Disposability of human life. Basic Outlines

by Francesco Viola

In the moral field general principles are valid for most cases, but there can be exceptions considering particular cases. In their turn the solutions to particular cases are subject to variations on the basis of the evolution of knowledge and technique.

The question of whether human life is never disposable or whether in certain conditions it is disposable cannot be answered once and for all in an abstract and clear-cut way. An answer of the kind can only be the result of research and a moral debate and not a presupposed principle. If it were so, in pluralistic contexts it could only be imposed with the strength of votes and not with that of reason. In turn such research can never be considered entirely complete, but should remain open to consideration of new situations and new circumstances.

It needs to be specified that this issue directly concerns biological life, that is to say the disposability of the life of the body as opposed to that of the soul or the conscience. Everyone agrees in excluding the latter, both in the Faustian sense of selling one's soul to Mephistopheles, and in the more secular sense of submitting one's identity, one's self, one's freedom of judgment, of conscience and expression to others' will and dominion. In this sense the disposability of one's person is to be excluded.

One may think that the corollary of the non-disposability of the person is that of the body, since corporeity is an essential element of the human person. It is significant that Chapter I of the *European charter of fundamental rights*, devoted to human dignity, directly concerns the bodily dimension of the person: his/her right to life and to physical and psychic integrity, the prohibition of eugenic practices, the prohibition of marketing of parts of the body, of reproductive cloning and of torture and slavery. Every action against the human body directly injures the dignity of the person. This holds first of all towards one's own self. Everyone is obliged to respect the dignity that is his or her and must be in a condition to respect it. This original duty precedes and founds rights, which in turn must be used to protect one's dignity *vis-à-vis* others or external threats and to bring it to

fulfilment or full flowering, but not to dispose of it as one likes. But does this also imply absolute non-disposability of one's biological life?

Evidently not. Both religious and non-religious thought agree that there are cases in which physical life can and must be subordinated to a higher value. It is almost superfluous to remember the ever-growing host of martyrs for religious or lay reasons and also that of those people that have given their lives to save that of other people or to defend the political community to which they belong. We can say that supreme religious values, ideal conceptions of the truth and other people too can constitute an adequate justification for the sacrifice of one's own physical life. Therefore, physical life is not an absolute value or one that is absolutely not disposable.

Though the possible disposability of one's life for clearly justified reasons cannot be denied, the time has come to wonder whether these reasons also include one linked to the extreme conditions of a terminal illness close to its tragic epilogue or to a persistent or permanent vegetative state. From now on we will refer to this as the "extreme case." And from now on our reflections will only concern this case, in order to see whether it can require a waiver of the general principle (not an absolute one) of the non-disposability of physical life.

It must immediately be observed that this case is not continuous with the previous one and cannot be included in the same category. In the case of donation of one's own life for a higher value, we have a real example of disposability. The goal of this action is not death, as in suicide: it is valid as a means in view of something else of greater value. Life is disposed of for something else. In the extreme case, instead, speaking of disposability of one's own life is inappropriate, because it has escaped our direct control and also that of medical science itself. We no longer dispose of life, so that we can give it or not give it according to our will, justified or not. What we are left with is only management of the last phase of our terrestrial existence.

The extreme case has much more reduced dimensions, though ones that are not rendered less dramatic by this fact: the freedom that we have is only to refuse treatment or not, and ultimately not to decide *whether to* die but *when*; the life that we have can hardly be considered "natural", since it has become dependent on the artifices of health technology. The extreme case is, precisely, a particular case, in which general principles that are valid in most cases have to be set in concrete situations.

We can imagine that the extreme case will manifest itself according to two possible modalities. In the first of them, the dying subject preserves acceptable lucidity of judgment and a sufficient degree of consciousness. In the second, the subject is instead no longer able to decide by himself or herself and his or her life is in the hands of other subjects, relatives and physicians.

If we now consider the first hypothesis, assuming that the patient is able to express his or her present wishes regarding the proposed therapies, then he or she will be able to participate with full awareness in their determination, entering into a relationship of cooperation with physicians and relatives. But in the last resort he or she cannot be forced into particular health treatment against his or her own wishes. As we know, this is a constitutional principle (art. 32 of the Italian Constitution) closely connected to the principle of informed consent, fully implemented both by other norms of the Italian legal system and by norms and trans-national and international principles. This fact is significant in itself, and moreover is corroborated by moral reasons.

Defence of the right to life and the duty of the state to guarantee the possibility of being treated cannot go to the extent of replacing the wishes of the person affected, especially if this person is in the situation of the extreme case, in which by definition treatment is for recovery and artificially prolongs the death agony. Here respect for the freedom to have treatment or not and respect for natural processes come together. This does not deprive religiously motivated patients of the right to decide how to exercise their wishes on the basis of an interpretation of life as a gift received from the Creator that cannot be disposed of.

I would like to point out that the extreme case is very different from the case of abortion, for which the argument of the right not to abort is not valid, since in abortion the decision of the mother has to reckon with the life of another human being. Here instead health is a pre-eminently personal fact in relation to which bonds with other human beings, though important, are secondary, while the relationship with oneself is pre-eminent and, for believers, the relationship with God is also pre-eminent. At least in relation to the extreme case, if we want to leave aside the general issue of the freedom to have treatment or not, there is no doubt that treating a human being against his or her own wishes would be an act of paternalism or violence and not an expression of respect for the human person.

The right to refuse treatment, and certainly treatment that is useless for the purposes of recovery, has to be respected by the health structure or by the national health service.

If we now consider the second hypothesis of the extreme case, that is to say that in which the patient is not able to take decisions by himself or herself, then – as is well known – the perspective

becomes that of giving some importance to his or her dispositions, that is to say the so-called "living will."
I believe that this expression is a very unhappy and equivocal one, not so much because it suggests the idea that physical life is patrimonial property to dispose of, but above all because it suggests that the affected person has already substantially gone away and that his or her last action has to be taken back to the moment when he or she was conscious. Even in the case of a persistent and irreversible vegetative state, the human being preserves his or her dignity and his or her personal character intact and as such demands respect. Hence we have to face the problem of how to take decisions in his or her place, and what importance to give to his or her previously declared wishes.

Let us assume that we are talking about unequivocal and explicit declarations, and not very doubtful suppositions (as in the case of Eluana Englaro), and that they are sufficiently recent. Here the difficulty that I see is that in the moral choices the presence of the specific circumstances and contexts is essential for the formation of the desire and the decision. One can certainly envision a future situation and foresee what would be decided in such a case, but, since we are not yet in that situation, we cannot fully prefigure our own psychological reactions and future preferences. Moreover, it may very well happen that in the meantime new treatment modalities have come into being and that there has been a significant change in the elements taken into consideration in the past decision. It is necessary to specify that an expression of personal will must be maintained stable only when it is binding for other subjects, as happens in a promise, but it is always subject to revision when one takes a decision that only concerns oneself. The possibility of re-examining one's own choices is closely connected to the concept of human liberty. So to what extent is this kind of will binding for others?
It seems to me it is reasonable to say that others (next of kin and physicians), that is to say those that are to render the patient's desires effective or to decide in his or her place, are as a matter of principle obliged to carry out such declared wishes, but not as an immutable diktat. They can deviate from it, but only on the basis of clearly justified reasons that could not be taken into consideration when the declaration of will was formulated. In this connection, we can never overemphasize the exclusive will of the patient. It is true that health is a wholly personal thing, but not in a strictly individualistic sense, as at times we are inclined to think. Treatment requires relationships with experts on health and the provision of health structures. The sick person, in turn, depends on the relatives that are to assist him or her. That is to say, other subjects are involved that in turn have their rights to uphold and duties to respect. For this reason it has already been observed

that treatment is a cooperative enterprise and that the other subjects involved are not testamentary executors, but custodians of an action directive that may in the course of time be modified and adjusted. It is better clearly to recognize this cooperative situation rather than to hide it through questionable operations involving attributing to the sick person the desires or demands of relatives or physicians. In short, the importance of the patient's will is only acceptable if it is inserted in a conception of treatment of a cooperative and not purely individualistic type. If the sick person is not conscious, undoubtedly the role of the other participants in the treatment enterprise necessarily takes on greater importance.

Lastly, we have to consider the issue of whether feeding and hydration, considered as living support, must be separated from therapies proper and, consequently, must not be among the treatments that the patient can refuse. In principle, everything that concerns living support is not part of therapies and through a long tradition of humanity is due to all human beings that need it for their elementary survival, and is to be provided by all those people (and therefore not only physicians) that are able to give such succour. This implies tremendous responsibility for the state and well-to-do citizens in relation to needy citizens and of rich nations in relation to the boundless number of people that still are dying of hunger and thirst in various parts of the world. It would be paradoxical to force a person to feed when they do not want to for comprehensible reasons and not to give food to those who instead ask for it for their survival.

In the extreme case this duty can only be carried out by physicians or under their control, since the systems for feeding and hydrating a patient in a persistent terminal or vegetative state require specific competences and the use of specific technology. This does not mean that living support is among therapies, and yet it still has an invasive character *vis-à-vis* the patient's body (a feeding tube) and can produce undesirable side effects that only medical control can avoid. Once again we have to consider separately the two hypotheses formulated above.

In the hypothesis of present ability of the patient to make conscious choices, then he or she must also be recognized to have the ability to decide about feeding and hydration regardless of whether they are to be considered therapies like the others or not.

When freedom to be treated or not is admitted on the legal and moral plane, it is certainly not ruled out that there is bigger freedom in the management of one's physical existence, though there remains the possibility of making immoral choices for which the chooser bears the full responsibility. On the other hand, refusal to have therapy can be just as life-threatening as refusal to be fed. In freedom to be treated or not one only wants to specify freedom in a specific field and,

above all, to set some limits to the law that forces one to have particular treatment (art. 32 of the Italian Constitution). Therefore if a sick person that is in the extreme case decides to forego living support, despite the suggestions and the warnings from the other subjects that cooperate in the management of the illness, then this decision has to be respected. Appealing in this case to a human duty to be respected, even against the wishes of the patient, would mean making humanity compatible with constraint and violence.

On the other hand, in art. 53 ("Conscious refusal to be fed") of the New Italian Code on medical ethics (2006), also present in the previous versions, the duties of the physician in this connection are identified as follows: "When a person voluntarily refuses to be fed, the physician has the duty to inform him or her of the serious consequences that an extended fast can involve for his or her health conditions. If the person is aware of the possible consequences of his or her decision, the physician is to undertake no coercive measures or to collaborate on coercive manoeuvres of artificial feeding of that person, though continuing to assist him or her." It is obvious that coercion cannot include the normal operative insistences about feeding coming from the relatives of the sick person or from those people who assist him or her.

In the hypothesis of the presence of clear, unequivocal and recent advanced directives that also *expressly* include foregoing living support in the extreme case, then one fails to see why this refusal is to be treated, in principle, differently from refusal of therapies proper. If the will of the sick person is important in relation to his or her medical treatment, no distinction can be made with respect to the contents, unless the request implies real euthanasia practices. The feeding probe is "medical treatment", even if it is not considered true therapy. Moreover, I do not believe that an omission, whose direct intention is to respect the sphere of personal freedom and not to cause a person to die, in the conditions of the extreme case can be seen as an act of euthanasia, even a passive one. Obviously, in this case too, and all the more so, advanced directives are not immutable and can be overridden on the basis of well-founded reasons or applied gradually in consideration of the circumstances, so as to accompany the sick person, with respect blended with wisdom, in the final phases of terrestrial life.

As regards these reflections on the treatment of the extreme case too we have to bear in mind the fact that we are dealing with general indications that then have to be contextualized in particular cases and, therefore, are subject to variations and adaptations. The norm, both legal and moral, does not set up a principle from which conclusions can always be derived in a purely deductive way. For this reason, especially in legal laws of a moral character, it is appropriate to leave open a certain

area of indeterminacy, though safeguarding the basic ideal orientations, especially when these have to reconcile different values (in this case the defence of the value of human life and that of the liberty of the person). In law, as in morality, the appropriate locus is the concrete case and the action to be taken here and now respecting principles and general rules.

This caveat is even more essential for a society marked by pluralism of conceptions of human life. Such a society certainly does not have to forego the idea of finding a point of convergence in the moral principles without which a real political community would be impossible, but it also has to have a sense of what it is reasonable to ask everyone for regardless of his or her particular visions of human life.