THE LAW AND BIOETHICS OF END-OF-LIFE DECISIONS IN BELGIUM

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At the end of the 1990s, an in-depth debate arose in Belgium about patients' rights and, specifically, end-of-life decisions. There was a common will to make progress in this field, and adapt the law both to the growing aspirations of citizens and to what was observed in practice – rendering it more transparent and objective, 'framing' it through detailed and strict conditions. Numerous testimonies and viewpoints, in Parliament and, through the press, in society in general, have nurtured that debate. It has also benefited from what we could call political courage – with a traditional freedom of individual (political) opinions when it comes to bioethical matters – as well as from the strongly established culture of consensus in Belgium, always aiming at finding the best balance between various viewpoints (cultural – including linguistic – religious and moral). As a result, we can say that the Belgian legal system is mature in this regard; the underlying reasoning bears the mark of pragmatic ethics ('discussion ethics'), rather than deontology ('ethics of principles'). Parliamentary work has resulted in the adoption of three complementary Acts:[1] on patient's rights (22 August 2002), which I will deal with in section 1; on euthanasia (28 May 2002), discussed in section 2; and on palliative care (14 June 2002), which I will

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[*] I was, at the time of writing, co-chair of the Belgian Federal Commission for Control and Evaluation of Euthanasia. 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 I am speaking solely on my own behalf, without in any way committing the Commission.

[1] Belgian legislation can be found on https://www.ejustice.just.fgov.be/doc/rech_f.htm (in French or in Dutch).

also briefly evoke. In sum, on the one hand, euthanasia has been decriminalised under strict conditions; on the other hand, it has been enshrined in law that end-of-life decisions should be made *by the patient* or an appointed representative *with decision-making power*. Such decisions should thus be seen as an autonomous step taken by the patient him- or herself, and not remain a (purely) medical decision made by doctors.

The *patient's decision-making autonomy* is indeed the cornerstone of Belgian medical law, and it remains – simply exercised in a different way – when the patient is no longer able to exercise his or her rights him- or herself. Briefly summarised, and euthanasia set aside for the time being, the scheme set up in Belgium provides for:

1. the absolute right of an adult patient to refuse any treatment, including in the form of binding advance directives;
2. the right to appoint a health proxy whose decision will be binding both on (other) family members and on the doctor; and
3. failing that, a 'cascade' mechanism designating in any event a person empowered to exercise the rights of a patient who is incapable of doing so, and giving the immediate family *a decision-making role* rather than a merely advisory one – priority being in this regard given to the cohabiting partner, whether married or not.

Such a scheme seems to adequately meet the needs of health care practice and the legitimate aspirations of citizens. By placing the centre of gravity of medical decisions on the side of the patient and not of the doctor, *including at the end of life*, the Belgian model is fundamentally different from a 'consultation scheme', which results in a decision that is probably shared, but remains a medical one. While it is true that the definition of an end-of-life situation will essentially depend on the assessment of doctors about what might still be attempted and hoped for, from a curative point of view, we should never forget that this assessment must take into account what the patient has indicated about the extent of care he or she will or will not accept (e.g. no intubation, DNR, no artificial feeding). The extent of a patient's treatment will be determined on a case-by-case basis (using criteria such as the chances of recovery, as opposed to the suffering inflicted by the treatment). In any case, a well-thought-out balance between 'therapeutic obstinacy' and the 'overall benefit' of the treatment (versus discomfort caused) must be assessed and constantly checked. Besides, and as it will be further explained below (without going into too much detail), each of the possible options – withdrawal of treatment, refusal of treatment, euthanasia, assisted suicide, palliative sedation – raises different and sometimes complex issues, which cannot be solved using the same instruments or lines of reasoning.

The Belgian legal framework illustrates what is, in my view, a crucial point in all medical matters, and especially at the end of life: *the decision-making* *model itself*. One might even argue that there is a real choice for society here: the law should suggest a model, which, in this area of intimate choices, is as much societal (and ethical) as strictly legal. In this respect, the salutary effect of Belgian law is that medical decisions are made as far as possible under the banner of the patient's self-determination, expressed, if necessary, in the form of binding advance directives or conveyed by a representative – freely chosen, or designated by the law or the judge – who has decision-making powers: he or she can legally take the patient's place and decide on his or her behalf. There will then be a one-to-one discussion between the patient (and/or his or her representative) and the physician, enriched by the testimony of (other) relatives, and the valuable opinion of the health care team – or even another practitioner, depending on the nature of the decision envisaged. This architecture enables due consideration to be given, not only to the fragility and vulnerability of the person, but also to his or her autonomy and intrinsic dignity.[2]

Such a scheme does not come from nowhere and has solid grounds. Based on the philosophical value of autonomy, and on the legal protection of physical integrity as a personality right, modern medical law tends to recognise the natural capacity of vulnerable patients – both in terms of sufficient and appropriate functioning of their psychological aptitudes, and of their ability to accomplish certain tasks and understand the consequences of an action. This implies their ability to exercise, with full and appropriate information, the prerogatives relating to their health: understand, appraise, reason and make choices.[3] Unlike children and adolescents, who are expected to become progressively more mature and are placed, as a rule, under the natural protection of their parents, adults whose autonomy is undermined – because of their advanced age, or their physical or mental state – are permanently immersed in such a state, and all the more fragile because they are sometimes isolated. The relationship generated by the medical care they require is specific and might be problematic. Physicians are regularly confronted with tricky situations and their questions are not always answered, or at least not clearly. While it is up to the law to provide for the necessary clarifications and guidelines, assessing capacity remains the prerogative of the doctor, if necessary – and this is here to be encouraged – in a multidisciplinary consultation with the other health professionals in contact with the patient.

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[2] As a consequence, and as will be further clarified, a case like that of *Vincent Lambert* (in France) could not have arisen in Belgium, since Belgian law designates who, within the family, must take precedence, and provides for a hierarchy among family members.

[3] Patients should indeed be able to: (1) understand essential information about the diagnosis and the related treatment, and to say/show that they understand; (2) appraise the situation in which they find themselves, recognise the problem and evaluate the consequences of a given treatment in their own situation, in relation to their own scale of values or view of things; (3) reason, compare the proposed options and weigh up their risks and benefits; and (4) express a choice, and maintain it over time.

Belgium is also, as we know, one of the very few countries in the world to have legalised euthanasia – it is, more appropriately, a decriminalisation with conditions. The other Benelux countries also have similar legislation (2001 in the Netherlands; 2009 in Luxembourg). The Belgian Act on Euthanasia was adopted on 28 May 2002. It is a specific and remarkable feature of Belgian medical law. It should be read in conjunction with the two other important legal instruments adopted that same year, which I have already mentioned: the Act of 14 June 2002 on palliative care and, most notably, the Act of 22 August 2002 on patient's rights. These general rights are indeed of the highest importance at the end of life. They will be presented and discussed first (section 1), before focusing on the law (and practice) of euthanasia (section 2). At this stage, I should mention that literature on the subject is, of course, plethoric. Those who wish to know more about Belgian law pertaining to end-of-life, and who read French or Dutch, will find many resources.[4] There is obviously also a vast English-language literature, both on regulation of end-of-life in general[5] and on the specific Belgian legal landscape in particular[6] – bearing in mind that, as one can frequently note, the

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[4] F. Bussche and W. Distelmans (eds), *Een goede dood. 2002–2012: tien jaar 'controversiële' euthanasiewet?*, VUB Press, 2012; F. Damas, *La mort choisie. Comprendre l'euthanasie et ses enjeux*, coll. Santé en soi, Mardaga, 2013; E. Delbeke, *Juridische aspecten van zorgverlening aan het levenseinde*, reeks Gezondheidsrecht, Intersentia, 2012; W. Distelmans, *Euthanasie et soins palliatifs: le modèle belge. Pour le droit à une fin de vie digne*, La Muette/Le Bord de l'Eau, 2012; N. Gallus, *Bioéthique et droit*, Anthemis/Université Libre de Bruxelles, 2013, pp. 273–84; G. Genicot, *Droit médical et biomédical*, coll. Faculté de droit de l'Université de Liège, 2nd éd., Larcier, 2016, pp. 759–813; Goffi, J.-Y., *Penser l'euthanasie*, coll. Questions d'éthique, PUF, 2004; D. Lossignol, *En notre âme et conscience. Fin de vie et éthique médicale*, coll. Liberté j'écris ton nom, Espace de Libertés, 2014; E. Montero, *Rendez-vous avec la mort. Dix ans d'euthanasie légale en Belgique*, coll. Vie et société, Anthemis, 2013; B. Mouffe, *Le droit à la mort*, Bruylant, 2019; H. Nys, *Geneeskunde. Recht en medisch handelen*, reeks Algemene Praktische Rechtsverzameling, Wolters Kluwer, 2016, pp. 314–65; T. Vansweevelt and F. Dewallens (eds), *Handboek Gezondheidsrecht*, reeks Gezondheidsrecht, 2nd éd., Intersentia, 2022, vol. II, pp. 1443–673, 'Het eindigend leven'. For comparative law see Association Henri Capitant, *Le droit de la santé: aspects nouveaux*, tome LIX, Journées suisses 2009, Bruylant/LB2V, 2012, pp. 681–912, 'La personne en fin de vie'. See also La Revue Nouvelle, *Choisir sa fin de vie?*, dossier, 2013.

[5] See e.g. M. Cholbi and J. Varelius, *New Directions in the Ethics of Assisted Suicide and Euthanasia*, International Library of Ethics, Law, and the New Medicine series, Springer, 2015; B. Feuillet, K. Orfali and T. Callus (eds), *Families and End-of-Life Treatment Decisions. An International Perspective*, coll. Droit, Bioéthique et Société, Bruylant, 2013; E.P. Foley, *The Law of Life and Death*, Harvard University Press, 2011; J. Kurle (ed.), *Euthanasia. The 'Good Death' Controversy in Humans and Animals*, IntechOpen, 2011; S.W. Smith, *End-of-Life Decisions in Medical Care. Principles and Policies for Regulating the Dying Process*, Cambridge University Press, 2012; S. Sterckx, K. Raus and F. Mortier (eds), *Continuous Sedation at the End of Life. Ethical, Clinical and Legal Perspectives*, Bioethics and Law series, Cambridge University Press, 2013; B.P. White and L. Willmott (eds), *International Perspectives on End-of-Life Law Reform. Politics, Persuasion and Persistence*, Cambridge University Press, 2021.

[6] See e.g., limiting myself to books: T. Devos (ed.), *Euthanasia: Searching for the Full Story. Experiences and Insights of Belgian Doctors and Nurses*, Springer, 2021 (open access); J. Griffiths, H. Weyers and M. Adams, *Euthanasia and Law in Europe (with Special Reference*

manner in which Belgian law is presented from abroad is all too often regrettably inappropriate and misleading.

1. PROTECTION OF THE (ELDERLY) PATIENT AND PRESERVATION OF DECISION-MAKING AUTONOMY AT THE END OF LIFE

The necessary protection of vulnerable adults must go hand in hand with a maximum preservation of their decision-making autonomy. It is essential to bear in mind that any person suffering from a pathology, including (and even particularly) a mental one, is not necessarily *ipso facto* vulnerable in the usual sense of the word: the essential question that should always be asked is whether that person has a real, effective ability to consent at the time and in the specific circumstances in which they find themselves. This involves the ability to listen and understand, to receive the necessary information, to reason with sufficient insight, to freely express a decision (and to resist possible pressures), and to maintain that decision over time. It is therefore necessary to examine whether or not – and if so, to what extent – these abilities are *actually* disrupted by the pathology. In this respect, the views of all those involved (health care team, relatives) are crucial – particularly when dealing with psychiatric disorders – and it is essential that these criteria are not assessed too hastily or superficially: in short, vulnerability is something that can be *observed*, not decreed.[7]

As I have already indicated, Belgian medical law is based on the Act of 22 August 2002 on patient's rights. Its intrinsic symbolic value is strong with regard to persons in a potentially vulnerable situation, and to the role assigned to the state in regulating legal relationships in the personal and intimate sphere.

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to the Netherlands and Belgium), Hart Publishing, 2008; D.A. Jones, C. Gastmans and C. MacKellar, *Euthanasia and Assisted Suicide. Lessons from Belgium*, Bioethics and Law series, Cambridge University Press, 2017 (which includes an unofficial English translation of the Act of 28 May 2002, pp. 305–15, as well as a comprehensive list of references, pp. 316–51); P. Schotsmans and T. Meulenbergs, *Euthanasia and Palliative Care in the Low Countries*, Ethical Perspectives series, Peeters, 2005; T. Smets, *The Euthanasia Practice in Belgium. Behavior and attitudes regarding reporting and adherence to legal safeguards*, VUB Press, 2010.

[7] See generally, on this subject: Association Henri Capitant, *La vulnérabilité*, tome LXVIII, Journées québécoises 2018, Bruylant/LB2V, 2020 (esp. pp. 25–345, 'Vulnérabilité et aptitude', and pp. 347–640, 'Vulnérabilité et intégrité physique'); F. Rouvière (dir.), *Le droit à l'épreuve de la vulnérabilité. Etudes de droit français et de droit comparé*, Bruylant, 2010; E. Thiry (dir.), *Actualités de droit familial et de droit médical. Les droits des personnes les plus faibles*, Bruylant, 2007; G. Genicot, *Droit médical et biomédical*, coll. Faculté de droit de l'Université de Liège, 2nd ed., Larcier, 2016, pp. 231–68; Y.-H. Leleu, *Droit des personnes et des familles*, coll. Faculté de droit de l'Université de Liège, 4th ed., Larcier, 2020, pp. 173–308; A.-C. Van Gysel (dir.), *Traité de droit civil belge*, t. I, *Les personnes*, coll. De Page, Bruylant, 2015, vol. 2, pp. 977–1252.

It enshrines the most fundamental right of the patient, that of *informed consent*: 'the patient has the right to freely consent to any intervention by the professional practitioner, subject to prior information' (section 8, §1). The patient's express, free and prior consent is therefore required for *all* medical acts, even those of a routine or minor nature, albeit with certain legal exceptions – among which, of course, emergency situations. This consent cannot, of course, be given under pressure from third parties. And one should take care not to assume that, per se, a person weakened by illness or confronted with existential distress would *necessarily* no longer be free to exercise his or her right to bodily autonomy.

In exercising his or her right to be fully and completely informed, with a view to giving or withholding his or her consent to the procedure, the patient may be assisted by a trusted third party or request that the information be communicated also (or even exclusively) to the latter (section 7, §2(3) of the Act). Any number of arrangements can be envisaged in this respect: communication exclusively to the trusted support person, in the absence of the patient; communication to both simultaneously, both being active interlocutors of the doctor; simple passive presence of the trusted support person, to accompany and reassure the patient; or communication of certain information only to the trusted support person, at the same time or later. The trusted support person, who *assists* a legally capable (or presumed legally capable) patient, should not be confused with the health proxy, who *represents* a patient who is legally or de facto incapable, as I will discuss below.

In theory, the patient him- or herself gives his or her consent to the medical act, and is the sole creditor of the information leading to that act. This is one of the lessons of an important decision of the Belgian Cour de cassation of 14 December 2001.[8] When the patient does not have the capacity or lucidity required for this purpose, there are several exceptions to this rule: a derogation system must be provided so that the patient may be assisted or represented in order to make his or her decision, without ever losing sight of the need to inform the patient him- or herself as comprehensively as possible about his or her condition and the treatment envisaged. In this respect, the Act on Patient's Rights must be read in conjunction with the Act of 17 March 2013 'reforming incapacity regimes and establishing a new status of protection in accordance with human dignity'. The provisions of this latter Act are essentially procedural but it salutarily confirms that, in the medical field, one should not stop at *legal* incapacity: the question here is how a decision that intimately affects the person in his or her body can be made, and not how a legal instrument such as a contract might be concluded.

The Act of 17 March 2013 allows the local judge (*juge de paix*) to provide vulnerable adults with an administrator who will take decisions on their behalf,

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[8] https://juportal.be/content/ECLI:BE:CASS:2001:ARR.20011214.4 (in French and Dutch).

in relation not only to their assets but also to their *personal affairs*, particularly their health. The judge must tailor the protection regime to the specific condition of the person needing to be protected; the system gives maximum priority to capacity, as long as it exists, with protection being only subsidiary and operating primarily through a regime of assistance and, only to the extent necessary, of representation. A judicial protection measure may be ordered for 'an adult who, owing to his or her state of health, is wholly or partially unable to assume responsibility for the management of his or her property or non-property interests, as he or she should, without assistance or any other protective measure, albeit temporarily, … if and insofar as the protection of his or her interests so requires' (Civil Code, section 488/1).[9] The judge must then decide which personal acts the protected person is incapable of performing, taking all the circumstances into account, including of course his or her state of health (Civil Code, section 492/1). The judge must expressly list these acts in his or her judgment and, in the absence of any indication therein, the protected individual remains capable for all acts relating to his or her person.

Certain interventions, intimately linked to the person – in the fields of family law and medical law, which are the two areas in which the potential infringement of personal rights is the greatest – must in this respect be the subject of an express decision by the judge. In each case, the judge must rule on the competence of the administrator to exercise the patient's rights on the basis of section 14, §2 of the Act of 22 August 2002, should the person not be able to exercise these rights him- or herself. Another list of acts are considered so personal that they cannot be accomplished by means of assistance or representation by the administrator (Civil Code, section 497/2). In medical law, the list of such acts includes, for example, a request for euthanasia, which, if the vulnerable person is de facto incapable, simply cannot be made.

The key provision for our purposes is section 14 of the Act on Patient's Rights, according to which the rights of a vulnerable adult are, as far as possible, exercised by the person him- or herself, provided that he or she is actually capable of expressing his or her will in the matter. In any event, the patient must be 'involved in the exercise of his or her rights, as far as possible and taking into account his or her ability for understanding' (section 14, §4). Care must therefore always be taken not to disregard the patient's personal opinion: as a matter of principle, he or she retains control over his or her body and autonomous decision-making

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[9] The Belgian Civil Code is currently progressively undergoing a complete rewriting. The Act of 13 April 2019 has created a (new) Civil Code. It states that, as from its entry into force, which took place on 1 November 2020, the Civil Code of 21 March 1804 shall be entitled the 'Old Civil Code' – which suddenly modifies longstanding habits of all legal practitioners in Belgium. In order not to complicate matters, I will here refer to the Civil Code as such – also bearing in mind that the provisions I refer to here remain untouched by the ample current reform.

(capacity is the rule, and incapacity the exception). This provision covers both legal incapacity and de facto incapacity of a person who is legally capable, but who is not in a position to exercise his or her patient's rights because he or she is de facto unable to give valid consent to medical treatment when the decision has to be taken. This may be a one-off situation (unconsciousness, coma, loss of all brain functions) or a lasting one (mental disorders, senility), which may not necessarily have led to the appointment of an administrator, either because this is not justified or because no one has (yet) initiated the procedure. In all of these cases, medical decisions will thus not be left at the discretion of doctors – although, of course, their expertise and advice will be of paramount importance for the relatives involved.

If incapacity is established, the patient's rights are first exercised by the proxy he or she has appointed, when he or she was still capable of doing so, to take his or her place for as long as he or she is unable to exercise his or her rights him- or herself (section 14, §1). This is a specific mandate, written, dated and signed by the patient and the proxy, who must agree to it and accept his or her mission. The patient must have exercised this prerogative in time, which implies that he or she has been informed of this possibility; an educational effort is still desirable in this respect, as the initiative is not (yet) customary. It is also up to the patient, as well as the proxy, to take the necessary precautions to inform the physician, who must also enquire about the existence of a proxy. An essential point is that the proxy *represents the patient* in the exercise of all his or her rights; therefore, unlike the trusted person, the proxy does not merely assist the patient in the exercise of these rights, but exercises them in his or her place when he or she is incapable of doing so.

If the patient has not appointed a proxy, or if the latter does not intervene (or no longer does so), a system of *cascade representation* is set up by section 14, §§2 and 3 of the Act. This is where the potential *administrator of the person* appointed under the Act of 17 March 2013 comes into play, in the first place: he or she will exercise the patient's rights of his or her 'protégé' if he or she has been declared competent in this respect by the judge (this would probably be the case if the administrator is a close family member, and maybe not if he or she is a lawyer, which is often the case). If no administrator is entitled to represent the patient, this leads to the actual 'cascade' system: the patient's rights are exercised primarily (and exclusively) by the *partner* (cohabiting partner, legal cohabitant or de facto cohabiting partner, without distinction). Cohabitation is the criterion adopted, which is a determining indicator of effective proximity to the patient, the legislator thereby corroborating the idea of substitute consent rather than 'representation' as such. This primacy seems to me to be legally wise and sociologically appropriate: we are talking about the person with whom the patient has chosen to build his or her life for maybe many years, whereas the links may have loosened with adult children or parents. Failing that, or if the partner does not wish to intervene, the patient's rights are exercised, in order of priority, by *an adult child, then a parent, then an adult sibling*. If no relative of the patient wishes to intervene, if there is no one in a position to do so, or if a conflict arises and persists, the *physician* will, insofar as the context permits, him- or herself defend the patient's interests.

It is essential to stress that, as the Act on Patient's Rights expressly provides, the patient's representation shall be finalised and supervised. His or her representative must obviously base their decision on the (multidisciplinary) medical expertise received, but also on the *presumed will/wishes of the patient*, or, if he or she does not know them, on their *best interests* assessed as objectively as possible.[10] The Act therefore appropriately confers on the practitioner the power to consider that the decision taken by the representative is evidently not in accordance with these interests, or even constitutes a threat to the patient's life, or risks seriously damaging his or her health (section 15, §2). In such a case, the physician is entitled to derogate from that decision, if necessary by acting in the context of a multidisciplinary consultation, and a written motivation must be added in the patient's file. However, by way of exception, the physician may not derogate from a decision taken by the proxy expressly designated by the patient if the latter is able to establish (by all legal means) that the patient's express wishes would indeed be in line with the decision he or she is taking for him or her. This is an additional indication of autonomy: it is assumed that a patient who expressly designates a person to represent him or her, in the event that he or she is no longer capable of exercising his or her rights him- or herself, will at the same time communicate to that person the necessary details about the treatment he or she wishes or refuses to receive, or has chosen that person because, owing to their closeness, he or she knows that this person already is aware of his or her wishes in this respect – hence the importance of drafting clear and precise advance directives.[11] It is therefore important not to thwart this

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[10] In this respect, the recent Act of 22 April 2019 on the quality of health care practice is not totally satisfactory when it states (section 4) that health care professionals shall, within the limits of the competences conferred on them by or under the law, freely choose the means they use in providing health care (no regulatory restrictions may be imposed on them in this context), and that they shall be guided, in this choice, 'by relevant scientific data and their expertise, *while taking into account the preferences of the patient*' (emphasis added). It should rather be, at least, a *joint decision* between the patient or his or her representative, and the physician. This Act, which for the main part entered into force on 1 January 2022, is important but does not in the least alter what is indicated here, and does not have to be further discussed within the scope of this paper (see, for a detailed presentation, T. Vansweevelt et al., *De Kwaliteitswet*, Gezondheidsrecht series, Intersentia, Brussels 2020).

[11] On this important subject, see C. Lemmens, *Planification anticipée des soins et déclarations relatives à la fin de vie*, coll. Droit notarial, Wolters Kluwer, 2020; C. Lemmens, 'Voorafgaande wilsverklaringen' in T. Vansweevelt and F. Dewallens (eds), *Handboek Gezondheidsrecht*, reeks Gezondheidsrecht, 2nd ed., Intersentia, 2022, vol. II, pp. 1587–673; C. Lemmens, *Voorafgaande wilsverklaringen met betrekking tot het levenseinde*, reeks Gezondheidsrecht, Intersentia, 2013.

wish, which will then certainly be that of the patient him- or herself – simply expressed by another person – and must therefore prevail.[12]

The legal framework for medically assisted end of life is one of the salient and progressive features of Belgian law. Firstly, the *right to refuse treatment* is fully guaranteed in Belgium. Expressed either by the patient him- or herself, as long as he or she remains de facto capable, or by his or her representative, it is as a matter of principle enforceable against the medical staff, provided that the patient really is expressing his or her own wishes and has not been misled or induced to refuse.[13] The physician should of course not give up too quickly; if the patient becomes reluctant, he or she should first take the time to re-explain the pros and cons of the planned intervention, to reassure him or her if necessary, to confirm that it is in the patient's best interests and to clarify as far as possible, without minimising them, the risks involved. At the end of life, it is very generally accepted that the patient may also *refuse palliative care* if he or she considers, in all sovereignty, that it shows 'unreasonable obstinacy' or is accompanied by modalities that he or she considers too harsh. The right of every person to control his or her own body implies, in essence, the right to refuse or withdraw consent to a medical intervention: the patient is free 'to refuse or withdraw consent … for an intervention' (section 8, §4(1) of the Act of 22 August 2002 on patient's rights). This broad and general provision covers *any* intervention which the patient does not wish (or no longer wishes) to undergo, even if it is vital. It therefore takes precedence over the physician's legal (and ethical) duty to assist the patient – but this does not extinguish the patient's general right to 'quality services that meet his or her needs, while respecting his or her human dignity and autonomy, and without any distinction being made', as stated in section 8, §4(3), referring to section 5, of the Act. This is another indispensable corollary of the right to self-determination.

Moreover, section 8, §4(4) of the Act on Patient's Rights gives binding force to the advance refusal validly expressed by a patient before he or she becomes incapable of exercising his or her rights: the advance refusal of any given intervention 'must be respected as long as the patient has not revoked

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[12] I should mention here that, during the whole year 2023, the Act on patient's rights has been undergoing some major reforms, which are about to be completed and adopted in Parliament, although that is still not the case upon finalisation of this report (December 2023). I have to stick to the current state of law, and so I will not go into its expected future. It should be stressed that, on the specific point discussed here, the reform extends this exception to *all representatives*, and not only the proxy expressly appointed by the patient – thus maximising the patient's autonomy.

[13] Artificial hydration and nutrition would undoubtedly be approached, in Belgium, as a medical treatment, purely because they are medically administered. When confronted with the question of limiting, withdrawing or withholding consent for such medical assistance, its intrinsic pertinence would be assessed by the doctor, but the right of the patient (or his or her representative) to give and/or withhold consent would be fully applicable.

it', which he or she can obviously do if he or she remains, or again becomes, capable of exercising his or her rights. This provision, innovative at the time, is formal. Equally formal is section 8, §5 of the Act, according to which, in an emergency situation, it is *only when there is uncertainty* as to whether or not there is a previously expressed will of the patient or his or her representative that the doctor may immediately perform any intervention which is *necessary* in the patient's interests – and only that. But there will be no uncertainty if the patient has taken the opportunity to write advance directives and/or appoint a proxy. Confronted with an advance directive in which a certain intervention is refused, which offers sufficient guarantees, the practitioner *must bow* to that directive, even if the life of the patient is at stake. In this way, it is possible to avoid prolonging life unreasonably, or to ensure that there will be no resuscitation when hope fades. However, the intervention for which the patient expresses his or her advance refusal must be precisely indicated, at a time when it is certain that the patient was fully capable: when this is in doubt, or when such a statement is formulated in vague, general or equivocal terms, the physician might validly proceed if, interpreting the statement, he or she can reasonably consider that the envisaged treatment is not covered by it. For the rest, there are no specific formal requirements, and it is good that this is the case.

These clear legal provisions are of the highest importance in many situations, not only at the end of life. And then there is, in Belgium, the specific possibility of euthanasia.

2. THE CONDITIONAL DECRIMINALISATION OF EUTHANASIA: A REMARKABLE FEATURE OF BELGIAN LAW

After a thorough and in-depth debate lasting over two years, with multiple hearings of witnesses or experts, the Belgian Parliament adopted on 28 May 2002 the Act on Euthanasia (which entered into force on 20 September 2002).[14] As is always the case with bioethical themes, members of Parliament were permitted to vote individually and freely, without any 'party discipline'. Twenty years later, the conditional decriminalisation of euthanasia *as such* is widely accepted and indeed defended in Belgium, both politically and sociologically. Meanwhile, given the importance of this particular subject, it is quite understandable that discussions regularly arise, and that some specific points are subject to debate and controversy – most notably, euthanasia on the grounds of psychiatric

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[14] See M.-L. Delfosse, *Vers la loi du 28 mai 2002 relative à l'euthanasie. Une approche des débats parlementaires et de leurs prolongements*, Courrier hebdomadaire du CRISP, 2019, 2 vols.

disorders.[15] But these should certainly not hide the basics and the core of the law, which I will try to summarise here.

The Act defines euthanasia as the act which *intentionally terminates the life of a person at his or her request*, and which is carried out by an individual other than the person in question (section 2). It has to be a physician (section 3) – and not a nurse, for instance. Under this Act, euthanasia thus becomes a medical gesture, and no longer a criminal one, provided all the prescribed conditions are met. This allows, on the one hand, the medical profession to be reassured and, on the other hand, patients' interests to be better met, since their self-determination is recognised. It is very important to stress that intentionally administering death to another person at his or 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 unnecessary treatment). 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 22 August 2002 on patient's rights: 'Every person should receive the most appropriate care from health professionals in order to prevent, listen to, assess, consider, treat and relieve pain'). The decision to administer sedation to alleviate distress in the terminal phase of a disease, or to terminate life support for persons in a permanent vegetative state, hastening death without directly causing it, falls beyond the scope of the euthanasia law and would be approached via the patient's rights system, which, as I have noted above, makes it clear who is responsible for the decision – a decision that must primarily be based on the patient's previous known wishes, if any. Euthanasia follows a different logic: it is based on the patient's *request* (and not on his or her 'consent'). This distinction is, to me, essential.

Equally essential is that, under Belgian law, the patient clearly does not have a so-called 'right to euthanasia', but rather the *right to request it* and to see that request listened to, investigated and (openly) matched with the legal criteria. 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. He or she will be reassured and comforted by the mere idea that the issues pertaining to his or her end of life can be discussed with empathy and honesty, and that several paths are open, including euthanasia, which might be a future option should his or her condition deteriorate. Euthanasia is one option among others. Legally offering this possibility aims at rendering things more frank and transparent.

Being so defined, euthanasia should not be 'opposed' to palliative care. Palliative care is the subject of the Act of 14 June 2002, as amended by the Act of

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[15] See the Opinion of the Belgian Advisory Committee on Bioethics no. 73 of 11 September 2017 on euthanasia in case of non-terminally ill patients, psychological suffering and psychiatric disorders, https://www.health.belgium.be/en/list-opinions.

21 July 2016, which has broadened its definition and accessibility. It is generally agreed that palliative care units function fairly well in Belgium, although they need to be constantly optimised – particularly in terms of their bed capacity, and sometimes in terms of the training of the carers. The Act of 14 June 2002, adopted at the same time as the Act on Euthanasia, gave this care a formal legal status. Section 2 states that 'every patient has the right to palliative care when he or she is in an advanced or terminal stage of a serious, progressive and life-threatening disease, regardless of life expectancy', and that palliative care 'offers the patient and his or her relatives the best possible quality of life and maximum autonomy' and 'aims to guarantee and optimise the quality of life for the patient and his or her relatives and close carers for as long as possible'. The same section also states – albeit in not very prescriptive terms – that 'a sufficiently wide range of palliative care, and the criteria for reimbursement of such care by the social security system, shall guarantee equal access to palliative care for all patients, throughout the range of care on offer', and that 'a multidisciplinary package of care shall be guaranteed to ensure that these patients are supported at the physical, psychological, social, moral, existential and, where appropriate, spiritual levels'.

Since the Act of 21 July 2016, section 2 of the Act of 14 June 2002 opportunely specifies that palliative care is to be 'provided from the moment the patient is identified as palliative, up to and including the terminal phase', and that it 'may also be initiated while (other) treatments are still underway'. The legislator expresses the wish – again not very prescriptive, but probably intended as inspiration – that 'ideally, palliative care should be used progressively, in accordance with care needs and wishes, regardless of life expectancy'. According to section 7 of the Act:

> Every patient has the right to obtain information about his or her state of health and the possibilities of palliative care. The attending physician shall communicate this information in an appropriate form and terms, taking into account the patient's situation, wishes and ability of understanding. Except in emergency situations, the patient's free and informed consent is required for all examinations or treatments.

All of this is almost self-evident, and hardly raises any legal questions.

Euthanasia of an adult, conscious and terminally ill patient is the cornerstone of the Act of 28 May 2002, and by far the most frequent practice under the scope of this Act. It is only possible if three fundamental conditions are met (section 3, §1, of the Act).

Firstly, there must be a *request from the patient*, which must be expressed in a recurring, voluntary and well-considered manner and not be the result of any external pressure. It is recorded in writing and may be revoked at any time (section 3, §4). This 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 his or her 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 or her incapable of doing so, may request euthanasia (for example at an early stage of a pathology such as Alzheimer's disease).

Secondly, 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 under Belgian law.

Thirdly, 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 equivalent to '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 and multifactorial, partly subjective, and it very often includes, in addition to a physical component, a psychological impact. The perspective of inevitable future degradation, and the growing suffering it will imply, can already be taken into consideration, for example when a diagnosis of neurodegeneration or amyotrophic lateral sclerosis is made. It is also essential to distinguish, on the one hand, the psychological aspect of somatic-based suffering and, on the other hand, the (purely) psychological suffering caused by a psychiatric disorder.

In addition to these three 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 of 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 or 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 his or her 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. These discussions will enable the doctor to ensure that the patient is not under any form of pressure, and his or her judgment should be trusted – on a subject that is per se of a subjective nature, and that cannot really be controlled externally.

However, this individual discussion 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 or 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 or she gives an opinion on the patient's medical situation, and therefore on the validity of his or her request, aims at providing an objective view of the patient's condition and constitutes an important element in the review process. The opinion of the consulted physician is not binding: it does not necessarily have to be entirely consistent. 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 or her own subjective assessment when faced with a procedure that is obviously anything but trivial for him or her.[16]

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. Here the recognition of the patient's autonomy takes on an even greater significance: his or her request is all the more important if his or her death does not appear to be imminent, and thus it is no longer a question of hastening or easing a process that is inevitable in the short term. These are cases where 'the physician is of the opinion that 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 when confronted with 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.[17] The legal

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[16] There is certainly a need to train physicians willing to 'specialise' in providing assistance in terminating life; it is done in Belgium through LEIF/EOL forums and seminars (https://eol.admd.be (French), https://leif.be/home (Dutch)). It is undoubtedly sometimes difficult for doctors to deal with this delicate process, especially general practitioners who would be confronted with it maybe once or twice in their whole career.

[17] The latest report of the Commission for Control and Evaluation of Euthanasia indicates that mental and behavioural disorders account in total for approximately 2% of all euthanasia cases, evenly distributed between psychiatric disorders (e.g. personality disorders, depression, post-traumatic stress disorder, schizophrenia, autism, etc.) and cognitive disorders (e.g. different forms of dementia, such as Alzheimer's disease or vascular dementia). It can be found here (in French): Rapport euthanasie 2022 – Chiffres des années 2020–2021, https://organesdeconcertation.sante.belgique.be/sites/default/files/documents/10_rapport-euthanasie_2020–2021-fr.pdf.

requirements are then strengthened: (1) consultation of a second physician, who must be a psychiatrist or a specialist in the disorder in question, and who shall ascertain 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 (2) allowing at least one month between the patient's (written) 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.

On the subject of euthanasia motivated by a psychiatric condition causing constant and intolerable suffering, I have to mention the only trial that has, since 2002, attracted media attention in Belgium. Three doctors involved in the euthanasia of a 38-year-old woman, Tine Nys, who suffered from severe Asperger's syndrome, had been brought before a Criminal Court (Cour d'assises) for committing murder by poisoning. All three were acquitted. It was not proven that the doctor who had performed the euthanasia had not respected the conditions and the procedure provided for by the Act of 28 May 2002. The first physician consulted, a general practitioner, had indicated that his patient was suffering from a serious and incurable psychiatric disorder, which was unbearable for her, that she wished to be euthanised and that he supported her decision, though regretting it. He could not be convicted as a co-perpetrator of murder, especially as it appeared from the investigation that he was convinced that this request was subject to prior approval by the Commission for Control and Evaluation of Euthanasia (see below – he was therefore unaware of the legal requirements, but this does not make him a murderer). As for the psychiatrist who intervened during the euthanasia procedure as the second physician consulted, in accordance with the provisions of section 3, §3, 1° of the Act, she fulfilled her task correctly and there was no reason to conclude that she had lost the required independence.[18]

This decision was partially invalidated, but only as regards the civil actions and not the criminal decision,[19] and, in the aftermath of these aspects of the case, the Constitutional Court was seized. It ruled that there was, in the Act of 28 May 2022, a breach of equality and fair treatment with regard to the sanctions that the physician may face: the legislator consciously chose not to provide for a separate offence, with a specific scale of penalties, in the event of non-compliance with the conditions and procedures of the Act that are not substantive conditions for euthanasia, having considered that *any* conditions and procedures prescribed constitute an essential element of the legislative

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[18] East Flanders Criminal Court (Cour d'assises), decision of 31 January 2020, *Jurisprudence de Liège, Mons et Bruxelles*, 2020/23, p. 1093, with a commentary by Y.-H. Leleu, *Revue de Droit de la Santé*, 2020–2021/4, p. 327, with a commentary by M. De Hert.

[19] Cour de cassation, decision of 15 September 2020 (no. P.20.0240.N), *Revue de Droit de la Santé*, 2020–2021/4, p. 336, with a commentary by M. De Hert.

framework within which euthanasia is permitted, insofar as all of these conditions and procedures help to ensure that euthanasia is only carried out in the circumstances referred to by the legislator, and that the competent bodies are in a position to exercise effective *ex post* control. Whereas it is not per se unreasonable to require that doctors should scrupulously comply with all these conditions and procedures and that any breach, however serious, may result in criminal sanctions, it is problematic that the Act does not make any distinction among these conditions and procedures: the effect is therefore that *any failure* to comply with any of these may result in identical treatment, under criminal law, of the doctors concerned. They may all be convicted under the existing provisions of the Criminal Code that criminalise the act, performed by a third party, of intentionally ending a person's life at the person's request, even though these conditions and procedures fundamentally differ with regard to their nature and purpose. In the view of the Constitutional Court, the application of a single incrimination to any lack of compliance with the conditions and procedures set out in the Act of 28 May 2002, however important, entails disproportionate consequences: the obligation of the legislator to provide effective safeguards to prevent abuses when euthanasia is carried out does not extend to the need for such a severe and disproportionate system of sanctions. The Court urges the legislator to modify the Act in order to remedy that unconstitutionality.[20]

Euthanasia can also be carried out following an *advance declaration* (section 4 of the Act) in which the patient records in writing, in the event that he or she is no longer able to express his or her will, his or 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. Such an advance declaration is therefore (much) more than a refusal of futile treatment, and different from a wish for palliative care. Since a legislative amendment of 15 March 2020, it is valid for an indefinite period. 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 health care team in regular contact with the patient, as well as with any trusted person and the relatives they may designate. This scenario remains extremely rare in practice (only 1–2% of cases, on average), since it only concerns *irreversibly unconscious patients* (coma, vegetative state, unresponsive wakefulness syndrome) – and not, for example people suffering from Alzheimer's

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[20] Constitutional Court, decision no. 134/2022 of 20 October 2022, available (in French and Dutch) on https://www.const-court.be, *Journal des Tribunaux*, 2022, p. 811. The Court expressly notes that this ruling has no impact on the decriminalisation of euthanasia as such, when the conditions and procedures prescribed by the Act of 28 May 2002 have been respected.

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 (see above, section 1), by means of which a person in good health preventively records his or her wishes concerning the treatment he or she will want – or most often will refuse – when he or she becomes incapable of making a decision.[21]

The issue of *minors* was resolved later, by the Act of 28 February 2014, which extends, 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 rare: there have only been five cases of euthanasia of minor patients since this Act came into force. Under the Act of 22 August 2002 on patient's rights (section 12), in all cases, minor patients, depending on their age and maturity, must be involved in the exercise of their rights, but more than that, they may exercise their patient's rights autonomously if they can be considered de facto capable of reasonably assessing their interests in the matter. This autonomy of the minor includes the right to refuse treatment, even if there is still some benefit; similarly, his or her consent is required, if he or she is deemed capable of deciding for him- or herself, for palliative treatment of pain, even if this accelerates the dying process, provided that the doctor deems it appropriate. In these cases, the consent of the parents is only required when the child is not sufficiently mature; otherwise, their voice should only be consultative, although they will naturally always be closely involved in the decision-making process. In this context, the Act of 28 February 2014 intended to put an end to this astonishing paradox: euthanasia was the only medical option 'closed' to competent teenagers, the only decision they could not legally take – although it is well documented that having a fatal disease tends to increase maturity, even at a young age, and taking into account that euthanasia is, in essence, an eminently intimate choice which, as a general rule, can only be made by the person concerned him- or herself.

The mechanism put in place (through an amendment to section 3, §1 of the Act of 28 May 2002 on euthanasia) is strict. It only applies to minor patients who possess the capacity for discernment, who are conscious at the time of their request – advance declaration is not covered here – and who are in a medically hopeless situation of constant and unbearable physical suffering that cannot be alleviated and that will lead to death in the short term, which results from a serious and incurable accidental or pathological condition. Only the terminal phase is therefore covered, and purely psychological suffering is deliberately

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[21] See C. Lemmens, *Planification anticipée des soins et déclarations relatives à la fin de vie*, coll. Droit notarial, Wolters Kluwer, 2020; C. Lemmens, 'Voorafgaande wilsverklaringen' in T. Vansweevelt and F. Dewallens (eds), *Handboek Gezondheidsrecht*, reeks Gezondheidsrecht, 2nd ed., Intersentia, 2022, vol. II, pp. 1587–673; C. Lemmens, *Voorafgaande wilsverklaringen met betrekking tot het levenseinde*, reeks Gezondheidsrecht, Intersentia, 2013.

excluded in the case of minors. The doctor receiving this request must consult a child psychiatrist or a psychologist, specifying the reasons for this consultation, who will examine the minor patient and ascertain his or her capacity for discernment. This opinion is binding: euthanasia will not be legally possible if this capacity is not confirmed. The doctor treating the minor must of course talk to the minor's parents, give them all the necessary information, and ensure that they agree to the minor's request. The patient's request, as well as the agreement of his or her legal representatives, must be recorded in writing. Incidentally, the 2014 Act specifies that, in all cases – whether the patient is an adult or a minor after the patient's request has been processed by the doctor, the possibility of psychological support must be offered to the persons concerned.

With such strict limitations, this development is coherent and reasonable. It should be noted that the Belgian Constitutional Court was seized of an appeal to annul the Act of 28 February 2014, for alleged infringement of various fundamental rights enshrined both in the European Convention on Human Rights – which is of course binding in Belgium, and constitutes the most important international human rights instrument for the Belgian national legal system – and in the Belgian Constitution.[22] It rejected this appeal, stating, in passing, that the right to life and the right to respect for physical integrity cannot give rise to an 'obligation to live' imposed on an individual who is capable of discernment, no matter the circumstances he or she may be faced with, and that, given the specific guarantees it contains, the 2014 Act strikes a fair balance between, on the one hand, the right of each individual to choose to end his or her life in order to avoid an undignified and painful end of life, which derives from the right to respect for private life, and, on the other hand, the right of the minor to be protected from abuse in the practice of euthanasia, which derives from the right to life and physical integrity. The Court also noted, very

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[22] It should be stressed that the ECHR does not restrict the possibility to decriminalise euthanasia: the right to life should certainly not be viewed as 'opposed' to the right to respect one's private life and physical integrity, seen as enabling each individual to make his or her own intimate end-of-life choices, and not only to oppose violations to which one has not consented. I cannot, in the limited scope of this report, go deeper into this. It seems sufficient to refer to the leading case law of the European Court of Human Rights in the matter: *Pretty v. United Kingdom*, no. 2346/02, 29 April 2002; *Haas v. Switzerland*, no. 31322/07, 20 January 2011; *Koch v. Germany*, no. 497/09, 19 July 2012; *Gross v. Switzerland*, no. 67810/10, 14 May 2013; and the important judgment *Lambert v. France*, no. 46043/14, 5 June 2015 – which I have studied, comparing French and Belgian law in G. Genicot, 'Arrêt de traitement, droit à la vie, autonomie personnelle et patients vulnérables. Réflexions autour de l'affaire *Vincent Lambert*', *Journal des Tribunaux*, 2016/2, p. 17. See also, and most notably, the recent case of *Mortier v. Belgium* (no. 78017/17, 4 October 2022) in which, for the first time, the European Court was asked to examine whether the Act on Euthanasia (and the prescribed procedure) are contrary to the Convention, concluding that they are not – this case is briefly discussed hereunder in the concluding remarks. Apart from that, Belgium has never been brought before an international jurisdiction for alleged breaches of its international commitments relating to end-of-life decisions.

sensibly, that, from a medical point of view, the situation of a minor patient is not fundamentally different from that of an adult patient, from which it follows that, in this matter, the legal incapacity of a minor may be waived in order to take account of the voluntary and well-considered choice of a young patient who is capable of discernment, and who is suffering constantly and unbearably.[23]

Afterwards, verification of compliance with the legal conditions is ensured by means of an effective *a posteriori* review procedure, to which the recognition of a cause for criminal justification is subject. The physician must report the euthanasia performed 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 should 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. The Act does 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 or her impunity is subject, 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.[24]

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[23] Constitutional Court, decision no. 153/2015 of 29 October 2015, available (in French and Dutch) on https://www.const-court.be. See my commentary: G. Genicot, 'Rejet du recours en annulation de la loi étendant l'euthanasie aux mineurs: validation d'une évolution logique et prudente', *Jurisprudence de Liège, Mons et Bruxelles*, 2015/41, p. 1933 (decision also published in the *Revue de Droit de la Santé*, 2016–2017/1, p. 29, with a commentary by T. Goffin). See also a subsequent decision of the Constitutional Court on euthanasia, no. 26/2022 of 17 February 2022, rejecting the appeal to annul the Act of 15 March 2020 amending the 2002 Act on Euthanasia. At the time, the appeals against this Act had also been rejected: Constitutional Court, decision no. 49/2003 of 9 April 2003, and decision no. 4/2004 of 14 January 2004, in which the Court noted that, 'by alleging that [patients] do not possess free will at the time of their request, the applicants, reasoning as if they presuppose that anyone who wishes to cease living is necessarily incapable of judgement, disregard the many guarantees contained in the provisions of the contested law in order to ensure that the person expressing his/her will under the conditions of sections 3 and 4 does so in complete freedom. The preparatory work of the contested law shows, moreover, that the competent committees of the Senate and then of the House of Representatives were constantly concerned with this aspect of the problem' (my translation).

[24] Not leading to any legal proceedings, the prosecutor having considered that this was actually not a case of euthanasia *stricto sensu*. If legal requirements are not met, exemption rules applied in other fields of law (i.e. state of necessity, or consent of the victim) might justify the assistance provided for ending the life of a person. There is, to my knowledge, very little (published) case law confirming this, probably because proceedings (1) are (very) rare, and (2) usually stop before being actually brought before a court. One decision held, firmly, that providing palliative care to patients for whom there is no hope of recovery, even if it has the unintended but accepted effect of shortening life, is accepted (and indeed acceptable) medical practice. The case concerned a nurse, and the judge considered that she had done nothing more than her 'emotionally very difficult' task of providing prescribed and accepted palliative

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.[25]

Besides, in the Belgian legal system, which allows life termination procedures, there are, obviously, 'conscientious objector clauses' which allow a doctor – or a nurse – to refuse to provide assistance in life termination. As appropriately amended by the Act of 15 March 2020, section 14 of the Act on Euthanasia states that no physician can be required to perform euthanasia, and that no other person can be required to participate in a euthanasia. At the same time, it is now clearly specified that no written or unwritten clause – in the internal rules of an institution – can prevent a doctor from performing euthanasia under the legal conditions.[26] The consequences of invoking a 'conscience clause' are detailed as follows:

- if the consulted physician refuses, *on the basis of his or her freedom of conscience*, to perform euthanasia, he or she must inform the patient or the

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care to a terminally ill patient (Ghent Court of Appeal, indictment chamber, decision of 9 December 2004, *Revue de Droit de la Santé*, 2007–2008/1, p. 39, with a commentary by E. Delbeke). On the contrary, a judgment of the West Flanders Criminal Court (Cour d'assises) of 31 January 2018 (*Revue de Droit de la Santé*, 2018–2019/1, p. 35, commentary E. Delbeke) found the accused guilty of four murders and one parricide, even though he invoked a 'euthanasia exception'. The court found that the established facts were not in any way acts of euthanasia. Indeed, the most essential element of euthanasia, namely the patient's right to self-determination, was not respected in any of the victims: euthanasia is in principle based on the patient's request in person at some point. Here, the accused repeatedly stated that none of the victims had asked him to carry out their euthanasia in any way, or to initiate any procedure to that effect. The defendant's otherwise unverifiable explanation, that he killed these people out of compassion or to relieve them of pain at the end of their lives, does not, in the court's view, imply that it is a matter of euthanasia, but rather of homicides inspired not only by excessive idealism, but also by some sense of power to decide on life and death. At no time did the victims have a say in the assessment of the 'residual value of their lives'. Moreover, there was no question of a good or soft death, since the methods used were accompanied by a struggle against death that could last several minutes.

[25] The latest report, covering the years 2020 and 2021, can be found here (in French): *Rapport euthanasie 2022 – Chiffres des années 2020–2021*, https://organesdeconcertation.sante.belgique.be/sites/default/files/documents/10_rapport-euthanasie_2020–2021-fr.pdf.

[26] This had been the subject of debate. See the Opinion of the Belgian Advisory Committee on Bioethics no. 59 of 27 January 2014 on ethical aspects of the application of the Law of 28 May 2002 on euthanasia (https://www.health.belgium.be/en/list-opinions) and S. Tack, *Het ethische beleid in zorginstellingen. Rechtspositie van de beheerder, de arts, de patiënt en de overheid bij medische beslissingen rond het levenseinde*, reeks Gezondheidsrecht, Intersentia, 2013. There is one published case on that matter. A nursing home had refused to allow an outside doctor, who was willing to do so, to perform euthanasia on a resident within its walls. Two days later, the woman had to leave the nursing home so that the euthanasia could be performed at home. Her children then claimed compensation for the moral damage they

trusted person, if any, of this refusal in due time, and at the latest within seven days of the first formulation of the request, stating the reasons and referring the patient or the trusted person to another physician designated by the patient or the trusted person;

- if the consulted physician refuses to perform euthanasia *for a medical reason*, he or she must inform the patient or the trusted person, if any, of this in due time, stating the reasons; in this case, the medical reason is recorded in the patient's medical file;
- a doctor who refuses to comply with a request for euthanasia is obliged, *in all cases*, to provide the patient or the trusted support person with the contact details of a centre or association 'specialising in the right to euthanasia'[27] and, at the request of the patient or the trusted support person, to communicate the patient's medical file to the doctor designated by the patient or the trusted support person within four days of this request.

3. CONCLUDING REMARKS

For many years, respect for autonomy has been placed at the forefront of the bioethics of end-of-life decisions – as well, of course, as decisions made during the course of life itself. It is consistent with this principle that the dominant moral approach has become that of *individual liberty*, implying that everyone is entitled to decide what one does with one's own body, or what should be allowed to be done with it, just as everyone is, to a maximum extent, free to decide how he or she wishes to lead his or her life – while it is of course also perfectly understandable that not everyone, among philosophers or legal scholars, agrees with this situation or evolution. Consequently, a necessary degree of *trust* should be given to the motivations of patients – as well as to the assessment of physicians, who are supposed to act with empathy, and hence beneficence and non-maleficence. As a result, dignity is generally to be interpreted as the ability to decide for oneself – insofar, of course, as one is, or remains, *in concreto* capable of doing so – without having to abide to 'moral duties coming from outside or above', for example based on one's membership of the human species.

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and their mother had suffered in this situation. The court found that the nursing home, by sending a letter stating that it did not want euthanasia to be performed on its premises, had clearly intended to prohibit, *contra legem*, the outside doctor from doing so. It found that, by prohibiting euthanasia, the nursing home had committed a fault that resulted in moral damage, and therefore declared the children's action well founded (Tribunal de première instance de Louvain (Leuven), 29 June 2016, *Revue de Droit de la Santé*, 2016–2017/5, p. 341, with a commentary by K. Van Assche).

[27] Inappropriate and unfortunate legal wording. There is no 'right to euthanasia' (as indicated above).

This necessary trust also implies that a psychological evaluation of the person could clearly not be a mandatory condition for assisted dying – even more so, that of family members.

The Belgian legal system is a civil law one, with a hierarchy of norms at top of which is the Constitution and the directly enforceable international instruments, mainly European law and the European Convention on Human Rights – which, as I have observed, cannot be viewed as an obstacle to the full decision-making power of the patient at the end of life, and to the conditional decriminalisation of euthanasia in particular.[28] In this legal landscape,[29] there is in Belgium a clear right to *control one's own body*, derived from – but more extensive than – the right to respect for physical integrity in its 'positive' aspect. The uses and interventions to which the human body may be subjected are dominated by the respect due to the self-determination of the individual. This prerogative is exercised within the general framework of ethical precepts which, according to a well-established tradition in Belgium, are intended to be open, tolerant and non-directive. Belgian law takes a modern approach to these questions, which signals a fairly clear retreat from public order as it was traditionally understood. We also have a tradition of pluralism and search for balance and consensus – for instance, in this case, between religious and secular views, although religion does not have a strong impact on the public debate in Belgium.

Specifically, the compatibility of the Act of 28 May 2002 on euthanasia with the standards enshrined in the European Convention on Human Rights has recently been confirmed by the European Court of Human Rights in the *Mortier v. Belgium* case, in which the son of a lady who died through euthanasia alleged that the Act, the procedure it provides and the way in which it was carried out in that specific case breached Articles 2 and 8 of the Convention. In its instructive

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[28] ECHR standards are enforced (1) through the power of every judge to set aside a national regulation that would infringe on the rights guaranteed by a higher source of law, and (2) by the Constitutional Court, since the Belgian Constitution guarantees the same fundamental rights as the ECHR, and forms 'an indivisible whole' with it – quintessentially, in this field, the right to respect for private life and physical integrity in their 'positive' aspects.

[29] In which the issues arising from end-of-life decisions might be covered, not surprisingly, by criminal law (although there is no specific incrimination), but most of all by civil law (medical responsibility), as well as disciplinary law (medical deontology). Case law is scarce when it specifically comes to end-of-life decisions. I have referred to the (published) cases that I know of. There is no 'established national doctrine on medical law' in Belgium, but there is clearly active legal research and literature, probably mostly in Dutch: see for example E. Delbeke, *Juridische aspecten van zorgverlening aan het levenseinde*, reeks Gezondheidsrecht, Intersentia, 2012; T. Goffin, *De professionele autonomie van de arts. De rechtspositie van de arts in de arts-patiëntrelatie*, Die Keure, 2011; C. Lemmens, *Voorafgaande wilsverklaringen met betrekking tot het levenseinde*, reeks Gezondheidsrecht, Intersentia, 2013; S. Tack, *Het ethische beleid in zorginstellingen. Rechtspositie van de beheerder, de arts, de patiënt en de overheid bij medische beslissingen rond het levenseinde*, reeks Gezondheidsrecht, Intersentia, 2013; E. Verjans, *Het recht op informatie en toestemming van de patiënt*, reeks Gezondheidsrecht, Intersentia, 2019.

and detailed judgment of 4 October 2022[30] – unfortunately only available in French – the Court observes that this is the first case in which it has had to examine the conformity with the Convention of a euthanasia that has been legally carried out, and deems it necessary to clarify the nature and extent of a state's obligations under Article 2 of the Convention in this context, before examining compliance with those obligations in the present case (para. 115). The Court summarises its jurisprudence pertaining to end of life (paras 118–24), points out that there is a general consensus on the primary role of the patient's wishes in decision-making, given that human dignity and individual freedom are the essence of the Convention, and reaffirms that the right of a person to choose the manner and timing of the end of his or her life, provided that he or she is able to freely form his or her own wishes in this regard and to act accordingly, is one aspect of the right to respect for private life under Article 8 of the Convention (paras 124–25).[31] It then finds that, while it is not possible to deduce from Article 2 of the Convention a 'right to die', the right to life enshrined in that provision cannot be interpreted as prohibiting the conditional decriminalisation of euthanasia per se – but, in order to be compatible with Article 2, such decriminalisation must be accompanied by adequate and sufficient safeguards to prevent abuse, and thus ensure respect for the right to life (paras 138–39).

Then the European Court concludes that:

- the Belgian legislative framework relating to acts prior to euthanasia ensures that an individual's decision to end his or her life has been taken freely and in full knowledge of the situation. It gives great importance to the fact that additional safeguards are provided for cases involving psychic suffering, and where death will not occur in the short term, and to the requirement of independence of the various doctors consulted, both in relation to the patient and in relation to the treating physician. In view of all of this and the margin of appreciation of the state, the Court considers that, as regards the acts and procedure prior to euthanasia, the provisions of the Act of 28 May 2002 constitute, in principle, a legislative framework ensuring the protection of patients' right to life as required by Article 2 of the Convention, which is thus not breached (paras 153 and 155);
- it did not appear from the evidence brought that the euthanasia of the applicant's mother, carried out in accordance with the established legal framework, had been performed in breach of the requirements of Article 2 of the Convention, which has thus not been violated in this respect either (para. 165);

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[30] ECtHR, *Mortier v. Belgium*, no. 78017/17, 4 October 2022. This judgment is final. It is accompanied by two separate opinions.

[31] See previously *Pretty v. United Kingdom*, no. 2346/02, 29 April 2002, para. 67, and *Haas v. Switzerland*, no. 31322/07, 20 January 2011, para. 51.

- but, concerning the *a posteriori* control by the evaluation Commission – which 'must be carried out in a particularly rigorous manner to meet the obligations under Article 2 of the Convention' (para. 171) – the Court, while approving the composition of the Commission itself, considers that the system set up by the Belgian law – in which euthanasia is reviewed on the basis of the anonymous part of the registration document alone – does not meet the requirements of Article 2 of the Convention, in that the procedure does not prevent the doctor who performed the euthanasia from sitting on the Commission and voting on whether his or her own actions were compatible with the substantive and procedural requirements of the Act on Euthanasia. In the view of the Court, leaving it to the sole discretion of the member concerned to remain silent when he or she finds that he or she was involved in the euthanasia under review cannot be regarded as sufficient to ensure the Commission's independence. Consequently, and taking into account the crucial role played by the Commission in the *ex post* control of euthanasia, the Court concludes that the applicable system did not ensure its independence, and that Article 2 of the Convention – in its procedural requirements – has been breached in this regard.[32]

The Belgian legislator has offered people who are suffering from unbearable and fatal conditions control over the end of their lives. I personally think this is to be commended. It is not appropriate, in my view, to reason coherently and constructively about end-of-life situations without examining them primarily in terms of the patient's self-determination, and not the physician's duties. In any case, it seems to me that 'good medical practice concerning end-of-life decisions' requires, first and foremost, openness and transparency towards the suffering patient. 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 legally fully integrates individual autonomy. In this sense, the Belgian Act of 28 May 2002 on euthanasia is characterised by the fact that the patient initiates the action that will free him or her from suffering – an action that is the prerogative of doctors, and is consistent with their therapeutic role when no other possibility remains. The scheme should thus be distinguished from the situation where the patient *consents* to the care offered.

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[32] The doctor who performed the disputed euthanasia is indeed a member of the evaluation Commission. The Court came to that conclusion irrespective of the actual influence this doctor may have had on the Commission's decision in the case at hand. It refers here to the general principles set out in its judgment in *Nicolae Virgiliu Tănase v. Romania*, no. 41720/13, 25 June 2019. In the view of the Commission, redressing that breach would imply an amendment of the Act of 28 May 2002 in order to suppress the anonymity of the document on the basis of which the control is performed (see https://organesdeconcertation.sante.belgique.be/sites/default/files/documents/cfcee_reaction_arret-cedh-221014_0.pdf).

The conditional decriminalisation of euthanasia, marked by the seal of humanity and the respect owed to a person who is suffering, illustrates the tolerance and pluralism of the Belgian legal system, while at the same time confirming that medical actions are not always discretionary, but might be subject to external control. Again, the Act on Euthanasia bears witness to the *trust* placed in the judgement of doctors and, above all, in the intimate motives of citizens. Belgian law accompanies them to the end of their journey and allows them to re-appropriate their own death, rather than waiting for it to seize them. By this, I mean that the Belgian legislator has provided a noble and dignified solution to a debate that is emerging everywhere. By giving the person more control over the way in which they will end their life, it meets a real social need. Since quality of life is quintessentially subjective, it seems to me 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. Modern medical law cannot indefinitely postpone this debate on the end of life, nor can it steer it in a direction opposite to that adopted on the subject of the general rights of patients, who are, almost everywhere, recognised as having control over their bodies and their destiny (empowerment).

Certain issues remain disputed, mainly the availability of euthanasia for psychiatric disorders – which should clearly not be confused with the existence of psychological suffering, which can of course also be present in the case of a somatic condition. To summarise very briefly, even though psychiatric illnesses can be very serious and painful, some observers doubt that, when dealing with them, the (remaining) capacity of the patient can be carefully assessed, their suffering can be appropriately measured, and it can be sufficiently verified that all available treatment options have been tried. The Tine Nys case, presented above, has shed renewed light on this debate. It is, of course, understandable that there are still discussions, and psychiatric pathologies must naturally be given special attention – they are, moreover, examined by the Commission for Control and Evaluation with great care and in depth. That being said, I think it is important that these discussions do not cast doubt on an overall legal system which – although it is not unconceivable that it may need to be refined here and there – really does appear to be coherent and satisfactory. The Belgian legal landscape, which I have tried to present in this report, meets the aspirations of both doctors and citizens – the vast majority of whom are proud and reassured to live in a country where they know they can have the control they want over their own lives, should they so wish.