

End of life: *a change in the law?*

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The question of the end of life is deeply rooted in all cultures and all societies: it affects all those who have experienced the end of life of someone close to them, and is part of the daily lives of carers.

A democratic continuum to fuel a major societal debate

“Is the end-of-life support framework adapted to all the situations encountered, or should changes be introduced?” This is the question the Prime Minister referred to the ESEC in October 2022. In response, two working groups have been set up: a Citizens’ Convention to gather the views of 184 citizens chosen by lot, and a temporary committee to hear the views of members representing the civil society organisations that make up the ESEC.

Drawing on the work of the Convention and taking account of its proposals, the committee has extended its thinking through hearings and interviews, as well as analyses by ESEC organisations directly or indirectly involved in the end-of-life issue.

QUESTION

HOW CAN WE SUPPORT PEOPLE AT THE END OF THEIR LIVES?

This highly complex issue cannot and must not be reduced to a contest between palliative care and active assistance in dying. This was already expressed by the ESEC in 2018 in its opinion: “End of life: France at a time of choices”. Back in 2018, the ESEC was already questioning the actual implementation of palliative care, and was in favour of amending the 2016 law, known as the “Claeys-Leonetti law”, by authorising “explicitly lethal” deep sedation,

a point on which there was dissent in the opinion.

In the same spirit, this opinion sets out first and foremost to form part of a humanist vision of a caring, inclusive and emancipating society, a vision supported by the ESEC. This is why particular attention is paid to the situation of the most vulnerable people. It then presents an assessment of the “Claeys-Leonetti” law, creating new rights for patients and people at the end of life. Lastly,

the opinion proposes a pathway for support at the end of life, similar to that proposed by the Citizens’ Convention.

Through its 13 recommendations, the ESEC is expressing the desire of its member organisations to become involved in this complex social debate, which touches on the most intimate issues and must continue.

1 Recall the principle of the right to effective end-of-life support in a supportive, inclusive and emancipatory society

- By guaranteeing this support to everyone, particularly the most vulnerable, everywhere (mainland France and overseas territories) and in all locations (home, establishments, reception facilities, etc.);
- By respecting the choice of type of support and the wishes of people until death, palliative care and active aid in dying (AAD), if the legislator decides to open up this possibility, as the Citizens' Convention and the ESEC would like.

2 Develop information and training

- By strengthening the National Centre for Palliative and End-of-Life Care (CNSPFV) in its missions and resources;
- By providing everyone with full and complete knowledge of the definition of the right to end-of-life support;
- By developing participatory debates and exchanges, in proximity by all means to the widest possible population;
- By conducting national information campaigns tailored to different audiences, to be renewed regularly following the example of prevention and/or public health campaigns
- By developing a culture of palliative care in initial training courses for doctors, nurses, care assistants and other paramedics

3 Extend the rights and roles of those involved to provide better support at the end of life

- By providing in the advance directives for the person concerned to express their choice of the type of support, assisted suicide or euthanasia, in accordance with the access arrangements laid down by law.

→ By recognising, through a specific lump sum, the time spent by the doctor in providing support for the drafting of advance directives.

→ By accessing an accelerated procedure before the courts in situations where conciliation is impossible (conflicts) between the patient's entourage/trusted person and professionals, but also for people in vulnerable situations (disabilities, minors, etc.)

→ By being vigilant about the changes to be made to the provisions of existing codes, and in particular the Criminal Code, the Civil Code, the Public Health Code and the Insurance Code, in order to prevent possible prosecutions, preserve the rights of beneficiaries/heirs under provident, death and life insurance policies.

→ By generalising the agreement of EHPADs (residential care homes) with EMSPs (mobile palliative care teams) for complete coverage and continuing to develop the culture of palliative care in all establishments.

4 A joint guarantee in the name of the principle of freedom

→ The right to have recourse to assisted suicide or to request their euthanasia for people suffering from serious and incurable illnesses, causing unbearable and unappeasable physical or mental suffering.

→ The right for healthcare professionals to refuse to perform acts themselves by asserting a conscience clause accompanied by the obligation to inform and refer patients and their care by one or another professional

→ Consider the acts necessary (medical prescription, lethal injection, etc.) to implement the patient's choice as medical acts falling within the provisions of the Public Health Code.

THE RAPPORTEUR

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