

END OF LIFE: FRANCE AT DECISION TIME

Well aware of citizens' concerns with regard to the end-of-life question, expressed both in recent surveys and online petitions that collected over 350,000 signatures, the ESEC took up the subject on its own initiative (having tackled it once before in an opinion of 24 February 1999) in a new context brought about by the enactment of the Claeys-Léonetti Law in 2016 and the opening of the Estates General on Bioethics on 18 January 2018, in line with the President of the Republic's wishes.

Although the current regulatory framework emphasises every person's right to receive appropriate palliative care and support at end of life, consideration of terminally ill individuals' wishes, in particular through the drafting of anticipatory directives and designation of a "trustworthy person", and the possibility, in certain conditions,

of implementing continuous deep sedation until death, it has to be said that these rights are still a long way from being fully applied. There is unequal access to palliative care across French soil, and what is available is not enough to meet present needs or those predictable over the middle term, in particular as regards homecare. Provisions designed to make the ill person central to decisions concerning him/her are still largely unknown, both by the general public and by professionals. Lastly, application of the right to continuous deep sedation, enshrined in the Law of 2016, is hampered by medical, legal and ethical difficulties alike.

The persistence of dramatic situations in this context, rare enough perhaps but recurrent all the same, leads to reflection on the need to open a new right to medically assisted death under



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strictly supervised conditions – in particular in the light of foreign experiences and contributions made by philosophical and religious thought.

THE ESEC CONSEQUENTLY HAS TWO SERIES OF RECOMMENDATIONS:

IMPROVING APPLICATION OF THE REGULATIONS IN FORCE

- **Increasing information on and appropriation of the regulations by stakeholders and the general public:**
 - in the context of the upcoming national plan for development of palliative care (2019-2021), launching an information campaign on the subject, in particular as concerns the drafting of anticipatory directives on designation of a trustworthy person;
 - declaring end-of-life support a "great national cause" in 2020.

✎ **Increasing the human and financial resources allocated to palliative care and end-of-life support:**

- providing the upcoming national plan for development of palliative care (2019-2021) with a large enough budget to make up for the delays observed across the country and meet needs by increasing the hospital palliative care offer from 20 to 40% compared with existing provision;
- developing the place that palliative care and end-of-life support occupies in health and care professionals' initial training programmes, and acting rapidly to increase the continuing training offer by some 20% compared with the existing offer;
- taking better account of the place of professional caregivers, live-in caregivers and natural caregivers in contracts between regional health agencies, healthcare institutions, medicosocial institutions and voluntary associations.

✎ **Taking better account of the diversity and complexity of end-of-life pathways:**

- increasing resources devoted to scientific research on palliative care and end-of-life support;
- stepping up monitoring and assessment of hospital and ambulatory systems involved in palliative care and end-of-life support;
- excluding hospital palliative care from tarification à l'activité (T2A – per-service pricing) by taking better account of the time required for such types of care;
- improving funding of home-based palliative care by taking better account, in the context of future pathology-based pricing, of remuneration of physicians coordinating or participating in palliative care, and that of other care professionals, by revaluing treatment rates at Établissements d'Hébergement pour Personnes Agées Dépendantes (EHPADs – care centres for dependent senior citizens) as well as appropriations to palliative care networks and mobile teams;
- authorising general practitioners to prescribe and local pharmacies to dispense the medicines required for continuous deep sedation;
- specifying collegiate procedure by decree, in order to strengthen the position of non-physician healthcare professionals and the role of community actors, and set an order of priority in consideration of family members' opinions;
- providing by law that all healthcare professionals have the right to call upon another member of their profession to administer continuous deep sedation.

WIDENING THE FIELD OF POSSIBILITIES BY AUTHORISING FINAL CARE

✎ **Adopting the law on "final care":**

- adding to sick people's currently recognised rights that of being able to request a physician, including via the drawing up of anticipatory directives or designation of a trustworthy person, to receive and, under strictly defined conditions, administer explicitly lethal deep sedation (this point being the subject of divergences on recommendation no.12, expressed in the opinion);
- setting legal conditions for admissibility of the patient's request, methods of assessing such admissibility and the physician's acceptance or refusal of the request, as well as the a posteriori control mechanism for such actions;
- including a "freedom of conscience" clause in the law enabling anybody of whatever profession to refuse to take part in any way in prescription, dispensation or administration of explicitly lethal deep sedation.

✎ **Carrying out an assessment of the "final care" law three to five years after its enactment, including any consequences that the freedom of conscience clause might have on the right's effectiveness.**