

WITHDRAWAL OF ARTIFICIAL HYDRATION AND
NUTRITION FROM A PATIENT IN A
PERMANENT VEGETATIVE STATE IN ITALY:
SOME CONSIDERATIONS ON THE *ENGLARO* CASE*

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Abstract

This paper discusses some issues related to end-of-life decisions in Italy: in particular, it addresses the question of withdrawal of artificial nutrition and hydration from a patient in a permanent vegetative state, investigated through the examination of the so-called *Englaro* case.

The acknowledgment of the right to withdraw this kind of treatment is analyzed focusing on three issues: the qualification of artificial hydration and nutrition as medical treatment; the maintenance of the right to refuse and stop this treatment as a corollary of the principle of self determination, sealed and implemented by the principle of informed consent; the possibility to claim this right by decisionally incapable individuals.

The article has a comparative approach: it compares the *Englaro* case with the U.S. *Terri Schiavo* case (sometimes, Eluana Englaro is called the "Italian Terri Schiavo") and examines the influence of U.S. case law on the former.

Finally, it expresses some considerations on the criticalities that have arisen in the Italian Parliamentary debate regarding living wills. It also tackles the question of the opportunity to enact a law on advance directives in Italy and of the features of such a regulation.

* This paper consists of the redrafting of a presentation entitled "*Withdrawal of Artificial Hydration and Nutrition from a Patient in a Permanent Vegetative State in Italy: Some Considerations on the Englaro Case*", given on 20 October 2010 at one of the Bioethics Seminars organised by the Joint Centre for Bioethics of the University of Toronto.

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1. Some preliminary remarks

This paper will discuss some issues related to end-of-life decisions in Italy: in particular, it will address the question of withdrawal of artificial hydration and nutrition¹ from a patient in a permanent vegetative state, investigated through the analysis of the so-called *Englaro* case.

Before examining this case, some preliminary remarks are necessary.

¹ "Withdrawing potentially life-sustaining treatment" means "stopping treatment that has the potential to sustain a person's life": for this definition see J. Downie, *Dying Justice. A case for Decriminalizing Euthanasia & Assisted Suicide in Canada* (2004), 6, whose work draws the attention of readers to the systemization of terminology when dealing with end-of-life issues. It should be noted that the expression "withdrawal" must be distinguished from "withholding" which is used to indicate "the failure to start treatment".

First of all, although law scholars claim they have a positivist approach and present their studies and analyses as neutral, based only on legislation and judicial decisions, it is impossible to tackle these complex and difficult issues, related to bioethics and, in particular, to “biolaw”², without being influenced by our personal convictions and beliefs.

Secondly, this article will not discuss euthanasia³ and assisted suicide⁴, because they are prohibited in Italy. In fact, the Italian Criminal Code punishes homicide (article 575), homicide of a consenting person (article 579) and aiding suicide (article 580)⁵.

² So-called “biolaw” aims at studying juridical dimensions regarding the life sciences and human healthcare: for the basic lines of this discipline see S. Rodotà-M. Tallacchini (eds.), *Ambito e fonti del biodiritto* (2010), in S. Rodotà-P. Zatti (eds.), *Trattato di Biodiritto*; C. Casonato, *Introduzione al biodiritto* (2009), whose work is distinguished by a line of inquiry that privileges comparative constitutional law. On this field of study also see G. di Rosa, *Biodiritto. Itinerari di ricerca* (2010); A. Gorassini, *Lezioni di biodiritto* (2007); L. Palazzani, *Introduzione alla biogiuridica* (2002). Finally, on the complex dialectics between law and life see P. Zatti, *Maschere del diritto. Volti della vita* (2009); S. Rodotà, *La vita e le regole. Tra diritto e non diritto* (2007); P. Veronesi, *Il corpo e la Costituzione* (2007).

³ By “euthanasia” is meant “a deliberate act undertaken by one person with the intention of ending the life of another person to relieve that person’s suffering”: B.M. Dickens, J.M. Boyle Jr., Linda Ganzini, *Euthanasia and assisted suicide*, in P.A. Singer, A.M. Viens (eds.), *The Cambridge Textbook of Bioethics* (2008), 72; in the same terms see J. Downie, *supra* note 1, at 6. Therefore, today, the expression euthanasia refers substantially to so-called active euthanasia: on the critical aspects of the by now overcome distinction between active and passive euthanasia see S. Tordini Cagli, *Le forme dell'eutanasia*, in S. Canestrari-G. Ferrando-C.M. Mazzoni-S. Rodotà-P. Zatti (eds.), *Il governo del corpo*, II (2011), 1819 ss., in S. Rodotà-P. Zatti (eds.), *Trattato di Biodiritto*. On euthanasia also see D. Neri, *Il diritto di decidere la propria fine*, *ibid.*, 1785 ss. and, within the framework of a broader discussion on the role of law in scientifically and technologically advanced societies, C. Tripodina, *Il diritto nell’età della tecnica. Il caso dell’eutanasia* (2004).

⁴ By “assisted suicide” is meant “the act of intentionally killing oneself with the assistance of another who deliberately provides the knowledge, means or both”: B.M. Dickens, J.M. Boyle Jr., Linda Ganzini, *Euthanasia and assisted suicide*, *supra* note 3, at 72; for a similar definition see J. Downie, *supra* note 1, at 6. On suicide and end-of-life issues see F. Faenza, *Profili penali del suicidio*, in S. Canestrari-G. Ferrando-C.M. Mazzoni-S. Rodotà-P. Zatti (eds.), *supra* note 3, at 1813 ss.

⁵ In the Italian Criminal Code the words euthanasia and assisted suicide are not used: it must be considered that the Code was enacted in 1939 and the referred provisions have never been amended.

Finally, as to the specific legal framework within which the question of end-of-life decisions in Italy must be settled, the starting point of every reflection is that in Italy there is still no legislation on advance directives⁶.

To address this issue it is therefore important to refer to judicial decisions, that have tried to overcome the lack of regulation.

Obviously, the essential pillar of the legal framework is the Italian Constitution and, in particular, article 32, specific to the right to health.

2. The Englaro case: an overview

The Englaro case⁷ represents for Italians what the Terry Schiavo case has represented for people living in the U.S. Sometimes, Eluana Englaro is called the “Italian Terri Schiavo”, even if there are some differences between the two cases as will be outlined in a subsequent section⁸.

All the main institutions of Italy were involved: the judicial system – including the Corte di Cassazione, that is the Italian Supreme Court, at the top of the judiciary –, the Government, the President of the Republic, the Constitutional Court. Even the European Court of Human Rights was involved.

This case attracted media attention: therefore every Italian could follow and share the vicissitudes of this 38-year-old woman, who on 18 January 1992 had had a car accident that resulted in

⁶ The subject of advance directives is dealt with thoroughly in S. Rodotà-P. Zatti (eds.), *Trattato di Biodiritto*: see M. Azzalini, *Le disposizioni anticipate del paziente: prospettiva civilistica*, in S. Canestrari-G. Ferrando-C.M. Mazzoni-S. Rodotà-P. Zatti (eds.), *supra* note 3, at 1935 ss.; D. Provolo, *Le direttive anticipate: profili penali e prospettiva comparatistica*, *ibid.*, 1969 ss. On this topic also see the monographic issue on end-of-life decisions and living wills of *MicroMega*, n. 2/2009; F.G. Pizzetti, *Alle frontiere della vita: il testamento biologico tra valori costituzionali e promozione della persona* (2008) and the book by the Fondazione Umberto Veronesi, *Testamento biologico. Riflessioni di dieci giuristi* (2006).

⁷ On the Englaro case see, in addition to the works that will be cited in the following notes, S. Moratti, *The Englaro Case: Withdrawal of Treatment from a Patient in a Permanent Vegetative State in Italy*, 19 *Cambridge Quarterly of Healthcare Ethics* 372 (2010); *Italy*, in J. Griffiths and H. Weyers-M. Adams (eds.), *Euthanasia and Law in Europe* (2008), 395 ss.

⁸ See, in particular, section 8.

severe brain damage. She had been unconscious for 17 years; in 1994 she was diagnosed as being in a permanent vegetative state (PVS), and died in February 2009, after the withdrawal of artificial nutrition and hydration.

As soon as the tragedy happened and during the whole period of her unconsciousness her father maintained that, since she was a very lively, energetic, self confident, autonomous person, with an intense social life – this is how she was described by people who knew her – she would have never wanted to be kept alive artificially, in conditions that would have violated her dignity. He also pointed out that she affirmed this conviction when one year before a friend of hers fell into an irreversible coma after a motorbike accident. In the following years this was confirmed also by some acquaintances.

However, the medical procedures went on in spite of Eluana's father's opposition.

When she was taken to the intensive care unit (ICU) in a deep state of coma because of severe brain damage, the doctors continued with the IC protocols, affirming that they were aimed first and foremost at preserving life, independently from all other considerations. Eluana also underwent a tracheotomy.

After one month of coma, Eluana started breathing by herself and opened her eyes, but she was still unconscious, paralyzed, hydrated and fed by a naso-gastric tube.

After two years of observation and sensory stimulation in a long term ward of a hospital – this time it was necessary to say definitively whether there were chances of regaining consciousness or not – in 1994 Eluana was diagnosed as being in a permanent vegetative state (PVS).

She was taken to a National Health Service-accredited nursing home, in Lecco, in Lombardy, close to her family, where she received all the assistance she needed, covered by public funds.

Given the absence of any possibility of recovery, when in 1994 Eluana's permanent vegetative state was assessed, Mr. Englaro decided to press on with his purpose of stopping Eluana's artificial hydration and nutrition.

He started the necessary procedures to have her declared incapacitated and on 19 December 1996 was appointed her

guardian⁹. As her guardian, Mr. Englaro asked the director of the nursing home to withdraw her artificial feeding, but he refused to do so.

Therefore, in 1999 Eluana's father started a judiciary battle to address a petition authorizing him, as the guardian, to direct the nursing home personnel to withdraw artificial feeding and hydration.

There followed many years of court proceedings, in which Eluana's father claimed the right of his daughter to refuse this treatment before every level of the judiciary system, without succeeding.

The arguments on which the Courts based their rejection of Eluana's father claim varied.

Some of them had to do with a potential conflict of interests between Eluana, whose will about the withdrawal of artificial nutrition and hydration was not ascertained, and her father, as guardian. This observation of the Corte di Cassazione, I civil section, expressed in ordinance n. 8291 of 20 April 2005¹⁰, led to the appointment of a special curator, as prescribed by article 78 of the Civil Procedure Code.

Other arguments addressed directly the core of the issue: artificial hydration and nutrition are basic care and not medical treatment, therefore they cannot be renounced; the Italian legal system gives unconditioned protection to human life; advance directives are not regulated in the Italian legal system, so there are no legal grounds for decisions to withdraw life-sustaining treatment.

Only on 6 October 2007 did the Corte di Cassazione, the Italian Supreme Court, reverse the rulings of the lower courts with decision n. 21748¹¹ of the I civil section and held the possibility to withdraw artificial hydration and nutrition from a person who for

⁹ Eluana Englaro was declared incapacitated with the ruling of the Court in Lecco on 19 December 1996.

¹⁰ Cass. Civ., sect. I, ord. 20 April 2005, n. 8291, 9 Foro it. I 2359 (2005).

¹¹ Cass. Civ., sect. I, 16 October 2007, n. 21748, 11 Foro it. I 3025 (2007), with comment of G. Casaburi, *Interruzione dei trattamenti medici: nuovi interventi della giurisprudenza di legittimità e di merito*. On this judgment also see D. Maltese, *Convincimenti già manifestati in passato dall'incapace in stato vegetativo irreversibile e poteri degli organi preposti alla sua assistenza*, 1 Foro it. I 125 (2008) and, among others, the comment of C. Casonato, *Consenso e rifiuto delle cure in una recente sentenza della Cassazione*, 3 Quad. cost. 545 (2008).

many years had been in a permanent vegetative state, as petitioned by the guardian (with the intervention of a curator), under specific conditions: a) rigorous clinical controls showing that the permanent vegetative state is irreversible and on the ground of medical standards, recognized at an international level, there is no possibility to regain even a feeble consciousness or perception of the external world; b) the request corresponds, on the ground of clear, unequivocal, convincing evidence, to the patient's voice, based on previous declarations, personality, lifestyle, convictions, in accordance with his/her way of conceiving human dignity before the state of unconsciousness.

The Supreme Court remanded the case to the Court of Appeal of Milan, that, with a decree of 9 July 2008¹², assessed that in the Englaro case the two requirements indicated were met and that consequently the naso-gastric tube could be removed. The final paragraph of the decision, written with the advice of a palliative care expert, prescribed how the withdrawal had to be carried out in practice.

The Prosecutor's office of the Court of Appeal of Milan appealed to the Corte di Cassazione again, but the Supreme Court declared the appeal inadmissible¹³, holding that the Prosecutor's office was not entitled to lodge it¹⁴.

3. The acknowledgment of the right to withdraw artificial hydration and nutrition: analysis of the fundamental ruling of the Corte di Cassazione, I civil section, n. 27148/2007.

The ruling of the Corte di Cassazione, I civil section, n. 27148/2007 is the result of a reasoning that develops through

¹² App. Milan, decr. 9 July 2008, 1 Foro it. I 35 (2009), with comment of G. Casaburi, *Autodeterminazione del paziente, terapie e trattamenti sanitari «salva-vita»*. On this decision see also R. Caponi-A. Proto Pisani, *Il caso E.: brevi riflessioni dalla prospettiva del processo civile*, 4 Foro it. I 984 (2009); D. Maltese, *Il falso problema della nutrizione artificiale*, 4 Foro it. I 987 (2009); E. Calò, *Caso Englaro: la decisione della Corte d'Appello di Milano*, 9 Corriere giur. 1290 (2008).

¹³ Cass., sect. un., 13 November 2008, n. 27145, 1 Foro it. I 35 (2009). with comment of G. Casaburi, *supra* note 12. On this decision see also R. Caponi-A. Proto Pisani, *supra* note 12; D. Maltese, *Il falso problema della nutrizione artificiale*, *supra* note 12.

¹⁴ In Italian civil suits the presence of the Prosecutor's office is exceptional, limited by law to particular controversies.

three main issues: the qualification of artificial hydration and nutrition as medical treatment; the acknowledgment of the right to refuse this kind of treatment as a corollary of the principle of informed consent; the possibility to claim this right by decisionally incapable subjects.

The fact that life-sustaining treatment is medical treatment is the assumption of the Supreme Court reasoning, that allows it to decide the case under article 32 of the Italian Constitution, that is the article that regulates the right to health¹⁵.

Notwithstanding this qualification it is the subject of an animated debate – we cannot forget that the lower courts had adhered to the different position that artificial nutrition and hydration are basic care – it is noteworthy that the Corte di Cassazione has tackled this issue not at the beginning of the decision, as a preliminary remark would have required, but at the end, almost incidentally, as if it was widely accepted: “there is no doubt”, in the Supreme Court’s view, that such treatment is medical, because it implies a scientific knowledge, is practiced by physicians, even if it is carried out by paramedics, and consists in giving chemical compounds, through technological procedures.

Given the qualification of life-sustaining treatment as medical acts, in the Corte di Cassazione’s arguments it is regulated by article 32 of the Italian Constitution.

After proclaiming that “The Republic safeguards health as a fundamental right of the individual and as a collective interest, and guarantees free medical care to the indigent”, article 32 maintains that “No one may be obliged to undergo any health

¹⁵ On the right to health in the Italian Constitution see, *ex multis*, R. Ferrara, *Il diritto alla salute: i principi costituzionali*, in Id. (ed.), *Salute e sanità* (2010), 3 ss., in S. Rodotà-P. Zatti (eds.), *Trattato di Biodiritto*; Id., *L’ordinamento della Sanità* (2007), 37 ss.; N. Aicardi, *La sanità*, in S. Cassese (ed.), *Trattato di diritto amministrativo. Diritto amministrativo speciale*, I (2003), 625 ss.; D. Morana, *La salute nella Costituzione italiana. Profili sistematici* (2002); C.M. D’Arrigo, entry *Salute (diritto alla)*, in *Enc. dir., Aggiornamento-V* (2001), 1009 ss.; M. Cocconi, *Il diritto alla tutela della salute* (1998); B. Pezzini, *Principi costituzionali e politica nella Sanità: il contributo della giurisprudenza costituzionale alla definizione del diritto sociale alla salute*, in C.E. Gallo-B. Pezzini (eds.), *Profili attuali del diritto alla salute* (1998), 1 ss.; M. Luciani, entry *Salute (diritto alla salute – dir. cost.)*, in *Enc. giur. Treccani*, XXVII (1991); Id., *Il diritto costituzionale alla salute*, 4 *Dir. e società*, 769 (1980); B. Caravita, *La disciplina costituzionale della salute*, 1 *Dir. e società*, 21 (1984).

treatment except under the provisions of the law. The law may not under any circumstances violate the limits imposed by respect for the human person”.

In the Constitutional perspective, the acknowledgment of the right to health, a many-sided right, also grants the right of self determination, that is the right of a patient to decide about medical treatment. This means that an individual may choose to receive a therapy, may express a preference for a particular treatment instead of another, but may also decide not to be submitted to any therapy at all: the right of self determination has both a positive dimension and a negative one.

The right of self determination has been sealed and implemented by the elaboration of the principle of informed consent¹⁶, that represents the legal grounds of every medical treatment. In fact, without it, a medical intervention is a tort, even if it is in the patient’s interest.

In the Italian Constitution the informed consent principle finds different bases: article 2, that protects the inviolable rights of the person; article 13, that guarantees personal freedom and, of course, article 32, specific to the right to health.

The principle of informed consent is established also by international sources, to which the Corte di Cassazione’s judgment refers: in particular, the Oviedo Convention, “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”, issued on 4 April 1997. It must be observed that its ratification has been authorized by law 145 of 28 March 2001, but the instrument of ratification has not been deposited with the Council of Europe; therefore the Convention is not in force in Italy; nevertheless authors and jurisprudence constantly refer to it as a fundamental interpretative means¹⁷.

¹⁶ On the principle of informed consent see, in general, M. Graziadei, *Il consenso informato e i suoi limiti*, in L. Lenti-E. Palermo Fabris-P. Zatti (eds.), *I diritti in medicina* (2011), 191 ss., in S. Rodotà-P. Zatti (eds.), *Trattato di Biodiritto*; A. Pioggia, *Consenso informato ai trattamenti sanitari e amministrazione della salute*, 1 Riv. trim. dir. pubbl. 127 (2011).

¹⁷ On the ratification process of the Oviedo Convention and its implications see C. Casonato, *supra* note 2, at 108-109.

Article 5 of the Convention establishes, as a “general rule”, that “an intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time”.

Finally, the principle of informed consent is also provided by the Charter of Fundamental Rights of the European Union, signed and proclaimed on 7 December 2000, to which the Treaty of Lisbon, that entered into force in December 2009, has conferred the same value as Treaties.

It is noteworthy that the Charter has a specific Title, Title I, entitled “Dignity”, article 1 of which proclaims: “Human dignity is inviolable. It must be respected and protected”. In the same Title article 3, related to the “Right to the integrity of person”, includes “the free and informed consent of the person concerned, according to the procedures laid down by law” among the principles to be observed in the fields of medicine and biology.

4. The withdrawal of medical treatment by decisionally incapable individuals

Recognition of the right to refuse medical treatment collides with two extreme cases that hinder individuals in their assertion of it¹⁸.

The first one can be identified in the condition of a decisionally capable person, that cannot physically withdraw a particular treatment. This is, for instance, the situation of patients affected by amyotrophic lateral sclerosis, muscular dystrophy, and so on: the wish of these subjects to interrupt the medical treatment they are undergoing (generally artificial feeding and artificial respiration), requires the intervention of a third person. In Italy this issue has been the subject of the case of Welby, who was affected by muscular dystrophy; however this case will not be analyzed in this paper.

¹⁸ For the analysis of these two situations see G.U. Rescigno, *Dal diritto di rifiutare un determinato trattamento sanitario secondo l'art. 32, co. 2, Cost., al principio di autodeterminazione intorno alla propria vita*, 1 Dir. pubbl. 85 (2008).

The second situation, embodied by the Englaro case, pertains to decisionally incompetent individuals, that are unable to decide the beginning, the prolonging and the end of a medical treatment¹⁹.

Even if the guardian, according to articles 357 and 424 of the Italian Civil Code, takes care of the incapacitated person, his entitlement to address a petition for the authorization to stop artificial hydration and nutrition has been uncertain in the jurisprudence.

Initially, the Corte di Cassazione²⁰ denied the possibility of the guardian to act as a substitute decision maker with regard to very personal decisions, like the ones involving life and death, that imply ethical, religious and, in any case, extra-juridical conceptions.

Also for this reason, as Eluana was incapacitated, and therefore unable to make her choices, in 2005 the Supreme Court held the necessity to appoint a special curator, provided by the Civil Procedure Code in case of conflict of interests with the guardian.

In decision n. 21748/2007 the Supreme Court has partially changed position, giving the guardian the possibility to take end-of-life-related decisions, always with the intervention of a curator. The Corte di Cassazione's ruling holds that the principle of informed consent, together with the principle of equal treatment of every individual, requires the recreation also in cases where decisionally incapable individuals are involved of the duality of subjects that characterize the medical decision, that is the doctor-patient relationship, with the consequence that the guardian has the right, in the exercise of his duty of care, to express the informed consent or deny it.

However, the role of the guardian encounters some limits.

¹⁹ On these specific issues see L. d'Avack, *Il rifiuto delle cure del paziente in stato di incoscienza*, in S. Canestrari-G. Ferrando-C.M. Mazzoni-S. Rodotà-P. Zatti (eds.), *supra* note 3, at 1917 ss.; E. Salvaterra, *Autodeterminazione e consenso nell'incapacità e capacità non completa. Capacità e competence*, in L. Lenti-E. Palermo Fabris-P. Zatti (eds.), *supra* note 16, at 341 ss.; M. Piccinni, *Autodeterminazione e consenso nell'incapacità e capacità non completa. Relazione terapeutica e consenso dell'adulto "incapace": dalla sostituzione al sostegno*, *ibid.*, at 361 ss.

²⁰ Cass. Civ., sect. I, ord. n. 8291/2005.

Since the right to health is personal and has a really private dimension, the guardian cannot replace the patient's will, depriving him/her of the power to decide regarding his/her health and, in the end, about life and death.

First of all, the guardian must decide in the patient's best interests.

Secondly, in doing so, he must act neither "in place of" nor "for" the patient, but "with" the patient, trying to reconstruct his/her presumed will before the state of unconsciousness. Finally, he must consider the subject's previous wishes, personality, lifestyle, inclinations, values, ethical, religious, cultural and philosophical convictions.

As specified by the Court of Appeal's decree of 2008, the guardian must be the patient's "spokesman", "nothing more and nothing less".

As we will see in the following pages²¹, Italian jurisprudence has borrowed these concepts from the legal tradition of the U.S.

It can be observed that, as to the definition of the guardian's role, the Oviedo Convention comes into consideration again.

Article 6, dedicated to "Persons not able to consent", after stating 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", establishes 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. The individual concerned shall as far as possible take part in the authorisation procedure".

Among the most significant provisions of the Oviedo Convention there is also article 9, according to which "The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account".

²¹ See, in particular, section 8.

5. The Englaro case before the Constitutional Court: the complex relationship between law and justice in granting Constitutional rights

After the Supreme Court recognized Eluana's right to stop artificial hydration and nutrition, claimed by her father as her guardian, there were many attempts at impeding its fulfillment²².

In September 2008 the Chamber of Deputies and the Senate challenged the Constitutional Court raising a conflict of competence between the judiciary, which would have intruded into legislative power, replacing the legislative function, and the legislature.

Firstly the legislature recognized an hypothesis of *vindicatio potestatis*, a kind of conflict that emerges when a branch of government is exercising a power that belongs to another branch of government. The Corte di Cassazione would have filled the gap of regulation in the end-of-life field with a ruling, whose principles had been applied by the Court of Appeal of Milan, that, according to the Parliament, was substantially a legislative act. Moreover, the Corte di Cassazione should have challenged the constitutionality of the provisions that, in the Italian Civil Code²³, exclude from the powers of the guardian the possibility to take decisions regarding the incapacitated person's life in the absence of a living will, instead of disapplying them, and substituting them with a regulation drawn up *ex novo*.

Secondly, the conflict would have derived from the interference of the Corte di Cassazione and of the Court of Appeal of Milan with the legislative procedure, regarding the enactment of a law on living wills, that was still in progress.

The Constitutional Court, with its decision n. 334 of 8 October 2008²⁴, declared the claim inadmissible, stating that there had not been any invasion or interference with the legislative

²² For an overview of such episodes see S. Rodotà, *Il caso Englaro: una cronaca istituzionale*, 2 *Micromega* 77, 81-83 (2009); T. Groppi, *Il caso Englaro: un viaggio alle origini dello Stato di diritto e ritorno* (5 March 2009), on <http://www.astrid.eu>.

²³ The reference is to articles 357 and 424 of the Italian Civil Code.

²⁴ Corte Cost., 8 October 2008, n. 334, 1 *Foro it.* I 35, (2009), with comment of R. Romboli, *I conflitti tra poteri dello Stato sulla vicenda E.: un caso di evidente inammissibilità*. On this decision see also R. Caponi-A. Proto Pisani, *supra* note 12; R. Bin, *Se non sale in cielo non sarà forse un raggio d'asino? (a proposito dell'ord. 334/2008)*, on <http://www.forumcostituzionale.it>.

power; in fact Parliament could enact a statute on advance directives at any time. Moreover, the Court held that the conflict of competence that had been raised set out a logical and juridical route which was different from the one followed by the judiciary and therefore had been transformed into an atypical instrument of impugment.

As regards the legislature's censure according to which the judiciary should have challenged the constitutionality of the existing regulation of the guardian's powers, it is important to observe that the Constitutional jurisprudence has progressively enhanced the interpretative powers of the judges, who are called to evaluate if it is possible to find an interpretation consistent with the Constitution, before challenging the constitutionality of a law. In short, a law cannot be challenged and declared unconstitutional because there may be unconstitutional interpretations; this can happen only when it is impossible to give interpretations consistent with the Constitution²⁵.

This implies that the judiciary can apply directly provisions of the Constitution.

An example of this reasoning in the health field can be read in the Constitutional jurisprudence²⁶ on so-called "biological damage"²⁷, which has given a Constitutional reading of article 2043 of the Civil Code²⁸, closely integrated by article 32 of the Constitution, which safeguards the right to health.

The Corte di Cassazione's ruling, which recognized Eluana Englaro's right to withdraw life-sustaining treatment, claimed by her father, as her guardian, can be also seen as the effect of the more active role of the ordinary judges encouraged by the Constitutional Court. This is the consequence of an evolution towards a "mild" coexistence of law, rights and justice, according

²⁵ On these aspects see the in-depth analysis of R. Romboli, *supra* note 24, at 52-53.

²⁶ Corte Cost., 14 July 1986, n. 184, Foro it. I 2053 (1986).

²⁷ According to articles 138, section 2, lett. a), and article 139, section 2 of Legislative Decree 7 September 2005, n. 209, which has implemented the precepts of the Constitutional Court, "biological damage" is "a temporary or permanent lesion to the psycho-physical integrity of the person ascertainable by medical examiners which has a negative impact on the daily activities and on the dynamic-relational aspects of the life of the damaged person, irrespective of any repercussions on his/her capacity to generate income".

²⁸ Article 2043 of the Italian Civil Code regulates liability for damages.

to which “law cannot be the object of the property of one, but the object of the care of many”²⁹.

6. The other attempts not to comply with the Corte di Cassazione and the Court of Appeal’s decisions. In particular: the administrative obstacles that brought the Englaro case before the Administrative Judge and the attempt of the Government to override the Courts’ rulings with a law decree

The Englaro case also crossed the Italian borders. Some associations of relatives and friends of severely disabled persons brought a suit before the European Court of Human Rights (ECHR), arguing that the ruling authorizing the withdrawal of Eluana’s naso-gastric tube was in contrast with the right to life and the principle of non discrimination laid down in the European Convention of Human Rights. The Court held that the petitioners had no relationship with Eluana Englaro and on 22 December 2008 issued an inadmissibility decision³⁰.

In complying with the Corte di Cassazione and the Court of Appeal of Milan’s rulings, Eluana’s father also faced many administrative obstacles placed by the Lombardy Regional Administration and the Minister of Health.

Despite the Court of Appeal’s permission to withdraw Eluana’s artificial hydration and nutrition, neither the nursing home where she was, nor the competent hospital were willing to stop them. Therefore Mr. Englaro asked Lombardy’s regional health care system to indicate an institution where it was possible to comply with the Court of Appeal’s decree.

The Director of the Lombardy’s regional health care regional system issued a statement replying that it was impossible to accomplish this request for two reasons. First of all, the health care system does not have the duty to admit patients that a priori refuse treatment necessary for their life; the duty of care does not encompass the admission of patients in need of interventions such

²⁹ G. Zagrebelsky, *Il diritto mite* (1992), 213. This position is recalled by R. Romboli, *supra* note 24, at 51-52, who draws an outline of the different forms and ways through which the legislature and the judiciary concur in law production.

³⁰ European Court of Human Rights, 22 December 2008, Rossi and others c. Italia, 3 Foro it. IV 109 (2009).

as the termination of current treatment. Secondly, the withdrawal of artificial hydration and nutrition constitutes a violation of the physicians' and paramedics' professional duties.

Eluana's father sought the annulment of this statement before the Administrative Tribunal of Lombardy-Milan, that issued a decision of annulment on 26 January 2009³¹.

According to Lombardy's Administrative Judge, not admitting a patient who needs support for stopping medical treatment – even if this will lead to the person's death – is a violation of article 32 of the Italian Constitution, that guarantees the right to refuse medical treatment.

The admission of a person to a health care institution cannot be made conditional on the renunciation of a fundamental right.

As to the supposed violation of the physicians' and paramedics' professional duties, the Administrative Tribunal replied that the respect of the right to refuse medical treatment is owed to any person that has a relationship with the patient, including the health care professionals.

In the Administrative Judge's view the admission of a patient cannot be denied even on the ground of conscientious objection³²: the Administrative Tribunal adhered to a position, shared by part of the legal literature, according to which conscientious objection must be established in law³³ and, in any case, the health care institution involved must guarantee the patient's right of self determination.

³¹ Lombardy Administrative Tribunal (TAR), sect. III, 26 January 2009, n. 214, 4 Foro amm. TAR 976 (2009), with comment of V. Molaschi, *Riflessioni sul caso Englaro. Diritto di rifiutare idratazione ed alimentazione artificiali e doveri dell'amministrazione sanitaria*. On this decision see also the comment of A. Pioggia, *Consenso informato e rifiuto di cure: dal riconoscimento alla soddisfazione del diritto*, 3 *Giornale dir. amm.*, 267 (2009).

³² On the possible conflictual situations that may arise, within the framework of relationships between a health care administration and users, between, on the one hand, the right of the latter to obtain a certain service and, on the other, the freedom claimed, by health care staff, of not providing treatment that contrasts with their own convictions, that is expressed in conscientious objection, be allowed, see V. Molaschi, *I rapporti di prestazione nei servizi sociali. Livelli essenziali delle prestazioni e situazioni giuridiche soggettive* (2008), 149 ss. and 280 ss.

³³ On this aspect see B. Randazzo, entry *Obiezione di coscienza (dir. cost.)*, in *Dizionario di diritto pubblico*, edited by S. Cassese, IV (2006), in particular at 3872-3873.

It can be noted that the idea that the health care system has only a “positive” duty of care reflects a strict view of health as a mere absence of disease or infirmity and not as “a state of complete physical, mental and social well-being”, according to the definition of the World Health Organization³⁴.

The value of the human being that inspires the whole Italian Constitution implies that health protection must be functional to the individual and not the contrary. Health is part of the development of persons and of their personality, as implied by a systematic interpretation of articles 2, 3 and 32 of the Italian Constitution.

Moreover, it is essential to observe that the “respect for the human person” prescribed by the Constitution with regard to involuntary treatment provided by law applies also to voluntary ones³⁵.

It was also difficult to find an institution that admitted Eluana because on 16 December 2008 the Minister of Health issued recommendations to all National Health System-accredited institutions against the withdrawal of artificial hydration and nutrition from permanent vegetative state patients³⁶.

Subsequently a Health System-accredited nursing home in Udine, in the region Friuli Venezia Giulia, that had volunteered to admit Eluana, on 16 January 2009 withdrew the offer.

On 17 January 2009, as a result of the Radical Party’s denunciation, the Minister of Health was under investigation by the Prosecutor’s office of Rome for the crime of coercion. It can be said in advance that a dismissal decree would be issued on 20 May 2009 by the competent Ministers’ Tribunal.

³⁴ “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”: Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946, signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, 100) and entered into force on 7 April 1948. The definition has not been amended since 1948.

³⁵ See R. Ferrara, *L’ordinamento della Sanità*, *supra* note 15, at 77.

³⁶ For a critical analysis of these recommendations see F.G. Pizzetti, *L’atto del Ministro Sacconi sugli stati vegetativi, nutrizione e idratazione, alla luce dei principi di diritto affermati dalla Cassazione nel caso Englaro* (29 December 2008), on <http://www.astrid-online.it/Libert--di/TESTAMENTO/>.

In the end, on 3 February 2009, Eluana was brought to another nursing home, that was in Udine too.

It is important to remember that other regions showed important autonomy from the Minister's recommendations: the Presidents of Piedmont and Tuscany declared that they did not see any obstacle to admitting Eluana in one of the health care institutions of their regions³⁷.

A team of health care professionals, led by the head of the ICU of the local university hospital, an anesthesiologist, volunteered to withdraw Eluana's artificial hydration and nutrition and take care of her in the last phase of her life, without being paid.

The Italian Government tried to intervene and stop the procedure of withdrawing hydration and nutrition with a decree, containing a unique provision, stating that pending the enactment of a complete and organic law on advance directives, nutrition and hydration, as life-sustaining treatment, physiologically oriented to soften pain, could not be withdrawn by those who take care of subjects that are unable to look after themselves.

Article 77 of the Italian Constitution establishes that the Government, in case of necessity and urgency, can adopt under its own responsibility a temporary measure, provided that it shall introduce such a measure to Parliament for conversion into law. In any case, according to article 87, decrees having the force of law are issued by the President of the Republic.

The President of the Republic refused to sign the decree aimed at prohibiting the withdrawal of life-sustaining treatment, writing an open letter to the President of the Council of Ministers³⁸, in order to avoid an institutional conflict³⁹.

The refusal of the President of the Republic was based on different reasons⁴⁰: the inappropriateness of a governmental

³⁷ See statements of the President of the Piedmont region Mercedes Bresso in the interview of Marco Todarello, *Bresso: il Piemonte pronto per Eluana*, on <http://www.lastampa.it> (20 January 2009).

³⁸ The President of the Council of Ministers is the Italian Prime Minister.

³⁹ The letter (6 February 2009) that the President of the Republic Napolitano sent to President of the Council of Ministers Berlusconi can be read on <http://www.astrid-online.it/FORUM--II-/>.

⁴⁰ On the refusal of the President of the Republic see, *ex multis*, some of the several articles published on <http://www.astrid-online.it/FORUM--II-/>: U. Allegretti, *Un rifiuto presidenziale ben fondato* (12 February 2009); M. Luciani,

decree to regulate end-of-life issues such as living wills and the withdrawal of artificial hydration and nutrition, a subject, involving fundamental rights, that must be regulated by Parliament; the absence of a situation of necessity and urgency, that cannot consist in the publicity and drama of a single case (nothing new had occurred during the Parliamentary debate on end-of-life decisions that could justify such a decree); the principle of the separation of powers, that does not allow the failure to comply with a final judgment such as the decree of the Court of Appeals, issued in accordance with the principles established by the Corte di Cassazione.

After the President's refusal the decree was converted into a bill (bill n. 1369), reproducing the unique provision of the decree, whose approval, according to the President of the Council of Ministers, should occur "within three days", introduced in the Senate on 6 February 2009.

On 7 February 2009, Eluana's feeding tube was removed. On 9 February Eluana died.

Eluana's death interrupted the Parliamentary debate on the bill. In any case, in the Italian legal system, the principle according to which the legislative intervention finds a limit in final judgments (*res judicata*) is in force. Therefore, according to scholars, such a law, if enacted, would have been, either "practically useless"⁴¹ or unconstitutional⁴².

After Eluana's death the Prosecutor's office of Udine took the medical record and Eluana's father and all the health

L'emanazione presidenziale dei decreti-legge (spunti a partire dal caso E.) (5 March 2009); V. Onida, *Il controllo del Presidente della Repubblica sulla costituzionalità dei decreti-legge* (9 February 2009); F.G. Pizzetti, *In margine ai profili costituzionali degli ultimi sviluppi del caso Englaro: limiti di legge e "progetto di vita"* (5 March 2009); A. Ruggeri, *Il caso Englaro e il controllo contestato* (11 February 2009); S. Stammati, *Breve nota sui problemi costituzionali suscitati dal caso Englaro* (15 February 2009); A. Pace, *L'inutilità pratica della legge "per Eluana"* (Text revised and integrated by the author of the article published in *La Repubblica* of 11 February 2009 entitled *Quella legge ancora inutile*). On this subject see also A. Spadaro, *Può il Presidente della Repubblica rifiutarsi di emanare un decreto legge? Le "ragioni" di Napolitano*, on <http://www.forumcostituzionale.it>; R. Caponi-A. Proto Pisani, *supra* note 12.

⁴¹ A. Pace, *supra* note 40.

⁴² See M. Luciani, *supra* note 40, at 18-19. For the claim of unconstitutionality see also R. Caponi-A. Proto Pisani, *supra* note 12, at 987.

professionals involved in the procedure of withdrawal of her life-sustaining treatment were investigated for the murder of the woman. After expert evidence from which the irreversibility of Eluana's permanent vegetative state was ascertained, the charges of the Prosecutor's office were dismissed on 11 January 2010 and the magistrate in charge of preliminary investigations closed the case.

7. The Terri Schiavo case: an overview

The Terri Schiavo case⁴³ split U.S. public opinion like the Englaro case transfixed Italy. It could be interesting to make a comparison between the two cases, to point out their similarities and differences and, in particular, to evaluate if and how the Terri Schiavo case, which occurred before the Englaro case, has influenced the latter.

In the knowledge and dialectic comparison with foreign experiences, the legal system finds a key factor for understanding its own dynamics and for assessing the suitability and efficiency of its own solutions.

⁴³ On the origins and the evolution of the end-of-life issues in the United States of America see F.G. Pizzetti, *supra* note 6, at 401 ss.; M. Motroni, *La giurisprudenza statunitense e italiana in tema di eutanasia e scelte di fine vita: spunti per una comparazione*, in U. Breccia-A. Pizzorusso, *Atti di disposizione del proprio corpo*, R. Romboli ed. (2007), 319 ss., where it is possible to read a complete analysis of the *Terry Schiavo* Case. On this case see, among the others, K.L. Cerminara, *Critical Essay: Musings on the Need to Convince Some People with Disabilities That End-of-life Decision Making Advocates Are Not Out to Get Them*, 37 *Loyola University Chicago Law Journal* 343 (2006); Id., *Tracking the Storm: The Far-Reaching Power of the Forces Propelling the Schiavo Cases*, 35 *Stetson Law Review* 147 (2005). For an accurate examination of the legal dispute see O. Carter Snead, *Dynamic Complementarity: Terri's Law and Separation of Powers Principles in the End of life Context*, 57 *Florida Law Review* 53 (2005); Steven G. Calabresi, *The Terri Schiavo Case: In Defense of the Special Law Enacted by Congress and President Bush*, 100 *Nw. U. L. Rev.* 151 (2006); Jay Wolfson, *A report to Governor Jeb Bush and the 6th Judicial Circuit in The Matter of Theresa Schiavo* (1 December 2003), on <http://abstractappeal.com/schiavo/WolfsonReport.pdf>. More in general, on advance directives in common law systems see R.E. Cerchia, *Le "advance directives" nei Paesi di common law, prospettive per il nostro ordinamento*, 6 *Riv. dir. civ.* 732 (2005). With particular reference to the end-of-life issues in Canada see V. Molaschi, *Le decisioni di fine vita in Canada: spunti di riflessione per il dibattito sul testament biologico in Italia*, 5 *Sanità Pubblica e Privata* 5 (2011).

The circulation of models appears as a natural support to legal studies and jurisprudential evolution; this is all the more valid if we consider the transnational character of the biomedical and biotechnological revolution, including in terms of “biolaw”.

Theresa Marie Schiavo was a severely brain damaged woman, who had been in a permanent or persistent vegetative state for many years, as a consequence of the neurological damage she suffered after an heart attack in 1990, which had left her brain without oxygen for several minutes. When this tragedy struck, she had not written a living will.

After having taken care of her, with her parents, for some years, her husband, Michael Schiavo, who was her legal guardian, petitioned the Circuit Court of Pinellas County, in Florida, for an order directing the withdrawal of her hydration and feeding tube. He claimed that his wife, who was completely unconscious, with no hope of improvement, before the heart attack had expressed to him her wish not to be kept alive artificially, in the case that she became incapacitated.

In February 2000, the Trial Court recognized that there was clear and convincing evidence that Mrs. Schiavo was in a permanent or persistent vegetative state, without chances of recovering capacity and that she would have wanted the removal of her feeding and hydration tube⁴⁴.

Terri Schiavo’s parents, Mary and Robert Schindler, who thought she was responsive and communicated with them and therefore wanted her to be kept alive⁴⁵, appealed.

⁴⁴ The opinion of the Trial Judge Greer in the Circuit Court of Pinellas County, Florida, is unpublished, but it is summarized in Florida District Court of Appeals Judge Altenbernd’s third appellate opinion regarding the case, *Schindler v. Schiavo (In re Schiavo)*, 800 So. 2d 640 (Fla. Sist. Ct. App. 2001), as follows: “(1) Mrs. Schiavo’s medical condition was the type of end-stage condition that permits the withdrawal of life prolonging procedures», (2) she did not have a reasonable medical probability of recovery capacity, so that she could make her own decision to maintain or withdraw life prolonging procedures, (3) the trial court had the authority to make such a decision when a conflict within the family prevented a qualified person from effectively exercising the responsibilities of a proxy, and (4) clear and convincing evidence at the time of trial supported a determination that Mrs. Schiavo would have chosen in February 2000 to withdraw the life prolonging procedures”.

⁴⁵ The Schindlers also argued that Michael Schiavo was not a fit guardian: he had been regularly dating other women since 1993 and he did not give adequate care to his wife.

In January 2001, the Court of Appeal of Florida, Second District, rejected Terri Schiavo parents' claim, confirming the lower Judge's decision⁴⁶.

The Schindlers sought review of the District Court decision, but in April 2001 the Supreme Court of Florida determined to decline to accept jurisdiction and ordered that the petition for review was denied⁴⁷. The next day Terri Schiavo's hydration and feeding tube was clamped.

Her parents filed a motion for relief of judgment, under the Florida Rule of Civil Procedure, maintaining that new evidence showed that Michael Schiavo and their daughter had never discussed her will in case of incapacitation. Pending the suit, the feeding tube was reactivated.

Followed a complex judicial battle, whose outcome resulted in various decisions authorizing termination of Terri Schiavo's life support⁴⁸. The decisions referred to the same grounds: Mrs. Schiavo's vegetative state was irreversible, without any possibility to increase her cognitive functions and there was clear and convincing evidence that she would have wished to withdraw artificial hydration and nutrition.

In October 2003, after the Florida Second District Court of Appeal⁴⁹ had rejected for the fourth time the Schindlers' request to conduct a de novo review of the Trial Court's judgment, affirming that, in any case, it would still have confirmed the lower Court's decision, the removal of Terri Schiavo's life prolonging measures was scheduled again.

⁴⁶ *Schindler v. Schiavo (In re guardianship of Schiavo)*, 780 So. 2d 176 (Fla 2d DCA 2001) (*Schiavo I*). The Court had no doubt about Terri Schiavo's conditions: "The evidence is overwhelming that Theresa is in a permanent or persistent vegetative state. (...) Over the span of this last decade, Theresa's brain has deteriorated because of the lack of oxygen it suffered at the time of the heart attack. By mid-1996, the CAT scans of her brain showed a severely abnormal structure. At this point, much of her cerebral cortex is simply gone and has been replaced by cerebral spinal fluid. Medicine cannot cure this condition". This is also the opinion of the following judicial decisions. However, some scholars have many doubts about the sufficiency of medical assessment of Terri Schiavo's brain activity: see Steven G. Calabresi, *supra* note 43, at 154-155.

⁴⁷ *Schindler v. Schiavo*, 789 So. 2d 348 (2001 Fla)

⁴⁸ *In re Schiavo*, 792 So. 2d 551 (Fla. 2d DCA 2001) (*Schiavo II*); *In re Schiavo*, 800 So. 2d 640 (Fla. 2d DCA 2001) (*Schiavo III*); *In re Schiavo*, 851 So. 2d 182 (Fla. 2d DCA 2003) (*Schiavo IV*).

⁴⁹ *In re Schiavo*, 851 So. 2d 182 (Fla. 2d DCA 2003) (*Schiavo IV*).

After the judiciary gave permission to withdraw Terry Schiavo's artificial hydration and nutrition, newspapers, radio and television focused great attention on the case. Part of the public opinion, moved by the perception of a disabled person who could not stand up for herself to get the care she needed, asked the Governor of Florida, Jeb Bush, brother of the President of the U.S. George W. Bush, to intervene, to stop what was seen as a death by starvation and dehydration.

The result of this popular pressure was Public Law 2003-41850, which allowed the Governor to issue a stay to prevent the withholding of nutrition and hydration from a patient under the specific circumstances: (a) that patient had no written advance directive; (b) the court had found that patient to be in a persistent vegetative state; (c) that patient had had nutrition and hydration withheld; and (d) a member of that patient's family had challenged the withholding of nutrition and hydration⁵¹.

Since it was clear that this law was apparently general, but, de facto, enacted for Terri Schiavo, it was called "Terri's law".

⁵⁰ Public Law 03-418: "An act relating to the authority for the Governor to issue a one-time stay; authorizing the Governor to issue a one-time stay to prevent the withholding of nutrition and hydration under certain circumstances; providing for expiration of the stay; authorizing the Governor to lift the stay at any time; providing that a person is not civilly liable and is not subject to regulatory or disciplinary sanctions for taking an action in compliance with any such stay; providing for the Chief Judge of the Circuit Court to appoint a guardian *ad litem*; providing an effective date".

⁵¹ The law, brief and unequivocal, stated: «Section 1. (1) The Governor shall have the authority to issue a one-time stay to prevent the withholding of nutrition and hydration from a patient if, as of October 15, 2003: (a) That patient has no written advance directive; (b) The court has found that patient to be in a persistent vegetative state; (c) That patient has had nutrition and hydration withheld; and (d) A member of that patient's family has challenged the withholding of nutrition and hydration.

(2) The Governor's authority to issue the stay expires 15 days after the effective date of this act, and the expiration of the authority does not impact the validity or the effect of any stay issued pursuant to this act. The Governor may lift the stay authorized under this act at any time. A person may not be held civilly liable and is not subject to regulatory or disciplinary sanctions for taking any action to comply with a stay issued by the Governor pursuant to this act.

(3) Upon issuance of a stay, the Chief Judge of the Circuit Court shall appoint a guardian *ad litem* for the patient to make recommendations to the Governor and the Court. Section 2. This act shall take effect upon becoming a law".

The bill was introduced one day and became a law the next, on 21 October 2003. Governor Bush issued an Executive Order to restore life support treatment to Terri Schiavo⁵², who, in the meanwhile, had been without nutrition and hydration for almost one week.

On the same day Michael Schiavo challenged the constitutionality of the law. The Circuit Court entered a final summary judgment on 6 May, 2004, in favor of him, finding the Act unconstitutional.

The Trial Court's decision was confirmed by the Supreme Court of Florida, which declared Chapter 2003-418 unconstitutional, as applied to Terri Schiavo⁵³.

Specifically, the Court based the declaration of unconstitutionality on the ground of the principle of the separation of powers, expressly codified in article II, section 3, of the Florida Constitution.

The doctrine of the separation of powers, which is “the cornerstone of American democracy”⁵⁴ too, embraces two fundamental prohibitions: “The first is that no branch may encroach upon the powers of another. The second is that no branch may delegate to another branch its constitutionally assigned power”⁵⁵. According to the Court, chapter 2003-418 violated both of these prohibitions.

As to the former, the Act, as applied to the Schiavo case, “resulted in an executive order that effectively reversed a properly rendered final judgment and thereby constituted an

⁵² Executive Order n. 03-201, Florida Governor's Office, 21 October 2003: “A. Effective immediately, continued withholding of nutrition and hydration from Theresa Schiavo is hereby stayed. B. Effective immediately, all medical facilities and personnel providing medical care for Theresa Schiavo, and all those acting in concert or participation with them, are hereby directed to immediately provide nutrition and hydration to Theresa Schiavo by means of a gastronomy tube, or by any other method determined appropriate in the reasonable judgment of a licensed physician. C. While this order is effective, no person shall interfere with the stay entered pursuant to this order. D. This order shall be binding on all persons having notice of its provisions. E. This order shall be effective until such time as the Governor revokes it. F. The Florida Department of Law Enforcement shall serve a copy of this Executive Order upon the medical facility currently providing care for Theresa Schiavo”.

⁵³ *Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2004).

⁵⁴ *Bush v. Schiavo*, 885 So. 2d at 328.

⁵⁵ *Chiles v. Children A, B, C, D, E, & F*, 589 So. 2d 260, 264 (Fla 1991).

unconstitutional encroachment on the power that has been reserved for the independent judiciary”⁵⁶. Terri’s law realized a sort of “legislative adjudication”⁵⁷.

As to the latter prohibition, expression of the non delegation doctrine, the Court established⁵⁸ that, “in enacting chapter 2003-418, the Legislature failed to provide any standards by which the Governor should determine whether, in any given case, a stay should be issued and how long a stay should remain in effect”. Moreover, the Legislature failed to provide any criteria for lifting the stay. The absolutely unlimited discretion to decide whether to issue and then when to lift the stay made the Governor’s decision “virtually unreviewable”⁵⁹.

The unrestricted Governor’s discretion in applying the law was particularly problematic, because it affected rights established in the Constitution: the open-ended delegation of authority by the Legislature to the Governor provided no guarantee for the incompetent patient’s right to withdraw life-prolonging procedures⁶⁰.

⁵⁶ *Bush v. Schiavo*, 885 So. 2d at 331. The Court stated (at 332): “When the prescribed procedures are followed according to our rules of court and governing statutes, a final judgment is issued, and all post-judgment procedures are followed, it is without question an invasion of the authority of the judicial branch for the Legislature to pass a law that allows the executive branch to interfere with the final judicial determination in a case. That is precisely what occurred here and for that reason the Act is unconstitutional as applied to Theresa Schiavo”.

⁵⁷ C. Dorf, *How The Florida Legislature and Governor Have Usurped the Judicial Role in the Schiavo “Right to Die case”*, on <http://writ.news.findlaw.com/dorf/20031029.html>, 4. For a different stance see G. LOMBARDI, *Il caso Terri Schiavo. Intervista a Giorgio Lombardi*, 3 Quad. cost. 695, 698 (2005).

⁵⁸ *Bush v. Schiavo*, 885 So. 2d at 334.

⁵⁹ “When legislation is so lacking in guidelines that neither the agency, nor the courts can determine whether the agency is carrying out the intent of the legislature in its conduct, then, in fact, the agency becomes the lawgiver, rather than the administrator of the law”: *Askew v. Cross Key Waterways*, 372 So. 2d, 913, at 918-919 (Fla. 1978).

⁶⁰ *Bush v. Schiavo*, 885 So. 2d at 336. See *In re Guardianship of Browning*, 568 So. 2d 4, at 12, which affirmed that an incompetent person has the same right to refuse medical treatment as a competent person.

The Schindlers immediately appealed to the U.S. Supreme Court on 24 January 2005, but the petition for writ of certiorari was denied⁶¹.

Terri Schiavo's feeding tube was removed again on 18 March 2005.

Republican leaders in the House of Representatives started a congressional inquiry of the House Government Reform Committee, which was to take place in Clearwater on March 25, and issued subpoenas for Terri and Michael Schiavo and several hospice workers. Because of her condition, Terri Schiavo evidently would not have been able to testify; this escamotage, giving to Terri Schiavo federal protection as a prospective witness, was aimed at avoiding the discontinuance of her life-sustaining treatment. The subpoena was ignored by the competent State Judge.

Because of the popular clamor brought about by the case, on 21 March 2005 President Bush signed into law the Act for the Relief of the Parents of Theresa Marie Schiavo⁶², also known as the "Palm Sunday Compromise", to recall the day in which it was passed by the U.S. Senate and House of Representatives⁶³: it allowed Terri's parents to move the case into a Federal Court. In fact, the second "Terri's Law" gave the Federal Courts jurisdiction "to hear, determine, and render judgment on a suit or claim by or on behalf of Theresa Marie Schiavo for the alleged violation of any right of Theresa Marie Schiavo under the Constitution or laws of the United States relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life".

Congress's intervention did not help. The United States District Court for the Middle District of Florida, Tampa Division, denied the Schindlers' motion for a temporary restraining order (TRO) against Michael Schiavo, the hospice and the State Judge,

⁶¹ 125 S. Ct. 1086 (2005).

⁶² Public Law n. 109-3, 119 Stat. 15 (2005). The law established: "In such a suit, the District Court shall determine *de novo* any claim of a violation of any right of Theresa Marie Schiavo within the scope of this Act, notwithstanding any prior State court determination and regardless of whether such a claim has previously been raised, considered, or decided in State court proceedings. The District Court shall entertain and determine the suit without any delay or abstention in favor of State court proceedings, and regardless of whether remedies available in the State courts have been exhausted".

⁶³ It was 20th March 2005.

seeking the reestablishment of nutrition and hydration to Terri⁶⁴. The Court of Appeals for the Eleventh Circuit found that the District Court properly denied the TRO⁶⁵. The application for a stay of enforcement of judgment pending the filing and the disposition of a petition for writ of certiorari were denied by the Supreme Court of the United States⁶⁶.

On 31 March 2005 Terri Schiavo died.

8. The Englaro case and the Schiavo case: a comparison. The influence of the Schiavo case and of U.S. case law on the Englaro case

While in the Italian context the Englaro case is a turning point on the road to the recognition of the right of self-determination – the ruling n. 21748/2007 of Corte di Cassazione's I civil section reversed the statements of the lower Courts and changed its position with respect to its ordinance n. 8291/2005 –, the Schiavo case does not represent a shift in the jurisprudential evolution of the U.S.⁶⁷ In the U.S. the end-of-life is characterized by well-established principles, maintained in important cases.

Moreover, that individuals have the right to refuse and withdraw life-sustaining treatment, even if incapacitated, is well settled under Florida law⁶⁸, under which the Schiavo case was decided, and the statutory law of the various States.

The existence of a regulation of advance directives is another difference between the U.S. and Italy, where such a law does not exist yet.

It is therefore noteworthy that in decision n. 21748/2007 the Italian Corte di Cassazione, given the lack of regulation and the absence of a clear jurisprudential framework, has referred to the end-of-life U.S. cases. In particular, it drew inspiration from In re

⁶⁴ *Schiavo ex rel. Schindler v. Schiavo*, 358 F. Supp. 2d 1161 (M.D. Fla., 2005).

⁶⁵ *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1289 (11th Cir. Fla., 2005), rehearing and injunction denied by *Schiavo ex rel. Schindler v. Schiavo*, 404 F.3d 1282 (11th Cir. Fla., 2005), rehearing, en banc, denied by *Schiavo ex rel. Schindler v. Schiavo*, 404 F.3d 1270 (11th Cir. Fla., 2005).

⁶⁶ 125 S. Ct. 1722 (2005).

⁶⁷ See F.G. Pizzetti, *supra* note 6, at 442.

⁶⁸ See Health care advance directives, Fla. Stat. Ch. 765.101-765.404 (2012).

Quinlan, Jobs and Cruzan, all of them regarding an incompetent person, without a living will, and from the Vacco case.

In the Italian Supreme Court's ruling there is no reference to the Schiavo case. The peculiarity of this case, in fact, lies in the conflict within the family⁶⁹, an aspect that is extraneous to the Englaro case: apart from the fact that Eluana was not married, there was full agreement between her parents regarding her end-of-life choices.

As to *In re Quinlan*⁷⁰, the first and oldest case, recalled by the Italian Supreme Court, the Supreme Court of New Jersey has stated that the right of privacy, which protects a person from intrusion into many aspects of personal decisions⁷¹, is broad enough to encompass the patient's decision to decline medical treatment under certain circumstances: the State's interest, that is the preservation of human life and the defence of the right of the physician to administer medical treatment according to his best judgment, "weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims". According to the Court, "Ultimately there comes a point at which the individual's rights overcome the State interest".⁷²

Moreover, the Court has established that the exercise of the right of choice – ascribable, in the Court's view, to the right of privacy – should be granted also to an incompetent person through the assertion of it, on his/her behalf, by a guardian or family, who render their best judgment, as to whether the patient would exercise it in these circumstances⁷³.

It is in particular this last principle, oriented to ensure that the surrogate decision maker takes as much as possible the

⁶⁹ Terri Schiavo's husband's version of the facts can be read in M. Schiavo-M. Hirsh, *Terri: The Truth* (2006), while the Schindlers' position has been illustrated in M. Schindler – R. Schindler, *A life that Matters: The Legaci of Terri Schiavo – A lesson for Us All* (2006).

⁷⁰ *In re Quinlan*, 70 N.J. 10; 355 A 2d 647 (1976).

⁷¹ For instance, the Supreme Court had stated that the right of privacy embraced also a woman's decision to terminate pregnancy under certain circumstances: *Roe v. Wade*, 410 U.S. 113; 93 S. Ct. 705 (1973).

⁷² *In re Quinlan*, 70 N.J. at 41.

⁷³ When a person is incompetent "the only practical way to prevent destruction of the rights is to permit the guardian and family ... to render their best judgment, subject to qualifications hereinafter stated, as to whether she would exercise it in these circumstances": *In re Quinlan*, 70 N.J. at 41.

decision that the incompetent person would take if he or she were capable, that has been followed by the Italian Supreme Court in authorizing Eluana's father, who was her guardian, to choose the withdrawal of her artificial hydration and nutrition.

With respect to this aspect, the Corte di Cassazione has been also inspired by the *Jobes'* case⁷⁴, in which the Supreme Court of New Jersey has given important indications about the so-called substituted judgment test. Under this doctrine, when the incompetent person's wishes are not clearly expressed, the surrogate considers the patient's system of values, his/her prior statements about and reactions to medical issues, his/her personality, with particular reference to his/her philosophical, theological and ethical convictions, in order to understand what course of medical treatment the person would choose⁷⁵.

The same reasoning was followed by the Italian Court to ascertain Eluana's wishes, given the absence of a living will.

Another pillar of the end-of-life issue in the U.S., that has marked the Italian jurisprudential shift represented by the *Englaro* case, is the *Cruzan* case⁷⁶, in which the Supreme Court of the United States has stated important principles about the informed consent doctrine (it referred to this, rather than the right to privacy, when ascribing the right to refuse treatment).

In particular, the constitutional challenge regarded the Missouri Living Will statute (1986). The Court has held that the due process clause of the Federal Constitution's Fourteenth Amendment does not forbid a State from requiring that evidence of an incompetent individual's wishes as to the withdrawal of life-sustaining treatment be proved by clear and convincing evidence, and thus a State could apply such a standard in proceedings where a guardian sought to discontinue nutrition and hydration of a person diagnosed as being in a persistent vegetative state⁷⁷.

⁷⁴ *In the matter of Nancy Ellen Jobes*, 108 N.J. 394; 529 A.2d 434 (1987).

⁷⁵ *In the matter of Nancy Ellen Jobes*, 108 N.J. at 414-415. See also *In re Roe*, 383 Mass. 415, 442, 421 N.E.2d 40, 56-59 (1981).

⁷⁶ *Cruzan v. Director, Missouri Department of Health*, 497 US 261; 110 S. Ct. 2841 (1990). This decision can be read also in *Foro it. IV 66* (1991), with comments of A. Santosuosso, *Il paziente non cosciente e le decisioni sulle cure: il criterio della volontà dopo Cruzan*, and of G. Ponzanelli, *Nancy Cruzan, la Corte degli Stati Uniti e il "right to die"*.

⁷⁷ "An incompetent person is not able to make an informed and voluntary choice to exercise a hypothetical right to refuse treatment or any other right.

In the Cruzan case there was not clear and convincing proof of the patient's desire to have hydration and nutrition withdrawn. However, this has become a fundamental precedent because, if Nancy Cruzan's will had been expressed without any evident doubt, her Constitutional right to be disconnected from the feeding and hydration tube would have been respected⁷⁸.

The Italian Corte di Cassazione's ruling has referred also to the Vacco case⁷⁹. This case, regarding the different situation of mentally competent terminally ill patients, is mentioned by the Court because it has drawn a "rational" distinction between withdrawing life-sustaining treatment and assisted suicide, prohibited by the overwhelming majority of State legislatures: the former corresponds to the "protected liberty interest in refusing unwanted medical treatment", and is grounded "on well established traditional rights to bodily integrity and freedom from unwanted touching", as maintained in cases like Cruzan; it has nothing to do with a supposed "right to hasten death" implied by the latter.

The more interesting aspect of the Schiavo case is its "politicization"⁸⁰, politicization that will be also one of the features of the Englaro case some years later, as we have seen in

Such a "right" must be exercised for her, if at all, by some sort of surrogate. Here, Missouri has in effect recognized that under certain circumstances a surrogate may act for the patient in electing to have hydration and nutrition withdrawn in such a way as to cause death, but it has established a procedural safeguard to assure that the action of the surrogate conforms as best it may to the wishes expressed by the patient while competent. Missouri requires that evidence of the incompetent's wishes as to the withdrawal of treatment be proved by clear and convincing evidence. The question, then, is whether the United States Constitution forbids the establishment of this procedural requirement by the State. We hold that it does not": *Cruzan v. Director, Missouri Department of Health*, 497 US at 280.

⁷⁸ See C. DORF, *How The Florida Legislature and Governor Have Usurped the Judicial Role in the Schiavo "Right to Die case"*, on <http://writ.news.findlaw.com/dorf/20031029.html>, 2: "the Court in *Cruzan* did not simply say that a State could recognize an incompetent patient's right to have their wishes respected if the requisite evidentiary showing were made. It also implied that a State had to do so, even if it preferred to keep the patient alive indefinitely, because the Constitution requires that the patient's wishes be respected".

⁷⁹ *Vacco v. Quill*, 521 U.S. 793, 117 S. Ct. 2293 (1997).

⁸⁰ Barbara A. Noah, *Politicizing the End of Life: Lessons from the Schiavo controversy*, 59 U. Miami L. Rev. 107 (2004).

the previous sections. From this point of view, it is possible to say that it is this second phase of the Schiavo case, involving the difficult balance between the branches of government (the judicial power, on the one hand, and the legislative and the executive ones, on the other hand), that has more influenced the Englaro case.

There is no doubt that the Italian Government borrowed from the U.S., where there were two “Terri’s laws”, the idea to intervene in the Englaro case with an *ad personam* regulation, affecting, *de facto*, a single lawsuit, which would have been realized through the enactment of a law decree and, subsequently, with a law, neither of which saw the light of the day.

It is interesting to underline that both legal systems have reacted to the governmental attempt to override the final judgments that had authorized the withdrawal of life-sustaining treatment from patients in permanent vegetative state on the grounds of the principle of the separation of powers.

As to the Englaro case, this was due to the Italian President of the Republic, who refused to sign the governmental decree aimed at prohibiting the discontinuance of Eluana’s feeding and hydration tube.

As to the Terri Schiavo case, the principle of the separation was recalled by the Supreme Court of Florida to declare the first “Terri’s law”, Chapter 2003-418, unconstitutional.

As regards the second “Terri’s law”, a comparison with what happened in Italy is more complex. This law pursued the same goal to nullify the prior State court decisions, but in another way: by “federalizing” the Schiavo case⁸¹. Differently from the U.S., Italy is not characterized by judicial federalism.

In any case, it must be highlighted that with the second “Terri’s law” Congress did not give Terri’s parents a real chance of success: it only gave them the possibility to have a Federal Court forum, without granting any new substantive rights⁸².

⁸¹ On this topic see F.G. Pizzetti, *Il giudice nell’ordinamento complesso* (2003).

⁸² For this observation see E. Lazarus, *Why Congress’s Intervention Predictably Didn’t Help the Schindlers: Putting Federal Judges In an Unfair Pressure Cooker In the Terri Schiavo Case*, on <http://writ.news.findlaw.com/lazarus/20050331.html>, 4.

9. Reflections on the opportunity to enact a law on advance directives in Italy and on the features of such a regulation. Brief analysis of the bill under discussion.

After Eluana Englaro's death, the Parliamentary debate on advance directives accelerated and on 10 February 2009 led to the approval of a motion that qualified artificial hydration and nutrition as life-sustaining measures⁸³. Then, on 26 March 2009, a bill was approved by the Senate, the so-called "Disegno di legge Calabrò"⁸⁴. The bill was later transmitted to the Chamber of Deputies, where it was approved, with amendments, after two years, on 12 July 2011⁸⁵. At present the bill is being debated in the competent Parliamentary commission of the Senate⁸⁶.

The Parliamentary procedure is marked by alternating accelerations and slowdowns. It is difficult to predict whether a law on advanced directives will be enacted by this Parliament: Italy has a technical Government, appointed by the President of the Republic to face the economic crisis; parties that support the Government are trying to find an agreement to carry out constitutional and political reforms and the end-of-life issue is undoubtedly a great source of division among them and within the parties themselves.

The level of the clash of ideas and ideologies should lead to taking a step backwards and to reposing a question the answer to which is not obvious: do we need authoritative guidance? Is a law on living wills necessary in Italy?

According to one viewpoint, the need for a law derives from the "juridical insufficiency" of article 32 of the Italian Constitution, that was conceived for decisionally capable subjects

⁸³ Motion n. 1-00086, signed by Senators Gasparri, Quagliariello and others.

⁸⁴ For an analysis see A. Pioggia, *supra* note 31, at 276 ss.; Id., *Brevi considerazioni sui profili di incostituzionalità del Ddl Calabrò*, on <http://www.astrid-online.it/FORUM--II/>.

⁸⁵ Bill C. 2350, sent from the Senate to the Chamber of Deputies on 31 March 2009 – combined with C. 625, C. 784, C. 1280, C. 1597, C. 1606, C. 1764-bis, C. 1840, C. 1876, C. 1968-bis, C. 2038, C. 2124, C. 2595. Commission examination concluded on 1 March 2011. Debate in the Chamber started on 7 March 2011 and the bill was approved, with amendments, on 12 July 2011.

⁸⁶ Bill S.10-51-136-281-285-483-800-972-994-1095-1188-1323-1363-1368-B, under examination. Debate started on 20 October 2011.

and does not consider the situation of incompetent individuals, as the Englaro case has shown⁸⁷.

According to another point of view, a systematic interpretation of the Italian Constitution provides end-of-life decisions with a sufficient legal framework⁸⁸, that has been implemented by the principles established by the Corte di Cassazione in decision n. 27148/2007; therefore, everyone can express them despite the absence of a regulation, and may be sure of their protection⁸⁹.

It is not easy to take a stance on the alternative between “law” and “no law”⁹⁰.

The truth probably lies in the middle: the absence of a specific law should not prevent people from expressing their living wills and having them respected, but Italy needs a regulatory framework, especially as to the guarantees for individuals and health professionals that comply with them.

What should be the features of such a regulation?

To answer this question it would be appropriate to move from the Parliamentary debate and, in particular, from the main criticalities of the bill that is under examination⁹¹.

Its sphere of application is very limited, regarding only patients with ascertained absence of integrated cortical-subcortical brain activity (art. 3).

As to the content of the advance directives, the patient expresses orientation and information useful for the physician only about the activation of therapeutic treatment (article 3). This provision does not seem to give the possibility to decide to withhold or withdraw medical treatment.

Hydration and nutrition, in the different ways they can be given to a patient according to science and technique, cannot be the object of an advance directive (article 3).

⁸⁷ G.U. Rescigno, *supra* note 18, at 88 ss.

⁸⁸ On this point of view see S. Rodotà, *supra* note 22, at 84.

⁸⁹ U. Veronesi, *Scrivetevi il testamento biologico*, La Stampa, May 7, 2009, at 1 and 39.

⁹⁰ Here the author takes up the title of the book by S. Rodotà, *supra* note 2.

⁹¹ For a critical comment, see U. Veronesi, *Così si apre la strada a tante cause legali*, La Stampa, July 13, 2011, at 1 and 33; M. Ainis, *La fiera dell'ossimoro in quattro paradossi*, Corriere della Sera, July 13, 2011, at 1.

At the basis of this choice there is the idea that this kind of treatment is non medical and, therefore, the safeguard of article 32 to refuse it does not apply.

In the previous bill approved by the Senate, to this extent hydration and nutrition were expressly qualified life-sustaining measures.

This definition was very controversial, because, generally speaking, the qualification of life-sustaining treatment as medical acts is really less discussed in the scientific field than in the bioethical one⁹². Moreover, the introduction of a distinction between what is a therapy and what is not would complicate the content of the advance directives, that would have a “variable geometry” extent.

Although the definition of nutrition and hydration as life-sustaining measures has been cancelled from the latest version of the bill, undoubtedly it is still inspired by this conception.

In any case, even if the view of such treatment as simply basic care and not medical could be accepted, this position would not lead to excluding it from the right of self determination that inspires the whole Italian Constitution. The Constitutional Charter guarantees freedom in general, not only in the health care sector. An example can be seen in another significant article: article 13, that safeguards personal liberty, defined as inviolable⁹³.

The introduction of a feeding tube against the will of a person is an unlawful coercion both in case of a subject that is decisionally competent and in case of an unconscious person who has expressed his or her refusal when he or she was capable.

Furthermore, the bill has drawn the exclusion of hydration and nutrition from the advance directives from the reference to the Convention on the Rights of persons with disabilities, approved on 13 December 2006 and ratified in Italy by Law n. 18

⁹² This aspect is pointed out by F.G. Pizzetti, *supra* note 40, at 14. Also on this subject see A. Pioggia, *supra* note 31, at 277.

⁹³ The importance of article 13 of the Italian Constitution is underlined by L. d’Avack, *supra* note 19, at 1929-1930, who observes how the freedom of each individual to decide what to do with his own body is a postulate of inviolable personal freedom, as sanctioned by the Constitutional Charter. In the same order of ideas see D. Maltese, *supra* note 12, at 987, according to whom the right to refuse any kind of assistance is part of the *status libertatis* that the Constitution recognizes to all individuals as the “unwithdrawable heritage of the personality”.

of 3 March 2009. According to article 25, specific to “Health”, “States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”. In particular, letter f) of the same article establishes that States Parties shall: “Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability”.

The bill implies a wrong interpretation of the Convention. It is important to point out that article 25 of it, at letter d), also provides that State Parties shall: “Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care”.

The Convention holds that the principle of free and informed consent applies also to individuals with disabilities. This means exactly the opposite of what the bill under discussion derives from the Convention: the principle of non discrimination requires the non misrepresentation of advance directives of persons with disabilities. Consequently, the prohibition of denying health care, health services, food and fluids regard individuals who wish them.

Another controversial issue of the bill is the provision according to which in case of urgencies or when the person is risking his/her life, his/her advance directives do not apply (article 4, last paragraph).

This provision seems once again to deny the possibility to withhold medical treatment in emergency situations. The individual’s right of self determination is again violated.

The idea of making a provision that establishes the non binding character of the advance directives for the physician (article 7) also raises perplexity. The physician should consider the patient’s advance directives, but is not obliged to follow them.

Such a provision would be a source of discrimination between patients that are capable and therefore able to have their wishes respected and patients that are decisionally incompetent, whose living wills are only a kind of orientation for the health professionals.

It would violate not only the right of self determination, but also the principle of equality, established by article 3 of the Italian Constitution.

In the view of some scholars the physician's substitution of the patient could be probably admissible only if scientific or technical progress made the advance directives no longer well-informed or correspondent to the wishes of the patient: this could be the case of a scientific discovery that makes the permanent vegetative state reversible.

However, the physician's assessment would not be easy at all: many problems related to the quality of life of the "reborn" patient would arise.

Another issue regards how advance directives should be expressed.

It can be observed that many of the main perplexities regarding the Englaro case result from the presumptive reconstruction of Eluana's advance directives.

There is no doubt that it is better to put living wills "in black and white". The crux is that the bill that is under discussion prescribes too precisely how end-of-life decisions should be drawn up: it requires the signature of the family doctor and establishes that the doctor is the only subject authorized to collect them; any statements of intent or orientation expressed by the individual not conforming to the forms and ways established by the law therefore have no value and cannot be used in order to reconstruct the individual's will (article 4).

However, in the legal literature the risks of an excessive bureaucratization have been underlined: the living will should not be the only way for individuals to express their convictions about the end-of-life⁹⁴.

The previous question "do we really need authoritative guidance?" could be probably reformulated as "do we really need such authoritative guidance?".

The analysis of the debate on advance directives shows the risks of an excessive "juridification": the creation of a legal

⁹⁴ For this observation see S. Rodotà, *supra* note 2, at 259.

framework that appropriates the “bare life”⁹⁵, areas that should belong to the conscience of individuals and their families⁹⁶.

In facing the alternative between “law” and “no law”, it would be advisable to have a minimal regulation, developed through principles, that protect the right of self determination, identifying an area of autonomy of the individual, to which the law, however, must remain extraneous⁹⁷. The legislator should give only general provisions that implement it, with the function of, for instance, establishing rigorous rules to ascertain the patient’s wishes in the absence of a living will, guarantees for individuals and health professionals that comply with his/her advance directives, etc., without intruding into the personal sphere of the patient.

⁹⁵ The reference is to the book by G. Agamben, *Homo sacer. Il potere sovrano e la nuda vita* (2005).

⁹⁶ On these aspects see S. Rodotà, *supra* note 2, at 9 ss.; Id., *supra* note 22, at 84 ss.

⁹⁷ For this analysis see, again, S. Rodotà, *supra* note 2, at 19 ss.; Id., *supra* note 22, at 84.