RIGHT OR DUTY TO LIVE?
EUTHANASIA AND ASSISTED SUICIDE FROM THE PERSPECTIVE OF THE EUROPEAN CONVENTION ON HUMAN RIGHTS

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The aim of this analysis is to direct the attention of legal scholars and legislators towards the legalisation of assisted suicide and euthanasia. This topic will sooner or later make inroads into the legal systems of all Council of Europe Member States, to the extent that is has not already. Two principles are at stake here: the protection of human life, on the one hand, and self-determination, on the other. The unconditional adherence to the principle of protection of life would entail that life should always be protected, even against the will of the person concerned. The unconditional adherence to the principle of self-determination would entail that each individual should have the right to die upon request, provided that their decision is based on their free will and informed. This article clarifies that, in their absoluteness, both alternatives should be rejected, and seeks to provide a reading of the limits of Member States' margin of discretion in end-of-life issues.

Keywords: euthanasia, assisted suicide, right to life, right to die, artificial nutrition, medical treatment

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I. INTRODUCTION

The extraordinary possibilities of medicine and its technical-scientific apparatus have made it possible to cure many previously incurable or fatal diseases, and even to save patients with serious health conditions from dying. At least some of the dilemmas presented in the present article arise because medical progress has generated situations which would have 'resolved' themselves spontaneously and rapidly in the past. Patients finding themselves in such precarious conditions not only ask for palliative care and pain management programmes. At times, they explicitly ask for assistance to die, to spare themselves great physical suffering or to avoid the perceived indignity of a dependent existence. In fact, living with an irreversible debilitating condition, potentially one even that ties them to technological support, can induce patients to reject medical assistance altogether, considering it futile, disproportionate, or dehumanising. Some people fear being forced to linger on in old age or in a state of advanced physical or mental decrepitude, a prospect which conflicts with their strongly held ideas of their own self and personal identity.[1]

The ability to choose and to exact those choices is increasingly perceived as an essential element of individual autonomy. Some patients demand the freedom to decide by what means and at what point their life should end. A 'de-absolutisation' of the value of life is taking place, both from an objective point of view (not every life is by default worthy of living) and from a subjective one (nobody can be obliged to live a life they deem intolerable), in the sense that life is not always and no longer considered an absolute right.

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[1] In *Gross v. Switzerland*, the applicant was not suffering from a terminal illness. She claimed her right to die to avoid the decline of her physical and mental faculties as a result of her advanced age. *Gross v. Switzerland* [GC], ECHR 2014-IV.

Against this growing tendency, one might argue that, because of its intrinsic dignity, human life is not disposable.[2] The healthcare situation in some countries raises the concern that a decriminalisation or legalisation of so-called medically assisted suicide and euthanasia, along the lines of what already exists in other European countries, will lead to a slippery slope.[3] More precisely, legislation permitting euthanasia and assisted suicide in particular, well-defined circumstances could be stretched to cover cases such as dementia or depression, which had not originally been intended.[4] The legalisation of euthanasia and assisted suicide, initially proposed for exceptional cases, could become a method of resource-led population control in a society marked by a progressively aging population and restricted healthcare expenditure. The basic concern is that legalisation could lead to certain conditions being considered generally unworthy of protection, which could ultimately culminate in a kind of 'duty to die', by which vulnerable groups would be disproportionately affected.[5]

The public debate concerning assisted suicide and euthanasia shows how difficult it is to reconcile two principles of bio-ethical relevance: the protection of human life on the one hand, and the autonomy and self-determination of the individual on the other. In its decisions on end-of-life issues, the European Court of Human Rights (ECtHR or 'the Court') has consistently focused on Articles 2 and 8 of the European Convention on Human Rights (ECHR), protecting the right to life and the right to respect for private life, respectively. Different ways of balancing these principles raise a series of bio-ethical concerns that are not easy to resolve on the legal level. Unconditional adherence to the principle of protection of life would entail that life should always be protected, even against the will of the person concerned. Unconditional adherence to the principle of self-determination

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2 See *infra* section 3.

3 Jean Morange, 'Les dangers d'un droit à l'euthanasie' (2018) Questions of International Law, Zoom-in 7, 15-16.

4 Davide Paris, 'Dal diritto al rifiuto delle cure al diritto al suicidio assistito (e oltre)' (2018) Corti supreme e salute 489, 496.

5 Luciano Eusebi underlines the fine line between right and moral duty to die. Luciano Eusebi, 'Dignità umana e indisponibilità della vita. Sui rischi dell'asserito "diritto" di morire', in Enrico Furlan (ed), *Bioetica e dignità umana* (Franco Angeli 2009), 218.

would entail that each individual should have the right to die upon request, provided that their decision is based on their free and informed will.

This paper seeks to establish whether, in light of the ECtHR case law, the ECHR and the Convention on Human Rights and Biomedicine (Oviedo Convention)[6] provide sufficient guidance to overcoming the conflict between the protection of the right to life and self-determination. As we will see, the will of the patient is a fundamental (though not the only) value to consider. Therefore, while involuntary euthanasia (against a person's will) is clearly inadmissible, the issue of whether euthanasia upon request is compatible with the ECHR deserves careful examination. A deeper analysis will show that the interpretation of factual reality is often difficult. When patients have never been competent and their wishes never been expressed,

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[6] Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Oviedo, 4 April 1997, European Treaty Series - No. 164. The Oviedo Convention as such does not produce any international obligations for countries such as Italy, who have not ratified it, or for countries like Germany, who are not even signatories to it. The Oviedo Convention can therefore not be said to be a formal legal source for these countries. Nevertheless, the ECtHR has taken the Oviedo Convention as a reference to interpret ECHR norms in a number of cases, for example when the consent to medical treatment was at stake or for defining the legal protection of embryos. For references to the Oviedo Convention and to its additional Protocols, albeit within the field of application of the ECHR, see ECtHR, *Glass v the United Kingdom*, App no 61827/00 (ECtHR, 9 March 2004) para 58; *Vo v France*, App no 53924/00 (ECtHR, 8 July 2004), paras 35 and 84; *Evans v the United Kingdom*, App no 6339/05 (ECtHR, 10 April 2007) para 50. With this it becomes a material source of law for all EU Member States, for the twofold reason of their being a party to the ECHR and because the Court of Justice of the EU makes reference to the ECtHR jurisprudence to interpret the EU Charter of Fundamental Rights. On the use of other international instruments to interpret the ECHR by the ECtHR, see Cesare Pitea, 'Interpreting The ECHR In the Light Of "Other" International Instruments: Systemic Integration Or Fragmentation Of Rules On Treaty Interpretation?', in Nerina Boschiero and others (eds), *International Courts And the Development Of International Law* (Springer 2013) 545-559. Some principles affirmed in the 'Oviedo system' are directly binding for EU Member States in any case, albeit only in respect of cases regulated by EU law, because they are reiterated in Articles 1 and 3 of the EU Charter of Fundamental Rights.

can euthanasia be deemed voluntary or should it be classified as forced euthanasia? Based on the conclusion reached, the paper will point out specific limits to Member States' margin of discretion.

II. Euthanasia and Assisted Suicide

A preliminary clarification is necessary on whether the notion of voluntary euthanasia can include assisted suicide. From a phenomenological point of view, the distinction seems clear: voluntary euthanasia involves people who wish to die but cannot achieve this objective single-handedly. Therefore, the fatal act must be carried out by a third party. Assisted suicide, on the other hand, requires the person concerned to commit the fatal act, limiting assistance to preparation of the means. In some cases, the procedure involves the use of machines to help patients with limited physical capacity to take a lethal dose of medication. In short, the term euthanasia is used to describe the intentional termination of life by someone other than the person concerned, whereas assisted suicide consists in providing assistance to someone who actively terminates their own life. Consequently, suicide remains an act committed by the person concerned. At least from an ethical point of view, letting someone die seems different from killing a person, even at their request.

Yet, from an ethical and legal point of view, these two phenomena are often linked. Arguably, helping a person who wishes to die to die 'single-handedly' and being the author of their death is substantially equivalent. In either case, the person concerned wants to die and the outcome is the same. Therefore, when defining the safeguards to prevent slipping down the slope, the distinction between assisted suicide and voluntary euthanasia could seem futile. Suicide, which by definition is an individual act when the person concerned commits it without third-party assistance, ceases to be suicide where they do receive assistance.[7]

If we assume that euthanasia refers to situations where a doctor administers a lethal dose of medication to a patient to make them die, the withdrawal from or refusal of life-support such as liquids and nutrients will never be

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7 On this debate, see further the Advisory Opinion of the Comitato nazionale di Bioetica, *Riflessioni bioetiche sul suicidio medicalmente assistito*, 18 July 2019.

euthanasia. This remains the case regardless of the intentions of those requesting it and those who carry it out. But the lexical border can easily be crossed. For this reason, when it comes to the extremely delicate balance between the protection of human life and of freedom of choice, clinging onto a mere terminological distinction is inadequate. A factual approach, based on the similar outcome of both practices, rather than a formal approach merely based on the terms used, is adopted in this article. This provides the first safeguard to prevent slipping down the slope.

III. Dignity and Quality of Life

According to Article 1 of the Oviedo Convention, State Parties 'shall protect the dignity and identity of all human beings'. The Charter of Fundamental Rights of the European Union (EU) states even more categorically that: 'Human dignity is inviolable. It must be respected and protected'.[8] Similarly, in Protocol no. 13 to the ECHR, dignity is described as 'inherent' in all human beings.[9] This is an undisputed constraint with which States must comply when they regulate end-of-life issues.[10] However, the concept of dignity is as ambiguous as it is evocative and is, in itself, unable to offer a univocal solution to the questions arising at the end of life. Assuming that dignity is an indefectible attribute of all human life, it cannot increase or decrease by reason of quality of life. Under this perspective, its intrinsic dignity would prevent human life from being considered disposable. Some authors note that if the law, in principle, considered human life disposable (even if only in exceptional cases), this would imply an element of arbitrariness. Those put in charge of deciding on the limits of such disposability would hold the power

8 Art. 1, EU Charter of Fundamental Rights.

9 Preamble to the Protocol No. 13 to the ECHR concerning the abolition of the death penalty in all circumstances Vilnius, 3 May 2002.

10 See also the Preamble and Article 1 of the Universal Declaration of Human Rights and the Preamble common to the 1966 International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. Among the many contributions on dignity, see Giorgio Resta, 'La dignità', in Stefano Rodotà, Mariachiara Tallacchini (eds), *Trattato di biodiritto* vol. I (Giuffré 2010) 259-291.

to recognise certain individuals as subjects of law while excluding others.[11] Dignity – in the legal sense of the term – should therefore not be derived from any further characterisation, whether physical, cultural, or moral, but rather be dependent on the sole condition of belonging to the human species.

This conception may nonetheless expose us to the risk of reducing human life to the level of pure material existence, ignoring the fact that emotional and intellectual faculties, as well as moral and spiritual facets, set 'human' life apart from other forms of biological existence. No doubt, individuals with limited or no capacity to interact with their surroundings can build an inner life full of meaning. And yet, in the case of terminal conditions, the possibility of a meaningful inner life is often lacking, because the disease puts at stake precisely what allows us to build our 'I' (memory, intelligence, ability to relate to others). In practice, there is a risk that, by adopting such a vision, we fall into the trap of protecting life 'at any price', even when patients perceive their own lives as intolerable. Conversely, one might argue that dignity depends on the quality of life, which would suggest that not all lives are worth living and protecting to the same extent. In this respect, quality of life becomes a *discrimen* below which the protection of life is no longer indisputable and assured.[12]

Quality of life is a *leitmotiv* in the case law dealing with individuals who have never reached a degree of capacity allowing them to formulate wishes about the withdrawal of treatments. In the *Gard* case, for instance, the domestic decisions repeatedly referred to 'quality of life' to dismiss the parents' claims and conclude that it was in the best interest of the child to be allowed to pass away peacefully, without any additional pain and suffering.[13] The focus on quality of life can offer an important warning, inviting us not to neglect the importance of the aforementioned emotional, intellectual, moral, and

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[11] In this sense, the opinion of Francesco D'agostino attached to the Advisory Opinion of the Comitato Nazionale per la Bioetica sulla proposta di risoluzione del Parlamento Europeo avente per oggetto l'assistenza ai pazienti terminali, 6 September 1991, 53

[12] Quality of life also becomes a method for determining how scarce resources should be allocated. On this issue see further Hazel Biggs, *Euthanasia. Death with Dignity and the Law* (Hart 2001) 42-43.

[13] See the domestic decisions quoted in *Gard and Others v United Kingdom*, App no 39793/17 (ECtHR, 27 June 2017) paras 27 and 44.

spiritual elements which distinguish human life from a mere 'organic' datum, and to safeguard its specificity.

However, if quality of life was a prerequisite for the protection of life, we would have to admit that there may be human beings whose dignity is worthy of being respected, but not of full protection.[14] This thesis seems to find legal support in the Oviedo Convention, under which State Parties shall protect the dignity and identity of all 'human beings' and guarantee 'everyone' – '*à toute personne*' in French – respect for their integrity, as well as other rights and fundamental freedoms.[15] The different terms used – 'human beings' versus 'everyone'/'*à toute personne*' – seem to suggest that only persons are entitled to rights and freedoms. Human beings solely possess dignity.[16] The Oviedo Convention neither provides a definition for the notion of 'human being' nor for that of 'person'. It therefore does not clarify whether a patient in a permanent vegetative state, for example, falls within either one category or neither. The Explanatory Report specifies that, in the absence of a unanimous agreement on the definition of these terms among member States of the Council of Europe, it was decided to allow domestic law to define them for the purposes of the application of the Convention.[17]

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[14] On the related philosophical debate, see Adriano Pessina, *Bioetica. L'uomo sperimentale* (Mondadori 1999) 79-81. Paolo Zatti, *Maschere del diritto volti della vita* (Giuffré 2009) 15-21.

[15] Article 1 of the Oviedo Convention.

[16] In this sense, see Antonello Tancredi, 'Genetica umana ed altre biotecnologie nel diritto comunitario ed europeo' in Nerina Boschiero (ed), *Ordine internazionale e valori etici* (Editoriale Scientifica, 2004), 393-394; B. Mathieu supports the view that the distinction between person and human being in Article 1 of the Oviedo Convention is not a coincidence. Cf. Bertrand Mathieu, 'De la difficulté d'appréhender l'emploi des embryons humains en termes de droits fondamentaux' (2003) Revue trimestrielle de droits de l'homme 387, 390.

[17] Explanatory Report to the Oviedo Convention, 4 April 1997, para 18 (hereinafter Explanatory Report). Along the same lines, the preamble to Directive 2004/23/EC specifies that "this Directive should not interfere with provisions of Member States defining the legal term 'person' or 'individual'". The Directive therefore assumes that the two concepts do not, or at least may not, overlap. Cf. Directive 2004/23/EC of the European Parliament and of the Council of 31 March 2004 on setting standards of quality and safety for the donation, procurement, testing,

The attempts to distinguish between human being and person, between rights-bearing subject and protected object, between life understood purely in the biological sense of 'being alive' and life in the biographical sense of 'having a life', all have something in common. They are all attempts to precisely restrict the field of legal protection to those who are effectively endowed with a will, even if all they may be capable of is oppose somebody else's decision, while denying the same subjectivity to those who are not yet or no longer capable of expressing their will.[18] And yet, long after the abolition of slavery, it is difficult to suggest that some human beings may not be persons[19] and that dignified human beings may have no rights. In addition, there is no consensus on the exact meaning of 'quality of life', the elements on the basis of which a boundary line between good and poor quality of life can be drawn, and who is competent to assess the quality of a person's life.[20] As long as quality of life becomes the *discrimen* of protection, it seems difficult to find adequate objections to those wishing to reduce or suspend social and medical care for severely impaired subjects purely for cost-benefit reasons. These observations make clear how difficult and risky it is to invoke the concept of quality of life to establish a limit for the protection of life. In this respect, it is noteworthy that, in the reasoning of the ECtHR, the notion of 'quality of life' takes on significance under Article 8 ECHR and not under Article 2.[21]

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processing, preservation, storage and distribution of human tissues and cells [2004] OJ L102, recital no. 12.

18 'What is the overriding reason, in the circumstances of the present case, justifying the State in not intervening to protect life? Is it financial considerations? None has been advanced in this case. Is it because the person is in considerable pain? There is no evidence to that effect. Is it because the person is of no further use or importance to society, indeed *is no longer a person and has only "biological life"*?'. [Emphasis added]. Partly Dissenting Opinion of Judges Hajiyev, Ŝikuta, Tsotsoria, De Gaetano and Gritco, in *Lambert and Others v. France*, App no 46043/14, (ECtHR, 5 June 2015) para 4.

19 In this sense, Andrés Ollero, 'Il rispetto per la dignità umana. Una prospettiva biogiuridica' in Enrico Furlan (ed), *Bioetica e dignità umana* (Franco Angeli 2009) 226-227.

20 On this issue see sections 10 and 11.

21 *Pretty v the United Kingdom*, ECHR 2002-III, paras 39, 65.

The emphasis on the right to die with dignity can be found both in the writings of those who consider euthanasia at the request of the patient and assisted suicide a dignified way of dying and in the writings of those who consider it the most undignified end conceivable. This shows the ambivalence of the notion 'dignity' across radically opposed positions. There is a lack of convergence among ECHR State Parties on the concept of human dignity. While some States lean towards solutions favouring a conservative approach to human dignity, others follow a utilitarian approach and therefore balance interventions and interferences in a different way.[22] To some extent, all of this erodes the prescriptive capacity of dignity, accentuating the space for political and jurisprudential discretion. When dealing with end-of-life issues, the ECtHR has coherently focused not on dignity, but on the right to life and to respect for private life.

IV. The First Term to Balance: The Right to Life

Article 2 ECHR protects the right to life. Strict interpretation and scrutiny are required for the limited circumstances in which deprivation of life may be justified.[23] The Court explains this limitation by reference to the very nature of the right to life, which cannot be disposed of within the same margins established by norms granting freedoms, with life being the very foundation of other rights and freedoms, and an indispensable prerequisite for their enjoyment.[24] The 'negative' aspect of, for example, freedom of religion, trade union freedom, or the right to representative democracy itself incorporates the freedom not to believe in any religion, not to join any union, or not to exercise one's 'right' to vote. By contrast, the Court has firmly rejected the

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22 Francesco Salerno, 'International Protection and Limits to the Right to Self-Determination for the Bio-Technological Strengthening of One's Own Person' in Debora Provolo, Silvio Riondato and Feridun Yenisey, *Genetics, Robotics, Law, Punishment* (Padua University Press 2014) 452; Francesco Francioni, 'Genetic Resources, Biotechnology and Human Rights: The International Legal Framework' in Francesco Francioni (ed), *Biotechnologies and International Human Rights* (Hart 2007) 20.

23 *McCann and Others v the United Kingdom*, App no 18984/91 (ECtHR, 27 September 1995) para 147; *Pretty v the United Kingdom*, ECHR 2002-III, para 37.

24 Ibid, para 39.

thesis that Article 2 protects 'the right to life and not life itself'.[25] According to the Court, Article 2 ECHR is unidirectional, because it cannot 'without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die'.[26] Accordingly, the Court finds that no right to die, whether at the hands of a third person or with the assistance of a public authority, can be derived from Article 2 of the Convention.[27]

According to the Court's case law, Article 2 ECHR 'enjoins the State not only to refrain from the intentional and unlawful taking of life, but also to take appropriate steps to safeguard the lives of those within its jurisdiction'.[28] Thus, Article 2 ECHR imposes positive obligations on the State Parties,[29] such as the obligation to effectively criminalise offences against the person, the obligation to protect an individual whose life is at risk,[30] and, under certain circumstances, even the obligation to protect individuals against themselves.[31] In the public health sphere, such positive obligations require States to make regulations compelling hospitals, whether private or public,

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25 Ibid, para 35.

26 Ibid, para 39.

27 Ibid, para 40.

28 *LCB v the United Kingdom*, App no 23413/94 (ECtHR, 9 June 1998) para 36; *Pretty v the United Kingdom*, ECHR 2002-III, para 38; *Lambert and Others v France*, App no 46043/14, (ECtHR, 5 June 2015), para 117.

29 The alternative between positive and negative obligations is not as rigid as to be neatly 'designed' for a specific protection. Cf. *Odièvre v France*, App no 42326/98 (ECtHR, 13 February 2003), para 40; *Godelli v Italy*, App no 33783/09 (ECtHR, 25 September 2012) para 47; *Knecht v Romania*, App no 10048/10 (ECtHR, 2 October 2012) para 55. See further Jean-François Akandji-Kombe, *Positive Obligations under the European Convention on Human Rights* (Council of Europe 2007).

30 *Osman v the United Kingdom*, App no 87/1997/871/1083 (ECtHR, 28 October 1998) para 115; *Kılıç v Turkey*, App no 22492/93 (ECtHR, 28 March 2000) para 62.

31 The Court has acknowledged a positive obligation to protect the individual against their own suicidal attempts in cases concerning detainees: *Keenan v the United Kingdom*, App no 27229/95 (ECtHR, 3 April 2001) para 91; *Trubnikov v Russia*, App no 49790/99 (ECtHR, 5 July 2005) paras 68-69; *Renolde v. France*, App no 5608/05 (ECtHR, 16 October 2008) para 83; *Ketreb v France*, App no 38447/09 (ECtHR, 19 July 2012) para 71, and in cases concerning army members: *Gündüz and Others v Turkey*, App no 4611/05 (ECtHR, 11 January 2011) para 63, i.e. situations where individuals are vulnerable and face situations of distress and pressure under the control of State authorities.

to adopt appropriate measures for the protection of patients' lives.[32] Precisely by leveraging the positive obligations stemming from Article 2 of the ECHR, as interpreted by the Court, one could argue against the legitimacy of medically assisted suicide and euthanasia.

However, the ECtHR has already balanced the protection of life with other values.[33] According to the most recent case law, Article 8 presents a high degree of protection capable of sacrificing other aspects also granted by the ECHR. For example, the ECtHR includes within the right to family life also the right to have children, if necessary through assisted fertilisation techniques that the State has a positive obligation to grant.[34] It also comprises the 'negative right' not to have children.[35] For this reason, the ECtHR includes in Article 8 the right to abortion as a legitimate expression of the mother's self-determination. The right to one's own private and family life therefore entails a restriction of the potential right to life of the suppressed foetus or embryo, such that it has no right to life under Article 2 of the ECHR.[36]

In the *Lambert* case, where the ECtHR dealt precisely with the end-of-life issue, the ECtHR stated that 'reference should be made, in examining a possible violation of Article 2, to Article 8 of the Convention, and to the right to respect for private life and the notion of personal autonomy which it encompasses'.[37] The opposite is also true, because in the context of examining a possible violation of Article 8 ECHR, it is appropriate to refer to

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32 *Lambert and Others v France*, App no 46043/14, (ECtHR, 5 June 2015) para 140.

33 See also the following emblematic statement of the Italian Court of Cassation: "la concezione della vita come oggetto di tutela, da parte dell'ordinamento, in termini di "sommo bene" [...] è percorsa da forti aneliti giusnaturalistici, ma è destinata a cedere il passo al raffronto con il diritto positivo" [The concept of life in terms of the 'highest good' to protect [...] is rich with naturalistic yearnings, yet has to retreat when facing against positive law]. Corte di Cassazione, Sez. III-Judgement, 2 October 2012, no 16754.

34 *Knecht v Romania*, App no 10048/10 (ECtHR, 2 October 2012) para 54.

35 *Evans v the United Kingdom*, App no 6339/05 (ECtHR, 10 April 2007) para 71; *A, B and C v Ireland*, App no 25579/05 (ECtHR, 16 December 2010) para 212.

36 *Evans v the United Kingdom*, App no 6339/05 (ECtHR, 10 April 2007) paras 54-56.

37 *Lambert and Others v France*, App no 46043/14, (ECtHR, 5 June 2015) para 142.

Article 2 of the Convention.[38] Therefore, the next step must be the analysis of the scope of the second term to balance: the right to respect for private life under Article 8 ECHR.

V. The Second Term to Balance: Self-determination

The right to refuse medical treatment is probably the first bioethical rule established in the post-WW2 period. This right was affirmed as early as the 1947 decision in *United States of America v. Karl Brandt and others*[39] and then incorporated into the so-called Nuremberg Code.[40] The role of informed consent as an ethical, deontological, and legal constraint was then progressively strengthened and with it the emphasis on therapeutic alliance.[41] The EU Charter of Fundamental Rights contains a provision on consent in its Chapter I, which is dedicated to 'Dignity' and suggests that free and informed consent is an indispensable safeguard for human dignity.[42] In similar terms, the Oviedo Convention attributes a crucial role to patient consent: 'An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it'.[43] The Convention further includes special norms for persons not able to consent.

The ECtHR jurisprudence makes it clear that any medical treatment requires the free and informed consent of the person concerned, as it is a

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38 Ibid.

39 Military Tribunal I, *United States of America v. Karl Brandt et al.* (Case 1), 21 November 1946 – 20 August 1947.

40 'The voluntary consent of the human subject is absolutely essential'. Article 1, Nuremberg Code (1947).

41 Plato already emphasised the importance of the patient's consent: 'But the free-born doctor is mainly engaged in visiting and treating the ailments of free men, and he does so by investigating them from the commencement and according to the course of nature; he talks with the patient himself and with his friends, and thus both learns himself from the sufferers and imparts instruction to them, so far as possible; and he gives no prescription until he has gained the patient's consent, and only then, while securing the patient's continued docility by means of persuasion, does he attempt to complete the task of restoring him to health'. Plato, *The Laws*, IV.

42 Art. 3, para 2, EU Charter of Fundamental Rights.

43 Art. 5, Oviedo Convention.

projection of the right to private life protected by Article 8 ECHR.[44] Indeed, with Article 8 ECHR being a 'principle', several 'rules' of various content stem from it and adapt to the continuous evolution of the State parties' 'legal conscience'. These prescriptive indications are not alien to the object of the ECHR, to the extent that the Court considers them an autonomous expression of the right to private life.

Article 8 ECHR therefore also covers the right to physical and psychological integrity and choices about one's own body in the negative sense. A person is entitled to make choices about their own body, even where the conduct poses a danger to health or, arguably, where it is of a life-threatening nature.[45] Consider, for example, the Court's case law on consensual sadomasochistic activities.[46] The same applies to the refusal of medical treatment. When the negative aspect of the consent to (read: refusal of) medical treatment is at stake, the relevance of respect for private life is perhaps even clearer. The focus shifts from physical and psychological integrity to a subjective dimension related to the personal way of conceiving one's relationship with illness, with one's own body, and ultimately with one's dignity and personal identity, as defined by each person's notion of life. A patient who rejects a transfusion, refuses the amputation of a limb, despite the surgical intervention being potentially life-saving, or asks for the discontinuation of artificial ventilation, might seek to protect the values and ideals that constitute personal identity, which might even prevail over their wish to stay

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44 *Storck v Germany*, App no 61603/00 (ECtHR, 16 June 2005) paras 143-144; *Jehovah's Witnesses of Moscow and others v. Russia*, App no 302/02 (ECtHR, 10 June 2010) para 135; *Shopov v. Bulgaria*, App no 11373/04 (ECtHR, 2 September 2010) para 41; *Pretty v the United Kingdom*, ECHR 2002-III, para 63. 'There is a general consensus based on Article 8 of the European Convention on Human Rights (ETS no 5) on the right to privacy, that there can be no intervention affecting a person without his or her consent'. Resolution 1859 (2012) Protecting human rights and dignity by taking into account previously expressed wishes of patients, 25 January 2012, para 1.

45 *Pretty v the United Kingdom*, ECHR 2002-III, para 62.

46 According to the case law of the ECtHR, the State's imposition of compulsory or criminal measures regarding consensual sadomasochistic behaviour posing a danger to health or life impinges on the private life of the person concerned within the meaning of Article 8, paragraph 1 and requires justification in terms of the second paragraph. *Laskey and others v the United Kingdom*, App nos. 21627/93; 21628/93; 21974/93 (ECtHR, 19 February 1997) paras 35-36.

healthy and alive. A Jehovah's Witness declining consent to a blood transfusion wishes to live but prefers death to eternal damnation.

The ECtHR correctly pointed out that, in the medical field, refusal to accept a particular treatment might lead to a fatal outcome. Yet, the imposition of medical treatment without the consent of a mentally competent adult patient would interfere with a person's physical integrity in a manner which could violate the rights protected under Article 8, paragraph 1 of the ECHR. Thus, a person may claim to exercise their choice to die by refusing their consent to a treatment which might prolong their life.[47] In this manner, as a substantive value, Article 8 ECHR balances and limits the scope of the State's obligation to protect life.

Along the same lines, assisted suicide and euthanasia, insofar as they are an expression of self-determination of a competent subject, find their foundation and protection under Article 8 ECHR. In *Pretty*, the Court declared that it was 'not prepared to exclude' that preventing a person from exercising a choice to avoid what they consider will be an undignified end of life may constitute an interference with the right to respect for private life under Article 8 ECHR.[48] Thus, notwithstanding the indirect formulation and the use of the term 'choice', the Court accepted that the wish to be assisted in committing suicide falls within the notion of private life.

In *Haas*, the ECtHR went further still. It considered that Article 2 requires national authorities to prevent individuals from taking their lives if the decision was not taken freely and based on the full understanding of what is involved.[49] Personal autonomy was therefore already implicitly considered as a possible counter-interest to be balanced against the right to life. Moreover, instead of referring to a 'choice', it considered that a right was at stake: the 'individual's right to decide by what means and at what point his or her life will end',[50] and specified that, when an individual is capable of freely making a decision and acting upon it, this right 'is one of the aspects of the right to

47 *Pretty v the United Kingdom*, ECHR 2002-III, para 63; *Jehovah's Witnesses of Moscow and others v. Russia*, App no 302/02 (ECtHR, 10 June 2010) para 135.

48 *Pretty v the United Kingdom*, ECHR 2002-III, para 67.

49 *Haas v Switzerland*, App no 31322/07 (ECtHR, 20 January 2011) para 54.

50 Ibid, para 51; *Koch v Germany*, App no 497/09 (ECtHR, 19 July 2012) para 52.

respect for private life within the meaning of Article 8 of the Convention'.[51] But of course to conclude that a person's wish to die falls under the protective umbrella of Article 8 ECHR does not imply the existence of a right to die, whether at the hands of a third person or with the assistance of a public authority.[52]

VI. The Lack of a European Consensus

Only three Member States of the Council of Europe – the Netherlands, Belgium, and Luxembourg – allow active euthanasia in their domestic law. Switzerland does not permit euthanasia, but it allows doctors to prescribe lethal drugs and considers assistance to suicide unlawful only when carried out for 'selfish motives'.[53] In the legal systems of the other Council of Europe Member States, killing on request and assisting others in committing suicide are generally criminal offences. Thus, the vast majority of Member States seem to attach more weight to the protection of the individual's life than to his or her right to terminate it.[54] Experience shows that where there is no

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[51] *Haas v Switzerland*, App no 31322/07 (ECtHR, 20 January 2011) para 51. *Gross v Switzerland*, App no 67810/10, (ECtHR, 14 May 2013) para 60. Jean Morange sharply criticises the legal reasoning followed by the ECtHR: *'on conçoit difficilement comment l'Article 8, qui avait pour finalité de protéger la vie privée et familiale des individus contre des intrusions extérieures, pourrait fonder le droit de demander une intervention extérieure, médicale en l'occurrence, pour mettre fin à ses jours'* [it is difficult to understand how Article 8, which was intended to protect the private and family life of individuals against external intrusions, could be used as a legal basis for a right to request an external intervention, eventually a medical one, to end their life] (my translation). According to the author, this is an abuse of power on the part of the ECtHR. Morange (n 3) 17.

[52] In *Haas*, the Court cautiously assumes but does not affirm: 'even assuming that the States have a positive obligation to adopt measures to facilitate the act of suicide with dignity, the Swiss authorities have not failed to comply with this obligation in the instant case'. *Haas v Switzerland*, App no 31322/07 (ECtHR, 20 January 2011) para 61.

[53] Art. 115 Swiss Criminal Code.

[54] *Haas v Switzerland*, App no 31322/07 (ECtHR, 20 January 2011) para 55. See also the univocal, but in its absoluteness outdated, Recommendation 1418 (1999), Protection of the human rights and dignity of the terminally ill and the dying, Parliamentary Assembly, 25 June 1999, para 9 (c) sub 3: 'a terminally ill or dying

specific rule permitting euthanasia and assisted suicide, domestic judges often become interpreters of social expectations, because the claims for individual rights to die are left for them to respond to.[55]

In view of the lack of a 'common consensus' within the Member States of the Council of Europe with regard to an individual's right to decide how and when his or her life should end,[56] and taking into account the sensitive scientific, legal, and ethical issues concerning the end of life,[57] the ECtHR has generally deduced that, in the balancing exercise, Member States enjoy a wide margin of appreciation between the individual right to respect for one's own autonomy and dignity, on the one hand, and the need to guarantee the protection of life and of vulnerable individuals, on the other.[58] There is therefore no positive obligation for the State to assist people in anticipating their own death, nor is there a right for individuals to die. Nevertheless, the wide margin of discretion State Parties enjoy in this respect does not mean that they are completely free to take any initiative, either preclusive or permissive. Specific limits can be deduced when focusing on the true meaning of the terms to balance. An interpretation will be proposed here, through

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person's wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death'.

55 The Italian situation is in this respect paradigmatic. See, for instance, the judgement of the Corte di Cassazione, n. 21.748 of 16 October 2007; and the already recalled decision of the Italian Constitutional Court, no 207 of 24 October 2018.

56 *Haas v Switzerland*, App no 31322/07 (ECtHR, 20 January 2011) para 55; *Koch v Germany*, App no 497/09 (ECtHR, 19 July 2012) para 70; *Nicklinson and Lamb v the United Kingdom*, Applications nos. 2478/15 and 1787/15, (ECtHR, 23 June 2015) para 85. Campiglio coherently stated that in this realm, "privatisation" is still at an early stage. C. Campiglio, 'Valori fondamentali dell'ordinamento interno e scelte di cura transfrontaliere' (2016) Rivista di diritto internazionale privato e processuale 371, 406.

57 *Nicklinson and Lamb v the United Kingdom*, Applications nos 2478/15 and 1787/15 (ECtHR, 23 June 2015) para 85; *Lambert and Others v France*, App no 46043/14, (ECtHR, 5 June 2015) para 144.

58 *Haas v Switzerland*, App no 31322/07 (ECtHR, 20 January 2011) para 55; *Koch v Germany*, App no 497/09 (ECtHR, 19 July 2012) para 70; *Lambert and Others v France*, App no 46043/14 (ECtHR, 5 June 2015) para 145; *Gard and Others v United Kingdom*, App no 39793/17 (ECtHR, 27 June 2017) para 84.

which Articles 2 and 8 ECHR reciprocally enhance and clarify rather than conflict with each other.

VII. The Provision of Specific and Strict Requirements

The first obligation for State Parties is to draft clear and comprehensive legal guidelines setting out the conditions for euthanasia and assisted suicide. The absence thereof entails a violation of the right to respect for private life under Article 8 ECHR,[59] and is also incompatible with the right to life under Article 2 ECHR.[60] The requirement of clarity is of course satisfied even by the extreme solution of a blanket ban which, the ECtHR deemed proportionate, albeit cautiously, in the *Pretty* case.[61] On the substantive level, it seems that, if a State Party chooses to allow assisted suicide and euthanasia, they ***must*** in any case be subject to strict requirements and limited to extreme situations. The Italian Constitutional Court, for instance, identified four cumulative requirements which justify on the part of a third party the execution of or collaboration with the patient in putting an end to their life: a patient must be affected by an irreversible pathology causing them intolerable physical or psychological suffering and must be kept alive through life-sustaining treatments, while also being capable of taking free and informed decisions.[62]

Mere tiredness of life or the intention to avoid old age and the related decline of physical and mental faculties do not seem sufficient to trigger the protection of Article 8 ECHR balancing and limiting the right to life. The exclusion of a right to die *ad libitum* stems from the absolute nature of the right to life in the first place. It is true that in the *Gross* case, having regard to the principle of subsidiarity, the ECtHR considered that it is primarily up to the domestic authorities to decide whether and under which circumstances an individual in the applicant's situation – that is, someone not suffering from a terminal illness – should be granted the ability to acquire a lethal dose of medication allowing them to end their life.[63] And yet, although the Court did

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59 *Gross v Switzerland*, App no 67810/10 (ECtHR, 14 May 2013) paras 63-69.

60 *Lambert and Others v France*, App no 46043/14 (ECtHR, 5 June 2015) para 160; *Afiri and Biddarri v France*, App no 1828/18 (ECtHR, 23 January 2018) para 31.

61 *Pretty v the United Kingdom*, ECHR 2002-III, paras 75-76.

62 In this sense: the Italian Constitutional Court, decision no 207 of 24 October 2018.

63 *Gross v Switzerland*, App no 67810/10 (ECtHR, 14 May 2013) paras 68-69.

not explicitly contemplate the limit defended here, it is an implicit assumption: the Court repeatedly emphasised the principle of sanctity of life, which arguably means that life shall be protected and prevents the deliberate taking of life except in very narrowly defined circumstances. If a right to die *ad libitum* were admitted, the principle of sanctity of life would be meaningless.[64]

Upon closer inspection, the exclusion of a right to die *ad libitum* is a limit inherent in Article 8 ECHR which cannot be overcome. Indeed, the patient's individual right to self-determination regarding their own lives is neither absolute, nor a dogma.[65] Despite the radical implications for the right to self-determination acknowledged by Article 8 ECHR, self-determination is limited whenever it could irreversibly deprive a person of their own capacity for self-determination. Since the exercise of the claimed freedom to die instantly determines the annihilation of that freedom and of its subjective basis, it seems contradictory to support the existence of a right to die as a direct expression of one's autonomy.[66] In itself, choosing and 'imposing' one's own death does not affirm self-determination, but rather destroys it.[67] Thus, a domestic practice legitimising euthanasia and assisted suicide upon simple request and with no requirements whatsoever would be incompatible with Article 2 ECHR and arguably with Article 8 ECHR.

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64 See *ex multis Pretty v the United Kingdom*, ECHR 2002-III, para 65. On the principle of sanctity of life, see Zatti (n 14) 299-300.

65 The Explanatory Report to the Oviedo Convention explicitly states that 'this principle [the freedom of consent] does not mean, for example, that the withdrawal of a patient's consent during an operation should always be followed. Professional standards and obligations as well as rules of conduct which apply in such cases under Article 4 may oblige the doctor to continue with the operation so as to avoid seriously endangering the health of the patient'. Explanatory Report (n 17) para 38.

66 Eusebi (n 5) 214; Antonio D'Aloia, 'Il diritto di rifiutare le cure e la fine della vita. Un punto di vista costituzionale sul caso Englaro' (2009) Diritti umani e diritto internazionale 370, 381.

67 See further: Francesco Cavalla, 'Praeter legem agere. Appunti in tema di struttura e fenomenologia dell'atto libero' in Francesco D'Agostino (ed), *L'indirizzo fenomenologico e strutturale nella filosofia del diritto italiana più recente* (Giuffré 1988) 53-73.

In this regard, it is worth noting that, following the logic of the human being as a 'social animal',[68] the ECHR legitimises measures that limit the sphere of liberties to protect the general interest of the human population as a whole[69] or whenever there is an 'abuse of rights' under Article 17 ECHR for the prejudicial effects deriving from the exercise of a legitimate right within another person's individual sphere. This is particularly relevant in this context, because there is no choice concerning the end of a human life that does not involve others, namely all those who are or will be involved in a person's decision to die (be they doctors, guardians, relatives, and so on). If life can be conceived as a construction, it is the result of a process of interaction with, for, or because of others. Nobody builds their own life; nobody builds the lives of others. We could claim that life was ours because it is the product of our personal history. However, we could also claim that it is not ours, because our personal history is inevitably linked to the people we meet throughout our lives.[70]

This does not imply that forms of individual self-determination which radically diverge from the conventional model of coexistence among human beings, such as the decision to live as a hermit, are prohibited. In such cases, there may at best be a need to control their individual self-determination if their behaviour, without being illegal, may pose a risk to society. Article 5, para 1 ECHR considers the figure of the 'vagrant' or other similar categories such as the persons of unsound mind, alcoholics, or drug addicts: the purpose is not to 'criminalise' choices of this kind, but rather to justify measures limiting the personal freedom of individuals who make such choices in order to protect general interests. This shows that the ECHR authorises States to

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68 Article 8 ECHR protects 'to a certain degree the right to establish and develop relationships with other human beings'. *Niemietz v Germany*, App no 13710/88 (ECtHR, 16 December 1992) para 29.

69 According to the European Commission of Human Rights, 'the claim to respect for private life is automatically reduced to the extent that the individual himself brings his private life into contact with public life or into close connection with other protected interests'. European Commission of Human Rights, *Bruggemann and Scheuten v Germany*, App no 6959/75, 12 July 1977, para 56.

70 Francesca Zanuso, 'Introduzione – Per un biodiritto dialettico' in Francesca Zanuso (ed), *Diritto e desiderio* (Franco Angeli 2015) 22-23.

prevent and repress behaviours resulting from lawful self-determination but with a potentially detrimental effect on society as a whole.

Obviously, the more serious the potential harm in question and the more widespread and profound the choice expressed by the individual, the heavier it will weigh when balancing considerations of public health and safety and crime prevention against the countervailing principle of personal autonomy.[71] In particular, the identification of specific and strict requirements for euthanasia and assisted suicide is well justified in order to avoid any devaluation of human life which might result from permitting the termination of life at peoples' discretion and to protect vulnerable individuals from potential abuse.

VIII. The Duty to Ascertain the True Will of the Patient

From the combination of Articles 2 and 8 ECHR, a further obligation arises: State Parties must prevent a person from dying, especially if that person is vulnerable,[72] 'if the decision has not been taken freely and with full understanding of what is involved'.[73] Forced euthanasia is therefore immediately inadmissible. This limit should not be ignored, as obvious as it may seem. Forced euthanasia has been practiced at various times in history – usually based on economic-demographic considerations, although most often 'justified' by humanitarian arguments – and was revived last century by Binding and Hoche in their book, *Die Freigabe der Vernichtung lebensunwerten Lebens,* which formed the theoretical basis for the eugenics selection

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71 *Pretty v the United Kingdom*, ECHR 2002-III, para 74. Any interference with the right to private life is lawful on the condition that it is justified in accordance with the terms of the second paragraph of Article 8, namely as being 'necessary in a democratic society' for one or more of the legitimate aims listed therein. According to the Court's settled case law, the notion of necessity implies that the interference corresponds to a pressing social need and in particular that it is proportionate to one of the listed legitimate aims pursued by the authorities.

72 Article 2 ECHR creates for public authorities a duty to protect vulnerable persons, even against actions by which they endanger their own lives. *Haas v Switzerland*, App no 31322/07 (ECtHR, 20 January 2011), paras 54-56 and see *supra* footnote n 31. See further, Stefano Semplici, 'Quali sono le caratteristiche del rapporto fra diritto e scienze della vita?' (2014) Forum, Biolaw Journal – Rivista di BioDiritto, 30.

73 *Haas v Switzerland*, App no 31322/07 (ECtHR, 20 January 2011) para 54

programme promoted by Nazism (the so-called *Aktion T4* programme).[74] However, as outlined above, the 'danger' of 'lives unworthy of being lived' being conceived did not disappear with the end of the Third Reich's *Aktion T4* programme. For this reason, it is necessary to stress once again that, in our pluralist and personalist societies, a right for society to suppress human lives by reason of their assumed lack of dignity cannot be accepted.[75]

In addition, the combination of Articles 2 and 8 ECHR gives rise to an obligation to ascertain that the will of the patient requesting euthanasia and assisted suicide is a genuine expression of the subject's autonomy, i.e. explicit, informed, aware, and free.[76] One might wonder whether a terminally ill patient can truly be capable of freely and rationally expressing such a wish. Indeed, one could argue – this being the core argument of those against the legalisation of assisted suicide and euthanasia – that terminally ill patients live in a limbo dominated by anxiety and uncertainty and are therefore far from being unequivocal in their views.[77] Their attitude is often ambivalent and inconsistent. They are often frail, distressed by the fear of suffering and lack of autonomy, sometimes plagued by economic and family problems, uncertain of their future, needing relief from the weight of making burdensome decisions, in a state of confusion or depression. Such conditions of terminally ill patients should be taken seriously to avoid that such people are abandoned in the name of an unconditional adherence to the principle of self-determination of the patient. However, it seems that those factual considerations are not such as to necessarily invalidate the self-determination of suffering people, nor can they justify limiting their freedom. Otherwise, additional burdens would be imposed on patients who already have enough

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74 Karl Binding and Alfred Hoche, *Die Freigabe der Vernichtung lebensunwerten Lebens* (Leipzig 1922).

75 Art. 2 (*Primacy of the human being*), Oviedo Convention. 'Euthanasia, in the sense of the intentional killing by act or omission of a dependent human being for his or her alleged benefit, must always be prohibited'. Resolution 1859 (2012) Protecting human rights and dignity by taking into account previously expressed wishes of patients, 25 January 2012, para 5. But see *infra* section 11 on the issue of the withdrawal of life-sustaining treatment to a patient in permanent vegetative state.

76 See also Human Rights Committee, General Comment no 36 (2018) on article 6 of the International Covenant on Civil and Political Rights, on the right to life, CCPR/C/GC/36, 30 October 2018, para 9.

77 In this sense, see Morange (n 3) 12.

to bear. If it is possible to ascertain the will of the person requesting the withholding or withdrawal of life-saving therapies,[78] which will lead to their death, it is hard to support the view that it is not possible to do the same for a person who asks for other types of assistance to achieve the same result.

By virtue of the combination of Articles 2 and 8 ECHR, any State Party that decides to open the way to assisted suicide and euthanasia certainly must establish conditions and procedures capable of ensuring that the decision to end somebody's life does correspond to the free will of the individual concerned, without being a mere passive acquiescence or acceptance of suggestions by others, nor the result of external pressures trying to take advantage of their state of vulnerability. In the view of the ECtHR, for example, a medical prescription issued on the basis of a full psychiatric assessment could be a means of satisfying this obligation by ensuring that an undiscerning patient does not receive a lethal dose of drugs.[79] Free will means that assistance to suicide can in no way affect the deliberative path of the patient by determining or reinforcing the purpose of their suicide. Assistance should merely consist of material conduct. As we have seen, the right to withdraw or withhold a particular medical treatment is protected under Article 8 ECHR, even in the event of a fatal outcome. Precisely in the event of a potentially fatal outcome, and in line with the factual approach recommended above, Member States should ascertain the true will of the patient, as in the case of request for euthanasia and assisted suicide. Otherwise, vulnerable people could end up being exposed to abuse in the name of unconditional adherence to the principle of self-determination and in violation of Articles 2 and 8 ECHR.

IX. Beyond the Free Will of the Patient

Whether death is a consequence of refusal of life-saving or life-sustaining treatment, or request for assisted suicide or euthanasia, doctors cannot simply accept the will expressed by the patient. It goes without saying that they cannot impose life-saving or life-sustaining treatment, but by virtue of the positive obligations of State Parties derived from Article 2 ECHR, they

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78 See *supra* section 5.

79 *Haas v Switzerland*, App no 31322/07 (ECtHR, 20 January 2011) paras 56-58.

are in any case required to protect life by non-coercive means, such as information, dialogue, encouragement, or psychological support, and to propose, whenever possible, alternative treatments to those which the patient refuses. The same applies to cases in which patients request the withdrawal of life-sustaining treatments combined with continuous deep sedation. In Italy, for example, Law 219/2017 allows a patient to ask for the withdrawal of medical treatment, including artificial nutrition and hydration.[80] Thus, through continuous deep sedation and without nutrients and liquids, patients already have the right to die if they so desire: regardless of whether or not they are terminally ill, exclusively depending on their will. In this case, the patient enters a permanent state of unconsciousness leading to occurrence of death as a consequence of the withdrawal of life-sustaining treatments. This leads to the same result as euthanasia and assisted suicide, even if death occurs slowly and not immediately in this case.[81]

By virtue of the positive obligations stemming from Article 2 ECHR, whenever a patient expresses their wish to die, the doctor must inform them (and medical records must provide evidence of such activity) about the nature of their pathology (if any), the possible developments of a multidisciplinary therapy, medication targeted at their pathology which is currently being tested and might eventually become available, as well as the effective

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[80] Law 22 December 2017, no 219, *Norme in materia di consenso informato e di disposizioni anticipate di trattamento*. (18G00006) (GU Serie Generale n.12 del 16-01-2018), Art. 1 para 5. See further: Comitato Nazionale per la Bioetica, *Sedazione palliativa profonda continua nell'imminenza della morte*, Advisory Opinion of 29 January 2016. See also, in similar terms, the French *Loi no 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie*, Art. 2.

[81] The Italian Constitutional Court correctly pointed out that '*la decisione di lasciarsi morire potrebbe essere già presa dal malato, sulla base della legislazione vigente, con effetti vincolanti nei confronti dei terzi, a mezzo della richiesta di interruzione dei trattamenti di sostegno vitale in atto e di contestuale sottoposizione a sedazione profonda continua*' [according to the existing legislation, the decision to allow oneself to die could already be taken by the patient, with binding effects on third parties, by requesting withdrawal of ongoing life-sustaining treatment coupled with continuous deep sedation] (my translation). Italian Constitutional Court, decision no 207/2018, 24 October 2018. On continuous deep sedation, see Simona Cacace, 'La sedazione palliativa profonda e continua nell'imminenza della morte: le sette inquietudini del diritto', (2017) Rivista italiana di medicina legale 469.

possibility of enrolling on a palliative programme. In particular, through the provision of information related to the availability of palliative therapy, patients can be induced to reformulate their wish to die into a request for help not to suffer. Because of the potential role palliative care may play in certain cases, State Parties shall ensure that, unless the patient chooses otherwise, a terminally ill or dying person will receive adequate pain relief and palliative care.[82] On the other hand, the obligation to protect life cannot be extended to legitimise therapeutic obstinacy, even where a patient insists on receiving a certain treatment which the doctor considers futile.[83] The ECtHR has repeatedly denied that the State has a duty to allow access to experimental treatment under Article 2 ECHR, pointing out that, even within the EU, this matter remains within the competence of the Member States and that the ECHR Contracting States deal differently with the conditions and manner of providing access to unauthorised medicinal products. Given the absence of a general consensus, the margin of appreciation is very wide in this context.[84]

X. In the Absence of a Term to Balance

The Oviedo Convention represents a development and an expansion of the underlying principles of the ECHR and contains specific norms to protect individuals who have never been able to or have lost their capacity to give their consent. The number of judgements dealing with these issues is

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[82] Recommendation 1418 (1999) (n 54) para 9 (a).

[83] Letizia Mingardo, 'Il testamento biologico e le ultime volontà del paziente sovrano' in Francesca Zanuso (ed) Diritto e desiderio (Milano, Franco Angeli, 2015) 109. The limit of therapeutic obstinacy is of course not univocal, but rather offers a general guideline. It needs to be defined for each specific case, as several factors – both medical and non-medical – come into play, including the patient's personal perception of their burden. Demetrio Neri, 'Il diritto di decidere la propria fine', in Stefano Canestrari and others (eds), *Trattato di Biodiritto*, vol. II (Giuffré 2011), 1788-1789.

[84] *Gard and Others v United Kingdom*, App no 39793/17 (ECtHR, 27 June 2017) paras 77-78, 87. *Hristozov and others v Bulgaria*, App nos 47039/11 and 358/12 (ECtHR, 13 November 2012) para 108.

increasing and they are also the most delicate to solve, particularly when patients have never had the capacity to consent and to express their wishes.[85]

After specifying that 'an intervention may only be carried out on a person who does not have the capacity to consent, for his or her direct benefit', Article 6 of the Oviedo Convention further specifies that

> where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law.[86]

Of course, the patient who is not able to consent at the time of the intervention might have been able to express in the past, through living wills, their aspirations regarding the type and extent of medical treatment they find acceptable.[87] Living wills are the sole means through which individuals who once were competent can maintain some control over treatment decisions instead of becoming mere objects of decisions made about them by others.[88]

By definition, however, these are not actual decisions. Having been drafted before a pathology develops or an accident occurs, they cannot take into account the circumstances giving rise to these conditions.[89] New therapies

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85 To assume that mere inferred wishes are the wishes of the person concerned is fiction. *Contra* the ECtHR: 'whilst CG [Charlie Gard] could not express his own wishes, the domestic courts ensured that *his wishes were expressed* though his guardian, an independent professional appointed expressly by the domestic courts for that purpose' [emphasis added]. *Gard and Others v United Kingdom*, App no 39793/17 (ECtHR, 27 June 2017) para 92.

86 Article 6, para 3, Oviedo Convention, for minors see para 2 of the same article. The Explanatory Report clarifies that: 'the term 'similar reasons' refers to such situation as accidents or states of coma, for example, where the patient is unable to formulate his or her wishes or to communicate them'. Explanatory Report (n 17) para 43.

87 Examples include advance refusals of blood transfusion or particular types of surgical intervention necessary to preserve life, where the treatment could, if given, restore health and prolong life.

88 See principle 1 (*Promotion of self-determination*), Recommendation CM/Rec(2009)11 of the Committee of Ministers to member States on principles concerning continuing powers of attorney and advance directives for incapacity, 9 December 2009.

89 Informed consent refers to a specific medical treatment, living wills have instead a general scope.

are continually being developed and people often revise their opinions about the kinds of treatment they find acceptable when they are actually confronted with the practicalities of an illness. Once again, there is a tension between respect for the individual's autonomy, as expressed in the past, and the protection of life here and now. What if the person concerned were to change their mind if they could?

The Oviedo Convention stipulates that previously expressed wishes 'shall be taken into account'.[90] Thus, the Convention uses the term 'wishes' ('*souhaits*' in French), which is weaker than 'will' and does not clarify the reasons that a doctor could legitimately invoke to disregard the wishes of the person concerned having taken them into account.[91] The Explanatory Report only provides an example: if a patient's wishes were expressed a long time before the intervention and science has since progressed, there may be grounds for not heeding them. The practitioner should thus ascertain to the best of their knowledge and belief that the patient's wishes apply to the present situation and are still valid, especially with a view to medical advances.[92] It seems clear that the application of the living wills cannot be automatic and uncritical. The interpretative filter of the doctor is necessary to guarantee the actual correspondence and adjustment of the patient's will to the concrete situation. The patient's wishes would otherwise become the sole criterion for reaching a decision, in the same manner as doctors paternalistically took every decision alone in the past.[93] In any case, when there is doubt regarding the interpretation of living wills, the protection of life prevails over the self-

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90 Article 9, Oviedo Convention. The Explanatory Report specifies that Article 9 covers not only emergencies but also situations where individuals have foreseen that they might be unable to give their valid consent, for example in the event of a progressive disease such as senile dementia. Explanatory Report (n 17) para 61.

91 Principle 15 (*Effect*) of Recommendation CM/Rec(2009)11 does not take position and leaves the right to decide to what extent advance directives should have binding effect to the Member States, while specifying in any case that 'advance directives which do not have binding effect should be treated as statements of wishes to be given due respect'.

92 Explanatory Report (n 17) para 62.

93 Carlo Casonato, 'Consenso e rifiuto delle cure in una recente sentenza della Cassazione' (2008) Quaderni costituzionali 545, 547.

determination that can no longer be exercised: *in dubio pro vita*.[94] In the absence of living wills, the combination of Article 6, paragraphs 1 and 3 and Article 9 of the Oviedo Convention seems to lead to the conclusion that the person with the power to authorise or reject a treatment must, as far as possible, reconstruct the will of the person concerned.[95] They should decide 'as if' the person concerned were to decide. This delicate hermeneutic activity is even more complex when the decision to be made concerns the withholding or withdrawing of life-sustaining treatments: artificial nutrition and hydration.

XI. Artificial Nutrition and Hydration

The use of artificial nutrition and hydration is a matter of some debate.[96] No doubt, if the patient has refused life-sustaining treatments in the terminal phase or before through living wills, their wishes should be respected because of the consent requirement for any medical treatment.[97] The most critical situation is when a patient has not previously expressed and can no longer express their wish to that effect.[98] According to one view, putting a patient on life-sustaining treatments when they are highly unlikely to regain consciousness would constitute a disproportionate and even aggressive action, i.e. an unreasonable obstinacy. An opposing view suggests that artificial nutrition and hydration constitute a form of care that meets the individual's basic needs, and for this reason cannot be withdrawn. The result

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94 'In case of doubt, the decision must always be for life and the prolongation of life'. Recommendation 1418 (1999) (n 54), para 9 (b) sub 4.

95 In this sense, see also Cristina Campiglio, 'Decisioni di fine vita: la sentenza del Bundesgerichtshof tedesco nel contesto della prassi europea' (2010) Diritti umani e diritto internazionale 543, 551.

96 The Guide on the Decision-making Process Regarding Medical Treatment in End-of-life Situations (Council of Europe 2014), qualifies as 'disputed' the issues of limiting, withdrawing, and withholding artificial nutrition and hydration.

97 *Ex multis* Lorenzo D'Avack, 'Fine vita e rifiuto di cure' in Stefano Canestrari and others (eds), *Trattato di Biodiritto*, vol. II (Giuffré 2011), 1929-1930. The author correctly points out that artificial nutrition and hydration, being an invasion into the physical sphere of the patient, both require their consent.

98 On this debate, and on the use of the principle of dignity to support both theses, see further Luca Marini, *Il Diritto internazionale e comunitario della bioetica* (Giappichelli 2006) 408.

would be to precipitate death, which would otherwise not occur in the foreseeable future and would have to be construed as a form of genuine forced euthanasia.[99]

Even among the Council of Europe Member States, there is a lack of consensus in this respect. Two paths of reasoning were available to the ECtHR here. One possibility was to emphasise the positive obligations stemming from Article 2 ECHR regarding the protection of life, particularly that of vulnerable individuals, a category within which persons in a vegetative state no doubt fall.[100] The second possible path was to emphasise the alleged lack of consensus in favour of permitting the withdrawal of artificial life-sustaining treatment, with the consequent wide margin of appreciation for Member States as to the balance between the right to life and respect for private life,[101] as well as to the organization of the decision-making process, including the designation of the person who takes the final decision.[102] This is the precise path the ECtHR has consistently followed in its case law.[103]

Problems arise especially when the various elements to be taken into consideration push in opposite direction, for instance where there is disagreement among the relatives or between relatives and doctors on the final decision to take. Indeed, the ECtHR has never pronounced on the balance of interests at stake nor provided substantive answers as to the prevailing consideration.[104]

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99 Partly Dissenting Opinion in *Lambert and Others v France*, App no 46043/14 (ECtHR, 5 June 2015) para 9.

100 In this sense: ibid, para 1.

101 *Lambert and Others v France*, App no 46043/14 (ECtHR, 5 June 2015), paras 147-148; *Afiri and Biddarri v France*, App no 1828/18 (ECtHR, 23 January 2018) para 29.

102 *Lambert and Others v France*, App no 46043/14 (ECtHR, 5 June 2015), para 165; 168; *Afiri and Biddarri v France*, App no 1828/18 (ECtHR, 23 January 2018) para 38.

103 The ECtHR nonetheless admits that the majority of States appear to allow the withdrawal of artificial life-sustaining treatment. *Lambert and Others v France*, App no 46043/14 (ECtHR, 5 June 2015), para 147; *Gard and Others v United Kingdom*, App no 39793/17 (ECtHR, 27 June 2017) para 83. *Afiri and Biddarri v France*, App no 1828/18 (ECtHR, 23 January 2018) para 28.

104 *Lambert and Others v France*, App no 46043/14 (ECtHR, 5 June 2015), para 162 ; *Gard and Others v United Kingdom*, App no 39793/17 (ECtHR, 27 June 2017) para 91; *Afiri and Biddarri v France*, App no 1828/18 (ECtHR, 23 January 2018) para 35.

The Court has nonetheless developed three requirements for Member States to comply with when administering or withdrawing treatments.[105] Firstly, there must exist in domestic law and practice a regulatory framework compatible with the requirements of Article 2, which essentially means, once again, that the legal framework must be clear.[106] Secondly, the applicant's previously expressed wishes and those of the persons close to them, as well as the opinions of other medical personnel, shall be taken into account. Thus, even in this context, the paramount importance of the patient's wishes in the decision-making process, whether expressed previously or merely inferred, is undebatable.[107] Moreover, and *a fortiori* here, such wishes should be considered together with other opinions in a dialectic procedure. To this end, being 'the natural and fundamental group unit of society'[108] and the first context where the personal identity of the individual develops and their rights are protected, the family of the patient unable to consent is invariably the first point of contact for the doctor in defining the therapy programme. Finally, there should be a possibility to approach the courts in the event of doubts or, most notably, in the event of conflict as to the best decision to be taken in the patient's interest.[109] The Court has recalled several times that Member States enjoy a wide discretion in designating the person who takes the final decision. However, this discretion can only be applied if there are no doubts or disagreements between the parties involved. Otherwise, no such discretion exists and a judge is called upon to decide.

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105 *Lambert and Others v France*, App no 46043/14 (ECtHR, 5 June 2015), para 143; *Gard and Others v United Kingdom*, App no 39793/17 (ECtHR, 27 June 2017) para 80; *Afiri and Biddarri v France*, App no 1828/18 (ECtHR, 23 January 2018) para 27.

106 *Lambert and Others v France*, App no 46043/14 (ECtHR, 5 June 2015), para 160; *Gard and Others v United Kingdom*, App no 39793/17 (ECtHR, 27 June 2017) para 89; *Afiri and Biddarri v France*, App no 1828/18 (ECtHR, 23 January 2018) para 31.

107 *Lambert and Others v France*, App no 46043/14, (ECtHR, 5 June 2015), para 147; *Gard and Others v United Kingdom*, App no 39793/17 (ECtHR, 27 June 2017) para 83; *Afiri and Biddarri v France*, App no 1828/18 (ECtHR, 23 January 2018) para 28.

108 Articles 23 of the International Covenant on Civil and Political Rights.

109 *Glass v. the United Kingdom*, App no 61827/00 (ECtHR, 9 March 2004) para 83; *Gard and Others v United Kingdom*, App no 39793/17 (ECtHR, 27 June 2017) paras. 96-97, 106; *Afiri and Biddarri v France*, App no 1828/18 (ECtHR, 23 January 2018) paras 42-46.

XII. Final Remarks

It has been observed that the provision of appropriate information related to the availability of palliative care can induce patients to reformulate their request for euthanasia or assisted suicide into a request for help not to suffer.[110] In fact, adequate palliative care can be an effective response for sufferers who simply seek relief from intolerable pain. However, it would be illusory to think that palliative care, pain therapies, medical-psychological assistance, and human solidarity support[111] would suffice to eliminate all requests for euthanasia and assisted suicide. In some cases, suffering is uncontrollable and some patients may refuse continuous deep sedation because they consider it contrary to their dignity. Such patients may prefer a more rapid path to death, in which case palliative care would not be an alternative, but preliminary to and synergistic with euthanasia or medically assisted suicide.

At the present time, it is not possible to deduce from the ECHR the existence of a duty to live, nor that of a right to die. It is therefore primarily for States to prohibit or allow euthanasia and assisted suicide after assessing the risk and the likely incidence of abuse in the event that the general prohibition not to kill was relaxed or if further exceptions were to be created.[112] However, we have seen that the wide margin of discretion State Parties enjoy in this respect does not mean that they are completely free to take any initiative, either preclusive or permissive. Articles 2 and 8 ECHR entail that State Parties must draft clear and comprehensive legal guidelines setting out the conditions for euthanasia and assisted suicide. The ECtHR case law so far suggests that the requirement of clarity is met even by the extreme solution of a blanket ban. If a State opts to open the way to assisted suicide and euthanasia, the argument of a slippery slope remains valid if understood as an invitation to caution. State Parties should establish precise and stringent conditions of admissibility and procedures capable of ensuring that the decision to end somebody's life does correspond to the free will of the individual concerned. Moreover, by virtue of the positive obligations stemming from Article 2 ECHR, doctors are in any case required to protect

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110 See *supra* section 9.

111 Recommendation 1418 (1999) (n 54) para 9 (a) 3.

112 *Pretty v the United Kingdom*, ECHR 2002-III, para 74.

life by non-coercive means such as information, dialogue, encouragement, or psychological support, and to propose, whenever possible, alternative treatments to those which the patient refuses, including palliative treatments.

Despite all the controversy surrounding this matter, it is easy to foresee a future where the ECtHR will be prompted to judge it a violation of Article 8 ECHR if euthanasia and assisted suicide are not legalised at least in extreme situations. Indeed, little attention has so far been paid to how death occurs following the withdrawal of treatment. A patient who needs a ventilator to survive will suffocate if it is removed, and those who are deprived of food and fluid will die from the effects of dehydration, despite being sustained by adequate palliation of their symptoms. Overall, slipping down the slope is still possible and can be even more dangerous in the absence of a regulation defining and limiting the possibility of euthanasia and assisted suicide. Experience shows that in Member States where there is no specific regulation, judges become the interpreter of social expectations, because individuals' wishes to die are left for them to respond to.[113] In this context, the domestic judge either unconditionally adheres to the prohibition to kill, whose exceptions are not open to analogy, or takes an evolutionary approach to interpreting domestic provisions which were nor drafted to deal with bioethical issues. Either way, the slippery slope of discretion widens, and with it the chances of slipping further down. This situation is all the more difficult to manage because, within the framework of the Oviedo Convention, no specific body is in charge of compliance control and the ECtHR has little inclination to tackle bioethical issues. The previously identified general principles could guide national legislators and, in case of their inertia, domestic judges, to guarantee at least minimum standards for the protection of human rights and to avoid bioethical 'dumping' practices between States.[114] In particular, domestic judges can use them to draw up interpretative guidelines, elements of regulation in case of lacunae in the domestic system, and as a framework for assessing the legitimacy of domestic rules.

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[113] See *supra* (n 55).

[114] See also Stefano Rodotà, 'Modelli culturali e orizzonti della bioetica', in Stefano Rodotà (ed), *Questioni di bioetica* (Laterza 1993), 421-422.