

Assisted dying – the current situation in Flanders: euthanasia embedded in palliative care

In Flanders (the Dutch-speaking, northern part of Belgium), in the course of the last ten years, physician-assisted dying and euthanasia have become embedded in palliative care. **Paul Vanden Berghe, Arsène Mullie, Marc Desmet** and **Gert Huysmans**, from the Federation of Palliative Care Flanders, describe how this major change happened and what issues it raises. After the Netherlands, this is the second article in our series aiming to shed light on assisted dying and euthanasia across Europe

In 2002, three laws concerning the end of life were almost simultaneously passed by the Belgian parliament: a law decriminalising euthanasia, a law affirming the right to palliative care for all and a law concerning the rights of patients in general. At that time, a substantial part of the Belgian palliative care community, like the Belgian healthcare community in general, was very reticent to become involved in euthanasia, for different reasons. One of them was the radical nature of the act of euthanasia (defined in Belgian law as ‘the intentional termination of the life of another person at his/her request’¹), which is completely at odds with everything

healthcare professionals are usually taught. Another reason was the widespread opinion that optimal palliative care, starting with a thorough clarification of the patient’s request for help to end their life, would eliminate the need for euthanasia.

Ten years later, in Flanders (the northern, Dutch-speaking part of Belgium), and to a lesser extent in the rest of the country,* the caring practice of ‘euthanasia accompaniment’ (*euthanasiebegeleiding*) is part of the daily work of palliative care professionals, who support the treating doctor and team in all aspects of the patient’s request, while only very occasionally carrying out euthanasia themselves. This ‘euthanasia accompaniment’ includes clarification of the request, communication with the family, consideration of other possibilities, medical and other assistance if euthanasia is performed, and support of the team afterwards. It takes place with full respect for each professional’s personal choice regarding their involvement.

How did this major shift happen and what questions does it raise?

Opening up to euthanasia

Leaving presuppositions behind

This shift in mindsets and attitudes was induced by different experiences. In some cases, palliative care professionals were finding that patients’ responses to palliative care

This article forms part of a series examining assisted dying and euthanasia across Europe. The views expressed do not necessarily reflect those of the Editor or Editorial Advisory Board, nor those of the EAPC. If you would like to respond to this or a previous article, please email: edit@hayward.co.uk

Key points

- In Belgium, a law decriminalising euthanasia was passed in 2002.
- Palliative care professionals in Flanders are now practising ‘euthanasia accompaniment’, supporting people who request euthanasia in all aspects of care. This takes place in full respect of each practitioner’s choice regarding their involvement.
- The introduction of euthanasia forced palliative care to develop further, which is a positive consequence; however, there are also some negative consequences: legalism and proceduralism; euthanasia following its own course; and instrumentalisation.

interventions were poor and that euthanasia effectively appeared to bring a 'good death'. In other cases, palliative care professionals were declining patients' requests for euthanasia and subsequently finding themselves confronted with a situation where patients nevertheless received euthanasia, but from an external medical practitioner. Even if this was done following state-of-the-art guidelines and good practice, the fact that it happened outside the context of the regular and familiar care team (treating physician, family nurse ...), sometimes without the knowledge of the family, made those palliative care professionals realise that it was not optimal care. For them, the change to a more positive engagement, first as witnesses only, was clearly a 'lesser evil'. In a large number of cases, they witnessed euthanasia that was being correctly administered from a medical point of view, after thorough clarification of the patient's request and adequate communication, and that had good results. Whether or not all palliative possibilities had been exhausted, the patient was relieved and grateful that their final days did not have to last any longer. This convinced those professionals that euthanasia could be part of genuinely good care.

Moreover, 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, but something that could be served by it.

These different experiences led to the growing involvement of palliative care professionals and teams in the accompaniment of euthanasia. In the name of continuity of care, they chose not to abandon patients asking for euthanasia by referring them to external practitioners, outside the familiar care environment, but to continue to provide them with all the necessary support.

An evolution supported at all levels

Through this growing involvement, what is and should be the natural stance gradually became clearer: for the sake of good care, transferring a palliative patient requesting euthanasia outside their familiar care environment is never the best option. This stance was actively supported from the beginning by the Federatie Palliatieve Zorg Vlaanderen (Federation of Palliative Care

Editor's note

We have recently launched a series of articles examining assisted dying and euthanasia across Europe, beginning with countries in which these acts have been decriminalised. The series was inaugurated in our July/August 2013 issue (*European Journal of Palliative Care* Vol 20 No 4) with an article by Carlo Leget describing the situation in the Netherlands.

This is now followed by a paper from Belgium written by four members of the Federation of Palliative Care Flanders. Many people within palliative care may disagree with, be shocked by or even condemn the recent developments that Paul Vanden Berghe *et al* describe and justify here. Assisted dying and euthanasia are controversial. However, we feel that one of the roles of the *EJPC* is to present different perspectives. Our willingness to give space to differing opinions reflects the mission statement of the European Association for Palliative Care (EAPC), which aims to 'bring together many voices to forge a vision of excellence in palliative care'.

The *EJPC* wants to take an active part in an essential debate. To that purpose, we have invited Fiona Randall (an outspoken opponent of assisted dying and euthanasia) to respond to this Belgian perspective. Her paper can be read on pages 273–276.

Julia Riley, *EJPC* Editor

Flanders [FPCF]) in numerous ways: through team consultation, guided group supervision of the different professionals involved in palliative care (doctors, nurses, psychologists, social workers ...) and education on how palliative care could open up to euthanasia. This happened at all levels, within care organisations but also within regional networks members of the FPCF.

In 2003, under the direction of its Steering Group for Ethics (with Professor Bert Broeckaert from the University of Leuven as ethical advisor), the FPCF published a reference text on how to deal with euthanasia and other forms of medically assisted dying.² In 2006, it published a framework document on treatment decisions in advanced disease.³

In 2011, a reference document on palliative care and euthanasia⁴ was unanimously accepted by the Federation's Board of Directors. It both confirmed and supported the evolution of the past decade. This document states that the complexity of a number of difficult-to-treat symptoms and end-of-life issues often exceeds the competence of primary caregivers. In such cases, the advice of the palliative team, which is particularly knowledgeable in crucial domains (physical suffering that is difficult to relieve, unrecognised depression, guilt issues, pressure from the family, loss of meaning, and so on) has an important added value. Specialist palliative care advice is particularly recommended when it comes to inform patients who ask for euthanasia about the

palliative possibilities, as required by the Belgian law on euthanasia. In this way, both patient and physician can be sure that there is really 'no other reasonable solution' to relieve the intolerable suffering – which again is a requirement of the law (see Box 1).

This reference document further states that palliative care teams, with their multidisciplinary character, possess the highest standards of palliative care skills (including communication skills) and thus are well qualified to practice end-of-life care and also provide euthanasia accompaniment both in a careful (regarding the legal conditions) and caring way. These palliative care teams act as secondary teams: they do not take over the patient's care but support the familiar primary healthcare professionals, who are thus trained, looked after and strengthened.

Where are we today?

Today, one in two non-sudden deaths in Flanders occurs with the support of specialist palliative care professionals,⁵ whether within mobile home care teams, hospital support teams (which are available in every hospital), hospital palliative care units (there are 29 in the region totalling 209 beds) or through 'reference persons for palliative care' in homes for the elderly.

In 2011, 1,133 cases of euthanasia were reported to the Belgian Federal Euthanasia Control and Evaluation Committee. Unofficial figures show 1,430 cases in 2012 and 445 in the first quarter of 2013. In 2011, 918 of the 1,133 cases were registered in Dutch, which amounts to about 1% of all deaths in Flanders.⁶ If the 2007 estimated number of unreported cases is taken into account,⁷ this figure comes to 1.9%.

No data are yet available on the provision and extent of specialist palliative support in the reported – and unreported – cases of euthanasia. However, we can safely say that, during the past few years, all palliative care teams in home care and hospital settings in Flanders have been providing support in the care of people requesting euthanasia. Some hospitals are more restrictive than others, imposing additional conditions on the practice of euthanasia, such as obligatory intervention by the palliative care team.

According to the WHO definition of palliative care,⁸ palliative care should not intend to hasten death. Therefore, euthanasia cannot be part of palliative care. However, we

Box 1. Main requirements of the Belgian law on euthanasia

According to the Belgian law on euthanasia passed on 28 May 2002,¹ the major legal requirements for performing euthanasia are:

- Repeated and consistent request from an adult patient who is competent (that is, who has full mental capacity), made under no external pressure and in writing (or expressed in a written advance directive in the case of a patient in an irreversible state of unconsciousness)
- Persistent and intolerable suffering, physical and/or mental
- Caused by an irreversible medical condition (accident or disease)
- If patient not expected to die within foreseeable future, two independent colleagues must be consulted and a moratorium of one month must be respected between the patient's written request and the administration of euthanasia
- Patient duly informed of their condition, life expectancy and other therapeutic options, including those offered by palliative care
- Patient and doctor reaching the conclusion that there is no other reasonable solution
- Discussion of the request by the doctor with significant others, if patient wishes so
- Euthanasia carried out by a doctor after consultation with the nursing team and one competent and independent colleague; the doctor has to be present until the patient's death
- Case reported to the Belgian Federal Euthanasia Control and Evaluation Committee

think that euthanasia and palliative care can occasionally be considered together when caring for one and the same patient. This does not necessarily mean that we systematically perform euthanasia when a patient requests it. Only a small number of requests eventually lead to actual euthanasia.

Palliative care not harmed but strengthened

Euthanasia was introduced in Belgium in a generally cautious way, and this certainly has something to do with the fact that palliative care, initiated in the 1980s by volunteers, was already well developed before 2002.^{9,10} Belgian palliative care had had a head start over euthanasia practice, which remained exceptional in the country (by contrast, in the Netherlands, the law authorising physician-assisted dying and euthanasia that came into effect in 2002¹¹ decriminalised an already existing euthanasia practice). In 2010, Belgium took joint 4th place worldwide on the quality of death index of the Economist

Intelligence Unit.¹² This provided a favourable context for palliative care professionals to support patients asking for euthanasia in the most careful and caring way.

After ten years of experience, an intermediate conclusion is that some of the consequences of the introduction of euthanasia initially feared by its advocates or opponents did not materialise. Palliative care did not obstruct or delay the performance of euthanasia. Conversely, it can also be safely stated that palliative care was not harmed by the introduction of euthanasia, but on the contrary was forced to develop further.

The overall feeling is that end-of-life care in general has substantially improved. Healthcare professionals and patients alike are more knowledgeable on end-of-life care; they are better able to distinguish between the six or seven broad choices that can be made regarding end-of-life care;³ the demands of patients are better acknowledged; and professionals are more aware of what they are doing. It is the experience of many of us that the developments seen in the last ten years have resulted in more professional end-of-life care that better responds to patients' wishes. End-of-life care is certainly not perfect yet, but this has more to do with the huge workload and lack of staff (notably nurses) to cope with increasing demand. Standards of care are rising – obviously a good thing – partly because of the influence of palliative care, which in a way has become a victim of its own success (professionals caregivers are significantly overburdened).

There is no indication of an alarming increase in the number of euthanasia cases or of significant misuse of any medically assisted end-of-life decision (such as alleviation of pain, palliative sedation, assisted dying without request, and so on). On the contrary, the decriminalisation of euthanasia has stimulated more thorough communication around end-of-life care, starting with advance care planning, between patients and their close relatives, but also between patients/relatives and professional caregivers. This communication is happening at the micro level of the individual, the intermediate level of institutions and organisations, and the macro level of public policy (including around financial and ethical issues). Patients have the right to consent to or refuse a treatment, at any moment, including at the end of life, as

well as the right to request euthanasia (which is not the same thing as the right to euthanasia, which does not exist in Belgium).

Our experience indicates that the provision of care at the end of life results in the greatest satisfaction when patients' families, proxies and informal caregivers are involved as partners in the process. In Flanders this is commonly called 'autonomy in relationship' (*autonomie in verbondenheid*): close relatives do not obstruct the expression of the patient's autonomy, but their involvement can help the patient clarify his/her own wishes and achieve their realisation in the most comprehensive way.

A true ethical labour

This article should not suggest that any of these matters are taken lightly, let alone trivialised. In all communication, special attention is given not to convey the implicit message that a palliative care professional is only a true professional if they can 'go the full way' in matters of euthanasia, whether as a physician, nurse, psychologist, social worker, spiritual caregiver or any other member of the palliative care team. The law states that no healthcare professional can be forced to be involved in the act of euthanasia. Every professional has the right to set their own ethical limits. What is expected of them is that they indicate these limits clearly, forthrightly and, above all, in a timely manner. From our experience, it is actually recommended that critical voices remain present in the team as it advances in the decision-making process.

It must be stressed that, in the course of these recent evolutions, the palliative care community of Belgium has been – and still is – carrying out a profound ethical labour. The situation described and views expressed in this article are the result of an intensive reflection, not only by ethicists, but first and most importantly by every single professional in Belgian palliative care, including on personal presuppositions, convictions, pace and outcomes, carried out at the level of the individual, teams and organisations involved.

Issues and concerns

Yet, despite the favourable context and the constant engagement of numerous healthcare professionals and organisations, there are

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issues and concerns, which can be described as insidious side-effects of the introduction of euthanasia in the general landscape of care in Belgium. There are three major threats – that of legalism and proceduralism, of euthanasia following its own course and of instrumentalisation – all of which are at odds with the spirit of (palliative) care.

Legalism and proceduralism

All (medical) care practice occurs against a general legal background, but the fact that there is a law for that one single intervention, euthanasia, has undoubtedly increased the trend towards proceduralism and legalism in end-of-life care. The regulation of euthanasia

All end-of-life interventions have their own indications and are not interchangeable

by a law articulating precise conditions and procedures provides not only society, but also healthcare professionals, with some reassurance that it is correctly performed. When (and only when) all legal conditions are met, euthanasia does not equate to murder, but to a legal life-ending act. The danger of legalism emerges when people think that meeting those legal conditions is in itself a sufficient condition for good care.

This problem does not only occur with legal requirements, or in end-of-life care, but also with all kinds of tools (for example, guidelines and care pathways), and in all healthcare domains. What is specific in the case of euthanasia is that some professionals start perceiving all other end-of-life interventions, which are not specifically subject to a legal framework, as not being legal. This erroneous view can be more or less explicit, but when it affects end-of-life care practice, it raises the threshold for interventions other than euthanasia – such as withdrawing or withholding treatment, refusal of treatment, intensification of symptom control or palliative sedation – which are no less necessary, have their own indications and occur far more often.

Conversely, some professionals may be tempted to avoid euthanasia and steer care towards other end-of-life interventions precisely because there is no specific legal framework regulating them (no formal procedure, no legal conditions, no obligation to declare them), and therefore no risk of questions being raised, or even prosecution being conducted by a body such as the Federal

Euthanasia Control and Evaluation Committee. It should be clear to professionals that all end-of-life interventions have their own indications and are not interchangeable.

This trend has given rise to repeated calls for legislating and/or introducing the compulsory registration of end-of-life interventions that, unlike euthanasia, are strictly medical acts: first palliative sedation, but by extension all types of end-of-life interventions. The assumption is that this would directly improve the quality of care. This is peculiar compared with other fields of healthcare, where it is commonly accepted that quality is not enhanced by legislation, which entails major risks such as loss of flexibility, inaccessibility of certain interventions and an overload of resource-consuming administrative work.

Euthanasia following its own course

Beyond this tendency to want to regulate a broader range of end-of-life interventions, there are also loud calls for an extension of the law on euthanasia to cover other population groups, such as minors, people with advanced dementia and those who are ‘tired of living’. There may well be good reasons, and possibly sometimes even majority support among the general public, for such an extension – including among palliative care professionals themselves. There is no indication of an increase in the number of reported cases of euthanasia performed for indications other than those legally accepted. However, these loud calls cannot be missed. Since 2002, over 20 proposals to change the law and extend the conditions under which euthanasia can be performed have been introduced – so far none have brought about a change in the law. At the time of writing, new proposals are expected to be examined by the Belgian Senate in October 2013.

The rationale behind such an extension follows a certain logic. Pointing to forms of suffering other than those covered by the current law that could be terminated by euthanasia, those advocating its extension denounce the existing criteria as arbitrary.

- Age – why euthanasia only from the age of 18, and not 17½ or 15?
- Full mental competence at the moment of the request – what about patients who made a written advance directive for euthanasia when they still had full mental capacity (for example, in the event of dementia), no

longer have it, but are not irreversibly unconscious (an irreversibly unconscious patient being the only case in which an advance directive is considered valid)?

- Disease or accident – what about those who are simply ‘tired of living’?
- Irreversibility – what about patients who may have a chance of cure if they accept further treatment, but decline it?
- Intolerable suffering – how can you distinguish between present suffering, which might be tolerable, and expected suffering, the expectation in itself becoming a source of intolerable suffering?

Relieving suffering at the end of life being one of the primary concerns of palliative care, these questions must be taken seriously and debated in a society that is in constant evolution. However, for the FPCF – an organisation that believes palliative care should be part of regular healthcare provision – the medical grounds of suffering should be paramount.

Given the radical nature of euthanasia – where suffering is ‘solved’ by terminating the life of the sufferer – it can never be a first resort. To avoid the risk of euthanasia being administered for improper reasons, extending it to further populations groups should only be considered if basic palliative care is fully provided to these groups. The force with which its advocates demand an extension of the law provides, in practice, a good incentive for improving the care given to these groups, which is a positive side-effect – just as greater interest in end-of-life care was a positive side-effect of legalising euthanasia. However, there is an indication that euthanasia, once the barrier of legalisation is passed, tends to develop a dynamic of its own and extend beyond the agreed restrictions, in spite of earlier explicit reassurances that this would not happen – in Belgium, such reassurances were given when the 2002 law was being debated.

The effort to extend the law on euthanasia, like the effort to legalise euthanasia in the first place, is not exclusive to Belgium but is on the agenda of many movements worldwide, which often enjoy strong public support. In Flanders, one such organisation, LEIF (LevensEinde InformatieForum – a Forum for End-of-Life Information), was set up in 2003 to provide information and training to physicians who give advice in case of euthanasia. An equivalent, Forum EOL (Forum End Of Life),

was later created in Wallonia, the southern, French-speaking part of Belgium.

It should be stressed that LEIF has played a major role in favour of patient emancipation and empowerment, which is resulting in better end-of-life care. However, the organisation’s outspoken promotion of the autonomy of the individual person – expressed, for example, by its claim to the right of radical self-determination – has made its philosophical viewpoint far removed from mainstream health- and end-of-life care. This restricts collaboration with the established representative organisations of healthcare professionals, in particular palliative care ones. This in turn leads to the risk of a ‘twin-track policy’ in end-of-life care, characterised by little genuine dialogue between each side and a separation between euthanasia and regular care, in spite of what is often good bedside collaboration between the professionals belonging to organisations supporting euthanasia and those working in organised, regular palliative care (several of whom belong to both groups).¹³

Instrumentalisation

Often, the endeavour to extend the law on euthanasia is not only an expression of genuine concern about suffering, but also a manifestation of the tendency to deal instrumentally with death. End-of-life interventions such as euthanasia are seen as an instrument to end a process of disease (or old age) that is demanding and difficult to bear, instead of letting it follow its course. Although euthanasia can make a good death possible under certain conditions, its legal introduction has set, or at least amplified, this trend towards instrumentalisation. Healthcare professionals note that family members and proxies tend, much more than before, to consider the dying process as undignified, useless and meaningless, even if it happens peacefully, comfortably and with professional support. Requests made by family members for fast and active interventions from healthcare professionals regarding elderly parents are often very coercive, with little nuance or subtlety. While the mediatisation of end-of-life issues has had many positive side-effects, including the growing awareness that one can express one’s own end-of-life care preferences, this trend is without doubt a negative one.

Euthanasia embedded in palliative care

The three major concerns described above tend to disconnect euthanasia from (palliative) care and thus threaten optimal end-of-life care. The problem is not euthanasia as such, but rather its dissociation from the context of (palliative) care. The antagonism is no longer between euthanasia on one hand and palliative care on the other, but between euthanasia outside and euthanasia inside the realm of (palliative) care.

Every patient at the end of life has the freedom to call on palliative care or not. In a common position paper, the three Belgian palliative care federations (the FPCF, the Fédération Wallonne des Soins Palliatifs and the Fédération Pluraliste Bruxelloise de Soins Palliatifs et Continus) insisted that they ‘respect the choice of patients who want

Palliative care can guarantee that euthanasia requests will be dealt with in a careful and caring way

euthanasia’ and ‘place them in the centre of the process’.¹⁴ They further stated that ‘patients must be able to freely and autonomously call upon one or more practitioners of their choice. For one patient, this will be their GP or the specialist in charge of their incurable disease. A second patient will also have recourse to the palliative team that has supported them since they learned about the incurable nature of their disease. A third patient will prefer to call upon a practitioner who is a member of an association such as LEIF or EOL’.¹⁴ This implies a clear rejection of the so-called ‘palliative filter’; that is, the obligation that all palliative care possibilities have been examined and exhausted before a patient can receive euthanasia – which is not a requirement of the current Belgian law on euthanasia.

While sharing this point of view, the FPCF also affirms its own vision that high-quality palliative care must offer continuity of care, up to and including euthanasia accompaniment, and at the same time respect the freedom of conscience of each individual professional. In our view, palliative care can guarantee that euthanasia requests will be dealt with in a careful and caring way.

The above-mentioned threats do not change the fundamental commitment of the FPCF to participate in the debate and work towards solutions in the face of new medical or societal challenges. The FPCF does not

claim to have a monopoly on good care, but affirms its preference for a model of care where euthanasia requests are addressed with an offer – not an obligation – of expert palliative care by the multidisciplinary team. We have learned through experience, including mistakes, that this is in the best interest of patients as well as their families and friends.

* This article is mostly about Flanders, the Dutch-speaking, northern region of Belgium. The developments it describes partly apply to the rest of the country as well: certainly to the Brussels region, but probably not yet to the same extent to Wallonia, the French-speaking, southern region.

Declaration of interest

The authors declare that there is no conflict of interest.

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