

Living Will and Provisions Concerning the End of Life: the Role of the Family Members in the Matter of Advance Provisions of Treatment (DAT) in the Italian legal system.

Federica Giardini

School of Law, University of Padua (Italy).

Abstract: The paper analyzes the contents of the Italian law on advance provision of therapeutic treatment (DAT), approved in December 2017 after many years of debates and parliamentary projects. In particular, it examines the role that the patient's family members can play in this area, highlighting the problems of interpretation that may arise from the notion of "family member" accepted here and from that of "cohabitant".

Keywords: family law, family member, advance provision of treatment (d.a.t.), Italian law reform on living will, kinship, cohabitees

Correspondence concerning this article should be addressed to Federica Giardini, School of Law, Department of Private Law and Critique of Law, University of Padua (Italy), Palazzo del Bo - Via VIII febbraio, 2, 35122 Padova (Italy) email: federica.giardini@unipd.it

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1. Introduction. Introduction. Delimitation of the object of the survey.

The progress of science, especially of the medical one, gives today the patient the possibility of being kept alive much longer than in the past. In particular, through the treatment of artificial nutrition, hydration and respiration, it is often possible to prolong the patient's state of life for a long time and not to reach the declaration of clinical death of the physical person as a human being, which the Italian legal system still regulates today through the norms of the law no. 578 of 29 December 1993, , that defines the methods for ascertaining the state of death for legal purposes ⁽¹⁾. A significant step forward in the direction of respect for the person and his/her dignity as a human being has also been achieved through the law no. 38 of 2010 regarding palliative care.

In the latter area, the law no. 38 of 15 March 2010, concerning "*Provisions to guarantee access to palliative care and pain therapy*" (Official Gazette No. 65 of March 19, 2010) is a highly innovative law, which for the first time guarantees access to palliative care and pain treatment for the patient, within the essential levels of assistance, in order to ensure respect for the person's dignity and autonomy, the need for health, equity in access to care, quality care and their appropriateness to specific needs ⁽²⁾. The health structures that provide palliative care and pain therapy must ensure an individual care program for the patient and his/her family, respecting the fundamental principles of the protection of the patient's dignity and autonomy, without any discrimination; the protection and promotion of the quality of life in every phase of the disease, especially in

⁽¹⁾ Under this law, death is identified with the so-called brain death, i.e. with the irreversible cessation of all brain functions.

⁽²⁾The law, among the first ones of this kind in Europe, protects "the right of citizens to access palliative care and pain therapy" (Article 1), identifying three assistance networks dedicated to palliative care, pain therapy and the pediatric patient. Precisely in regard to the pediatric patient a special protection and attention is acknowledged, as the subject is considered to have specific needs and necessities.

the terminal one, and of adequate health and social care assistance for the sick person and the family.

A first important index of the role of the family in the ambit of the anticipated provisions of treatment is contained in the law no. 76 of 20.5.2016, (also known as the Cirinnà law), which introduces into the Italian legal system the institution of civil unions for homosexual couples and at the same time recognizes for the first time legal effects on cohabitation between heterosexual partners. Only with the law of 2017 on DAT, however, this role becomes, as we shall see, an organic role, inserted in the system of treatment and care of the patient, in implementation of his/her advance treatment provisions.

2. Informed consent to health treatments and the relationship of care between doctor and patient.

The recent law no. 219 of December 22, 2017 ⁽³⁾, completes a long and complicated path of legislative projects that had remained unsuccessful until then in terms of approval by Parliament. The delay with which the Italian law finally comes to regulate an area so important for the life of people, is also shown by the provisions in this regard, mentioned by other regulations of the Western legal tradition ⁽⁴⁾. Among all, English law intervenes to regulate the same requirement already in 2005, with the Mental Capacity Act. Under section 24 of the Mental Capacity Act 2005, a person may, at a time at which they retain capacity, create an advance directive to refuse certain treatments ⁽⁵⁾.

⁽³⁾ In the Official Gazette of January 16, 2018. The law comes into force on January 31, 2018. J Herring and J Wall, 'Autonomy, Capacity and Vulnerable Adults: Filling the Gaps in the Mental Capacity Act' (2015) 35 Legal Studies 698–719

⁽⁴⁾ On the issue: DENARD VESHI; GERALD NEITZKE, *Advance Directives in Some Western European Countries: A Legal and Ethical Comparison between Spain, France, England, and Germany*, 22 Eur. J. Health L. 321 (2015).

⁽⁵⁾ On the issue see: CRESSIDA AUUCKLAND, *Protecting Me from My Directive: Ensuring Appropriate Safeguards for Advance Directives in Dementia* (2017) *Medical Law Review*, vol. 0, No.0, pp. 1-25; doi: 10.1093/medlaw/fwx037/4083527, but also BA RICH, *Prospective Autonomy and Critical Interests: A Narrative Defense of the Moral Authority of Advance Directives* (1997) 6 Cambridge Quart Healthcare Ethics 138; J HERRING AND J WALL, *Autonomy, Capacity and Vulnerable Adults: Filling the Gaps in the Mental Capacity Act* (2015) 35 Legal Studies 698–719 and among others O'NEILL. *Autonomy and Trust in Bioethics*, Cambridge, Cambridge University Press 2002.

The principles to which the Italian law is linked are contained both in the Italian Constitution and in the Charter of Fundamental Rights of the European Union. From the constitutional point of view, the new legislation is inspired by the Articles 2, concerning the recognition and guarantee of the inviolable rights of man, 13, concerning the inviolability of personal freedom and 32, regarding the right to health. This right, in the constitutional text, is recognized at the same time as a fundamental right of the individual and as an interest of the community. With regard to the principles contained in the fundamental charter of the rights of the European Union, the law is inspired by Article 1 on the inviolability of human dignity, which must be respected and protected, of the right to life provided for in Article 2 and of the right to the integrity of the person, as referred to in Article 3. In the latter context, the Charter expressly provides that each individual has the right to physical and mental integrity and that in the field of medicine and biology the free and informed consent of the person concerned must be respected, according to the procedures established by law.

In the specific context of the constitutional principles and principles derived from the Charter of Fundamental Rights of the European Union, now highlighted, the general provision, that the new Italian legislation expressly states in Article 1, is included: the one concerning informed consent.

The law establishes that no health treatment can be initiated or continued without the free and informed consent of the person concerned, except in cases expressly provided for by law. Informed consent is conceived as an act that establishes the relationship of care and trust between the doctor and the patient, since it merges the patient's decisional autonomy and the doctor's professional competence and responsibility. This relationship can include, if the patient so wishes, also his family members or the partner of the civil union or the patient's cohabitant, but also a different person, who is a trustee of the patient himself/herself.

The law specifies in detail how the object of consent should be. Every person has the right to know his / her health conditions and to be informed in a complete, up-to-date and comprehensible way regarding the diagnosis, prognosis, benefits and risks of the diagnostic tests and indicated health treatments, as well as the possible alternatives and the consequences of the possible refusal of health treatment and diagnostic assessment or renunciation of the same. The patient cannot demand health treatments that are contrary to the law, professional ethics or good clinical-care practices.

The completeness of what must be the subject of the explanations that the patient has the right to obtain therefore concerns both the type of treatment and the possible outcomes of the treatments themselves, but it also

concerns the possible consequences of the patient's renunciation of diagnostic treatment. It is necessary that the explanation that the patient receives also extends to the possible alternatives to treatment, with respect to that suggested. The patient may also refuse to receive all this information, or may delegate a family member or a trusted person to receive them on his/her behalf. Any refusal to receive or delegate a different person is noted in the medical record and in the electronic health record. The law also provides that informed consent must be received in writing and only in the hypothesis in which the patient is not able to receive it with this form because of his/her health conditions, the law allows the expression of consent through other means, such as videotaping or any device that allows the disabled person to communicate.

The informed consent, with the characteristics described above, is inserted in the medical record and in the electronic health record. In the same way all the changes to the consent already given are noted in the health record and in the electronic health record or in any case the manifestations of the patient's will concerning health care and treatment. In fact, every adult person capable of understanding and wanting has the right to refuse, in whole or in part, with the same forms provided by the law for the provision of informed consent, any diagnostic assessment or medical treatment indicated by the doctor for his/her pathology or individual acts of the treatment itself. Furthermore, every person has the right to revoke, at any time, with the same forms described above, the consent already given even when the revocation leads to the interruption of treatment, including artificial nutrition and hydration.

The new legislation is also concerned with establishing a general rule that regulates the cases in which the patient refuses the medical treatment indicated by the doctor and those in which they withdraws their consent, already previously granted to the treatments themselves. In such cases, the doctor is however obliged to respect the patient's will and, in case of refusal or renunciation of the therapies, the doctor is exempt from both civil and criminal liability. It is also expected that in any case it is not possible to verify the therapeutic abandonment. For example, palliative care is provided for by the law no. 38 of March 15, 2010, already mentioned above, as well as the involvement of the family doctor. Even in emergency situations, the doctor ensures essential health care, where possible respecting the wishes of the patient.

The importance of informed consent for the law is explicitly consecrated by the fact that the time of communication between doctor and patient constitutes time for treatment. The principle is explicitly stated. Equally explicit is the obligation of the doctor to be borne by any public or

private health organization, to guarantee with full organizational methods the full and correct implementation of the principles established by the law, ensuring the necessary information to patients and the adequate training of the personnel with whom he/she works in health facilities.

The law also expressly speaks also of shared planning of health care ⁽⁶⁾. In this context, in the relationship between doctor and patient regarding the evolution of the consequences of a chronic and disabling pathology or characterized by unstoppable evolution with poor prognosis, a shared care plan can be realized between the patient and the doctor, to which the doctor is required to comply if the patient is in the condition of not being able to give his/her consent or in a condition of incapacity. The patient and, with his / her consent, his / her family members or the civil union partner or the cohabitant or a person of his / her trust are adequately informed, with the modalities already specified, in particular regarding the possible evolution of the pathology in progress, of what the patient can realistically expect in terms of quality of life, of the clinical possibilities to intervene, of palliative care. The patient expresses his/her consent with respect to what is proposed by the doctor and his/her intentions for the future, including the possible indication of a trustee. The consent of the patient and the possible indication of a trustee are expressed in written form or, in case the physical conditions of the patient do not allow it, through video recording or devices that allow the person with disability to communicate and they are included in the medical record and in the electronic health record. The care planning act can always be modified at the request of the patient, with the same forms seen previously.

2a) Informed consent subjects incapable by law.

The law pays particular attention to situations in which the patient is under age, to the so-called pediatric patient, and to those in which the patient is not able to understand the information object of the informed consent.

With regard to the minor, the informed consent to the child's treatment is expressed or refused by the parental responsibility or guardian, taking into account the will of the minor, in relation to his/her age and his/her degree of maturity, and having as its purpose the protection of the psychophysical health and life of the child. The informed consent of the person denied under Article 414 of the Italian Civil Code is expressed or refused by the guardian, having heard the interdiction where possible, with the aim of protecting the psychophysical health and the life of the person.

⁽⁶⁾ See Article 4 of the DAT Act.

Likewise, the informed consent of the incapacitated person is expressed by the same disabled person and the trustee. The law also explicitly takes into consideration the hypothesis in which a support administrator has been appointed. In this hypothesis, when the appointment of the support administrator provides the necessary assistance or exclusive representation in the health field, the informed consent is expressed or refused also by the support administrator or only by the latter, taking into account the will of the beneficiary, in relation to his/her ability to understand and to want. However, the judge's intervention is necessary in some cases. The judge intervenes, for example, when the legal representative of the minor or interdicted or incapacitated or the support administrator, in the absence of the anticipated treatment provisions (DAT) ⁽⁷⁾, refuses the treatment proposed and the doctor considers instead that these are appropriate and necessary. In these cases, the appeal of the judge can be proposed by the legal representative of the person concerned or the doctor or the legal representative of the healthcare facility in which the patient is located

3. The advance treatment provisions (DAT).

The advance dispositions of treatment (DAT), are manifestations of will expressed by the adult person, able to understand and willing and able to act, with which he/she expresses his/her convictions and choices regarding health treatments, as well as consent or refusal regarding diagnostic or therapeutic choices and individual health treatments, including artificial nutrition and hydration practices. In them, the persons can appoint a trusted person, called a trustee, who takes their place and represents them in relations with the doctor and with the health facilities. The trustee, who must be an adult and capable of understanding and will, accepts his / her appointment by signing the DAT or by a subsequent act, which is attached to the DAT. The trustee may renounce the appointment by written act, which is communicated to the settlor. At the same time, precisely because of the delicacy and importance of the functions attributed to the trustee, the law also expressly provides that the appointment of the trustee may be revoked by the settlor at any time, with the same procedures as for appointment and without the need for motivation.

The judge can also be appointed to appoint the trustee. The same judge can invest the administrator in support of the functions due to the trustee in this area. These are procedures in which the judge precedes to

⁽⁷⁾ The regulation of the anticipated disposals of treatment (DAT) is contained in the article 3 of the law.

listen to the spouse of the patient or his partner in the civil union or, failing that, the children, or, failing that, the ascendants.

DAT must be drafted by public deed or by private deed. They are exempt from the registration obligation, stamp duty and any other tax, tax, duty and tax. In case the physical conditions of the patient do not allow it, the DAT can be expressed through video recording or devices that allow the person with disability to communicate. With the same forms they are renewable, modifiable and revocable at any time. The doctor is obliged to respect the DAT which can be disregarded, in whole or in part, by the doctor himself, in agreement with the trustee, if there are therapies that are not foreseeable at the time of subscription, capable of ensuring the possibility of improvement of the conditions of life. In the event of a conflict between the trustee and the doctor, the procedure is followed according to the provisions of the appeal to the tutelary judge.

4. Availability of DATs, regional databases and information to citizens.

The law expressly provides that the regions adopting computerized procedures for the management of the medical record or the electronic health record or other data processing modalities of the individual registered with the National Health Service can, by their own act, regulate the collection of copies of the DAT, including the indication of the trustee, and their inclusion in the database, while leaving to the petitioner the freedom to choose whether to give a copy or indicate where they can be found. Within sixty days from the date of entry into force of the law, that is from January 31, 2018, the Ministry of Health, the regions and the health companies provide information on the possibility of drafting the DAT according to the law.

Since before the approval of the special law on the DAT the requirement was so strongly felt that many local administrations had been activated autonomously, outside of its specific competence, to gather the will of the citizens in the area, today the legislator takes into account this phenomenon, providing that all the documents that express the wishes of the persons regarding the health treatments, and that are already deposited in the municipality of residence or before a notary before the date of entry into force of this law, apply the provisions of the same law.

5. The role of family members in relation to advance treatment provisions: from the so called Cirinnà law of 2016 to the law no. 219 of 22.12.2017.

In this complex regulatory framework, the result of years of parliamentary discussions and draft laws that have followed one another over the years, it is clear that the family and its members can actively participate in supporting the patient and implementing his/her wishes in matters of advance provisions for medical and therapeutic treatments.

If one observes carefully, in fact a first important index of the recognition of the role of the family in the anticipated provisions of treatment is already contained, as we said at the beginning of these reflections, in the so-called Cirinnà law of 2016, the law that introduces into the Italian legal system the institution of civil unions for homosexual couples and, at the same time, the law that recognizes for the first time legal effects on coexistence between heterosexual partners.

Article 1, paragraphs 40 and 41 of this law, expressly provides that each cohabiting partner may designate the other as his representative with full or limited powers in the case of illness which leads to an inability to understand and to choose, for decisions concerning health and in case of death, as regards organ donation, methods of body treatment and funeral celebrations. The designation referred to in paragraph 40 shall be made in writing and autograph or, in the case of impossibility of drawing up, in the presence of a witness.

The Courts have already expressed themselves in favor of the involvement of family members in these areas, even with rulings that examine the role of the support administrator in this regard. Among others, for example, the Court of Reggio Emilia, on July 24, 2012, examining a particularly delicate case, in which the patient was unable to self-determine autonomously and subject to support administration, expressly recognizes among the criteria to be followed that of hearing of the patient's family members. There is a real obligation on the part of the support administrator to involve the patient's family members. The provision of the Court of Reggio Emilia, while granting substitutive power to the administrator, obliges him to consult the other family members, and this is established in order to ensure that the decision is as consistent as possible with the presumed will of the patient. In fact, family members have a precise role in

terms of the possible reconstruction of the patient's will, of his convictions, of his lifestyle, of his personality ⁽⁸⁾.

It is only with the DAT law of December 2017, however, that the family members can assume a role that is not only central in the discipline that ensures the implementation of the patient's wishes in matters of treatment and medical treatment, but a role that we can define institutionalized.

The basic problem, however, as we shall see, is that the law does not provide a precise definition of "family", therefore this must be deduced at an interpretative and systematic level.

Let us first consider what the role of the family members in this area may be, and then analyze the notion of "family" that comes to light.

In the legal setting, the patient's family members becomes part of the care relationship that unites patient and doctor. In fact, if the patient so desires, the family members contribute to the treatment relationship. In this context, those who consider themselves as family members derive at an interpretative level from the modalities with which the normative text is expressed. In fact, the law says that if the patient so desires, those who are involved in the care relationship are "also his family members or the part of the civil union or the cohabitant or a person of trust of the patient himself". Among the traditional family members, who may fall within the diction used by the law, the spouse and children are undoubtedly included. We believe that the parents and siblings can be included as well, at least in a second hypothesis. To these relationships of kinship the law expressly adds the figure of the partner of the civil union and that of the cohabitant. In the latter case, however, the law does not bother to assess whether there is a minimal duration of cohabitation to be sought in this area. The law says nothing about it. Nor are there any additional requirements in the area of cohabitation, such as the necessary registration according to the 2016 law on registered civil partnerships and cohabitation (c.d. Cirinnà law). A similar expression is used by the law of 2017 when it speaks of family members with reference to the hypothesis of shared care planning. Article 5 provides, as previously analyzed, that the patients and, with their consent, their family members or the part of the civil partnership or the cohabitant or a person of their trust must be adequately informed on the evolution of the disease, on the possible expectations of life in terms of quality of vision itself and the clinical possibilities of resorting to palliative care. Also in this context the considerations just carried out on the notion of relevant family are valid. In

⁽⁸⁾ The Court of Reggio Emilia, July 24, 2012 is commented by M. PICCININI, in *Nuova Giur. Civ. Comm.*, 2013, 10209.

such a delicate matter, however, perhaps greater caution of the legislator in listing the relevant requirements to be included in the notion of family members or in the more specific notion of cohabitants would have been appropriate. In fact, where the task of providing the interpretative contents of the concepts is left to the interpreter and therefore to the doctrine and the jurisprudence, one risks seeing the appeal to the judicial litigation necessarily increase. The problem is even more important if only it reflects on the fact that on the one hand the "time" factor in some cases could be decisive. On the other hand, some of the subjects considered as family and/or cohabitants could actually be in conflict of interest with the decisions that they are called to take, because they may be named heirs or because, on the contrary, they have not previously been named heirs of the patient.