

Paris, 19th September 2022

Ethical Issues Relating to End-of-Life Situations: Autonomy and Solidarity (Opinion 139)

There are several recurring debates in society about the end of life. Citizens, parliamentarians, NGOs, caregivers, intellectuals, etc. are discussing whether the law should change, as current laws do not provide for the delivery of active assistance in dying. Although the CCNE has examined ethical issues relating to the end of life on several occasions, it wished, in the light of legislative, medical and societal developments in recent years, to examine certain ethical issues in the debate in greater depth. This is the purpose of its Opinion 139 "Ethical Issues Relating to End-of-Life Situations: Autonomy and Solidarity", in which it makes several proposals.

All the reflections that the CCNE has carried out on the end of life since 1983 have been based on the search for a fair articulation of the principles of freedom, dignity of the person, solidarity and respect for autonomy. French legislation reflects these major principles through four laws that have radically changed the approach to the end of life. Thus, "unreasonable obstinacy" is prohibited; respect for the individuals is guaranteed in situations where they are no longer able to express their wishes, by means of advance directives, the designation of a "trusted person" and a collegiate procedure for end-of-life decisions; any patient whose condition so requires has the right to access palliative care and support and is recognized as having the right to refuse treatment; a person suffering from a serious and incurable pathology whose vital prognosis is at risk in the short term is entitled, in certain situations, to deep and continuous sedation until death.

In its new Opinion "Ethical Issues Relating to End-of-Life Situations: Autonomy and Solidarity" (Opinion 139), the CCNE addresses the ethical issues generated by the application of current law in the various end-of-life situations. It completes its analysis with a number of proposals. This CCNE intends for this opinion to contribute to the reflections of all: legislators, citizens, healthcare professionals, researchers, etc.

Developments and Limits

Although the CCNE has observed a positive evolution over the last twenty years, in particular thanks to the Claeys-Leonetti law of 2016¹, it notes a gap between the law and its application. From this point of view, he regrets that there have been no real evaluations of the impact of the various laws. The CCNE also deplores the insufficient application of successive plans in favor of palliative care. It also notes that our fellow citizens do not take sufficient advantage of the measures allowing them to appoint a “trusted person” and to draw up advance directives.

In spite of these limitations, the CCNE considers that the current legal framework is satisfactory when the prognosis for survival is short term, "offering mechanisms that respect the dignity of people suffering from serious and advanced illnesses". On the other hand, certain people suffering from serious and incurable illnesses that cause refractory suffering, whose prognosis for survival is not short term but “**medium term**”, do not always find a solution that is adapted to their distress within the scope of the legislative provisions. The same applies to situations of dependence on life-sustaining treatments whose cessation, decided by the individuals when they are conscious, without altering his or her cognitive functions, does not lead to death in the short term. These situations, which remain infrequent, are leading some to reopen the debate on active assistance in dying, based on the experience of countries that have legalized assisted suicide or euthanasia for patients whose vital prognosis is committed in the medium term.

Solidarity and Autonomy

The CCNE is basing its reflections on the reconciliation of two fundamental principles: the duty of solidarity towards the most vulnerable people and respect for the autonomy of the person. If the legislator were to take up this subject, the CCNE considers that "there is a way to ethically apply active assistance in dying, under certain strict conditions, with which it seems unacceptable to compromise". These conditions must be inseparably linked to a strengthening of public health measures in favor of palliative care and the taking into account of major ethical benchmarks in the legislative measures that are taken.

The CCNE's Proposals

Palliative Care: Strengthening Public Health Measures

It is imperative to strengthen public health measures in the field of palliative care. This implies supporting the early expression of wishes (designation of a “trusted person” and advance directives), promoting the inter-professional nature of the collegiality of the medical decision to stop treatment, and extending deep and continuous sedation beyond specialized units.

¹ In particular, the 2016 law created a right to deep and continuous sedation until death for patients with a short-term life-threatening condition, with all treatments stopped.

Ethical Benchmarks in the Event of Legislative Change

If the legislator decides to legislate on active assistance in dying, a number of ethical criteria will have to be respected. Thus, in this case *"the possibility of legal access to assisted suicide should be open to adults suffering from serious and incurable illnesses, causing intractable physical or psychological suffering, whose vital prognosis is committed in the medium term"*. The request for active assistance in dying should be expressed by a person who has autonomy of decision at the time of the request, in a free, informed and reiterated manner. The decision to proceed should then be documented and argued and would be taken by the doctor in charge of the patient following a collegial procedure involving other healthcare professionals.

Leaving out of the scope of the law those who are not physically fit for such a gesture would raise an ethical problem of equality between citizens. This is why some propose that these patients should have legal access to euthanasia, in this circumstance alone, "under the same condition of a vital prognosis engaged in the medium term. Others believe that the law should not establish exceptions to the prohibition on giving death and want medical decisions in exceptional cases to be left to the discretion of the judge, if necessary. The CCNE leaves it to the legislator, should he take up the subject, to determine the most appropriate approach to these situations".

Healthcare professionals should be able to benefit from a conscience clause, accompanied by an obligation to refer the patient to another practitioner in case of withdrawal. Such a law, if envisaged, should be evaluated regularly.

A Necessary National Debate

The extreme complexity of the subject of the end of life, which brings together symbolic and spiritual representations of death, fear and anxiety, the ongoing experience of the Covid epidemic, which has led to an unprecedented crisis in our healthcare system, and the difficulty for caregivers in accompanying patients through their life course, require a time for dialogue and respectful listening. The CCNE calls for the organization of a national debate in which it will participate.

A "cautious opinion"

Although the majority of CCNE members voted for this text, eight members wished to express a "cautious opinion" which appears at the end of opinion 139.

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