

## ADVANCE DIRECTIVES AND LIVING WILLS

Laura Palazzani, Professor of Philosophy of Law, LUMSA, Member of the Italian National Bioethics Committee, Rome, Italy

**LIFE-SUSTAINING TREATMENTS AND VEGETATIVE STATE: Scientific advances and ethical dilemmas**  
**17-18-19-20 March, 2004 Rome, Italy**

1. The debate on the legitimacy or non-legitimacy of “Advance directives” and “Living wills” is one of the most pressing questions in the context of bio-juridical studies on the end of human life.

First of all, it must be specified: “Advance directives” should not be confused with “Living wills” in the real sense. “Advance directives” concern previously made decisions about the patient’s possible preferences with regard to the various diagnostic-therapeutic choices proposed by the doctor (together with the preliminary information on the advantages and disadvantages of the possible options): these are advance general indications expressed by the patient for the purposes of deciding which treatment they prefer to undergo, in particular in the specific situation in which they were deprived of the possibility of directly expressing their will to the medical staff (doctors and nurses); the “Advance directives” also generally foresee the patient’s choice concerning future arrangements with regard to religious assistance (before dying), their intention (after certified death) to allow the use of their organs for transplants or their body for experimental or didactic activity. The “Living will”, in the real sense, is not the same as the “Advance directives” *tout court*, but is an extremely precise advance directive: it is a matter of the expression of the last wishes, generally in a written document, of a person who is sound of judgement (a healthy person, before, that is, the start of the illness, or a person who is already ill but still at the initial stage of the illness), in advance with respect to the possible discovery of certain pathological conditions (or of the extreme consequences of certain incurable degenerative pathologies), the precise aim of which is to authorise the doctor (with the possible procedural control by a tutor) to carry out euthanasia (in the so called **of rights** “assisted or rational suicide”): it is therefore a matter of the possibility of expressing one’s own choices not only with regard to the treatment to undergo in specifically foreseen cases, but also with regard to the way in which one dies. Or more precisely, the request not to receive treatment, and therefore to suspend treatment of vital support which may determine the maintaining of a state of unconsciousness or loss of consciousness (reversible or irreversible), but also in the cases in which the patient remains in a state of semi-consciousness, which are states considered unacceptable by the signatory of the biocard. This document may foresee, besides the suspension of treatment, also the authorisation for active intervention in order to

anticipate natural death (therefore provoking the death). Usually this kind of document includes the proxy to a “fiduciary” who would have the task of controlling the execution of the wishes expressed and of guaranteeing their material application and of integrating possible wishes not explicitly manifested by the signatory.

2. It is absolutely necessary to make this distinction before proceeding to the bioethical and bio-juridical consideration. What has to be debated is not so much the possibility or not to express one’s own preferences concerning possible treatment following diagnosis or therapy or even instructions of a religious kind or, the use of one’s organs and body after death (these “Advance directives” are without doubt legitimate, and easily obtain unanimous consensus, having no need for debate, given the common acceptance of the principle of informed consensus in the biomedical and bio-juridical context), but the consideration of the legitimacy or non-legitimacy of being able to decide (with an advance decision with respect to the concrete manifestation of an existential condition of illness) about one’s own life, delegating to others (doctor and tutor) the authority to carry out euthanasia (passive or active). It is at this point that several unavoidable bio-juridical questions arise, in relation to the final phases of human life.

To what extent, in what measure, within what limits can the individual decide on his own death (or rather, can he decide how and when to die)? Does a right “to die” exist, or rather a right to decide about one’s own life and death (the ways of anticipating and carrying out one’s own death)? Are the specific conditions identifiable (illness or suffering) which may justify its putting into effect? What is the basis of this right (admitted that it exists)? Is the demand for the legalisation of the “Living will” legitimate? There is no univocal answer to these serious bioethical and bio-juridical questions in the present pluralistic context. The philosophical reasoning must now be carefully examined of those who support the possibility to legalize this practice and the sustainability of their arguments must be verified, from the point of view of the bioethical and bio-juridical analysis.

3. There are two main arguments supporting the “right to die”, according to the facts set down in the “Living will”: the utilitarian argument of the quality of life and the liberal one of autonomy.

In the context of the utilitarian conception, with regard to the ethical and juridical objective of social usefulness by means of the maximisation of preferences and the minimisation of suffering for the greatest number of persons involved, it is considered lawful (or indeed dutiful in some aspects) to dispose of life (one’s own and other people’s) in the measure in which suppressive interventions are carried out painlessly on lives which suffer too much and/or cause too much

suffering to others (but it is also foreseen, which will suffer too much and/or will cause too much suffering to others). Life, according to this conception, has no value in itself, but rather in relation to the social utilitarian calculation: there follows the ethical and juridical legitimisation of the disposal of one's own human life (even with the intervention of others) in the case of suffering that is considered unsustainable, but it is also considered lawful (if not dutiful) to suppress lives (with or without consent) that are considered not worth living as they do not enjoy sufficient quality of life in relation to the costs benefits calculation.

Within the context of liberal conception, which puts autonomy as the central criterion for morals and rights, it is considered lawful to dispose of life (one's own) in the measure in which the individual is a moral agent (having one's faculties, able to think rationally, with a moral sense and able to make a fully informed decision). Life, according to this conception, does not have an intrinsic value, but relatively to the subjective evaluation of the autonomous individual: there follows the legitimisation of the disposal of one's own life (also by means of the intervention of others) in the case of pathological conditions that are considered unacceptable. On the basis of different arguments, both the utilitarian theory and the liberal theory justify the ethical and juridical legitimacy of the "Living will", inviting the signatory (supposing that the individual is of sound judgement) to decide in which existential conditions his life has no value (what the conditions of suffering or dependence are, understood as absence of autonomy); not only, but to decide that in the case of the conditions established in advance should come to be (conditions in which there is a state of suffering considered unbearable and the progressive loss of one's faculties and rationality) he may ask a third party to intervene to suppress his life (the doctor) or check that the procedures agreed upon are carried out correctly (the tutor).

Both the utilitarian and liberal conception, on the basis of different arguments (inspired by the principle of beneficence and autonomy), but having a common origin (in the separation of biological life from personal subjectivity), promote the legalisation of the "Living will", and therefore the bio-juridical recognition of the legitimacy of claiming a "right to die", or to decide when and how to die (or to anticipate death, by ceasing to give treatment or by actively intervening, for the purposes of ending a human life of a purely biological body, in so much that it is completely lacking quality of life and autonomy).

4. It is important to look more closely at some of the philosophical-juridical considerations on the utilitarian concept of quality of life and the liberal one of autonomy and at the role of the biolaw as a guarantee of the quality of life and autonomy understood as such, in relation to the final phases of human life and the points set down in the "Living will".

As can clearly be seen, the utilitarian debate making an appeal to the quality of life, established on the basis of the costs/benefits calculation, assumes the objective calculability of pleasure and pain. Pleasure and pain however are not objectively ascertainable, as pleasant and unpleasant sensations are structurally subjective. The consideration of the perception of pleasure and pain by others is even more problematic, or the definition of the threshold of bearing pain and suffering, as each individual can only reason by inference, starting from the extrinsic demonstration of behaviour and from associations with previous experience (which are also inevitably subjective). For these reasons it is difficult, or at least problematic, to accept the legitimisation of suppressive interventions on human beings: the elimination of a life can never be “painless” (it is one thing to take away pain and another to take away life: how can you give a benefit by suppressing the beneficiary?); furthermore, a pain which appears to be unbearable to one person may be (and we can certainly not exclude this a priori) for another or others (but also for the individuals themselves, in different existential moments) not only bearable but even a reason for living; and, even admitting that a determined existential situation of illness causes suffering for others, the indirect effect with respect to others can never prevail over the direct effect with regard to the individual.

The liberal debate, rooted in the concept of autonomy, understood in the “strong” sense, is laid open at least to one question (which has repercussions exactly in the reference to the “Living will”): if the right guarantees individual autonomy, how can the conflict of autonomies among autonomous individuals be resolved? If the right formally protects the possible conditions for the expression of the autonomies of autonomous subjects, in the case in which the autonomies are contextual and simultaneous (or rather, should they be shown at the same time and in the same place), diverging and opposed (or, if the wishes expressed are in contrast), the right would not be able to manage the conflict neutrally, but would end up letting the strongest will prevail (of the subject) over the weakest (who would be reduced to object). If the respect for freedom is the respect for any free choice (leaving aside the content and the evaluation of the content of the choice), why privilege the patient’s choice with respect to the other possible conflictual choices, like the doctor’s or the family’s choice. The only way out seems to be that of deciding who must decide; but in this case the choices would not be equal.

An example of the difficulty in managing the conflict between autonomies is that of the decision to carry out euthanasia. It must not be forgotten that it is not a matter of only a subjective decision, but a choice involving the inter-subjective relationship (in particular, the one between doctor and patient): the patient does not only put forward the request to refuse medical treatment, but also asks for the doctor’s collaboration to help and assist his decision to die. To

what extent does the patient have rights and to what extent does the doctor have corresponding obligations? If it is considered that the autonomous individual (of sound judgement) has the right, in the strong sense, to publicly decide his own death by expressing advance directives to others (in fact, the doctor) in relation to the possible presentation of existential conditions (such as the absence of autonomy) considered unacceptable: in this case, it can be concluded that the individual asking for death is imposing his will onto the doctor's will. The person asking for advance death becomes the strongest subject over the doctor's conscience, whose will is weakened to blindly carry out the orders of the applicant, even in the case of the requests going against his own will (that is, even if the doctor considered, according to his deontological conscience, that the circumstances do not exist that could justify the act and however, that those conditions of life are acceptable and anyway deserve to be maintained). This argument could be turned around. If the autonomous person's request for euthanasia to the doctor is "weak", or if the will to die is censurable, disputable and not guaranteed in the strong sense; if the sick person desires euthanasia but leaves the final decision to the doctor: then the doctor would become the strongest subject, who would end up by prevailing over the individual's will (who would be reduced to weak object). It seems difficult to get away from this alternative: either the autonomous individual asking to die imposes himself on the doctor's will (leaving him with no other possibility of choice); or the autonomous individual asking for euthanasia accepts his subordination to the doctor's will. Either the patient has power over the doctor (that of forcing him to give him death); or the doctor has power over the patient (that of identifying, at his discretion and free will, whether or not to go ahead with euthanasia).

With regard to this it must also be mentioned that, if it is undoubtedly true that there are different types of individual behaviour belonging to the private sphere which have no public importance and which however should come into the discretionary powers of the single person, it is also true that the "Living will" does not come into these (as the liberal perspective claims). The relationship between doctor and patient, in this case, is a contractual relationship going beyond the relationship between the parties. This is because it both takes place in public structures and in a social context: the recognition of a right to rational assisted suicide is not equivalent to the freedom to commit suicide, since it implies the participation and the collaboration of a series of professional figures and public structures designed to give services and assistance to the whole society. In any case, the "Living will" could not be a private agreement, but would have inevitable implications on the entire hospital system (on the consideration of the medical profession's role).

It must also be considered that the autonomy mentioned in reference to the advance directives for euthanasia is extremely ambiguous: it is an autonomy expressed with a “cold mind”, abstracted from the situation and chronologically distant (it is not by chance that it is revisable and revocable only in conditions of clearness of mind and not of illness). The autonomous adult person, of sound judgement and in good health, can decide that, should certain circumstances come to be, the doctor (with the control of a tutor) is authorised to take his life. It is inevitable that, even intuitively, at least one doubt arises: how can we be certain that the will can express a really informed consent about a future situation that it does not know (even though all the details have been supplied descriptively)? How can an autonomous individual in existential conditions of efficiency, an individual who has still an open and indefinite future in front of him, project his will into a completely different context, which furthermore he has never previously experienced, a context where there is no future? Would it not be possible, perhaps just in that situation, for the instinct of self preservation to re-emerge, the hope to continue to live, that the clear rationality is not able to percept coldly or wants to intentionally remove? This is a doubt which also extends to the will expressible in the “Advance directives” of being informed about the state of health in the case of a serious and incurable illness: how can one exclude a priori that finding oneself in that situation, wouldn't one perhaps have more need of a hope or to be given the fatal prognosis gradually?

It cannot be excluded a priori that the subject may cling onto life desperately even in moments of suffering, or consider the suffering that he thought would be unbearable, bearable at the moment of experiencing it. In short, the will can change with respect to the initial decision, or can also alternate in different states of mind and in contrasting requests, when confronted by illness and death. The giving of the same will to the signatory of the “Living will” when he is no longer able to manifest it can constitute juridical forcing. And this is without considering the fact that, given the continuous evolution of the progress in biomedical knowledge, some situations deemed incurable can be modified: the continuous discovery of new therapeutic possibilities could force one to continually revise one's will, but could also reach the situation in which there is no more congruity between what is written and reality.

One final consideration must be made on the person of the delegate, the biocard “fiduciary representative” or “substitute” or “surrogate decider”, called upon to guarantee the respect of the will expressed during life and in conditions of mental competence by the signatory of the “Biocard”. The tutor is not only the person who mechanically applies the clearly expressed will on the card (otherwise, perhaps, his presence would have no sense at all): but he is also the interpreter of the decisions explicitly not expressed by the signatory. The intervention of the

tutor is (or can be) therefore also personal and creative, with respect to the will of the signatory: in this sense the tutor's intervention is open to the risk of possible misunderstandings.

5. Starting from a consideration of the very meaning of right, as the protection of coexistence and human dignity even with respect to the scenarios of the new millennium presented by technical-scientific development, and from a reflection on human rights, we cannot but agree with the need for the protection of the biological body of the human being (from the beginning to the end, whatever their existential condition may be), when faced with the new possibilities of manipulation: the human biological body must be protected as a seat of fundamental relationality, the seat of subjectivity and human identity, even if this is manifested in "residual" and faint existential conditions, during the terminal phases, of illness and suffering. The right is called upon to recognise the biological body of the human being as an intrinsically normative source, of responsibility: even empirically different bodies, ill, deformed or impaired, inactive or without consciousness, are "like" any other body, by virtue of the common human nature. The right is called upon to defend the relationality and equality between men: in this way the body, each human body, is the bearer of an objective concern. Asking to be recognised and towards which each man is debtor (also leaving aside the recognition of one's own concerns). Even the human being that is no longer able to claim their own rights, who needs the help of others to exist, deserves the protection of that right.

From a theoretical aspect, when put before the requests for the legalisation of the "Living will", the right is called upon to assert its constitutive function, or the function of defending human dignity in the social dimension of the relationality among human beings. Indeed, the right cannot be neutral with respect to values: the constitutive function of bio juridical questions is the defence of the minimum ethics conveyed by the right, the ethics of human dignity and coexistentiality. In the light of the real meaning of right, a right "of" dying or the right "to" die (or the right to decide in advance when and how to die) is not configurable, but rather a right to be helped "in" dying. The strong right of the individual to manage his own death is not justifiable, as the advance directives of euthanasia claim.

On the other hand, the patient's right to demand to be "accompanied" in a dignified way to death is justifiable along with the doctor's duty to do everything possible to help him to "humanize" his death (and not drown it in bureaucracy). The humanisation of dying can take place through the commitment of the doctors and nursing staff in order to alleviate suffering, with the use of palliative treatment making a less painful death possible: indeed, palliative care should be a patient's right. The humanisation of dying can only take place by means of a refusal

of therapeutic persistence: exaggerated therapeutic persistence and intervention aimed only at the painful prolonging of death, is a form of dehumanisation of death: it should not be accepted, even if explicitly asked for by the patient.

From this point of view, the advance directives could foresee, besides the instructions relative to choices of therapy and assistance, also the request for palliative care at the terminal stage: but it would not be necessary to specify the request to suspend therapeutic persistence (but not however the administration of ordinary treatment), as this constitutes the duty of the doctors and nursing staff, leaving aside the specific request. The suspension of therapeutic persistence does not mean therapeutic abandon: the extraordinary treatment is suspended, but not the ordinary treatment. If the objective of the “Living will” is that of avoiding therapeutic persistence, it is of no use at all: it should not be indispensable to declare one’s will with regard to this in writing, as it is implicit in deontological duty.