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## **EUROPEAN COURT OF HUMAN RIGHTS (GC), CASE OF *LAMBERT AND OTHERS V. FRANCE*, JUDGMENT OF 5 JUNE 2015, APPLICATION NO. 46043/14**

### **Abstract**

*This case commentary provides an analysis of the judgment of 5 June 2015 in Lambert and others v. France, handed down by the Grand Chamber of the European Court of Human Rights. The case at issue concerned the discontinuation of treatment (artificial nutrition and hydration) of a patient who was unconscious and not able to express his wishes. It can undoubtedly be classified as one of the "hard cases" decided by the ECtHR, as it touches upon end-of-life dilemmas and the scope of patient's autonomy. Legal regulation of these issues proves to be very difficult because it needs to avoid vagueness and has to balance conflicting interests and rights.*

*This comment proceeds as follows. Part I offers introductory remarks and explains the fundamental nature of the underlying dilemmas. Part II describes the basic facts of the case, followed by part III which describes the scope of the claim. Part IV discusses admissibility questions – that is – of locus standi and jurisdiction *ratione personae*. The next part provides some insight into the French legislation concerning the rights of patients in end-of-life situations (Loi Leonetti). Part VI discusses major questions that have been raised in the judgment. The final part offers some conclusions and points for further discussion.*

### **Keywords**

*persistent/obstinate therapy – medical futility – incompetent patients – informed consent – advanced directives – patient's autonomy – right to life – State's positive obligations*

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## I. INTRODUCTION

One of the consequences of the constant and rapid progress in medicine is the narrowing of the already thin line between sustaining life and prolonging the process of dying<sup>1</sup>. Many illnesses or injuries that some years ago would inevitably have lead to death, today are described as “incurable” and “chronic”. This phenomenon has coupled with another change – that is – evolution from paternalistic to patient-oriented medical care. During the last decades, patients’ right to take an active role in their own health care has increasingly been recognised<sup>2</sup>. But does this right extend to decisions as to how or when to die, or does it cover the right to refuse treatment? The problem becomes even more difficult when a person is incapable of active participation in health care decisions, because of a serious illness or injury. Even though many European countries have decided to regulate end-of-life issues<sup>3</sup>, the normative answers to these dilemmas are very diverse<sup>4</sup>. While only a few countries have legalised some forms of euthanasia or assisted suicide<sup>5</sup>, the others are increasingly recognising procedures for withholding/withdrawing persistent (obstinate) treatment in a situation of medical futility<sup>6</sup>. However, the

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<sup>1</sup> S. Paulson et al., *Prolonging Life: Legal, Ethical, and Social Dilemmas*, Annals of The New York Academy of Sciences 2014, no. 1, pp. 19-39; S. Woods, *The “Good Death”, Palliative Care and End-of-Life Ethics*, [in:] L. Hagger, S. Woods, *A Good Death? Law and Ethics in Practice*, Routledge 2012, available from: eBook Academic Collection (EBSCOhost).

<sup>2</sup> ECtHR in *V.C. v. Slovakia*, judgment of 8.11.2011, appl. no. 18968/07; ECtHR in *Glass v. United Kingdom*, judgment of 9.03.2004, appl. no. 61827/00; Report of the International Bioethics Committee of UNESCO on Consent, 2008, available at: <http://unesdoc.unesco.org/images/0017/001781/178124e.pdf> [last accessed: 14.08.2016]; T. Beauchamp, R. Faden, *A History and Theory of Informed Consent*, New York 1979, pp. 53-140; E. Dantas, *Autonomy, Consent and Informational Negligence: Origins and Perspectives*, [in:] E. Sarnacka (ed.), *Health Law. Selected Issues*, Jastrzębie-Zdrój 2015, pp. 45-57; J. Munby, *The Right to Demand Treatment or Death*, [in:] Hagger, Woods, *supra* note 1.

<sup>3</sup> In Poland there is still no specific legislation regarding withdrawal of persistent therapy.

<sup>4</sup> I rely here on the information provided in the judgment under review, see para 72. However, this matter requires more comprehensive comparative research in the future.

<sup>5</sup> The Netherlands, Belgium, Luxembourg, and Switzerland.

<sup>6</sup> The possibility of withdrawing treatment is either provided in the legislation (as in France), in non-binding instruments (such as codes of medical ethics – see i.a. British Medical Association, *Withholding and Withdrawing Life-Prolonging Medical Treatment. Guidance for Decision Making*, Oxford 2007) or recognised in the jurisprudence (as in Italy).

practice has proved that defining “persistent treatment” or “medical futility” and distinguishing them from passive euthanasia may be very difficult and controversial. Awareness of this delicate subject is also raised by means of terminological modifications – for example “Do Not Resuscitate” orders were further differentiated by adding the word attempt (“Do Not Attempt Resuscitation”) or replaced by the term “Allow Natural Death”<sup>7</sup>.

These and similar dilemmas are illustrated by a number of court cases reviewed by national courts<sup>8</sup> and by the European Court of Human Rights (hereinafter as ECtHR)<sup>9</sup>. With the publicity surrounding these “high-profile” cases, end-of-life matters are almost permanently an issue of public debate. These questions are not new in an academic and ethical debate. Nevertheless, their importance has not faded. Apart from the debatable merits, the case represented a precedent with respect to admissibility linked to the victim’s status and *locus standi*.

In this case-review one of such “high-profile” cases will be discussed. The judgment on the case was released by the Grand Chamber of the ECtHR on June 5 2015. Apart from analysing the judgment itself, I intend

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<sup>7</sup> S. Venneman, P. Narnor-Harris, M. Perish, M. Hamilton, “Allow Natural Death” Versus “Do Not Resuscitate”: Three Words That Can Change a Life, *Journal of Medical Ethics* 2008, vol. 34, pp. 2-6.

<sup>8</sup> In Ireland, *Re a Ward of Court* (No. 2) case established that a competent individual’s ability to control his/her treatment and care also extends to the right to refuse treatment to facilitate a natural death (judgment of the High Court of 5.05.1995; judgment of the Supreme Court of 27.06.1995). Similarly, the Italian Court of Cassation determined that informed consent includes the right to refuse medical care (Court of Cassation judgment of 16.10.2007, no. 21748 – as commented on in: G. Gentili, T. Groppi, *Italian Constitutional and Cassation Courts: When the Right to Die of an Unconscious Patient Raises Serious Constitutional Conflicts Between State Powers*, *ILSA Journal of International and Comparative Law* 2001, vol. 18, p. 75 et seq. With respect to the United Kingdom see judgments in *Airedale NHS Trust v. Bland* [1993] 789 HL; *R(Burke) v. General Medical Council* [2005] EWCA Civ., [2006] QB and *W v. M and others* [2011] EWHC 2443 (Fam). With respect to Canada see Supreme Court of Canada judgment in *Cuthbertson v. Rasouli*, 2013 SCC 53, [2013] 3 S.C.R. 341. Regarding the USA see the widely-discussed case of Terri Chiavo – commented on i.a. by L.O. Gostin, *Ethics, the Constitution, and the Dying Process. The Case of Theresa Marie Chiavo*, *Journal of the American Medical Association* 2005, vol. 293, no. 19, pp. 2403-2407.

<sup>9</sup> Cases concerning capable patients that requested euthanasia/assisted suicide: *Pretty v. United Kingdom*, judgment of 29.04.2002, app. no. 2346/02; *Haas v. Switzerland*, judgment of 20.01.2011, appl. no. 31322/07; *Koch v. Germany*, judgment of 19.07.2012, appl. no. 497/09; *Gross v. Switzerland*, judgment of 14.05.2013, appl. no. 67810/10.

to give some more insight into the French *Loi Leonetti* that provides for a possibility of discontinuation of an obstinate and futile therapy. I will also include some basic comparative perspective, however a comprehensive and detailed comparative research would be welcomed in the future.

## II. FACTS OF THE CASE<sup>10</sup>

Vincent Lambert sustained serious head injuries in a road-traffic accident on 29 September 2008, which left him tetraplegic and in a state of complete dependency. From September 2008 to March 2009 he was hospitalised in Châlons-en-Champagne Hospital. From March to June 2009 he was cared for in the heliotherapy centre in Berck-sur-Mer, before being moved on 23 June 2009 to the unit in Reims University Hospital providing care to patients in a vegetative or minimally conscious state, where he remained until the date of the judgment. Vincent Lambert received artificial nutrition and hydration which was administered enterally, through a gastric tube. In 2011 his condition was characterised as minimally conscious and in 2014 as vegetative.

In early 2013 the medical team initiated the collective procedure provided for by the Act of 22 April 2005 on patients' rights and end-of-life issues (known as the Leonetti Act). Rachel Lambert, the patient's wife, was involved in the procedure, which resulted in a decision by Dr Kariger, the doctor in charge of Vincent Lambert and head of the department in which he was hospitalised, to withdraw the patient's nutrition and reduce his hydration.

In September 2013 a fresh collective procedure was initiated. Dr Kariger consulted six doctors, including three from outside the hospital. He also convened two meetings with the family, on 27 September and 16 November 2013, following which Rachel Lambert and six of Vincent Lambert's eight brothers and sisters argued in favour of discontinuing artificial nutrition and hydration, while the applicants argued in favour of maintaining it. On 9 December 2013 Dr Kariger called a meeting of all the doctors and almost all the members of the care team. He and five of the six doctors consulted stated that they were in favour of withdrawing

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<sup>10</sup> Facts of the case summarised on the basis of the press release available on HUDOC.

treatment. On conclusion of the consultation procedure Dr Kariger announced on 11 January 2014 in a decision, stating reasons – a summary of which was read out to the family – his intention to discontinue artificial nutrition and hydration from 13 January 2014, subject to an application to the administrative court.

Conseil d'État delivered its ruling on the case on 24 June 2014. It concluded that all the conditions imposed by the law had been met and that the doctor's decision of 11 January 2014 to withdraw the artificial nutrition and hydration of Mr Vincent Lambert could not be held to be unlawful.

### III. SCOPE OF CLAIM

An application against France was lodged by Vincent Lambert's parents, a half-brother and a sister. The applicants submitted that the withdrawal of Vincent Lambert's artificial nutrition and hydration would be in breach of the State's obligations under Article 2 (Right to life) of the Convention, would constitute ill-treatment amounting to torture within the meaning of Article 3 and would infringe his physical integrity, in breach of Article 8 of the Convention. They further alleged that the lack of physiotherapy since October 2012 and the lack of therapy to restore the swallowing reflex amounted to inhuman and degrading treatment in breach of Article 3 of the Convention.

### IV. *LOCUS STANDI* AND JURISDICTION *RATIONE PERSONAE*

Before discussing the merits of the case, the Court reflected upon the applicants' standing to act in the name and on behalf of Vincent Lambert. This admissibility issue has also been a precedent, since never before had the Court had the opportunity to consider comparable circumstances.

Article 34 ECHR provides for a mechanism whereby an individual application may be lodged by "(...) any person, nongovernmental organisation or group of individuals claiming to be the victim of a violation of the rights set forth in the Convention or the Protocols". The concept (notion) of a victim has autonomous meaning and has been interpreted

in an evaluative manner and in the *pro homine* spirit. Thus, it does not only refer to a direct victim, but also to an indirect victim and a potential victim<sup>11</sup>.

The application at issue was lodged by four relatives of Vincent Lambert in his name and on his behalf. There is no doubt that Mr Lambert could be classified (regarded) as a direct victim of alleged violations, because he was “directly affected” by the measures and actions complained of. There was however a fundamental problem, because as a consequence of his physical state, he was unable to file the application himself. Moreover, it was unclear if he would wish to do so.

As a matter of principle, where the application is not lodged by the victim himself/herself, Rule 45 § 3 of the Rules of Court requires a written and duly signed authority to act. It is essential for the representatives to demonstrate that they have received specific and explicit instructions from the alleged victim on whose behalf they purport to act before the Court<sup>12</sup>. Only exceptionally, applications lodged by individuals on behalf of the victim (or victims) without a valid form of authority, were deemed admissible<sup>13</sup>.

The circumstances of the present case were very specific owing to the fact that while the direct victim was unable to express his wishes, several members of his close family wished to express themselves on his behalf, presenting diametrically opposed points of view<sup>14</sup>. Four applicants (Vincent Lambert’s parents, a half-brother, and a sister) argued that withdrawal of Vincent Lambert’s artificial nutrition and hydration would

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<sup>11</sup> Council of Europe, Department of the Jurisconsult, *A Practical Guide on the Admissibility Criteria*, Strasbourg 2014, pp. 14-16; P. van Dijk, G.J.H. Hoof, *Theory and Practice of the European Convention on Human Rights*, The Hague 1998, pp. 46-58; A. Mowbray, *Cases, Materials, and Commentary on the European Convention on Human Rights*, Oxford 2012, pp. 30-32; W.A. Schabas, *European Convention on Human Rights: A Commentary*, Oxford 2015, pp. 737-746.

<sup>12</sup> *Lambert* judgment, para 91 and case-law cited thereto.

<sup>13</sup> In the majority of cases, the application was lodged by a close relative and the direct victim was either dead or missing. Only a few were lodged by other persons or entities – i.a. a solicitor acting in the interest of children or an NGO or the husband of a woman who has been in a vulnerable position because she underwent a forced gynaecological examination in Police custody (*Y.F. v. Turkey*, judgment of 22.07.2003, appl. no. 24209/94). For more details see the *Lambert* judgment, paras 92-95 and Council of Europe, Department of the Jurisconsult, *supra* note 11, p. 18.

<sup>14</sup> *Lambert* judgment, para 98.

breach his Conventional rights (in particular the right to life and freedom from torture, inhuman and degrading treatment), whereas the individual third-party interveners (his wife, nephew and half-sister) claimed that continuation of treatment would be contrary to his previously expressed wishes, and as a consequence amount to a violation of the right to private life. For the first time, the Court had to deal with such divergence among the family members. The fundamental question was whether the applicants would in fact represent the victim's wishes and best interests. To this purpose the Court relied on criteria, established in previous case-law, that had to be fulfilled when assessing the *locus standi* of a third party: (1) the risk that the direct victim will be deprived of effective protection of his or her rights, and (2) the absence of a conflict of interests between the victim and the applicant<sup>15</sup>. As regards the second criterion, the facts of the case, as well as the submissions of interveners, revealed a degree of uncertainty as to the correspondence of interests. The first criterion was in my opinion more difficult to assess, because it would be unacceptable to "close the door to the ECHR" for the victim because the first criterion has not been met. The only possibility (way out) in this situation was to judge the part of the application that could be filed by the applicants on their own behalf. These considerations led the Court to the conclusion that the applicants did not have standing to raise the complaints under Articles 2, 3 and 8 of the Convention in the name and on behalf of Vincent Lambert<sup>16</sup>.

The final outcome of the assessment of admissibility *ratione personae* was that the Court decided to examine the case under Article 2 of the Convention, as the applicants could raise their claim also on their own behalf. To sum up, the applicants were no longer acting on behalf of Vincent Lambert, but in their own name as indirect victims. This status could be given to applicants to whom the violation (of the rights of the direct victim) would cause harm or who would have a valid and personal interest in seeing it brought to an end<sup>17</sup>. So far this concept has been limited to situations when a direct victim has died or disappeared. In such

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<sup>15</sup> Ibidem, para 102.

<sup>16</sup> Ibidem, para 105.

<sup>17</sup> See i.a. *Vallianatos and Others v. Greece* [GC], judgment of 7.11.2013, appl. nos 29381/09 32684/09, para 47.

cases, the victim's next-of-kin<sup>18</sup> could have a legal interest in raising a complaint<sup>19</sup>. In my opinion, the solution the Court has opted for has not been clearly and convincingly reasoned. Granting the applicants the status of indirect victims implies that their interest is similar and not in conflict with the rights and interests of Mr Lambert. The applicants' submission that the withdrawal of Vincent Lambert's artificial nutrition and hydration would be in breach of the State's obligations under Article 2 of the Convention<sup>20</sup> is based on an assumption that the measures would be against his will, which could not have been established with certainty.

To close the remarks devoted to admissibility, I would like to raise the following question. Would it not be more logical for the applicants to rely on Articles 3 and 8 of the Convention and lodge the claim as direct victims of violations of these rights? The applicants could have argued that the lack of clarity and precision of the 2005 Act and the procedure that has been followed caused them mental suffering amounting to degrading or even inhuman treatment and also violated their right to family life.

## V. LOI LEONETTI OF 2005 – *RATIO LEGIS*, INTERPRETATION AND SUBSEQUENT AMENDMENTS

The Act on patients' rights and end-of-life issues (so-called *Loi Leonetti*<sup>21</sup>) was adopted on 22 April 2005 (*Loi relative aux droits des patients en fin de vie*)<sup>22</sup>. Its objective (aim) was to prevent euthanatic practices and assisted suicide and to allow doctors to discontinue treatment (in accordance with a prescribed procedure) only if continuing it would demonstrate unreasonable obstinacy. As explained in the Rapport presented by Mr Leonetti at the Assemblée Nationale before the discussion on its final text, two reasons convinced the drafters of the necessity

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<sup>18</sup> See more about the concept of a "direct relative" and the evolution of the case-law in: Schabas, *supra* note 11, p. 739.

<sup>19</sup> In the majority of applications a violation of Article 2, Article 3 or Article 5 had been invoked.

<sup>20</sup> *Lambert* judgment, para 113.

<sup>21</sup> The Act was passed following the work of a parliamentary commission chaired by Mr Leonetti.

<sup>22</sup> <http://www.legifrance.gouv.fr> [last accessed: 17.06.2016].



of legislating on the certain questions concerning end-of-life<sup>23</sup> – “*Le premier impératif est de respecter la dignité du patient, en tenant compte de sa volonté, lorsqu’il est en état de l’exprimer, en l’accompagnant par des soins palliatifs et psychologiques dont le développement doit être encouragé. Le deuxième impératif consiste à conférer un ancrage législatif aux conditions de limitation ou d’arrêt de traitement, qui n’ont été encadrées jusqu’à présent que par les bonnes pratiques de sociétés savantes telles celles des médecins réanimateurs qui arrêtent chaque année entre 75 000 et 100 000 appareils de réanimation. A cet effet, il convient d’éviter de laisser le juge arbitrer le flou juridique entourant la définition des droits des malades et des obligations professionnelles des médecins, sachant qu’un contentieux de plus en plus abondant pèse sur l’exercice de la profession médicale et sur son attractivité*”.

The Act of 22 April 2005 amended several provisions of the Public Health Code (*Code de la Santé Publique*). Its Article L. 1110-5 refers to a concept of “unreasonable obstinacy” (fr. *obstination déraisonnable*)<sup>24</sup>. According to this provision they could be defined as preventive or exploratory acts that “appear to be futile or disproportionate or to have no other effect than to sustain life artificially”. Such acts may be discontinued or withheld.

Article L. 1111-4 provided for the right of a patient to self-determination and to free and informed consent. It provides that the patient, together with a health care professional shall take decisions concerning his or her health. It further regulates the situation of persons who are unable to express their wishes. It provides that “no intervention or examination may be carried out, except in cases of urgency or impossibility, without the person of trust (...) or the family or, failing this, a person close to the patient having been consulted”. The article also

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<sup>23</sup> Rapport de l’Assemblée Nationale n° 1929 fait au nom de la Commission Spéciale chargée d’examiner la proposition de loi (no 1882) de M. Jean Leonetti et plusieurs de ses collègues relative aux droits de malades et à la fin de vie, 18.11.2004, pp. 5-6.

<sup>24</sup> Article L. 1110-5 – “Toute personne a, compte tenu de son état de santé et de l’urgence des interventions que celui-ci requiert, le droit de recevoir les soins les plus appropriés et de bénéficier des thérapeutiques dont l’efficacité est reconnue et qui garantissent la meilleure sécurité sanitaire au regard des connaissances médicales avérées. Les actes de prévention, d’investigation ou de soins ne doivent pas, en l’état des connaissances médicales, lui faire courir de risques disproportionnés par rapport au bénéfice escompté. Ces actes ne doivent pas être poursuivis par une obstination déraisonnable. Lorsqu’ils apparaissent inutiles, disproportionnés, inutiles ou n’ayant d’autre effet que le seul maintien artificiel de la vie, ils peuvent être suspendus ou ne pas être entrepris”.

provides for some procedural requirements in a situation where a decision to limit or withdraw treatment would endanger the patient's life. Such a decision cannot be taken without a collective procedure defined in the Code of Medical Ethics having been followed and without the person of trust referred to in Article L. 1111-6 or the family or, failing this, a person close to the patient having been consulted, and without any advance directives issued by the patient having been examined<sup>25</sup>.

Almost from its adoption, the 2005 Act has been the subject of debates, but the case of Mr Lambert has undoubtedly triggered the most serious questions. In December 2012 a Report of the *Commission de réflexion sur la fin de vie* was presented to the President of the Republic<sup>26</sup>. The Report did not recommend changes to *Loi Leonetti*; nevertheless it pointed out deficiencies in applying the existing law and in medical practice.

In July 2013 an important opinion n° 121 entitled "*Fin de vie, autonomie de la personne, volonté de mourir*" was presented by the CCNE<sup>27</sup>. The Committee highlighted the necessity to eliminate situations when human dignity is not respected during the process of dying. It observed, that to this end, it is indispensable to provide wide access to palliative care and palliative drugs, also for in-house use. Another point was raised concerning relations between the patient, the doctor, and the family. The Committee insisted on the necessity to respect advanced directives when the patient made use of this possibility. Moreover, when an advance directive has been drafted in the presence of the treating doctor, and a serious illness (fr. *maladie grave*) has been diagnosed, the CCNE suggested that it should as a principle (subject to duly reasoned exceptions) be binding on the caregivers. Finally, the opinion firmly stated that medical staff should respect the right of the patient at the end-of-life to deep sedation (fr. *sédation profonde*) until the decease, if the patient has

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<sup>25</sup> "Lorsque la personne est hors d'état d'exprimer sa volonté, la limitation ou l'arrêt de traitement susceptible de mettre sa vie en danger ne peut être réalisé sans avoir respecté la procédure collégiale définie par le code de déontologie médicale et sans que la personne de confiance prévue à l'article L. 1111-6 ou la famille ou, à défaut, un de ses proches et, le cas échéant, les directives anticipées de la personne, aient été consultés".

<sup>26</sup> <http://www.elysee.fr/assets/pdf/Rapport-de-la-commission-de-reflexion-sur-la-fin-de-vie-en-France.pdf> [last accessed: 17.06.2016].

<sup>27</sup> [http://www.ccne-ethique.fr/sites/default/files/publications/avis\\_121\\_0.pdf](http://www.ccne-ethique.fr/sites/default/files/publications/avis_121_0.pdf) [last accessed: 18.06.2016].

so requested. Similarly, the patient's will to withdraw all treatment, including nutrition and hydration, should be respected. All this should be seen as a form of assistance in the realisation of the right to die in dignity and without suffering. From the point of view of human rights law and ongoing debates concerning the concept of the "right to die in dignity", it is important to note that the Committee clearly limited the scope of this right to situations when death is close and inevitable. In other words, it would not apply to even seriously ill patients if they are not in a terminal phase.

As is usually the case with legal provisions, the devil is in the details. Even though the *ratio legis* of *Loi Leonetti* has been rather clearly articulated, certain notions and concepts turned out difficult to interpret and define. Domestic courts that have been reviewing the case of Mr Lambert have had opposing views as to the interpretation of "unreasonable obstinacy" and when a treatment is to be regarded as "futile or disproportionate". The Administrative Court in its judgment of 16 January 2014 stated that as long as the treatment did not cause any stress or suffering, it could not be characterised as futile or disproportionate<sup>28</sup>. The Conseil d'État's standpoint and interpretation of the relevant provisions of the Public Health Code was however different: "(...) the legislature intended to include among the forms of treatment that may be limited or withdrawn on the grounds of unreasonable obstinacy all acts which seek to maintain the patient's vital functions artificially. Artificial nutrition and hydration fall into this category of acts (...) "<sup>29</sup>.

Ten years after the adoption of the *Loi Leonetti*, a new law on the rights of persons at the end-of-life has been approved by Parliament, and entered into force on August 5 2016<sup>30</sup>. The *Loi Claeys-Leonetti*<sup>31</sup> proclaims a right

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<sup>28</sup> *Lambert* judgment, para 19.

<sup>29</sup> *Ibidem*, para 24.

<sup>30</sup> <http://www.gouvernement.fr/argumentaire/les-nouveaux-droits-des-personnes-en-fin-de-vie-pleinement-effectifs> [last accessed: 29.07.2016].

<sup>31</sup> *Loi n° 2016-87 du 2.02.2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie*, JORF no. 0028 of 3.02.2016.

to demand deep sedation until decease, under certain conditions prescribed in detail by regulatory (executive) acts<sup>32</sup>.

## VI. THE RIGHT TO LIFE, THE PATIENT'S SELF-DETERMINATION AND THE DISCONTINUATION OF PERSISTENT (OBSTINATE) THERAPY

The merits of the case at issue were concentrated on Article 2 of the Convention and State's positive obligations to take appropriate steps to safeguard the lives of those within its jurisdiction. Both parties to the case, as well as the Court, were in agreement that there should be a distinction between the intentional taking of life and "therapeutic abstention"<sup>33</sup>. While the first situation would engage negative obligations, the other related to positive ones.

In the applicants' view, the French legislation at issue was vague and open to divergent interpretations. They argued in particular that the notion of unreasonable obstinacy, as well as the criterion concerning treatment having "no other effect than to sustain life artificially", was extremely imprecise. They also disagreed with the classification of artificial nutrition and hydration as treatment rather than care. In their opinion Vincent Lambert was not at the end of life and the notion of unreasonable obstinacy did not apply to his medical situation<sup>34</sup>.

### 6.1. MARGIN OF APPRECIATION AND EUROPEAN CONSENSUS

One of the major points raised in the judgment was the concept of margin of appreciation, which is by far one of the most widely discussed and controversial issues concerning the ECtHR judicial practice<sup>35</sup>.

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<sup>32</sup> The first regulation sets out conditions for the withdrawal of all treatments followed by a deep sedation. The second regulation circumscribes the criteria and validity of advanced directives.

<sup>33</sup> *Lambert* judgment, para 124.

<sup>34</sup> *Ibidem*, para 125.

<sup>35</sup> See i.a. S. Greer, *The Margin of Appreciation: Interpretation and Discretion Under the European Convention on Human Rights*, Council of Europe 2000; Y. Arai-Takahashi, *The Margin of Appreciation Doctrine and the Principle of Proportionality in the Jurisprudence of the ECHR*, Antwerp 2002; A. Wiśniewski, *Koncepcja marginesu swobody oceny w orzecznictwie Europejskiego Trybunału Praw Człowieka* [*Margin of Appreciation Doctrine in the European Court*].

The Court recalled that, in the context of the State's positive obligations, when addressing complex scientific, legal, and ethical issues concerning in particular the beginning or the end of life, and in the absence of consensus among the Member States, a certain margin of appreciation has been recognised<sup>36</sup>.

When analysing the margin of appreciation, comparative data are indispensable for establishing a consensus (or its absence) among the Council of Europe Member States. Comparative analysis has led the Court to the conclusion that although the majority of States allow for the withdrawal of artificial life-sustaining treatment, there appears to be no consensus as to the detailed conditions and the procedure for withdrawal<sup>37</sup>. When lack of consensus is identified, States are offered (in principle) a wider margin of appreciation.

## 6.2. CONDITIONS FOR THE WITHDRAWAL OF THERAPY – GENERAL REMARKS

The primary condition for both starting and withdrawing any kind of treatment (or any kind of medical intervention) is the patient's consent. There is no doubt that the principle of free and informed consent is today of paramount importance<sup>38</sup>. Thus, a capable patient may decide to stop or not to start a treatment, even if this decision would not prolong his/her life. With incompetent patients, as in the case of Vincent Lambert, a fundamental problem lies within a procedure and the persons empowered to take such decision. In the absence of an advance directive (that is regulated in some countries), the decision lies with a third party,

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of Human Rights Jurisprudence], Gdańsk 2008; A. Legg, *The Margin of Appreciation in International Human Rights Law: Deference and Proportionality*, Oxford 2012; S. Matthew, *The European Court of Human Rights Margin of Appreciation and the Processes of National Parliaments*, Human Rights Law Review 2015, vol. 15, no. 4, pp. 745-774; F. van Hoof, *The Stubbornness of the European Court of Human Rights' Margin of Appreciation Doctrine*, [in:] Y. Haecck, B. McGonigle Leyh, C. Burbano-Herrera, D. Contreras-Garduño (eds), *The Realisation of Human Rights: When Theory Meets Practice. Studies in Honour of Leo Zwaak*, Cambridge/Antwerp/Portland 2014, pp. 125-149.

<sup>36</sup> *Lambert* judgment, para 144.

<sup>37</sup> *Ibidem*, para 147 and paras 72-76. The Court relied on the data from 39 of the 47 Council of Europe Member States.

<sup>38</sup> See Article 5 of the Convention on Human Rights and Biomedicine and Explanatory report to the convention. See also ECtHR judgment of 10.06.2010 in *Jehovah's Witnesses of Moscow v. Russia*, appl. no. 302/02, GC, para 135.

usually a person's relatives or a doctor. At this point, another problem may emerge, that is a disagreement between the doctors and the family, or between the members of a family. In this event, the law should provide for a procedure to solve the problem in a way that would not be contrary to the Convention. As has been mentioned above, States are offered a margin of appreciation when regulating this delicate matter.

Apart from the requirement to seek a valid consent, domestic laws (or jurisprudence) regulate and define the condition or state of health of a patient whose treatment could be withdrawn<sup>39</sup>. Domestic laws also vary in this respect. For example, the Italian Court of Cassation in the well-known case of Eluana Englaro has established two conditions that have to be met in order to withdraw life support treatment: 1) no prospect for recovery – vegetative state is irreversible and incurable, 2) there is clear, unambiguous and convincing evidence that it would be consistent with the patient's mind/will – which, as the Court has suggested – could be deduced from his/her personality, lifestyle, values, ethical, religious, and philosophical beliefs<sup>40</sup>.

At this point, the biggest challenge is, in my opinion, to identify which and whose rights should be taken into account in a "fair balance test". In other words, should the patient's right to life be given priority over their right to respect for their private life and their personal autonomy?<sup>41</sup> What to do, when, as in Mr Lambert's case, the patient's wishes cannot be established with absolute certainty? Should the rights of the family members also be taken into account? And finally, what role should the concept of dignity play in the balancing process?

To sum up this part of the discussion I would like to address the last question. Even though the concept of human dignity is a meta-concept that

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<sup>39</sup> *Lambert judgment*, para 76. "The patient must be dying or suffering from a condition with serious and irreversible medical consequences, the treatment must no longer be in the patient's best interests, it must be futile, or withdrawal must be preceded by an observation phase of sufficient duration and by a review of the patient's condition".

<sup>40</sup> Court of Cassation judgment of 16.10.2007, no. 21748 – as commented in: G. Gentili, T. Groppi, *Italian Constitutional and Cassation Courts: When the Right to Die of an Unconscious Patient Raises Serious Constitutional Conflicts Between State Powers*, *ILSA Journal of International and Comparative Law* 2001, vol. 18, pp. 75-76.

<sup>41</sup> *Lambert judgment*, para 148.

serves as the source of all human rights<sup>42</sup>, it somehow unexpectedly (or even paradoxically) is called upon to support the idea of individual autonomy and self-determination in the situation of a clash with one's right to life. End-of-life decision-making cases definitely serve as an example of conceptual conundrums with relations between human dignity and individual rights that international and domestic courts have to struggle with. From the ECtHR jurisprudence it follows that even though the principle of the sanctity of life is protected under the Convention, the patient's autonomy may prevail in certain circumstances because respect for human dignity and human freedom is "the very essence of the Convention"<sup>43</sup>. The Italian Court of Cassation in the Englaro case similarly stated, that the guardian and the court should balance the protection of the patient's life with his/her conception of dignity and a decorous life<sup>44</sup>.

### 6.3. A QUESTION OF LAW – DID LOI LEONETTI APPROPRIATELY PROTECT THE RIGHT TO LIFE?

A fundamental question raised in the Vincent Lambert case was whether the definitions of "unreasonable obstinacy" and "treatment" offered by the French courts were compatible with the State's obligation to protect life. Could artificial nutrition and hydration be regarded as a "treatment" that may be withdrawn?

Unlike artificial ventilation, artificial nutrition and hydration raise different opinions, as to whether they are a form of treatment (that may be withdrawn) or form of basic care (which cannot be limited). Even the Committee on Bioethics (DH-BIO) of the Council of Europe in its "Guide on the decision-making process regarding medical treatment in end-of-life situations" (which was drafted with the intention of facilitating

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<sup>42</sup> P.G. Carozza, *Human Dignity*, [in:] D. Shelton (ed.), *The Oxford Handbook of International Human Rights Law*, Oxford 2015, pp. 345-359; E. Klein, *Human Dignity: Basics of Human Right*, [in:] H.P. Hestermeyer et al (ed.), *Coexistence, Cooperation and Solidarity. Liber Amicorum Rüdiger Wolfrum*, Leiden 2012, pp. 437-452; J. Habermas, *The Concept of Human Dignity and the Realistic Utopia of Human Rights*, [in:] C. Corradetti (ed.), *Philosophical Dimensions of Human Rights: Some Contemporary Views*, Dordrecht 2012, pp. 63-79.

<sup>43</sup> *Pretty v. United Kingdom*, judgment of 29.04.2002, app. no. 2346/02, para 65.

<sup>44</sup> Court of Cassation judgment, supra note 40, p. 75.

the implementation of the principles enshrined in the Convention on Human Rights and Biomedicine) has not taken any definitive position on that question<sup>45</sup>. In its judgment of 24 June 2014 the Conseil d'État stated that artificial nutrition and hydration fell into that category of treatments that could be withdrawn when the criteria for unreasonable obstinacy were met<sup>46</sup>. The ECtHR, when analysing the Conseil d'État judgment, rightly emphasised that the interpretation presented therein did not allow for an automatism in making decisions<sup>47</sup>. This has led the Court to the conclusion that the *Loi Leonetti* and its interpretation were sufficiently clear, for the purposes of Article 2 of the Convention.

#### 6.4. A QUESTION OF PRACTICE – DID THE DECISION-MAKING PROCESS REACH A FAIR BALANCE?

This question addresses the applicants' allegations that the decision-making process had not been genuinely collective and did not provide for mediation in the event of disagreement between the family members. The Court's analysis of this point seems incomplete. The Court concentrated on establishing whether the decision-making process followed the conditions set up by French law, and it rightly concluded, that it did<sup>48</sup>. Nevertheless, the Court did not really elaborate on the question of whether the law reached a fair balance in a situation of disagreement and when the patient's wishes were not known for certain. The Court shielded itself by stating that Article 2 of the ECHR does not impose any requirements as to the procedure to be followed with a view to securing a possible agreement and that it falls within the State's margin

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<sup>45</sup> Text available at: [www.coe.int/en/web/bioethics/guide-on-the-decision-making-process-regarding-medical-treatment-in-end-of-life-situations](http://www.coe.int/en/web/bioethics/guide-on-the-decision-making-process-regarding-medical-treatment-in-end-of-life-situations) [last accessed: 2.08.2016].

<sup>46</sup> Conseil d'État further elaborated that the doctor in charge of the patient must base his or her decision on a range of medical and non-medical factors – see *Lambert* judgment, para 48.

<sup>47</sup> Conseil d'État stated that “the sole fact that a person is in an irreversible state of unconsciousness or, *a fortiori*, has lost his or her autonomy irreversibly and is thus dependent on such a form of nutrition and hydration, does not by itself amount to a situation in which the continuation of treatment would appear unjustified on grounds of unreasonable obstinacy”.

<sup>48</sup> *Ibidem*, para 157.



of appreciation<sup>49</sup>. While all this is true, the Court is still empowered to appraise the measures and acts of State. In other words, the Court is not expected to “impose” or list any particular requirements, but to address the issue of fair balance, necessity, and proportionality. Thus, at this point it seems relevant to raise a question as to whether the lack of provisions that could resolve the problem of disagreement between the family members (either in the form of mediation or the order in which family member’s views should be taken into account) reached a fair balance. Another element of the judgment that is debatable is the statement that Vincent Lambert’s wishes could have been established on the basis of the testimony submitted by some of his family members<sup>50</sup>.

## VII. CONCLUSIONS

The commented judgment was definitely one of the “hard cases” of 2015. Therefore, in the conclusions I would like to concentrate on more general remarks, instead of on specific issues such as admissibility or the margin of appreciation.

The *Lambert* case illustrates a wider problem of contemporary societies in developed and ageing countries – that is – a problem of end-of-life decision-making and of an adequate standard of care of terminally ill patients or patients in a vegetative state. The decision-making process becomes far more complicated when a patient is unable to express his/her wishes and in the absence of an advance directive (AD). Some authors have already advocated the necessity of regulating AD’s and their popularisation relying on a legitimate assumption that advance directives serve to enhance the patient’s autonomy<sup>51</sup>. Even though there is still some controversy about the role, strengths, and shortcomings of advance health

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<sup>49</sup> Ibidem, para 153 and 159.

<sup>50</sup> Ibidem, para 171. See also some doubts raised by the dissenting judges in joint partly dissenting opinion, para 5.

<sup>51</sup> R. Andorno, N. Biller-Andorno, S. Brauer, *Advance Health Care Directives: Towards a Coordinated European Policy?*, European Journal of Health Law 2009, vol. 16, p. 208.

care decisions<sup>52</sup>, legal regulation is better than the chaos caused by the lack of statutory response<sup>53</sup>. The need for regulation has also been addressed in a Council of Europe Parliamentary Assembly Resolution 1859 (2012), “Protecting human rights and dignity by taking into account the previously expressed wishes of patients”, where the Parliamentary Assembly recommended that countries with no specific legislation on the matter – put into place a “road map” towards such legislation promoting advance directives, living wills and/or continuing powers of attorney, on the basis of the Oviedo Convention and Recommendation CM/Rec(2009)11.

A final remark would be devoted to the quality of law, the fair balance principle, and its relevance for the decision-making procedures. In the *Lambert* case, the ECtHR was satisfied with the clarity of the law and its interpretation made by the French courts. While I would generally concur with this conclusion, I see one missing element that the lawmakers (not only French ones) should take into account. Assuming that advance directives will probably not become a widespread practice soon, the law has to foresee mechanisms for resolving disagreement between the members of a family and/or family members and doctors. When deciding on the particularities of such mechanisms, it should be remembered that the procedures should primarily serve the best interests of the patient, but the rights of the families should not be forgotten. To achieve a truly fair balance, empirical research ought to be conducted and taken into account, to avoid making law that is based solely on ethical and legal theories<sup>54</sup>.

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<sup>52</sup> Ibidem, pp. 209-210. See also: R. Andorno, *Regulation Advance Directives at the Council of Europe*, [in:] S. Negri, *Self-Determination, Dignity and End-of-Life Care: Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston 2011, pp. 76-77.

<sup>53</sup> For example, in Germany until 1.09.2009 there was no statutory law on AD's – as a consequence, judicial decisions were often inconsistent and unable to provide a precise guidance – see: U. Wiesing, R.J. Jox, H.J. Hessler, G.D. Borasio, *A New Law on Advance Directives in Germany*, *Journal of Medical Ethics* 2010, vol. 36(12), p. 779.

<sup>54</sup> As an example: C. Kitinger, J. Kitinger, *Withdrawing Artificial Nutrition and Hydration From Minimally Conscious and Vegetative Patients: Family Perspectives*, *Journal of Medical Ethics* 2015, vol. 41, pp. 157-160; C. Kitinger, J. Kitinger, *Court Applications for Withdrawal of Artificial Nutrition and Hydration from Patients in a Permanent Vegetative State: Family Experiences*, *Journal of Medical Ethics* 2015, vol. 42, pp. 11-17.

