Ethics, Medicine and Public Health 33 (2025) 101054

Contents lists available at ScienceDirect

Ethics, Medicine and Public Health

journal homepage: www.sciencedirect.com/journal/ethics-medicine-and-public-health

Short report

The conditional decriminalisation of euthanasia, a remarkable feature of Belgian law

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ARTICLE INFO

Keywords:
End of life
Euthanasia
Patient's self-determination
Substantive and procedural conditions

ABSTRACT

Context: Belgium is one of the first countries in the world to have legalised euthanasia. It is, more appropriately, a decriminalisation under conditions, which are both substantive and procedural, and which are briefly summarised here. The European Court of Human Rights has recently confirmed that nor the Belgian euthanasia law, nor the way in which it is implemented in practice, are contrary to the right of life and the right to respect for private and family life.
Methodology: The way in which the law understands reality differs from that of other disciplines, including the humanities and social sciences. For this subject, reality is studied through the development of rules (issues, content, spirit), but also through their practical application, especially in the case of litigation, through the study of court decisions that may be handed down. This method is used here in relation to euthanasia.
Results/discussion: The availability of euthanasia goes beyond the (obvious) obligation to refrain from providing care or administering treatment that lacks any therapeutic benefit; it proceeds from a different logic, which fully integrates individual autonomy. By allowing persons who are suffering from unbearable (terminal) illness control over the way in which they will end their lives, rather than having to wait for death to seize them, Belgian law introduces a scheme where *the patient initiates the action* that will free him/her – an action that is consistent with the therapeutic role of doctors, when no other possibility remains – and which is to be distinguished from the situation where the patient *consents* to the care offered.
Conclusion/outlook: End-of-life situations should be examined *primarily in terms of the patient's self-determination*, and not the physician's duties. This would meet a real social need – that debate, which is emerging everywhere, and should be promptly solved, cannot be steered in a direction opposite to that adopted about the general rights of patients, who are recognised as having control over their bodies and their destiny (*empowerment*). Since the quality of life is quintessentially subjective, it seems that there is hardly any other conceivable solution than to *open up to the will of the person* who is no longer able to cope with the situation in which they find themselves.

Belgium is, as we know, one of the few countries in the world to have legalised euthanasia. It is, more appropriately, a decriminalisation under conditions. The other Benelux countries, among others, have also adopted, for quite some time now, similar legislations (2001 in the Netherlands; 2009 in Luxemburg). The Act on Euthanasia was adopted on May 28th, 2002 (hereunder: the Act) [1–6]. It is a specific, long-lasting, and salient feature of Belgian medical law [7]. It should be read in conjunction with two other important legal instruments voted that same year, as a result of a joint and very thorough parliamentary work: the Act of June 14th, 2002 on palliative care and, most notably, the Act of August 22nd, 2002 on patient's rights. These general rights are indeed of the highest importance in the overall context of end-of-life care [8–14].

The Act defines euthanasia as the act which intentionally terminates the life of a person at his/her request, and which is carried out by an individual other than the person in question (section 2) [2,15]. It has to be a physician (section 3) – and not a nurse, for instance. With this Act, euthanasia thus becomes a medical gesture, and no longer a criminal one, provided all the prescribed conditions are met. This is likely, on the one hand, to reassure the medical profession and, on the other, to better meet the interests of the patient, whose self-determination is recognised. Intentionally administering death to another person at his/her request must be distinguished from other attitudes that may be adopted at the end of life (palliative care, refusal of treatment or withdrawal of

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https://doi.org/10.1016/j.jemep.2025.101054
Received 5 October 2024; Accepted 21 January 2025

unnecessary treatment). Being so defined, euthanasia should not be "opposed" to palliative care. Alleviating or suppressing pain, humanising the end of life without the intention of ending it, is an *ethical and legal obligation for the physician* (see section 11 *bis* of the Act of August 22nd, 2002 on patient's rights) [16–19]. Euthanasia follows a different logic: it is based on the patient's *request* (and not on their "consent"). It is important to stress that the patient does not have a "right to euthanasia", but rather the *right to request it* and to see that request being listened to and investigated. We should understand that such a free and conscious wish cannot *always* be met by providing comfort and pain relief. The choice belongs to the patient, whose suffering and dignity must be recognised and respected [2,7,16].

In the recent case *Mortier v. Belgium* (labelled as key case; judgment of October 4th, 2022, final) [20], the European Court of Human Rights has found no substantive violation of the Convention nor in the Act of May 28th, 2002 itself, nor in the way it was implemented in that particular instance (death by euthanasia of the applicant's mother, who had suffered from depression for about 40 years, as authorised by the legal framework). Only on the procedural aspect has it concluded to violation of Article 2 (lack of independence of the board subsequently reviewing all acts of euthanasia, allowing the doctor who carried out a specific act to vote on its legality, and excessive length of criminal investigation).

Euthanasia of an adult, conscious and terminally ill patient is the cornerstone of the Act, and by far the most frequent case in practice (the issue of minors was resolved later, by an Act of February 28th, 2014 extending, under more stringent conditions, euthanasia to minor patients who possess the ability of discernment and are able to request it themselves (with the approval of their legal representatives). It is extremely exceptional: there have only been 5 declared cases of euthanasia of minor patients since this Act came into force). Euthanasia is only possible if three fundamental conditions are met (section 3, § 1, of the Act):

1° a *request from the patient*, which must be expressed in a recurring manner, voluntary, well-considered and not be the result of any external pressure. It is recorded in writing and may be revoked at any time (section 3, § 4). The patient's request is obviously an essential requirement, in which the medical shortening of life finds its *basis* and *justification*. The patient must have capacity and be conscious at the time of making their request: adults who are legally or *de facto* incapable cannot have access to euthanasia, even through their legal representative. Conversely, a person who remains sufficiently conscious and who is not (yet) placed under a legal protection status rendering him/her incapable of doing so, may request euthanasia (for example at an early stage of a pathology such as Alzheimer's disease).

2° the patient must be suffering from a *serious and incurable disorder caused by illness or accident* and therefore be in a *medically hopeless condition*. This point is obviously also essential. It may be a combination of several conditions (poly-pathologies), especially chronic or age-related ones, but, in the absence of *any* serious and incurable disorder, a feeling of accomplished life, tiredness of living or old age are *absolutely not valid reasons* to request euthanasia.

3° the patient must, because of this condition, be experiencing *constant and unbearable physical or mental suffering that cannot be alleviated*. Such suffering is therefore not sufficient in itself: it must *result* from a serious and incurable accidental or pathological condition. In the spirit of the Act, "suffering" is not the same as "pain": pain can most often be alleviated, or even eliminated, by analgesic drugs, particularly in the context of palliative care; the notion of suffering is broader, multifactorial, and very often includes, in addition to a physical component, a psychological impact. It is essential to distinguish, on the one hand, the psychological aspect of a somatic-based suffering and, on the other, the *purely psychological suffering* caused by a psychiatric disorder.

In addition to these essential substantive conditions, the Act provides for detailed *procedural requirements* (section 3, § 2). The mechanism is based on a *one-to-one discussion* between physician and patient: the Act has deliberately moved away from the perspective of an *a priori* (social) control on the legitimacy of the euthanasia request. It thus considers the dignity of the patient as a subjective prerogative, and not as a "social value" transcending individual desires. It is the responsibility of the physician who receives a request for euthanasia to make sure that the legal conditions are met. He/she must discuss with the patient the therapeutic possibilities that may still be envisaged, as well as the possibilities offered by palliative care and their consequences, and "come, together with the patient, to the conviction that there is no reasonable alternative in their situation and that the patient's request is completely voluntary". In order to ascertain the continued physical or mental suffering of the patient and the recurring nature of the request, the physician must have several conversations with the patient over a reasonable period of time, taking into account the evolution of the patient's condition.

This individual discussion is the core of the law. However, it must be broadened to include the opinion of certain third parties, in order to avoid excessive subjectivity or compassion on the part of the doctor treating the patient. He/she must, in each case, consult another physician about 1 ° the serious and incurable nature of the disorder, and 2 ° the constant and unbearable nature of the suffering that cannot be alleviated. That physician's written report, in which he/she gives an opinion on the patient's medical situation, and therefore on the validity of his/her request, aims at objectifying the patient's condition and constitutes an important element in the control process. The opinion of the consulted physician is not binding: it does not necessarily have to be entirely consistent with that of the treating physician. This is however, in practice, nearly always the case. This openness to the assessment of a colleague also ensures that the doctor receiving the request is not left to his/her own subjectivity when faced with a procedure that is obviously anything but trivial.

The *degree of progression of the disease* is not in itself a legal criterion: "medically hopeless condition" is not synonymous with "terminal phase", and it is not required that death should be expected in the near future. The recognition of the patient's autonomy thus takes on an even greater significance: their request is all the more important if their death does not appear to be imminent, and it is thus no longer a question of hastening or softening a process that is inevitable in the short term. These are cases where "the physician is of the opinion that the death is clearly not expected in the near future" (section 3, § 3 of the Act) – i.e. in the next few weeks or months, thus in the case of a condition that is not progressing or progressing very slowly (e.g. amyotrophic lateral sclerosis, paraplegia or quadriplegia). These cases are quite rare (about 15% of all euthanasia cases). They most often concern degenerative neurological conditions (neuromuscular or neuropsychological) and, very marginally despite the emotion they arouse, psychiatric disorders. The latest reports of the Commission for Control and Evaluation of Euthanasia indicate that mental and behavioural disorders account in total for approximately 2% of all euthanasia cases, evenly distributed into psychiatric disorders (e.g. personality disorders, depression, post-traumatic stress disorder, schizophrenia, autism…), and cognitive disorders (e.g. different forms of dementia such as Alzheimer's disease or vascular dementia) [21,22]. The legal requirements are then strengthened: (a) consultation of a *second physician*, who must be a psychiatrist or a specialist in the disorder in question, and who ascertains the constant and unbearable nature of the physical or mental suffering, which cannot be alleviated, and the voluntary, well-considered and recurrent nature of the request; and (b) allowing at least one month between the patient's request and the euthanasia, in order to avoid any haste. It is important to stress that the global "waiting time", and the overall length of the process, is in reality usually much longer.

Euthanasia can also be carried out following an *advance directive* (section 4 of the Act) in which the patient records in writing, in the case where he/she is no longer able to express his/her will, his/her wish that a physician should perform euthanasia if this physician recognises that the person is affected by a serious and incurable disorder, caused by illness or accident, is unconscious, and that the condition is irreversible given the current state of science. In such a case, the physician must consult a colleague about the irreversibility of the patient's medical condition – there is no longer any question of suffering, since it is then impossible to verify its presence, even if the imperceptibility of suffering, and the fact that the patient is unaware of it, do not imply its absence –, and discuss with the healthcare team in regular contact with the patient, as well as with any trusted person and the relatives they may designate. Such an advance directive is therefore more than a refusal of futile treatment, and different from a wish for palliative care. The hypothesis remains extremely rare in practice (only 1–2% of cases, on average), since it only concerns *irreversibly unconscious patients* (coma, vegetative state, waking unresponsive syndrome) – and not e.g. people suffering from Alzheimer's disease in its third or fourth stages. It is important not to confuse the advance declaration of euthanasia with the "general" advance directives based on the Act on patient's rights, by means of which a person in good health preventively records his/her wishes concerning the treatment he/she will want – or most often will refuse – when he/she becomes incapable of making a decision [7]. Since a legislative amendment of March 15th, 2020, the advance declaration of euthanasia is valid for an indefinite period.

Afterwards, verification of compliance with the legal conditions is ensured by means of an effective *a posteriori* control procedure. The physician must report the act to a *Federal Commission for Control and Evaluation*, which verifies compliance with the legal framework, before the judicial authorities if necessary. This guarantee has the social virtue of expressing that, more than any other, this specific medical treatment is not purely discretionary but must be *transparent*. The Commission's role is to analyse the documents that physicians who carry out euthanasia must complete. If necessary, it will request certain additional information or make "didactic" remarks on how to fill in these documents. For a long time, the Act did not provide for any specific sanction in the event that the doctor fails to comply with one of the conditions (substantive or procedural) to which his/her impunity is subjected (this has led to an amendment Act of March 27th, 2024, following a decision of Belgium's Constitutional Court of October 20th, 2022 [23]), but the Commission may, by a two-thirds majority decision, refer the case to the public prosecutor, who will then decide whether or not to prosecute - this has only happened once so far -, and complaints by someone else are also possible. The second important role of the Commission is to *evaluate the application of the Act* by means of a report to Parliament every two years. This report includes a statistical component, based on the information collected in the (anonymous) declarations, as well as a description and evaluation of the implementation of the Act, together with possible recommendations that may lead to a legislative initiative and/or other measures. These instructive reports are available online [21].

Funding

This work did not receive any grant from funding agencies in the public, commercial, or not-for-profit sectors.

Declaration of competing interest

The author declares no competing interest. He was a member of the Belgian Federal Commission for Control and Evaluation of Euthanasia from 2007 until 2023. This contribution might somewhat benefit from the experience and concrete knowledge acquired in this capacity, but it is obviously intended to be purely scientific. It goes without saying that the author is speaking solely on his own behalf, without in any way committing the Commission.

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