

## **Delphine HUGLO Lawyer - Edited on 05-04-2016**

Law "Leonetti Claeys' No. 2016-87 of 2 February 2016 published in OJ No. 0028 of 3 February  
2016 creating new rights for sick people at end of life

### **Introduction:**

Advances in medicine leads to new issues: the extension of the life of patients with advanced age, or after a serious accident raises ethical questions: how do we respect the dignity of people reaching the end of their lives?

We all remember the story of Vincent Humbert who after a very serious accident is in a minimally conscious state. His story has made a major contribution to the adoption of a special law on end of life April 22, 2005: Law No. 2005-370 of 22 April 2005 on patients' rights and end of life, the Leonetti legislation.

In particularly serious cases, the judges in correctional courts have been faced with dilemmas to make tough decisions in « borderline cases ».

Given these situations and the lack of an applicable law, it became necessary to think of adopting a new law. This is the objective of the new law "Leonetti Claeys' No. 2016-87 of 2 February 2016 creating new rights for the sick and people in later life.

### **Part 1: Background / problem**

The existing legislation:

Article 37 of the Code of Medical Ethics states: "In all circumstances, the physician must strive to alleviate the suffering of the patient by means appropriate to his condition and assist him morally. He must refrain from any unreasonable obstinacy in investigations or treatment and may refrain from undertaking or pursuing treatments that appear useless, disproportionate or that have no other purpose or effect than maintaining artificial life support."

Article L 1111-4 of the Public Health Code provided prior to the Act of 2 February 2016: "The physician must respect the will of the person after having informed of the consequences of his choices. If the will of the person to refuse or discontinue any treatment puts his life in danger, the doctor must do everything possible to convince the patient to accept essential care ".

These provisions appearing to be insufficient, a mission had been entrusted to the deputy Jean Leonetti leading to the adoption of the Law of 22 April 2005 on the end of life called the Leonetti legislation providing a framework for good medical practice, giving preference to the expression of collective solidarity by helping people in later life and an individualistic vision of the human person enabling each one to decide to end his life.

The law does not decriminalize euthanasia, medical ethics code stating that "the physician does not cause death. " The law lead to the inclusion in the Public Health Code of a section called "expression of the will of patients at end of life"

The provisions of the law were also included in the Code of Medical Ethics Articles 36 37 and 38. Those decrees provided:

- The obligation of the doctor to respect the refusal of care expressed by the patient;
- the exclusion of unreasonable obstinacy (avoid unnecessary and disproportionate care);
- the prohibition of deliberately causing death

Thus the patient "participates" in the medical decision. As for the doctor, it can relieve the patient end of life by administering treatments with the side effect of shortening life (administration of analgesics), but this is by no means allows any act having for effect to shorten life.

The law also provides for the development of palliative care. These treatments designed to relieve pain are too often used to take over after curative care and end of life, when they could be used earlier as a treatment.

### **Three situations were dealt with by the Leonetti Law:**

- The conscious person who is not the end of life:

the 2005 Act aims to strengthen the patient's consent who can refuse any and all treatments, including that of artificial feeding.

- The sick person in later life:

If the patient is in an advanced phase or terminal phase of a serious and lasting affection and decided to stop all treatment, the physician must respect his wishes and inform the patient of the consequences of his choice, he must safeguard the dignity of the dying, ensure quality of life by providing him with palliative care.

- The unconscious person:

Any person hospitalized or not can designate a trusted person who would be consulted if he/she was unable to express their will.

Any adult can write advanced directives.

### **Criminal proceedings:**

Several cases have resulted in random decisions considering end of life situations that are often dramatic.

The criminal law does not qualify euthanasia, but the facts can be qualified as murder, poisoning or failure to assist a person in danger.

A 1987 law punishes incitement to suicide and a 2001 law strengthens the prevention and suppression of organisations (sects) which infringe on human rights.

In the case of Vincent Humbert, the Marie Humbert case was dismissed. In another cases, there were felony conviction.

Other cases have involved healthcare personnel who committed euthanasia to terminally ill patients. In these cases, judges have been willing to appear lenient in terms of convictions by qualifying the acts as misdemeanours instead of crime or in minimizing the penalties.

## **Towards a new law:**

Following the case of Chantal Sebire, deceased, who was denied euthanasia, the Leonetti law was considered insufficient.

Several reports and opinions were issued with the report Sicard, the report Claeys-Leonetti, the opinion of the CCNE (National Consultative Ethics Committee), all of which wished to strengthen existing shortcomings concerning the end of life and the strengthening of palliative care.

## **Part 2: Content of the new law of February 2, 2016**

The law of February 2, 2016 creating new rights for the sick and people in later life amends a number of provisions in the legislative part of the Public Health Code concerning the rights of patients and users of the health system.

It clarifies and reinforces the provisions that existed before.

- The rejection of unreasonable obstinacy

First, the right to refuse unreasonable obstinacy brought about by the Leonetti law of 22 April 2005 is further clarified in Article L. 1110-5-1 of the Code. Not only, the doctor should not pursue unnecessary procedures, disproportionate or which have no other effect than to only artificially maintain life, but the new law adds that the doctor should not put in place these treatments which constitute an unreasonable obstinacy, in accordance with the patient's will, or if the patient is unable to express his will, after decision in a collegial process.

Inspired by Vincent Lambert case and the decision of the State Council of 24 June 2014, the legislator said that nutrition and artificial hydration treatments are likely to be stopped under the refusal of unreasonable obstinacy (Art. L. 1110-5-1, para. 2).

- The right to refuse care expressed by the patient

Article L. 1111-4 modified enshrines the right to refuse care by the patient by removing the obligation for the doctor to do everything possible to convince his patient to accept essential treatment. Now, the doctor must respect the will expressed by the patient after having simply informed of the consequences and the seriousness of his choice.

- The right to easing the suffering

The new Article L. 1110-5-3 solemnly dedicated the right to calm the patient's suffering is a right to receive treatment and care to ensure the best possible healing of suffering, even though they may have the effect of shortening life.

- Advance directives

Article L. 1111-11 on advance directives are a number of changes in the direction of a better respect of anticipated will expressed by the patient for his end of life. These

advance directives express the will (and not just the wishes) of the patient concerning the end of life. Any adult can write them in case he would one day be unable to express his will.

With the Act of 2 February 2016, the scope of advance directives has expanded: they can anticipate in advance the conditions "of the pursuit, the limitation or refusal of treatment or medical procedures ". Furthermore, these guidelines are now subject to revision rather than dismissed at any time and by any means. If they previously had a validity of three years, they are now considered pertinent indefinitely. Parliament has provided a model of drafting of these guidelines, the content of which will be set by decree of the State Council (French Supreme Court).

Finally, the most significant development on these advance directives concerns the ability to make them effective in the doctor patient relationship. Previously, the doctor only had the duty to consult the guidelines with no real binding effect. The law of February 2, 2016 provides that these guidelines now require the doctor to take them in consideration prior to any decision of investigation, intervention or treatment. However, in order not to impose excessive strain on the medical team and leave some leeway, the law provides two exceptions to the guidelines' enforceability. The doctor can deviate from the guidelines in life-threatening emergencies in order to have sufficient time to assess the medical situation or when the advanced directives can be estimated to be manifestly inappropriate or inconsistent with the medical situation. If necessary, the doctor's refusal to implement the patient's advance directive is done after a medical collegial process and inscribed in the medical record. The person of trust or by default the family or relatives are informed of the decision.

### **The person of trust**

Respect for the patient's will in later life is also re-affirmed in a new provision concerning the person of trust, Article L. 1111-6. Any adult can designate a trusted person who will be consulted in case she would be unable to express their will.

The role of the support person has been strengthened: now, his testimony prevails over any other evidence of the family or relatives. It is stated that the appointment of the person of trust is co-signed by the latter. This designation is not only revocable now, but also can be revised at any time.

Finally, if earlier a person under guardianship could designate a support person during the period of guardianship, the new law provides that a person under guardianship is now authorized to designate such a trusted person with the authorization of the family council or the judge. The new law codifies the hierarchy of the various elements of information in order to search for the will of the person unable to express themselves. Thus the advanced directives, failing this, the testimony of the person of trust or, if not available the testimony of the family or close friends is admissible under the new Article L. 1111-12.

### **The right to a deep sedation and continues until death**

Surely the most significant development of the law resides in the consecration of a new right to a continuous deep sedation until death and in Article L. 1110-5-2 with the objective of avoiding the suffering of the patient and unreasonable medical obstinacy. If this form of sedation is already practiced in palliative care, it lacked homogeneity. The law has now harmonized the practice by providing deep and continued sedation causing altered consciousness maintained until death. It must be associated with analgesics and termination of all life-sustaining treatments.

This sedation may intervene only at the request of the patient and in two cases. The first case concerns the patient with a serious and incurable disease, with a short term prognosis, and with suffering that cannot be alleviated by treatment. The second case is the patient with a serious and incurable disease who asks that treatment be stopped, engaging a short-term prognosis of death and is likely to cause unbearable pain.

About the patient unable to express his will, the new law authorizes the doctor to engage a terminal sedation to avoid suffering and unreasonable medical obstinacy, condition that dictates interruption of life-sustaining treatments. This deep sedation decision is taken after a collegial process of the healthcare team. It is registered in the patient's medical record. Continuous deep sedation and may be put in place not only in the hospital, but also the patient's home, in institutions of care or services for elderly people.

## **Conclusion**

Without taking a position on the delicate terrain of active euthanasia or assisted dying as some of our European neighbours, the new law attempts a search for balance while correcting some flaws or absences of the law Léonetti 2005. In this, it is a step towards more humanity to patients at end of life.

By Delphine HUGLO  
Bar of Paris