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THE LIVING WILL. MY PERSONAL VIEWPOINT AND REASONS FOR INTRODUCING IT INTO ITALIAN LEGISLATION

Abstract

Human dignity, the right to health and life, the freedom of self-determination of the patient regarding treatments, the position of a healthcare proxy and of the doctor – are not so easy to reconcile. By means of the living will and the particular attention of the Legislator to these important themes it is possible to avoid frequent discussions and conflicts, above all when the legislation is non-existent, as in Italy which is still characterized by the lack of solid specific ad hoc legislation. This measure, essentially, is particularly effective in order to prevent ex ante, or to solve ex post, the difficult dilemmas which arise in situations which are characterized by the absence of a capacity for self-determination, safeguarding, forever and in all situations, the dignity and the identity of the human being.

Keywords

living will – informed consent – self-determination principle – advanced directives information – death – Italy

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I. INTRODUCTION

Among the numerous bioethical themes, to which we address in this paper we have, certainly, to number the living will, around which revolves orbits a debate, seems to be most controversial – just because the matter is extremely “ethically serious, a battleground among several moral, political and ideological instances”¹.

By means of this legal institution “a person in full possession of his mental abilities, expresses his will or entrusts a third party to carry out his will with regard to the treatments to which he would like or would not like to be subjected, in the event that, owing to the course of an illness or a sudden trauma he was no longer able to express his consent or informed dissent”².

The most important constitutional values and fundamental principles of our legal system, such as human dignity, the right to health and life, freedom of self-determination of the patient regarding treatments, and the role of a guarantee of the doctor, are involved in this compelling topical theme. They tend to prevail on one other in a duel to which we could put an end, only by the meticulous, careful and certainly not easy task of balancing the conflicting interests to be brought back into the meshes of the system through the reconstructive effort of the legislator, interpreters and all operators of the law.

For these reasons I believe that initiatives like today’s are extremely appropriate and through a better discussion, these so delicate and deep issues can enjoy, in time, a deeper common understanding, and minimise possible conflicts in the future.

II. ISSUES RELATED TO THE CURRENT LACK OF SPECIFIC *AD HOC* LEGISLATION IN ITALY

The living will presents such a peculiar character as to be far from the most typical institutions of the Italian legislative experience.

¹ M. Sacchi, *Il testamento biologico tra tutela del diritto alla vita e libertà di autodeterminazione*, Vita notarile 2009, no. 3, p. 1345.

² S. Amato, *I fuochi fatui del living will*, Jus 2005, no. 52, pp. 283-284.

The lack of solid specific *ad hoc*³ legislation and the most recent cases of refusal to the continuation of the therapeutic treatment (*Welby* and *Englaro* above all⁴) have set new challenges both to law and bioethics. Thanks to these initiatives it will be possible to draw clearer rules and respect *pro futuro* decisions of the patient, instead of relying on the choices and preferences of other persons involved⁵.

The serious lack of legislation in the Italian legal system⁶ has compelled us to search among the meshes of law, i.e. one of the general principles and constitutional values on which our legal system relies, valid aids which may allow the person concerned to prepare a living will properly, to the therapist to be able to apply for, the judge to decide whether to agree to interruption of the therapy, in deference to the provision in this regard which was made in advance by the person concerned. Until this moment, in substance, the law (both ordinary and constitutional), by an intense interpretative almost “creative” activity has shown us the way forward. A law on the regulation and requirements

³ As sharply observed by L. Iapichino, *Testamento biologico e direttive anticipate. Le disposizioni in previsione dell'incapacità*, Assago: Ipsoa 2000, p. 13: “il diritto italiano non ha espresso un'organica disciplina atta a regolamentare le attività biotecnologiche e biomediche e (...) il legislatore tende a rimettere tale disciplina alla dottrina e alla giurisprudenza” [Italian law has no systematic legislation to supervise biotechnological and biomedical activities and (...) the legislator refers this legislation to the doctrine and to the judges].

⁴ It is necessary to underline, however, that the sad story of Mrs. Eluana Englaro, still emblematic, does not fall within the topic, because it considers the power of the guardian (in this case her father), when there is no specific will on the part of the subject.

⁵ Sacchi, *supra* note 1.

⁶ It is important to remember that for a large part of Italian doctrine there is not necessarily a law to regulate the living will, because it can be permitted under the Italian legal system by virtue of the constitutional principles (this opinion is presented by i.a. M. Casini, M.L. Di Pietro, C. Casini). Similar to the functions of the living will is the administrator who takes care of the affairs of incapable, *ex lege* 6/2004, who has some powers to protect the incapable person, in accordance with his needs and wills, above all his existential ideas. The designation of this type of administrator is made to the person concerned, thinking about his possible next incapacity, but this is formalized from the judge (this is present in M. Barni, *Sul dissenso attuale e anticipato ad un trattamento medico. Dal rispetto dell'autonomia all'amministratore di sostegno*, Responsabilità civile e previdenza 2006, p. 1002). For another Author, on the contrary, it is necessary that the legislator regulates this topic to avoid uncertainty and to permit to the subject to nominate a trustee to protect the health, because a *pactum fiduciae* between the subject and the trustee involves the trustee acting as an *alter ego* of the patient. The trustee could thus make and apply a living will, even changing it according to circumstances. In this way it is possible to realize a therapeutic alliance to protect a decision that a patient can possibly express in a living will.

of the validity of the living will made within the parameters of a «mild law» and drawn up for principles characterized by a high degree of flexibility and/or indeterminateness, while respecting the strict requirements of validity and effectiveness of statements expressed by the person interested on matters of such great importance, may, indeed, predict “the possibility that a patient might rely on a formal declaration of refusal to some medical treatments, (drawn up in advance) in all those cases in which he is prevented from expressing a manifestation of will”⁷, giving him the certainty that his will be respected. We ask the law, essentially, “not to remain deaf in front of more and more pressing solicitations of protection, more closely existential choices before which the individual of today can find himself”⁸.

A legislative intervention, in this sense, certainly, would not solve, all ethical and legal problems⁹. Specifically, the relationship between law, politics, science, ethics, and the relationship with the religious beliefs of individuals. Nonetheless such legislation would help to avoid a situation where “the problems of life and death were solved according to ethical and ideological variables of individual judges”¹⁰.

Pushed by the emotional wave of the conclusion of the sad story of Eluana Englaro and the suspension of forced nutrition and hydration disposed by the Court of Cassation¹¹, the debate on the living will in Italy has undergone a substantial acceleration, leading to the approval of a legislative text by the Senate in March 2009 (entitled “Provisions

⁷ A. Ridolfi, *Rifiuto delle terapie mediche e testamento biologico in Italia: aspetti problematici e spunti critici*, *Politica del diritto* 2011, no. 4, p. 610.

⁸ G. Salito, *Il testamento biologico nell'ordinamento italiano e di altri paesi*, Fisciano: Università degli Studi di Salerno, Dipartimento di diritto dei rapporti civili ed economici nei sistemi giuridici contemporanei 2003.

⁹ In other countries, however, the living will is not much utilized by the citizens, perhaps because is not useful to avoid trials. This is present in N. Viceconte, *La sospensione delle terapie salvavita: rifiuto delle cure o eutanasia? Riflessioni su autodeterminazione e diritto alla vita nella giurisprudenza delle Corti italiane*, *Aic* 2001, no. 1.

¹⁰ F. Mantovani, *I requisiti di validità del testamento biologico*, *Iustitia* 2002, no. 3, p. 293.

¹¹ The Cassation Court, sez. I civ., 16.10.2007, No. 21748, very important on this specific topic, arranged that the suspension of treatment on a patient who is in a permanent vegetative state is allowed when there is irreversible damage and if the patient previously showed his purpose to not accept this type of treatments. The informed consent allows the patient to choose not only the another possible treatment, but also, if necessary, to refuse the treatment and consciously to decide to cut off it, at any stage of his life.

on the theme of therapeutic alliance, informed consent and directives for treatments brought forward". The c.d. the so-called bill "Calabrò" was approved by the Senate on 26th March 2009 with n° 2350 and subsequently by the Chamber of Deputies with amendments on 12th July 2001).

This text, which has not been approved definitively yet, regulates, though in a very restrictive way the living will, the decision-making of patients and their rights to self-determination in refusing medical treatment, in such a case, stating that the right to life is inviolable - *ergo* presents significant criticism from the point of view of the legal policy.

In fact, Article 7 (paragraphs 1 and 2) of the "Calabrò" bill does not protect patient's decisions *pro futuro*, thus a legislative response is undoubtedly required. Currently, the end-of-life decisions (living wills) are not binding for the doctor, who may not follow the patient's wish for one of the reasons foreseen in the act (such as new advancements in medicine or doubts as for the reliability of the patient's declaration).

The draft law in question explains, with a definitely excessive formalism and rigor, that any probable declarations stated by the patient not in the written form required by the legal procedural requirements *ad substantiam* have no value and cannot be used to reconstruct the will of the subject¹²; these statements must be kept by a notary public free of charge¹³; the first paragraph of the Article 6, besides, states that it is necessary to provide for the assistance of a confidential doctor in drafting the act (risking, in the opinion of the writer, inhibiting the settlor, restraining his intention to proceed with the drafting of the living will) which cannot be suspended not even if this suspension is expressly requested by the person concerned in his directives, because the treatment of forced nutrition and hydration must not to be considered as acts or medical treatment¹⁴, but rather acts necessary in both an ethical

¹² The formality, that in this case requires (if not a public act) a private written statement with a signature and the date, is useful to protect the careful reflection of the subject on this particular act, and above all to safeguard and to show the will of the subject.

¹³ It is necessary to specify, waiting for a desirable law, that in a lot of Italian municipal districts passed a resolution to setting up the special book that, guaranteeing the patient's privacy, collect the living wills, in case it is necessary to trace them.

¹⁴ This is to comply with the consolidated approach of Bioethical National Committee.

and a legal sense¹⁵ to avoid incurring forms of euthanasia by omission (debasement thus the very meaning of that procedure that should be applied especially in such critical situations). Contrary to the law on organ donation (that adopted a mechanism of tacit/constructive consent), the proposed law on advanced directives provides that declarations/directives have to be reviewed every three years, in order to inform the patient about the progress in medicine and possible new therapies¹⁶.

Likewise, there is a legally recognized assumption, which seems acceptable, that only to an adult, and therefore, a subject endowed with mental capacity, is awarded the right to express a valid anticipated declaration of treatment considering that, as we have just seen, such a declaration requires a proper, careful reflection and an extremely thorough and full capacity of discernment of existential choices and the meaning itself of life and death, suffering and disease.

III. PRECISIONS AND DIFFERENCES AMONG THE INSTITUTIONS

In my reflections I will be able to develop only some of the numerous hints that the living will raises, but for a whole reconstruction of the institution, in question, I believe it is necessary, from now on, to distinguish two types of living wills. The first type of the living will consists of the anticipated “directives concerning treatment” and, as such, allow the person concerned to indicate explicitly treatment and/or therapies which should be excluded or, quite the opposite, included, in the course of the disease, or in the terminal condition. The content of the directive can be shaped elastically¹⁷ and while making the will the person concerned may take various aspects of health, physical psychophysics integrity, including support of vital functions, into consideration. The second type are “directives by proxy”, that allow the person concerned

¹⁵ F.G. Pizzetti, *Alle frontiere della vita: il testamento biologico tra valori costituzionali e promozione della persona*, Milano: Giuffrè 2008, p. 274, study that is very useful to have a complete and accurate approach on this institute and to find a large bibliography.

¹⁶ *Ibidem*, p. 254.

¹⁷ In regards to this, G. Caparezza Figlia, *Profili ricostruttivi delle dichiarazioni anticipate di trattamento*, *Famiglia* 2004, no. 6, p. 1059.

to appoint a trusted person who will be the “spokesman” of his will and take therapeutic decisions when this patient will be no longer able to take them because of worsening in his condition¹⁸.

It is worth, likewise, underscoring the nominalist issue that is related to the possible deception into which we could be drawn on account of the use of the term “will”. It is necessary to state, in fact, that the ontological connotation of the living will draws away from the legal concept of the will according to Article 587 of the Italian Civil Code. In fact, the living will is not a typical act consisting in a manifestation of will with *mortis causa* (result of death) effects and the patrimonial provisions (as the civil Italian will present in the Civil Code), but being, however, a very personal legal act with an *inter vivos* (between living)¹⁹ character and with provisions of an existential character, suspensively conditioned (according to and owing to the Article 1353 c.c.), namely, intended to produce effects in a time in which the author, upon the occurrence of the clinical condition foreseen, will not be able to express or modify his own will²⁰, but will, nevertheless, still be alive.

In order to be as clear as possible I should also point out the distinction between the institution in question and the practice of euthanasia as, if through the living will some choices are accomplished, *now for then*, related to *modus vivendi* and the use or not of medical treatment whose support is vital for, enabling the patient to choose that his illness takes its natural course, to the patient is given one of the most important tools of autonomy and self-determination: by the request of euthanasia, instead, the person expresses his *voluntas moriendi* that is his own will to be the receiver of a direct active intervention of a third party (usually the doctor himself) that puts an end in a shortened and forced way even by the administration of a lethal drug, to his wretched existence, before the end of the natural course of the disease²¹.

¹⁸ G. Spoto, *Direttive anticipate, testamento biologico e tutela della vita*, Europa e diritto privato 2005, no. 1, p. 182.

¹⁹ Sacchi, *supra* note 1.

²⁰ Iapichino, *supra* note 3, p. 6 et seq.

²¹ It is necessary to distinguish the right to let oneself die, and the right to ask a third person to assist in suicide. V. Giammusso, *Luci e ombre del testamento biologico*, Trieste: Rotary club 2006, p. 221 et seq., sustains that the aim of the living will is the direct treatment or other

IV. HISTORY AND *RATIO*

In my opinion, to get to an appropriate level of deepening of the institution is proper to outline, even very shortly, a historical overview that will allow us to understand the reasons for which has been necessary to foresee the living will and for which, in my opinion, we should protect it and support its validity.

The living will, in fact, “was the result of an intuition born and developed in the USA at the end of the 60s in the last century, within the framework of the battles that were fought for the extension of civil rights to the categories of the weakest and the most disadvantaged people”²².

The protectionist and supportive perspective in which the institution in exam is opportunely set, in fact, makes it possible perfectly to understand the purpose for which it was created, as it tends to subtract the individual from the arbitrariness of the public authorities, permitting the interested party to project his will beyond the termination of his mental capacity of acting, assuming so, as stated authoritatively, “that it is possible that some clinical conditions may occur in which a person devoid of consciousness continues living (...) for a certain period which could be also very long, thanks to the application of therapies and really powerful machinery (...) replacing artificially the functions essential to life”²³.

The living will, born, therefore, in a technological panorama rich in potentialities for further developments enables biomedicine to manipulate the different phases of human life and prolong artificially the existence itself. Today, the modern medicine often transforms a person into an “artificial life”²⁴ and even though death still belongs to the nature,

measures targeted on the patient’s pathological condition, not the only goal that the subject wants to obtain, like in the euthanasia practice.

²² Pizzetti, *supra* note 15, p. 14. The United States of America is the first country to regulate the living will, that is today even in the legal order of countries like i.e. Canada, Germany, Switzerland, etc.

²³ *Ibidem*, p. 15.

²⁴ *Ibidem*, p. 44.

it is more and more controlled by man²⁵. Finally, the dignity of dying²⁶ should be taken into account as “the declarations aim neither to put an end to life nor to affect health, but to avoid prolongation of an artificial life characterized by suffering without hope”²⁷.

This procedure, essentially, is particularly effective in the context of both Italian and European law in order to prevent *ex ante* or solve *ex post* all those difficult dilemmas which arise in such situations characterized by the absence of the capacity for self-determination, safeguarding, forever and in any case, the dignity and the identity of the human person and ensuring, through an anticipated planning, the autonomy and the decisional freedom related to a quality of life and existence *subjectively acceptable*²⁸, allowing the biological process continue on its course²⁹.

²⁵ Ridolfi, *supra* note 7, p. 618. Other important Authors on the topic are S. Rodotà, *La vita e le regole. Tra diritto e non diritto*, Milano: Feltrinelli 2006; E. Boncinelli, G. Sciarretta, *Verso l’immortalità? La scienza e il sogno di vincere il tempo*, Milano: Cortina 2005.

²⁶ In order to the emergence of new rights, called rights of third generation and born before the technological innovation, and include in Article 2 of Italian Constitution, important is Iapichino, *supra* note 3.

²⁷ A. Bellelli, *Decisioni di fine vita e disposizioni anticipate di trattamento*, *La nuova giurisprudenza civile commentata* 2011, no. 2, p. 86. The Author states that with the living will “il soggetto non decida tanto della propria salute, che è definitivamente compromessa, quanto della propria qualità di vita, del grado di esistenza soggettivamente accettabile” [the subject decides about the our quality of life, about the our satisfactory existence, not about our health that is definitively damaged]. For Sacchi, *supra* note 1, it is necessary “non un indiscriminato riconoscimento di un diritto a morire dell’individuo ma, piuttosto, a fronte di casi clinicamente disperati che escludono a priori concrete possibilità di miglioramento o guarigione, un diritto a morire con dignità qualora la condizione in cui il malato versa non sia più per lui sostenibile e configgente con il suo modo di concepire l’esistenza e la dignità umana” [not a general right to die, but above all a right to die with dignity if there is no clinical possibility of improving or healing and the patient’s condition is contrary to the his way of life with dignity].

²⁸ According to the laic bioethics, biographical life is superior to biological life, in observation of a qualitative principle of life, more than a quantitative principle of life. In regards to this see VV. AA., *Manifesto di bioetica laica*, manifesto approved during the meeting of the Consulta Turin for the secularism of institutions held in Turin (Italy) on 2007, available at: <http://www.paleopatologia.it/articoli/articolo.php?recordID=31> [last accessed: 27.10.2015].

²⁹ G. Ferrando, *Fine vita e rifiuto di cure: profili civilistici*, [in:] S. Rodotà, P. Zatti (eds), *Trattato di biodiritto*, vol. II, Milano: Giuffrè 2011, cap. V, p. 1867.

V. INFORMED CONSENT

The problems on the acts of instructions of our body are interwoven to the theme of the *informed consent* or *dissent* to a therapeutic treatment (natural corollary of the Article 32 of Italian Constitution by virtue of which, as all know, no one can be obliged, as a rule, to undergo a medical treatment against his will to). It is right, in fact, to state that this institute represents “the logic landing of the process of the progressive validation of the informed consent”³⁰, this assumption has, all the time, legitimized the medical activity and the relationship of doctor and patient. As it is authoritatively argued, in particular, “it is neither the consent which is the source of obligations according to and by the effects of the Article 1372 c.c. (...), nor the consent from which the agreement between the doctor and health facilities originates and (...) for which the rules of the IV book of c.c. are valid, but it is the consent to a single medical act which entrusts the patient’s body to the doctor and authorizes the latter to overcome the threshold of the patient’s intangibility. The consent is not a mere simple initial consent, but it claims the treatment through the whole course of its duration as a permanent condition of legality”³¹.

In the medical care, provided in a continuous process, some delicate problems may arise such as when the patient “does not have the technical capability any longer, that is, the physical energy to proceed to the interruption of the treatment autonomously, but through a medical treatment”³².

In such situations it is impossible to be able to respect all the typical requirements of the consent of the patient³³. More specifically, therefore,

³⁰ L. Balestra, *Efficacia del testamento biologico e ruolo del medico*, [in:] Fondazione Umberto Veronesi, *Testamento biologico. Riflessioni di dieci giuristi*, Milano: il Sole 24ore 2006, p. 95. Even the Charter of the Fundamental Rights of the European Union, signed in Nizza in 2000, in Article 3 sanctions that the free and informed consent has to be respected in biology and medicine.

³¹ Ferrando, *supra* note 29, p. 1881.

³² Balestra, *supra* note 30.

³³ In regards to this see V. Donato, *Note in tema di consenso informato all’atto medico. La sfida del diritto tra innovazione scientifica e nuova domanda etica*, in *Contributi di diritto civile, Quaderni*

to be more compromised are: the personality of the consent of the interested party (here his legal representative could be involved), the contemporaneity of the decisions taken (in the absence of the directives of the patient of the character of contextuality), the full awareness of choices made in the imminence of information received by the therapist (they had been made before the onset of the disease) and the revocability when the subject loses his mental capacity and provisions. Of course, in practice these elements may have legal consequences.

The “informed, conscious and current” consent³⁴, therefore, through the institutionalization of instruments such as the living will (which safeguards and protects the will also in advance), must be able to cover the whole span of existence even in the case of the temporary or permanent loss of clear-headedness allowing “the government of life from the part of the person concerned”, guaranteeing “the right to give up the therapies with the withdrawal of consent and the refusal of care”, setting “the limits thereby of every possible external intervention, starting from that of the therapist himself”³⁵, because it is always and in any case, the patient that having been informed of the different kinds of therapies and their possible success who must be able to exert fully his rights to choose the exit from the treatment itself.

Sharing the thesis supported authoritatively³⁶, I would like express the opinion that the major dilemma discussed here is the right to life as such, neither its unavailability. We should rather concentrate on the decision to lead or not to lead an artificial existence, and on the definition of “life” and its end, which is to a large extent influenced by the use of more and more advanced machinery and technologies.

del Dipartimento di Scienza e Storia del Diritto - Università di Catanzaro, Torino: Giappichelli 2004.

³⁴ In regards to this, the bibliography is very extended. For numerous criminal references, G. Dassano, *Il consenso informato al trattamento terapeutico tra valori costituzionali, tipicità del fatto di reato e limite scriminante*, Torino: Giappichelli 2006.

³⁵ Rodotà, supra note 25, p. 250.

³⁶ In regards to this, Pizzetti, supra note 15, p. 34. Even Ferrando, supra note 29, p. 1892, who sustains that there is no disposal act of itself in this case, but the subject exercises the own individual liberty.

The patient, therefore, must be able to choose, even in advance, whether to consent or not to such treatments, in case he can express his decision no longer³⁷.

VI. OUTLINES OF CRITICALITIES AND DOCTRINAL POSITIONS

From the legal perspective, the major issue is the legal force of the patient's will, since it is aimed to produce effects in specific circumstances – that is, when an individual is no longer able to express his opinions and decisions³⁸.

The problem, therefore, lies in an anticipated planning of the medical treatment as a “logical consequence of the patient's right to give consent or refuse treatment”³⁹.

As we have observed⁴⁰, there is a difference in the context of the anticipated declaration of treatment, expressed by an individual who is fully responsible and correctly acquainted with his own current pathological conditions, and the condition of incapacity in which he finds himself had been predicted as an inevitable consequence of a degenerative

³⁷ The problem of a consent in which there is no longer the character of actuality, in which there is no longer any more suitable and complete information and which cannot certainly be sustained if the subject revoked it in a critical condition, is included in important sentence of Cass., 15.09.2008, No. 23676. In particular, in this sentence, the requirement of the patient's consent (even if consent was declared in advance as dissent) is present because the will has to be: “*non astrattamente ipotetica, ma concretamente accertata, un'intenzione non meramente programmatica, ma specifica (...) un dissenso che segua e non preceda l'informazione, che suoni attuale, non preventivo, un rifiuto ex post e non ex ante*” [not in the abstract supposed, but concretely verified, an intent not only programmatic, but specified (...) a dissent consecutive and not previous the information, that is actual, not previous, a refusal *ex post*, not *ex ante*].

³⁸ In the Italian regulatory intervention about the living will, legal support has been shaped in the mechanism of a legal representation. But the Italian doctrine, Ferrando, *supra* note 29, observes that the health authorities of attorney are not well explained (indeed there are many disputes about his authority to ask, i.e., the interruption of therapeutic treatments necessary to the life of the patient) but, above all, this legal support is debatable with regard to some bodily rights (that cannot be represented), and because in such situations the attorney has to act always with the full respect of the patient's will, and also because the attorney's acts have to be controlled by legal authority.

³⁹ Ferrando, *supra* note 29, p. 1884.

⁴⁰ P. Casali, A. Gamba, A. Santosuosso, *Il paziente inguaribile in fase avanzata*, [in:] A. Santosuosso, *Il consenso informato. Tra giustificazione per il medico e diritto del paziente*, Milano: Cortina 1996, p. 95.

disease or a surgical operation⁴¹, respect to an anticipated will, given by a person in good health and referred to a future and uncertain event, which will take effect on a condition of incapacity of accidental origin which lies outside, therefore, the development of a specific disease or the consequences of a given medical operation. In this last and more complex case, the doctrine and the body of law present two different approaches: the first one aims at absolute protection of our self-determination and therefore supports elimination of any interference of unrelated parties with the existence of an individual⁴², and the second one the proponents of which are skeptical about the idea of a hypothetical will which is made prior and out of the circumstances in which it is actually applied⁴³. I definitely cannot accept a vision of those who argue that only the current will which allows an individual to refuse treatment and therapies is sacred and untouchable, and who believe that decisions that have been made in advance and in the absence of a pathological condition should not have legal effects.

I do not believe, in fact, that when an individual loses his mental capacity, even his own freedom of self-determination vanishes because of a supervening incapacity to express his own legitimate dissent to medical treatment and allowing in this way, that this person can be subjected to any treatment decided by others on the basis of the objective parameter of the best interest⁴⁴.

⁴¹ However, to complete the analysis it is necessary to highlight that the doctrine is divided, indeed A. Gorassini, *Appunti sparsi sul testamento biologico*, *Rassegna di diritto civile* 2011, no. 1, 2011, pp. 41-62, maintains that even when the subject's will is current and contemporary it is impossible to assert in every case that this will isn't compromise for the difficult and painful situation that in which patient lives.

⁴² The principal explanations of this theory are founded on the consideration that the decision expressed in the living will has to be considered as other important rights of freedom, constitutionally protected. Look at V. Frosini, *Intervento*, [in:] L. Reale (ed.), *Il testamento di vita [The Living Will]*, Roma: Istituto italiano di medicina sociale 1985, pp. 11-15. For the Author the law cannot infringe in any way respect for the human person because the person cannot undergo any treatments which violat his conscious, free and justified decision expressed in a living will.

⁴³ An in-depth study is in M. Barni, *I testamenti biologici: un dibattito aperto*, *Rivista italiana di medicina legale* 1995, no. 4, p. 835.

⁴⁴ Even Pizzetti, supra note 15, sustains that the problem of different personal conditions in which the person that expresses himself with a living will (an action that, as is known, which produces some effects in a different and consecutive moment regarding the draft of the act) is really a fake problem. So because the law attests the will that, as is known, has

Some legislative assumptions in the opposite direction to this approach can be found, in fact, even on supranational level, in the Charter of the Fundamental Rights of the European Union and, even more, in the Convention of Oviedo⁴⁵, underscoring with clearness the importance of the individual's not losing his own autonomy with respect to medical treatments with the onset of the state of incapacity, recognizing his legitimate right to dictate in advance the directives that must be followed in situations of impossibility to provide an informed and current consent. In such sense, therefore, "the conscious informed dissent of the sick person to the continuation of his therapeutic treatment expresses the most general concept of freedom of the individual and endues him with the dutiful respect for the right to refuse medical treatment. This law finds in the Italian Constitution its most complete protection"⁴⁶.

VII. PRINCIPLE OF SELF-DETERMINATION

Once recognized, as things are, the right to refuse the medical treatment, the conditions of its exercise should be clarified⁴⁷, since the issue becomes even subtler, above all when the right to refuse the treatment is expressed, either in advance or not, with references to life-saving therapies whose lack or interruption might lead to sure death. In this case, in fact, "there will be an inevitable contest between the rights protected

the same character. Indeed, the possibility to revoke in any moment both the dispositions is a very important guarantee of the author's actual consent.

⁴⁵ This is the 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, 1997, that actually is not still valid in Italy, but the ratification is approved in Law 28.03.2001, No. 145. Pizzetti, *supra* note 15, p. 100, "la regola base per le situazioni in cui manca la capacità di prestare consenso fissata nella Convenzione è quella che il medico non può agire se non per diretto beneficio dell'interessato e senza l'autorizzazione di un sostituto", sustains that "in the situation in which there is no capacity to give the consent which is necessary for the doctor to act only for a patient's direct benefit, even without any authorization". Article 9 of the Biomedical Convention expressly admits the right of an incompetent patient to specify his/her wishes about the our possible health treatments. The same in the Italian Code of Medical Ethics, 2006, Article 38, because it is specified that the doctor has to respect the sure patient's will, provided with documentary evidence.

⁴⁶ Sacchi, *supra* note 1, p. 1346.

⁴⁷ T. Pasquino, *Autodeterminazione e dignità della morte*, Padova: Cedam 2009.

by the Italian Constitution since the rights to health, in its negative meaning comes into the conflict with the right to life which also finds evident constitutional protection in the Article 2 with the greatest difficulties in settling the controversies raised in front of the law⁴⁸.

The right of the individual to the self-determination, in fact, must be respected also in comparison with such medical treatment, in order to be able to enjoy as long as the patient is in life, the right to choose the kind of life he wants to live, that is, how he would like to continue leading his existence. Therefore, essentially, the issue of the faculty or not of the individual to give up (even in advance) the medical care (*ex* Article 32 Constitution) or the treatments which enable his artificial maintenance in life must be confronted not only to the principle of the necessary consent of the patient (see above par. 4) but also, and above all, to the respect of the identity of the human person and his dignity (*ex* Articles 2 and 3 Constitution) which leads, indeed, to the respect of the sense and meaning that everyone, in accordance with his own personal perspective of existence, can give to his life⁴⁹, even beyond the threshold of his capacity.

“And it is for this, to the extent that allows you to project your future health care decision, taken in the past, before falling into a state of incapacity. The living will represents a proper, new advanced form of legal civilization in the sense of a progressive enhancement of the principle of self-determination of the individual”⁵⁰.

In this sense, therefore, “the living will can be as the extreme act of determination of a subject in terms of his very personal sphere which touches the dimension itself of existence”^{51 52}.

⁴⁸ Viceconte, *supra* note 9.

⁴⁹ Look at Cass., sez. I civ., 16.10.2007, n. 21748, *Englaro*, from which it is clear that in a government that respects the freedom of choice and the right of self-determination in the doctor-patient relationship, must respect also the freedom of a person who cannot survive (artificially and for an undefined period of time) with a condition of life removed from the perception of the outside.

⁵⁰ Balestra, *supra* note 30.

⁵¹ *Ibidem*, p. 86.

⁵² Even the Article 1 of Charter of the Fundamental Rights of the European Union concerns human dignity and, if we understand this concept as right to self-determination on the part of the individual, this involves, as a clear corollary, the right to have an acceptable human death, that is considered in the Article 1 of Oviedo Convention.

The ethical pluralism, basis of the Italian legal culture, receives warrant through “the principle of self-determination of the individual thanks to which it is acknowledged the power to take decisions autonomously in relation to his own purely personal interests. On the level of law, the self-determination means the recognition and guarantee of the decisional freedom of each individual. The Secular State (...) is restricted by a balancing of the involved interests to recognize and protect the gaps of autonomy (...). The law is, in this perspective, an instrument for the protection and defense of the patient’s autonomous choices”⁵³.

VIII. DEVELOPMENT OF THE DOCTOR-PATIENT RELATIONSHIP

Another fundamental aspect, as also the Italian National Bioethics Committee has supported authoritatively, is the reinforcement, which develops through the living will, of the therapeutic alliance as we have already said, that is the basic element constituting the relationship of doctor with patient. This relationship develops, in fact, that necessary dialogue to its extreme potentialities between the two parties and even at a distance and planned into a future time “even in those extreme situations in which no links seem possible between the loneliness of a person who cannot express himself and the loneliness of the doctor who must take a decision”⁵⁴.

It is impossible to decide, in substance, on “an excessive and obstinate medical intervention that, instead of alleviating the suffering of the patient, makes him remain prisoner of the care”⁵⁵, but it needs an active collaboration between doctor and patient. In accordance with the Italian constitutional principles in fact, the doctor has the precise obligation to give effect to the patient’s will expressed by the patient himself consciously and therefore, the refusal of the patient must constitute the limits beyond which the abstention of the doctor is not only legitimate but really

⁵³ Bellelli, supra note 27, p. 85.

⁵⁴ Italian National Bioethics Committee, *Dichiarazioni anticipate di trattamento*, 18.12.2003.

⁵⁵ Rodotà, supra note 25.

compulsory⁵⁶ to avoid incurring a liability for breach of constitutional rights whereby subjecting the sick person to the torment of useless, invasive therapies because his maintenance as a living person is not always something that corresponds to the best interest of the patient, but has to be parameterized to the life spent and to the life-project of every individual.

The sufferer, in fact, is not “a mere object of medical actions, but a person who has a right to decide upon any intervention into his body”⁵⁷.

Therefore, it is right to persist in overcoming the view of the doctor conceived in a paternalistic manner (because he is no longer delegated to perform a protective, solidaristic function) to the complete advantage of the paternalistic conception of the patient’s rights⁵⁸ with a change of perspectives that, certainly, it is not of little consequences but full of important ones.

According to this scheme, in substance, the action of the doctor not respectful of the will of the sick person constitutes an extremely illegal act, a source in Italian law of civil and penal liability. In particular, in fact, “this disrespectful action is located in the principle of voluntariness of medical treatments, the support in the medical field, of the recognition of the liable autonomy of the individual and of the capacity for self-determination respect to the choices which affect him and adhere to his existential dimension”⁵⁹. The basic principle of voluntariness of the medical treatments, in fact, reflects the values to which our constitutional system is inspired by, being full expression of personalistic principle of the inviolability of personal freedom, respect for human dignity, the right of self-determination of the individual, protecting his whole personality⁶⁰.

As well as the right to be cared for, likewise the right not to be treated must be recognized together with the right to refuse or suspend the treatments voluntarily choosing to set up in a non-coercive way,

⁵⁶ Ridolfi, *supra* note 7, p. 627.

⁵⁷ A. Santosuosso, *Eutanasia, in nome della legge*, MicroMega 2007, no. 1, p. 33.

⁵⁸ Look at Mantovani, *supra* note 10, pp. 293-300.

⁵⁹ Pizzetti, *supra* note 15, p. 77.

⁶⁰ *Ibidem*, p. 82.

continue or terminate the medical treatment⁶¹ and in the face of dissent expressed by a conscious person, not even the risk of death can legitimate the intervention of the doctor.

More particularly the refusal of aggressive treatment⁶², i.e. in which there is a serious disproportion of suffering inflicted on the patient compared to the hypothetical and only possible benefits that the patient could get, must be ensured through institutions as that of anticipated planning of the treatments, even to that patient who cannot express himself, but has expressed his will previously.

So, “it must be recognized” to the individual “(...) the right to choose among the different options of the medical treatments and therapies (...), refuse, give up, therapy in all the phases of life, even in the terminal stage, in which it must be recognized to the individual the freedom of choosing how and when terminate the vital cycle, when the end of life is inevitable”⁶³, relieving also the medical operators from facing difficult ethical and professional dilemmas and avoiding the quarrels and conflicts among the settler’s relatives themselves⁶⁴.

IX. CONCLUSIONS

To sum up, we can quote an effective reflection by Ernst Bloch⁶⁵ who states that birth is an event independent from the will of the person who is coming to light, but once the person is alive he must want the life and must be able to choose, I add, the manner in which to lead and to put an end to his life. To my support, lastly, I can also mention Seneca who

⁶¹ Involuntary treatments are an exception to this opinion, so because without them there is a serious risk to public health or public integrity (i.e. the mandatory vaccination or operations on mentally disturbed patients).

⁶² In the Article 16 of Italian Code of Medical Ethics this is: “*un’ostinazione in trattamenti diagnostici e terapeutici da cui non si possa fondamentalmente attendere un beneficio per la salute del malato e/o un miglioramento della qualità della vita*” [a persistence in diagnostic and therapeutic treatments that essentially cannot make Any improvement in the patient’s health and/or any improvement in the quality of life].

⁶³ Pizzetti, supra note 15, p. 110. On the contrary it is important to highlight that a part of Italian doctrine and law still sustains the importance of the right to life to on the freedom of therapy.

⁶⁴ The sad story of Italian-American Terry Schiavo is symbolic.

⁶⁵ E. Bloch, *Diritto naturale e dignità umana*, ita trad. by G. Russo, Torino: Giappichelli 2005.

argued wisely that life must not always be retained, since the wellbeing does not consist in living, but in living well and therefore the wise man will live as long as he must, not as long as he can, because he has to pay attention to the quality not the length of life.

For all the foregoing reasoning and as conscious of the asperities of the legislative actions that in this matter are never easy and often imbued with difficulties and lively debates, but as sure of the fact that the difficulties cannot exempt ourselves from attempting to settle the conflicting interests, I think that with all achievements of civilization it is more than a juridical obligation to recognize the individual's right to express, even in advance, directives concerning medical treatments and interventions in the living will. These are the reasons of my "yes" to the living will.