditions. The thirteen years since the passage of this decree have culminated in a clash between two opinions: one affirms that the decriminalization of euthanasia has truly enabled the development of continuous, palliative care; the other, conversely, stresses that making euthanasia commonplace is cannibalizing, and, little by little, distorting the concept of palliative care, which, in principle, focuses on support until death, but without triggering it.*

*After we have explored the evolution of the philosophy of palliative care in Belgium, it will be useful to examine the consequences of this integrated approach, as much for the well-being of patients as for the proper practice of medicine and management of life's end in health care institutions.*

### END OF LIFE CARE IN BELGIUM SINCE 2002

#### DEFINITION OF PALLIATIVE CARE

In 2002, the World Health Organization defined palliative care as follows:

***"Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; and uses a team approach to address the needs of patients and their families".***

In the same year, the French researcher Isabelle Baszanger wrote: "[the term 'palliative' has become a necessary wayside shrine in every politically correct discussion. Everyone imagines patients 'holistically', is 'listening', 'taking care of their pain' and attempting to 'ease their suffering' while

'respecting their dignity'. Yet we know what great differences in practice lie hidden behind the consensus that these words imply, differences that can often be traced back to different uses of the word palliative]"<sup>1</sup>.

In Belgian legal terms, "palliative care" is "[the combination of treatments and care given to a patient who has a disease that may cause death when the disease no longer responds to curative treatment]"<sup>2</sup>.

It is important to note that in the aforementioned WHO definition, in that of INAMI (National Institute for Health and Disability Insurance, 2005) and in that of the Belgian Law of 14 June 2002, palliative care clearly excludes euthanasia from its scope<sup>3</sup>.

We will first look into the context surrounding Belgium's adoption of three pieces of legislation on life's end, and then into how this particular legal framework has been interpreted since 2002.

## BELGIAN LEGISLATION

In 2002, in the space of several months, Belgium adopted a triple legal framework for taking care of life's end, namely, in chronological sequence:

- The Act of 28 May 2002 on **euthanasia** to permit a patient, under certain conditions, to request that a physician **end the patient's life**;
- The Act of 14 June 2002 on **palliative care**<sup>4</sup>, which grants all citizens **the right to palliative care in the context of support through to the end of life**;
- The Act of 22 August 2002 on **patients' rights**, which specifies the **relationship between the patient and the medical profession**.

In fact this new legal framework was the legislative culmination of three concurrent movements, initiated in the 1980s:

- The first, which after the first palliative care initiatives launched by some health professionals, intended to make palliative care a real right available to all;
- The second, comprising partisans of the "right to choose life's end" or euthanasia<sup>5</sup>, pursued their fight for the sake of a person's right to decide what happens to his or her own life;
- The third, forged in reaction to the sometimes paternalistic attitude of physicians trained to master the latest technology and to persevere tenaciously in the treatment of diseases, wanted to give patients back their central role in the medical decisions that affect them.

Although the option taken by the legislator showed, from the start, the desire to reach a fair compromise between these different points of departure, the parliamentarians nonetheless went to the trouble of producing two separate pieces of legislation to signal that euthanasia and palliative care are not of the same order. Nevertheless, a study of the expert hearings, conducted in the context of parliamentary debates for the development of the law on palliative care, shows us how polarized the debate between palliative care and euthanasia already was at that time: while some speakers reaffirmed that "[palliative care and euthanasia are not underpinned by the same philosophy and cannot be

*regarded as complementary]*"<sup>6</sup>, others, also citing the principle of human dignity, were already refusing to cast euthanasia into conflict with palliative care, and even went so far as to say that the examination of requests for euthanasia necessitated the involvement of experts in palliative care<sup>7</sup>.

## THE DYNAMIC OF THE BELGIAN TRIPLE LEGISLATION SINCE 2002

### 1. Euthanasia ever less subject to regulation

In 2002, the decriminalization of euthanasia law had three objectives: take euthanasia out of hiding, guarantee impunity for the physician who practiced it, and ensure respect for the patient's wishes. After several years of debate, parliamentarians upheld the "right to euthanasia on demand" and decriminalization in the case of an act performed by a physician after consulting an independent colleague on an adult patient or an emancipated minor patient who is conscious, in a hopeless medical situation and who has a serious and incurable disorder that causes "*constant, unbearable and unrelievable physical or psychological suffering*" or on an irreversibly unconscious patient who has written an "advance directive" within the previous five years. The law also put in place a "Federal Commission for Monitoring and Assessment" of Law Enforcement (*[Commission fédérale de contrôle et d'évaluation de l'application de la loi]* hereinafter, "Control Commission") charged with checking, on the basis of mandatory reports written by physicians after euthanasia [*a posteriori*], the conformity of the procedures followed and, in cases of irregularities, with seeking clarification or even referring the matter to the courts.



Since then, the statistics on the reports received by the Control Commission have shown a steady increase in the number of euthanasia cases from year to year. The milestone of 1000 cases was passed in 2011, and Belgium recorded 1816 euthanasia cases in 2013, or about 5 cases per day. The reports, of which more than 80% are written in Dutch, imply either that Dutch-speaking patients are euthanized in much greater numbers or that francophone practitioners do not bother to comply with the formalities required by law. In twelve years, the Control Commission has not sent a single case to the public prosecutor. In its regular reports to the legislative chambers, the Control Commission has stated that it "*[does not have the possibility of assessing the number of reported euthanasia cases versus the number of euthanasia cases actually performed]*", which, in the eyes of the law's opponents, casts doubt on the reality of control.<sup>9</sup>

On the legislative front, after various proposals to expand the scope of the law<sup>10</sup>, on 12 February 2014, the Belgian House of Representatives finally adopted a "bill amending the Act of 28 May 2002 on euthanasia with a view to extending it to minors"<sup>11</sup>. Among the main arguments of the proponents of this extension was the equality of patients' rights regardless of age. During expert hearings, Professor Wim Distelmans explained that it was incoherent to set an age limit for euthanasia, while "*[through the law on patients' rights, minors may always refuse treatment, even if this treatment can save their lives. This right is not related to age]*"<sup>12</sup>.

So, after its initial acceptance, the practice of euthanasia has developed according to its own internal dynamics. Although initially an exceptional action subject to legal conditions intended to be very strict and well-controlled, euthanasia has become commonplace over the years and with experience, in a context of ever weaker and uncertain control. Today, autonomy and patient choice prevail, so much so that the initial conditions of the law on euthanasia are no longer invoked.

In Belgium, several irregular cases of euthanasia have been publicized that gainsay the exceptional nature of euthanasia, the strict conditions and the controls on the reports of physicians, which brings to mind the phenomenon of the "slippery slope". Notably, the Belgian legislative system has gradually accepted that, if based on a validly expressed wish, the anticipation of a "dramatic change" in an incurable disease or a combination of pathologies related to advanced age can be classified as "unbearable psychological suffering" thus opening up the possibility of a request for euthanasia within the meaning of the law. Thus died the writer Hugo Claus in 2008, when he showed the first symptoms of Alzheimer's disease, and Nobel Prize laureate in medicine, Christian De Duve, in 2013, at the age of 95. Euthanasia was also granted in September 2013 to a Belgian transgender, after a sex change operation that he said had dissatisfied him.

## **2. The shift of "conventional" palliative care to "integrated" palliative care**

For partisans of "the right to end one's life", the three laws of 2002—palliative care, euthanasia and patient rights—"complement each other harmoniously". As certain Belgian practitioners point out<sup>13</sup>, care providers who initially opposed the practice of euthanasia and then passively witnessed this act of death have gradually been persuaded that, indeed, euthanasia might be a "lesser evil" if, on medical grounds and in accordance with the patient's wishes, it allows a "gentle death".

Following this logic, euthanasia has entered the field of "good medical practice". This idea of complementarity seems to have been quickly adopted in the field by the three federations of palliative care in Flanders, Wallonia and Brussels. Since 2003, the Flemish Palliative Care Federation [Federatie Palliatieve Zorg Vlaanderen] has endorsed the vision of "integrated palliative care". In 2011, the Flemish Palliative Care Federation clearly expressed its vision: "*[the palliative care team is available to all patients, even those who request euthanasia. Palliative care guarantees full and proper consideration of these requests for euthanasia]*".<sup>14</sup>

In the francophone medical world, this view seems to have been slower to catch on. Nonetheless, during the discussion in the Committee on Public Health in the House of Representatives on 21 March 2006, Vincent Baro, President of the Walloon Palliative Care Federation [Fédération Wallonne de Soins Palliatifs] had already remarked in similar terms: "*[it is very dangerous to oppose euthanasia to palliative care, which are the subject of separate laws. In the field, what matters is ensuring the best support for the patient, whatever his or her request may be. This debate is sterile]*".

As an option for "managing" the end of life—notably in the cases where the patient wishes to specify the time of his or her death so as not to become dependent—euthanasia is no longer seen as a failure of palliative care or even as a practice in conflict with it, but rather as an act that can be carried out within a palliative care service<sup>15</sup>.

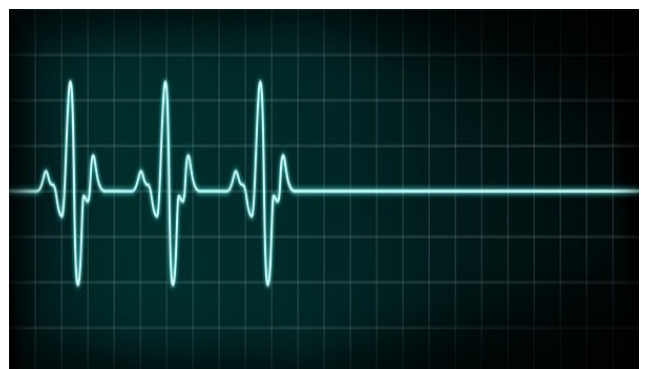
In this respect, the recently published testimony<sup>16</sup> of Dr. Corinne Van Oost is eloquent. Dr. Van Oost, a palliative care physician initially opposed to euthanasia, was "drawn" into practicing it on one of her patients, which led to a real shift in her attitude and an integration of this practice into her approach to end of life care, to the point that she asserts that "[a society that permits euthanasia is a society that has gained in humanity]".

The formulation of "integrated palliative care" has become well-established in most official studies in Belgium. In this respect, it is interesting to note the semantic evolution in the three reports issued since 2005 by the Federal Palliative Care Evaluation Unit (the "Evaluation Unit"):

- In 2005, the first report on palliative care made no mention of the practice of euthanasia.
- In 2008, the second report devoted a section to the link between "palliative care and euthanasia". Arguing that "*the choice of euthanasia does not exclude palliative care*" and vice versa, the Evaluation Unit says that "*[it is of little use to polarize the debate between euthanasia and palliative care]*" and endorses the concept of an

integrated palliative care<sup>17</sup> that "*[implies that we recognize that the patient has the right to **decide that pursuing conventional palliative care is no longer serving its purpose** and that his or her wish for euthanasia be supported and accepted]*".<sup>18</sup>

- Finally, in its last report in March 2014, the Evaluation Unit adopted the WHO's definition of palliative care cited above, but truncated the final words and omitted saying that palliative care "***intends neither to hasten or postpone death***". This same report also documents the changing practices: "*since 2002, some cases of euthanasia have occurred in the framework of palliative care, which increases the work of the teams involved and also calls for more support from **specialized palliative care teams** (...) that should receive the necessary resources (in terms of personnel) so as to be able to **support a palliative care patient who has requested euthanasia***." The report also reiterates that "*it is important to maintain the possibility for the patient to have recourse to euthanasia in a context of holistic, palliative support*".





### 3. The primacy of patients' rights

The "Patients' Rights Act" of 2002 introduced the right of the patient *"to quality services"* (Article 5), *"to being informed about his state of health and the probable course of it"* (Article 7), and *"to consent freely to any treatment after receiving correct information"* (Article 8).

Of the three laws, this is probably the one whose passage into law attracted the least attention. Ultimately, however, it appears that this law is the cornerstone of the set of decrees, and is moreover the law which anchors all later changes to the laws. Twelve years on, patients' rights have become entrenched in the common mores and no one questions their validity. The law's logic in terms of patient autonomy is sometimes taken to extremes, going so far as to propose to individuals that they take the initiative to define their "plan for life's end". As explained by Professor Wim Distelmans: *"Euthanasia has this about it that is very important and specific: it is the only decision for which we know with certainty that the initiative comes from the patient. For the other end of life decisions, it is not as clear. It can happen that physicians stop treatment without prior consultation; it may also be the case that they have no other choice"*<sup>19</sup>.

"Patients' rights" also served as a fundament for the opponents to the "palliative filter"; this "filter" would impose treatment against pain in an effort to make the flow of requests for euthanasia evaporate<sup>20</sup>. The logic of the "filter" depended on the view that euthanasia could only be granted in cases of "unbearable and unrelievable" suffering, which presupposes that we have first tried to relieve suffering. *"[We have avoided the pitfall of the palliative filter, which in some ways infringes upon the principle recognized by the legislation of the patient's right to refuse medical treatment]"*, as the President of the ADMD explained at the end of 2011<sup>21</sup>, evoking the debates of 2002 and pointing out that the right of the individual to free choice must allow him or her alone to decide the time of death and, for that purpose, to call on the services of a physician.

In the three regions of the country, the official public policy was the same from then on: at each step in the evolution of the illness, listen respectfully to the patient's requests, expectations and wishes, and provide care and treatment that meet his or her wishes. Proponents of euthanasia encouraged the deployment of this model of integrated palliative care in which euthanasia was no longer regarded as an exceptional act, but rather as an option with the same standing as any other medical procedure. The idea that euthanasia would from then on be integrated into palliative care seemed to have been confirmed<sup>22</sup>, with some people going so far as to consider euthanasia the "ultimate treatment"<sup>23</sup>, which, if performed with prudence, was in line with their commitment to palliative care.

Over several years, euthanasia as an option at life's end has inexorably made its way into Belgian public opinion. Often presented in the media as "an ultimate gesture of compassion" through real cases, the act of death administered by a physician is no longer seen as an exception in the context of criminal law, but as a choice equivalent to natural death.

Through its desire to develop a culture of palliative care while decriminalizing euthanasia so as to "make the patient the master of his or her own destiny"<sup>24</sup>, the Belgian model has drawn euthanasia into the sphere of palliative care philosophy. It remains for us to try to understand the practical implications of this shift for people at life's end and the ethical questions raised by this vision of "continuing care" that erases the boundary between "let die" and "cause to die".

**« Patients' rights also served as a fundament for the opponents to the palliative filter »**

## THE IMPACT OF THE NEW "OWNERSHIP" OF LIFE'S END ON THE PHILOSOPHY OF PALLIATIVE CARE



Supporters and opponents of "the Belgian model of integrated palliative care" disagree on how to assess the impact of this development on medical practice, on taking care of the sick, and on the values that sustain society as a whole. Indeed, it is difficult to understand objectively the reality of practice, because studies on the subject are quite incomplete, empirical and limited. At best, the evolution of the debates and the analyses of the questions that have arisen provide arenas for thought.

### A NEW "PALLIATIVE CULTURE" FOR MEDICAL TEAMS

#### *Two competing models of training on end of life care*

Training in palliative care has long been neglected in the medical training curriculum. In the 1990s, local initiatives by physicians gradually led to the incorporation of "palliative care" modules in Belgian university programs. In September 2000, the network in support of extramural palliative medicine (RAMPE), which had been set up in 1998 at the instigation of the Scientific Society of General Medicine (SSMG), proposed a training program spread

over three years, including workshops with twelve to twenty physicians, with a curriculum covering the treatment of symptoms and the ethical, philosophical and spiritual aspects of support at life's end. Since then, these opportunities for long training programs in "palliative care and the quality of life" have evolved and expanded, for students as well as for general practitioners and for the various medical professions that are directly affected<sup>25</sup>. However, these programs do not include instruction in the practice of euthanasia.

In the wake of the three laws of 2002 and "confronted with the insecurity and lack of experience of physicians", training programs have gradually been rolled out in parallel in the different regions of the country in order to adapt the content and quality of end of life care to the new legislative framework. In Dutch-speaking Belgium, this planned familiarization of care providers, patients and families with the content of the new laws was very quickly entrusted to LEIF (LevensEinde Informatie-Forum/Forum d'information Fin de vie [End of life information forum]), founded in 2003 on the impetus of the association Recht op Waardig Sterven (RWS: right to a dignified death). Since then, LEIF has organized training for LEIF physicians, LIEF nurses and other care providers, and provides telephone support on end of life questions.

In French-speaking Belgium, the task has fallen to Forum EOL (End of Life), formed in November 2003 with logistical assistance from the Association for the Right to Die with Dignity (ADMD). It currently comprises a hundred physicians who have been especially sensitized to managing the end of life. It is obviously expected of EOL and LEIF physicians that they consider euthanasia a perfectly valid ethical option and that they be available to train and help their colleagues on the conditions and procedures to follow if euthanasia is requested.

## Cases of conscientious objection

**Euthanasia is presented there as a "complementary act to palliative care for the most difficult end of life cases"**

The lectures at the LEIF and EOL forums, which provide most of these short courses, leave no doubt about their commitment to the "philosophy of continuous care". The stated objective is to enable "spreading skills in the domain of end of life" and the message consists in convincing medical staff that the act of administering death also has a place in the logic of palliative care. Euthanasia is presented there as a "complementary act to palliative care for the most difficult end of life cases", which requires multidisciplinary expertise (physicians, psychologists, oncologists, etc.).

This policy makes some Belgian physicians who specialize in palliative care uncomfortable. During her speech on this issue in Canada, Dr. Catherine Dopchie summed up her judgment of the types of courses currently offered: "*[in Belgium, training in providing palliative care and training in providing "supportive" care (whose goal is to relieve the side effects of the disease or treatment, especially pain) that is sometimes followed by euthanasia have evolved in parallel and without any collaboration, reflecting differences in approach. Today, in the curriculum of physicians, training in real palliative care has been neglected. Organizing a short postgraduate course in end of life decision-making, including euthanasia, but neglecting the philosophy of palliative care and not incorporating any practical internship, skews information, spreading an erroneous concept of integrated palliative care]*"<sup>27</sup>.

While some medical teams have easily adopted a position in favor of supporting any person right to the end, with the risk of having to administer death, conversely, other physicians and nurses have expressed their trouble assuming a function that breaks radically with the ethics traditionally associated with medical practice. In consequence, in the field, they complain that they sometimes feel a certain pressure from patients, their families or their colleagues and that it will be viewed badly if they refuse to practice euthanasia. They denounce the growing danger of informally categorizing care providers according to their philosophy on life's end, their difficulty in calling on external colleagues for help and the negative impact of these cases of conscientious objection on the nursing teams' daily experience of their work.

In face of this resistance, partisans of euthanasia continue to remonstrate that too few physicians are willing to "cooperate", denigrating in passing what they refer to as "*obstinate perseverance in palliative care*"<sup>28</sup>. For Professor Wim Distelmans, President of the Control Commission, too often, physicians still have a "*negative attitude*" to euthanasia and even more so to its application, because "*their professional curriculum has virtually exclusively trained them to cure*"<sup>29</sup>. Opponents of this argument point out that medical science has never specified that one should make patients die<sup>30</sup>.



### ***The problem of the conscientious objection clause***

This ethical debate also raises a two-part dispute about the "conscientious objection clause". Currently, the law stipulates that a physician who refuses to perform euthanasia must inform the patient *"within a useful time"*. For euthanasia partisans, this vague notion leads to *"stretching the conscientious objection clause"*. *"[We find ourselves in very painful situations when the patient no longer has the possibility of starting a therapeutic relationship with another physician, as the refusal arrived in extremis]"*, Jacqueline Herremans, president of ADMD protests. The introduction of a response period has been proposed, which would clarify things<sup>32</sup>.

Furthermore, the current law specifies that if a physician refuses to euthanize, the task of finding a possibly more conciliatory physician falls to the patient. However, some lawmakers want to change the law on this point by stipulating that a physician who invokes the conscientious objection clause has an *obligation* to refer the patient to a colleague, without waiting for the patient himself to designate a physician. This development, quite broadly supported by the Bioethics Committee<sup>33</sup>, was recently couched as a new bill of law<sup>34</sup>.

### ***Should we impose the practice of euthanasia on all health care institutions?***

Authors who deplore *"stretching"* the conscientious objection clause also stress that this freedom is *"a strictly individual right granted to the physician to not perform any medical procedure that his conscience condemns. This conscientious objection clause cannot be extended to an institution that would impose it on care providers."*<sup>35</sup> Continuing with this logic, they point to the fact that some health care facilities in Belgium—particularly those inspired by, or part of, the Christian tradition—have *"institutionalized"* the clause of individual conscientious objection by publicly declaring that they will not practice euthanasia. According to these authors, it must be possible to perform euthanasia wherever the patient requests it, whether at home, in hospi-

tal, or in nursing homes and care institutions. They therefore advocate that all health care providers and institutions consider these end of life options to be equivalent, and provide, right up to the end, the *"best care"* of each patient via palliative care plans that have been tailored to him or her.

The question of the ethical legitimacy of these policies has been submitted to the Belgian Bioethics Advisory Committee: *"Can a health facility (hospital or nursing home with or without health care services) prohibit the practice of euthanasia within its walls or add, in its regulations, additional conditions to those prescribed by the said law?"* In a recent very detailed opinion on the issue, committee members indicated that they were not unanimous on the issue of institutional policies; they held two divergent positions:

- *Some members, fiercely opposed, remonstrated, for the sake of the right to the protection of health and to medical assistance and of patients' rights, that patients "have the right to quality services from a professional practitioner corresponding to their needs, with respect for their human dignity and autonomy and without any institutional prejudice whatsoever".*
- *Other members were, on the contrary, in favor of the institutional policies; reiterating that euthanasia is not a right and that "a health care institution is not reducible to being just a building where health care is provided", they also stressed that it was "essential to develop an ethical vision in each health care institution".*





At the request of the Belgian Minister of Health<sup>37</sup>, the Bioethics Advisory Committee also considered the ethical, social and juridical aspects of the question whether, to take a different tack, it might be necessary to *create clinics or competent specialized institutions (whose sole purpose would be to support end of life patients) that would notably aim to permit each patient who meets the legal conditions to have access to a medical environment that is not ideologically opposed to the principle of euthanasia*. On this question also, the Bioethics Advisory Committee's members expressed different opinions. Nevertheless, they unanimously emphasized the need in any case to preserve the "one-to-one discussion" [colloque singulier], the special relationship between patient and physician, stating that *"such clinics could not be institutions that would impose euthanasia in a 'mandatory', routine and impersonal way. They could also not be a destination for automatic transfers, in the framework of a 'protocol', of patients coming from institutions that apply institutional policies prohibiting or restricting euthanasia"*<sup>38</sup>.

Not long ago, the standards for licensing a "nursing and health care institution" were amended by royal decree<sup>39</sup>; they now expressly stipulate that medical staff must ensure *"compliance with the legislation on euthanasia and palliative care and respect for the resident's wishes with regard to the end of life and/or to his or her advance declaration pertaining to euthanasia"*.

**"Requesting euthanasia is, for many people, equivalent to guaranteeing a painless death."**

## WHAT CHOICES DO PATIENTS HAVE FOR THEIR LIFE'S END?

Recently, the Belgian model proposed to offer patients at life's end a "global therapeutic plan" for continuous palliative care, including euthanasia as an optional component. Thus the Flemish Palliative Care Federation (FPZV) has proposed, based on its experience, that every patient be referred to a

"multidisciplinary" palliative care team that could optionally practice euthanasia.

Some professors of Flemish medicine who are regularly invited abroad to give their opinion on this philosophy of care<sup>40</sup> promote it. They defend the thesis that the Belgian legislation on euthanasia "has reinforced and not detracted from palliative care" in Belgium, and they point out the further advantage that, with it, "obstinate perseverance in palliative care is not possible". Their argumentation relies on some essential points:

- making euthanasia possible has succeeded in inciting physicians and patients to finally dare to talk about death and to maintain the physician-patient relationship, enabling them to consider palliative care;
- this practice has ushered in a decline in clandestine practices and *'an increasing prudence on the part of health care staff when the time comes to take end of life decisions'*;
- requesting euthanasia is, for many people, equivalent to guaranteeing a painless death;
- permitting the practice of euthanasia in the home and in all health care units will obviate a surge in end of life clinics;
- there is no epidemiological indication that medical end of life practices are likely to endanger vulnerable people. On the contrary, listening to requests for euthanasia and showing an "open mind" on this topic ultimately help reduce the actual number of euthanasia cases.

The argumentation nonetheless cannot come to grips with the question of the meaning of life's end or with the patients' moral distress at feeling that, at life's end, they are a burden to their nearest and dearest and to society. It denies the risk of considering euthanasia in the context of integrated health care to be an effective and comfortable shortcut when facing conventional palliative treatment that has become increasingly difficult due to the current overload of palliative care institutions and their cost<sup>41</sup>.

The argument for integrated care also fails to take into account the risk of developing "end of life care at two speeds", distinguishing between "palliative care patients" with a good support network<sup>42</sup> and those in a precarious, insecure financial situation, who would then potentially be more inclined to request euthanasia.

Starting from this perspective, some physicians are quick to assert that, on the contrary, the culture of euthanasia is detrimental to the improvement of palliative care. For Dr. Catherine Dopchie, *"[Spreading the skills acquired in palliative care for taking charge of a patient's holistic suffering has been very inadequate and funding for this has not been allocated. Research is incomplete, especially on our ability to address squarely the existential suffering of the most vulnerable, and even less complete on the best way to try to respond to it. (...) Progress can only be made by stubborn perseverance and by confronting our assumed impotence. (...) The representation of euthanasia as a dignified and courageous solution derails our contemporaries, disfigures and thwarts the offer of palliative treatment and, more broadly, medicine and society.*

*Euthanasia is now commonplace; it offers an avoidance response and nips progress in the bud. (...) It taints the quality of medical service and relativizes the interest in the dying person and therefore the interest in palliative care]"*<sup>43</sup>.



## CONCLUSION : THE BELGIAN MODEL, EXCEPTION OR PROTOTYPE?

For the sake of compromise, the 2002 triple legislation on end of life care intended to enable the various philosophical views to coexist. Today, there seems to be a consensus that this triple legislation has revolutionized the understanding and management of life's end in Belgium. The philosophy of "continuous care, whatever the patient's attitude" has meanwhile penetrated everyone's mind and the idea that everyone should be able to "put forward an end of life plan" in keeping with his or her philosophical convictions is making headway in public opinion.

For supporters of euthanasia, this Belgian arsenal of "continuous palliative care" offers the ideal legal framework for considering life's end: for the patient, access to appropriate care and to a "dignified and gentle death"; for the medical profession, protection vis-à-vis patient requests; and all of this in "a climate of sharing and trust" between the health

care professionals and the patient and of pluralism that respects everyone.

However, this trend has sometimes created confusion and confronted patients, care providers, and institutions with delicate new ethical issues: how do we ensure that the conscientious objection clause of the medical profession is respected? Can we allow different institutional practices? In face of the ever more commonplace practice and acceptance of euthanasia, does this model not inevitably pressure physicians, patients and society at large to prescribe "an efficient end of life"? In sum, does this philosophy constitute a response to the mortal distress and feeling of vulnerability of people at the end of their life?

In foreign countries, where the future of palliative care is also being debated in the context of aging populations, many people are watching the "Belgian laboratory" closely. Since the passage of laws on euthanasia in the Netherlands and Belgium in 2002, only Luxembourg has followed suit. Outside the Benelux borders, this broad definition of "integrated palliative care" that includes euthanasia has not been accepted. "[We believe that euthanasia is not part of palliative care for children and that it is not an alternative to palliative care]"<sup>44</sup>, the International Children's Palliative Care Network (ICPCN) insisted in a recent statement on the occasion of the adoption of the Belgian law extending the decriminalization of euthanasia to minors.

In today's debate, the "Belgian model" serves as an example for some and a foil for others. Both groups nevertheless acknowledge that, insofar as the evolution of Belgian law since 2002 is con-

cerned, with the lifting of the ban on administering death in the context of palliative care, not only the nature of end of life care, but also the nature of medicine in general, has thereby been transformed.

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1. Ibaszanger (2002), *Quelle médecine voulons-nous?* [What kind of medicine do we want?] La Dispute, Paris.

2. Law of 14 June 2002 on palliative care. *Moniteur Belge*, 26.10.2002.

3. Institut Européen de Bioéthique [The European Institute of Bioethics] (2008), «Les soins palliatifs, un accompagnement personnalisé en fin de vie» "[Palliative care, personalized support at life's end]", *Dossier de l'Institut Européen de Bioéthique*.

4. Clarification that the law on palliative care significantly expands the definition of the art of medicine, specifying that the latter "encompasses medicine practiced on human beings as well as preventive, curative, **continuous and palliative** medical practices that concern them". Cf. Article 9 of the Law amending Article 1 of Royal Decree n.78 of 10 November 1967 on the practice of the health care professions.

5. In 1983, the Belgian Leon Favys founded the Flemish section of the Association for the Right to Die with Dignity: Recht op Waardig Sterven (RWS).

6. Cf. Hearing of Mr. Alain Schoonvaere, Director of the palliative care center "Foyer Saint Francis" in Namur, Annex to the Report of the Joint Commissions of Justice and Social Affairs, Legislative Document 2 246/7, Belgian Senate, 9 July 2001.

7. Cf. Hearing of Dr. Arsène Mullie, Head of Intensive Care and Emergency Resuscitation AZ Sint-Jan Brugge, member of the Flemish Palliative Care Federation and Chair of the working group "Ethics" of the same Federation, Legislative Document No. 2 246/7, the Belgian Senate, July 9, 2001.

8. Institut Européen de Bioéthique [The European Institute of Bioethics] (2012), « Dix ans de dépénalisation de l'euthanasie en Belgique » "[Ten years of decriminalized euthanasia in Belgium]", *Dossier de l'Institut Européen de Bioéthique*.

9. Cf. Prof. E. Montero, "[The Commission is in the end nothing but a recording chamber. It operates a posteriori, remains dependent on the declaration of physicians and interprets the law in a very flexible manner, especially in assessing the concept of "unbearable and unrelievable psychological suffering]", "[Confronting medicine with life's end: a disunited Europe]", France-Culture radio broadcast, February 17, 2014.

10. In February 2013, the socialist senators filed 13 bills to "refine the decree". Among the proposals was one requiring a physician who refuses to perform euthanasia to state this "within seven days" and then send the patient to a colleague, facilitate the procedure of "advance directive" and make it valid indefinitely, improve the "training" and "information" physicians and care providers receive, notably through the creation of a center of expertise in each province, and lastly, study the possibility of taking into account the cases of people with Alzheimer's or other degenerative mental illnesses.

11. With 86 votes for, 44 against and 12 abstentions, the proposal was supported by an "ad hoc majority" (socialists and liberals, francophones and Dutch speakers, Greens and NV-A). The text grants "[to minors at life's end, who report unbearable and unrelievable physical suffering caused by an accident or illness, whose death is expected in the near future]" the possibility of requesting euthanasia and to have the request granted, with the consent of their legal representatives. It does not specify a minimum age, but retains only the criterion of the child's "capacity to discern", as certified by a psychologist.

12. Hearing of Prof. Wim Distelmans, Professor of palliative medicine at the VUB [the Free University of Brussels], <http://senaat.be/actueel/homepage/docs/euthanasie.pdf>, p. 180 (in Dutch), May 15, 2013.

13. P. Vanden Bergh, A. Mullie, M. Desmet, G. Huysmans (2013), "Assisted dying—the current situation in Flanders: euthanasia embedded in palliative care", *European Journal of Palliative Care*, 20(6).

14. Over palliatieve zorg en euthanasie [On palliative care and euthanasia]. Federatie Palliatieve Zorg Vlaanderen [Flemish Palliative Care Federation], 22 September 2011.
15. P. Vanden Berghe, A. Mullie, M. Desmet, G. Huysmans (2013), "Assisted dying—the current situation in Flanders: euthanasia embedded in palliative care." *European Journal of Palliative Care*, 20(6). p. 267 : "[Since the key reasons for euthanasia requests appeared to be a desire to be in control, fear of dependency and existential despair, euthanasia no longer seemed a failure of, or antagonistic to, palliative care]". However, we report the comments on this article by Fiona Randall, which refute the idea that the decriminalization of euthanasia does not affect palliative care: "The authors note as "an insidious side-effect of legalized euthanasia that family members and proxies tend, much more than before, to consider the dying process as undignified, useless and meaningless and that requests made by family members for fast and active interventions... are often very coercive. Any such coercion, especially towards euthanasia, is surely a considerable harm to patients, professionals and palliative care", *European Journal of Palliative Care*, 2013; 20(6).  
<http://www.haywardpublishing.co.uk/NeedRegisterE.aspx?pageid=58&JID=4&Year=2013&Edition=488>
16. C. Van Oost & J. Bataille (2014), *Médecin catholique, pourquoi je pratique l'euthanasie* [Why I, a Roman Catholic physician, practice euthanasia], Presses de la Renaissance, Paris.
17. Cf. 2008 Report of the Federal Palliative Care Evaluation Unit, p. 101.
18. Idem.
19. Cf. presentation by Wim Distelmans in *Rapport de la conférence « fin de vie » du conseil interparlementaire consultatif de Benelux* [Report on the conference on "end of life" of the Benelux Interparliamentary Advisory Council], 2 December 2011, Brussels, p. 40.
20. Already present in the debates of 2002, the question of a palliative filter was raised again in 2010. See "Proposed law of 16 December 2010 introducing a mandatory palliative filter into the Act of 28 May 2002 on euthanasia".
21. Cf. presentation of Jacqueline Herremans in *Rapport de la conférence « fin de vie » du conseil interparlementaire consultatif de Benelux* [Report on the conference on 'end of life' of the Benelux Interparliamentary Advisory Council], 2 December 2011, Brussels, p. 28.
22. D. Lossignol (2012), « Soins palliatifs et euthanasie ; la fin du conflit » [Palliative care and euthanasia: an end to the conflict], *Revue des soins palliatifs en Wallonie*, n.14.
23. C. Van Oost & J. Bataille (2014), *Médecin catholique, pourquoi je pratique l'euthanasie* [Why I, a Roman Catholic physician, practice euthanasia], Presses de la Renaissance, Paris, p.160.
24. Proposal by Senator Philippe Mahoux on the topic of the three laws of 2002, in Proposed law to amend the law of 28 May 2002 on euthanasia in order to extend it to minors. Legislative document no. 5-2170/1. 26 June 2013.
25. Cf. for example, the "intercollegiate certificate of competence in continuous and palliative care" and the "diploma in intercollegiate specialized study of continuous and palliative care" established by the Faculties of Medicine of the Catholic University of Leuven, the Free University of Brussels and the University of Liège.
26. [www.leif.be](http://www.leif.be)
27. Cf. Conference in Quebec, 3 December 2012. <http://www.ecdq.tv/fr/videos/7d2b92b6726c241134dae6cd3fb8c182>.
28. W. Distelmans (2012), *Euthanasie et soins palliatifs : le modèle belge. Pour une fin de vie digne* [Euthanasia and palliative care: the Belgian model. For a dignified end of life]. Ed. Le Bord de l'eau.
29. Idem.
30. « 10 ans d'euthanasie, un heureux anniversaire ? » "[Ten years of euthanasia: Happy Birthday ?]", Collectif de professionnels, in *La Libre Belgique*, 13 juin 2012.
31. Cf. presentation of Jacqueline Herremans in *Rapport de la conférence « fin de vie » du conseil interparlementaire consultatif de Benelux* [Report on the conference on 'end of life' of the Benelux Interparliamentary Advisory Council], 2 December 2011, Brussels, p. 30.
32. Cf. Bill n.5-1919 / 1 January 2013 to amend Article 14 of the Act specifying that the refusal to perform euthanasia for non-medical reasons must be communicated to the patient by the physician within seven days of the formulation of the request.
33. Opinion No. 59 of 27 January 2014 on the ethical aspects of the application of the law of 28 May 2002 on euthanasia.
34. Proposed law amending the law of 28 May 2002 on euthanasia on the obligation to refer, *Doc. parl.*, House of Representatives, April 10, 2015.
35. Proposed law amending the law of 28 May 2002 on euthanasia, *Doc. parl.*, Belgian Senate, January 10, 2013.
36. Opinion No. 59 of 27 January 2014 on the ethical aspects of the application of the law of 28 May 2002 on euthanasia.
37. In a letter dated 3 February 2011, Ms. Laurette Onkelinx, Federal Minister for Social Affairs and Public Health, in the Bioethics Committee.
38. Opinion No. 59 of 27 January 2014 on the ethical aspects of the application of the law of 28 May 2002 on euthanasia.
39. Royal Decree of 9 March 2014 amending the Royal Decree of 21 September 2004 fixing the standards for the special licensing of nursing and health care institutions, day care centers and centers for the treatment of acquired brain injuries.
40. Cf. Palliative care development in countries with euthanasia law, Report for the Commission on Assisted Dying Briefing Papers, European Association of Palliative Care, 4 October 2011.
41. Dr. C. Dopchie remarked in this connection that "Demonstrably, it is this last year of life that generates the highest care expenses", whereas euthanasia costs 250 euros.
42. Cf. Report 2014 of the Federal Palliative Care Evaluation Unit. The Belgian health care system applies a specific price for palliative care. The Unit is currently working on a new expanded definition of "palliative care patient", with the intention of identifying patients earlier and measuring the seriousness of their needs as a function of their prognosis. It is also a question of redefining and extending the status of "palliative care patient" to other categories of people who are heavily dependent or handicapped, such as dementia patients.
43. C. Dopchie (2013), « L'euthanasie tue-t-elle les soins palliatifs ? » [Is euthanasia killing palliative care?], *Les Cahiers francophones de soins palliatifs*, Volume 13, number 2.
44. Declaration of the ICPCN of Mumbai, 12 February 2014.