Minors in the Belgian Law on Euthanasia: a Welcomed Extension of Patient's Autonomy

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1. Introduction

On 13 February 2014, the Chamber of Representatives voted on the extension of euthanasia to minors of age: 86 MPs voted in favour, 44 against and 12 abstained. The Law was enacted on 28 February 2014. Since then, a minor of age who has the capacity of discernment and who is suffering from a severe and incurable condition causing intolerable physical suffering is entitled to request that his/her life be put to an end. In September 2016, i.e. more than two years after this Law was adopted, the first medical file concerning the euthanasia of a minor was sent to the Federal Committee for the Assessment and Control of the Law on Euthanasia. The minor was 17 and in palliative care.

2. The Law of 28 May 2002 on Euthanasia

In order to understand how Belgium was able to apprehend this delicate and sensitive issue, it is useful to take a brief look back at the strides made since the initial debates on euthanasia.
In 2002, the Belgian legislator adopted three important laws, which have had an undeniable impact on medical legislation, and more particularly on end-of-life medical decisions. The first one, the Law on Patients' Rights, a governmental initiative, enshrined some principles already established by both doctrine and jurisprudence, namely respect for the patient's autonomy, which implies that any medical treatment is subject to the patient's informed consent. The other two, namely the Law on Euthanasia and the Law on Palliative Care, were initiated by Parliamentarians whose intention was to build a bridge between palliative care and euthanasia by promoting and generalizing access to palliative care on the one hand, while simultaneously making a big leap forward by conditionally de-criminalizing euthanasia on the other hand.
Article 2 of the Law of 28 May 2002 defines euthanasia as **the act performed by a third person that intentionally ends a person's life at that person's request.** This implies that the following medical practices are not deemed to constitute euthanasia: abstaining from initiating a treatment, discontinuing an on-going treatment, administering painkillers, or even administering terminal sedation.
This is a hybrid piece of legislation: while it appears in the « civil » part of our codes, as part of the chapter on medical law, it also encompasses elements of criminal law since euthanasia, when performed by a medical doctor in conformity with the conditions and procedures provided in the law, is no longer viewed as a criminal offence.
While the core of the law of 28 May 2002 is respect of the patient's autonomy, it should be stressed that, in this area, the principle of human self-determination is not absolute. A request for euthanasia expressed by the patient is not sufficient: it is also necessary for the practitioner to reach, together with his patient, the conclusion that the conditions laid down by law have been met. The patient's right to have his autonomy and his physical integrity respected is

mirrored by the doctor's duty of care and goodwill.

The act of euthanasia must be performed **by a doctor**, who may under no circumstance delegate this responsibility, for example to a nurse.

The practitioner must ascertain that the following three basic conditions are met: (1) the **request** must be deliberate, well thought through, reiterated, and **free of any external coercion**; it must be formulated **by the patient** himself/herself, who must be a fully conscious adult; (2) the patient has to suffer **unbearable and impossible to alleviate physical or mental suffering**; (3) the suffering has to be **caused by a severe and incurable condition** – its origin being accidental or pathological – with no hope of improvement.

The legislator has stipulated formal and procedural conditions in order to guarantee that these essential conditions have been met. The patient must be fully informed of his/her condition, of the prognosis, and of any available treatments, including palliative care. Repeated interviews must be conducted with the patient and designated close relatives, as well as with the nursing staff. The patient's referring physician also needs to consult a colleague who will have to meet the patient and study his/her medical records, after which he will write a report assessing the severe and incurable nature of the medical condition and the unbearable nature of the physical or mental suffering. In cases where a fatal outcome is not expected in the short term, another opinion must be sought from another doctor, either a psychiatrist or a doctor with specialist expertise in the relevant pathology, who will have to deliver an opinion on the constant and intolerable nature of the suffering, and on the quality of the request. In such cases, there is a statutory waiting period of at least one month between the patient's written request and the act of euthanasia.

Within four business days of the act of euthanasia, the doctor must report it to the Federal Committee for Assessment and Control of the Law on Euthanasia. The Committee is comprised of 16 members: 8 medical doctors, 4 lawyers, 4 members involved in issues related to patients with incurable diseases. The primary role of this Committee is to ensure the control of euthanasia acts by society. Based on the reports received, it will therefore have to assess whether practitioners abided by the conditions laid down by law. Anonymity of all parties involved is *a priori* preserved. The Committee may only decide to waive anonymity when there is some doubt and more information has to be asked to the practitioner; this is subject to a simple majority vote. If the Committee, following a two-thirds majority vote, considers that the law's essential conditions have not been met, the case will be communicated to the Public Prosecutor's Office. The Committee's mission is also to assess how the legislation is applied, and it sends a report to Parliament every other year. The seventh report, covering the 2014-2015 period, was published in September 2016.

Moreover, any adult (or emancipated minor) is entitled to draft a **written advance statement on euthanasia**, which must have been written no more than five years prior to the moment when the patient becomes unable to express his/her wish. The doctor will only be able to act upon this statement if its author is in a state of **irreversible unconsciousness**, based on current scientific knowledge.

Finally, it is worth stressing once more that this law leaves everyone free: no-one can be "forced" into requesting euthanasia, and no-one can be obliged to take any part in a process

of euthanasia. Should a medical doctor intend to invoke a conscience clause, he then has an obligation to forward the medical records to a colleague chosen by the patient.

3. Specific provisions for the euthanasia of a minor

As it stood, the Law of 28 May 2002 on euthanasia was open only to adult patients or to emancipated minors. Since the age of majority was brought down to 18, occurrences of minors' emancipation have become extremely rare, and no case of euthanasia involving an emancipated minor has ever been registered.

There remained the very delicate and sensitive issue of requests for euthanasia formulated by children or adolescents. The question had already been publicly raised in public by health professionals dealing with minors suffering from incurable conditions. Faced with such a request from a minor, should they refuse to hear it, or accept the risks involved in infringing the law? There was always the option to use the notion of "state of necessity" as a defence to justify an infringement to criminal law in the name of respect for higher moral values. But there was no legal security for doctors.

If the legislator was convinced that this issue needed to be addressed by law, how would he be able to resolve the apparent incompatibility between the child's legal incapacity versus the principle that euthanasia may not be requested for a third person? Were we going to open the law to children above the age of 12, as it had been done in the Netherlands, thus introducing some sort of "medical majority" at a younger age than 18?

It was essential to remain within the framework of the Law of 28 May 2002, i.e. the fundamental principle that for an act of euthanasia to be lawfully performed, there needs to be a least a request from the patient. It is therefore out of the question that a third person, legal representative or not, could request euthanasia in the name of the patient.

3.1. Age limit or ability to understand?

After lengthy discussions around minors' capacity, the legislator has chosen to emphasize on the notion of (factual) *ability to understand*, rather than to opt for the arbitrary barrier of a specific age limit.

The Law of 22 August 2002 on patients' rights was already indicative of the reasoning the legislator would adopt here, as it does contain the seeds of a notion of *medical capacity* distinct from general legal capacity. Article 12 paragraph 2 states that, depending on age and maturity, young patients a) are involved in the exercise of their rights, and b) may exercise them autonomously provided that, although minors of age, they can be deemed capable of reasonably evaluating their interests in this matter.

This implies that a minor patient is entitled to refuse treatment, even if the outcome is that his/her life will be shortened, providing he has the required ability to assess the stakes involved in accepting or refusing the treatment proposed by the physician.

The referring practitioner, who has been following a young patient for months, even years, will certainly have a view on the patient's ability to understand. It must also be stressed that a child suffering from an incurable and painful condition usually develops a maturity out of proportion with his/her age. He must often deal with lengthy hospital stays and therefore learns earlier than peers what death means, as he sees hospital companions disappear. The legislator has nevertheless prescribed *a third party's intervention*, psychologist or child psychiatrist,

whose role is to certify this ability to understand.

In this respect, it is interesting to refer to the Constitutional Court's decision of 29 October 2015, following recourse against the Law of 28 February 2014 extending euthanasia to minors. Assessing the fundamental rights at stake, the Court concludes that the law under scrutiny, given the guarantees it contains, is based on a fair balance between, on the one hand, every person's right to choose to end his/her life in order to avoid painful agony and unbearable suffering, based on respect for his/her private life, and, on the other hand, the minor's right to get protected from abuse regarding resort to euthanasia, deriving from the right to life and to protection of bodily integrity.

More particularly, regarding the ability to understand, the Court refers to the law's preparatory work:

«The ability to understand can only be assessed on a case-by-case basis, depending on the nature and importance of the proposed act. The Swiss federal Court or Canada's Supreme Court have given a definition of the notion of ability to understand. This gives guidelines and indications. Elements to be considered include: the nature, the finality, the usefulness of the medical treatment, risks and benefits, the child's intellectual capacity, the level of understanding required to comprehend the information that will enable him to take a decision and assess the possible consequences thereof, the child's determination, the question as to whether these truly reflect his values and deepest beliefs, etc.

All these criteria have been considered since this is a case-by-case assessment and this logic is followed by the authors of the legislative proposal in order to make assessments all the more precise that the proposed act has extremely serious consequences» (Doc. parl., Senate, 2013-2014, n° 5-2170/4, pp. 69-70).

«This notion (of ability to understand) cannot be interpreted at a strictly legal level. It is a clinical term targeting effective capacity and it must be understood in the light of the specific act to be performed – the accomplishment of a request for euthanasia. The minor must indeed have the required ability to understand since it is to him – and to him alone – that is granted the right to die in dignity. This right is strictly individual by nature and is an exclusive prerogative of the minor ». It is clear from excerpts of the preparatory work, as well as from the object and the general scope of the law under scrutiny, that the notion of « ability to understand » relates to the capacity of the minor patient to assess the true scope of his request for euthanasia and the consequences thereof. In this context, it was stressed during the preparatory work that « the objective is to extend euthanasia to minors capable of expressing their desire, which obviously excludes the newly born and infants» (Doc. parl., Senate, 2013-2014, n° 5-2170/4, p. 65).

Regarding the written opinion by the psychologist or child psychiatrist, the Court insists on its compulsory nature: it considers that the referring physician cannot reasonably pursue euthanasia if the psychologist or child psychiatrist were to consider that the minor patient does not have the requested ability to understand.

3.2. Role of the parents - legal representatives

Once the principle had been established that euthanasia could be requested by a minor with the ability to understand, there remained to define the parents' role. It is absolutely clear that the decision is not *taken* by the parents or the legal representatives. Nevertheless, it would be inconceivable that they should be absent from

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the decision-making process (in the Netherlands, their consent is required for a child aged 12 to 15, and they participate in the process if the adolescent is 16 or more).
The Belgian legislator has opted for parental consent. Some would have preferred that there should be less of a weight on the parents' shoulders, and feared that euthanasia would not have been possible in case either the father or the mother objects. However, for those with a good knowledge of these situations, this solution involving the parents' consent is practicable. Such a decision must be given time to mature. Many interviews take place before the decision is reached, and children with severe and incurable conditions can often find the words to speak about their suffering, their (need of) love, and how their parents need not to feel guilt for accepting their child's decision.

3.3. Timing of the fatal outcome

The fatal outcome must, as far as minors are concerned, be expected in the short term. In other words, it is required that the minor's medical condition will result in his/her death within the following days, weeks or months. For adults, as we have seen above, there is no such condition.

3.4. Severe and incurable conditions and physical suffering

The legislator has denied the minor the possibility of referring to (mere) psychic suffering. One may wonder why this exclusion. Why wouldn't knowing that his/her severe and incurable condition is a death warrant make a child or adolescent suffer psychologically as much as it would an adult? Thanks to scientific progress, physical suffering can often be alleviated. Cannot a child living in hospital, away from his family, cut off from any contact with his classmates, suffer from it? In reality, by not referring to psychic suffering, the legislator wanted to avoid involving cases of psychiatric conditions. It is however regrettable to have amalgamated psychological suffering and psychiatric illness in such a way.

3.5. No anticipative statement

The legislator has wished to address cases of incurable condition, and for which death can be expected in the short term. Following the same logic, it was deemed not really thinkable for a young patient to already project oneself into the future by means of an anticipative statement. This mechanism was thus, understandably, excluded for minors.

4. Conclusion

Belgian law entitles a child with the required ability to understand his/her situation and the nature and extent of a request for euthanasia, suffering from a severe, incurable and irremediable condition, causing unbearable suffering that is impossible to alleviate, to formulate a request for euthanasia. This condition must be expected to bring about a fatal outcome in the short term. The referring physician is not entitled to pursue the euthanasia procedure without the parents' consent, and a written opinion by a psychologist or child psychiatrist certifying that the child has the required ability to understand, that he comprehends the stakes involved and that he is aware of what it means to die, has to be obtained.
Everyone concerned by this topic will hope that the number of children who will make use of this law will be as small as possible. In any case, the parliamentary debate has brought under scrutiny the question of paediatric palliative

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care, which has yet to be developed further, particularly for care delivered at home.

The de-criminalization of euthanasia for children has opened the door for debate. A request does not necessarily conclude with an act of euthanasia, and extensive dialogue should make it possible to consider all possible options. The Belgian law has, in this regard, freed the speech of everyone confronted with nearing end-of-life, while affirming that what matters is not age, but factual capacity, thoroughly assessed.

In reality, what is shocking is not a minor's euthanasia as such, but the fact that a child or adolescent is condemned to spend most of his time in hospital, that he should not be able to live a normal life, and that he is expected to die soon, under the eyes of his parents, grandparents, siblings and friends.

All we can do, then, is to humanize the departure and make is as serene as possible, with all due respect for the patient, the family and the practitioners involved. In this regard, it can be that, when everything else has been attempted, when death is nigh, euthanasia might be the better option.

Relevant materials

- An English translation of the Law of 28 May 2002 on euthanasia – albeit before the amendments brought by the Law of 28 February 2014 – can be found at http://www.ethical-perspectives.be/viewpic.php?LAN=E&TABLE=EP&ID=59.
- For those reading French, its current and complete version can be found by using the search engine http://www.ejustice.just.fgov.be/loi/loi.htm.
- The Constitutional Court's decision of 29 October 2015 concerning the Law of 28 February 2014 extending euthanasia to minors is available in English at http://www.const-court.be/public/e/2015/2015-153e.pdf.
- For those reading French, a comprehensive overview of the Belgian legislation on end-of-life matters can be found in G. GENICOT, *Droit médical et biomédical*, Larcier, 2nd edition, 2016, pages 751-813 (http://editionslarcier.larciergroup.com/titres/134413_2/droit-medical-et-biomedical.html).

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