

ifop



Citizens' Conference on End-of-Life
Citizen Opinion
December 14th 2013



We are a group of eighteen citizens reflecting the diversity of the French population, coming from various regions in France. We were asked to spend four weekends thinking about conditions prevailing at the end-of-life and to hear some twenty personalities on this subject.

As a first step, we wish to make some preliminary points on the general issues arising out of end-of-life in French society:

- We find that death is still a taboo subject which society tends to try and obliterate. We believe that several factors contribute to this situation. One of them is that significant medical advances have relegated death to somewhere remote from the reality of life as French citizens know it. As an example, a majority of people in France reach the age of fifty without ever having had any direct contact with death. Medical science had advanced to such an extent that death has become an occurrence in the distant future requiring little attention in the meantime. We are born and bred in the midst of this medical technology and we expect it to prolong our lives. As for the health professionals, we found that, unlike other countries, in France curative and palliative medicine are generally structured and staffed in separate compartments.

Another factor is that there appears to be a general rejection of suffering and pain, with which French people are no longer familiar. Pain and suffering are frightening and arouse an expectation that medical attention will relieve them or even make them disappear.

- We discovered during our working sessions that, as a consequence of this death taboo, there is a whole world of rules and regulations on the end-of-life that many of us were unaware of: advance directives, trustees or proxies, sedation, etc.

French people seem to be only partially informed on the subject even though the question may be addressed of society's motivation in taking an interest in end-of-life as long as everyone is not as yet personally concerned. French people do know what is forbidden, but are ignorant of the circumstances governing the end-of-life.

Paradoxically, by focusing information on this subject to sensational news items, the media tend to play on the public's emotions and sensitivity and in so doing, stifle any general reflection on the subject.

- In France today, more often than not, people die in a hospital, in a retirement home, alone, sometimes unattended, and in any case away from their usual home and family environment. This development in end-of-life circumstances is a cause for anguish for those concerned, all the more so because schools of thought and religious faiths that used to offer some 'prescriptions' to make death less fearsome have now lost their influence over French society or at least, no longer have any exclusive right to providing solace.



- Finally, end-of-life issues raise more general concerns: that of the cost of health care and economic constraints, that of intergenerational solidarity, that of society's attitude to ageing, be it its unbridled youth culture, its loss of respect for extreme old age or its loss of appreciation for the value of experience. We have also noted the existence of social and geographical end-of-life inequalities and the inadequate number of facilities specialising in care for the dying.

Apart from these findings on the end-of-life issue, we also consider the following points to be fundamental and crucial:

- At the end of their lives, regardless of age, social status, pathology, degree of dependence, state of consciousness, individuals are human beings in their own right with their own life history, meaning a past, a present and a future. To this group's thinking, end-of-life is one of the phases of life. A pathology is not an identifier. A body's deteriorated condition does not in any way detract from a person's human identity or dignity.
- When life is ending, if a person's wishes are expressed, they must be heard and respected when decisions need to be made.
- To the extent that medical science can now alleviate pain, pain management (the treatment of pain) is a right to which all patients are entitled and members of the medical professions are duty bound to provide it.



Finally, the end-of-life theme raised a broad range of questions within our group on its meaning, individually and collectively, in today's France.

- The first of these questions refer to each person's **freedom** to experience end-of-life on his or her own terms.

To what extent can individuals be allowed to choose their own end-of-life circumstances and how much freedom of individual decision is acceptable? How should each person's wishes be heard in respect of trivial or critical decisions and what should be done to ensure that those at the end of their lives remain active and respected participants of their own end-of-life circumstances?

- When the importance of death with dignity is discussed, a definition is required: what is meant by **dignity** in its relationship to death? How do we make sure that everyone dies with dignity? What are French society's perceptions on such a complex and intimate subject?

- We consider **information** to be a central issue. How do we go about educating and raising people's awareness of the end-of-life so that they begin to think about their own death and prepare for it rather than banish it from their minds?

Concurrently with raising public awareness, what training on the issues connected to end-of-life needs to be given to members of the medical professions? And more to the point, how much time should be devoted to the subject in higher and continuing education?

- Economic constraints raise a number of issues. What contribution can or should **national solidarity** make to the management of care dispensed at the end-of-life and how should this be accomplished? What is the cost for society of end-of-life in France? To what extent does the republican principle of equality apply to end-of-life management?

What model should be chosen to finance care at the end-of-life? And beyond the question of institutional solidarity, how can we reestablish real solidarity so that people do not die alone?



- The “**legislative framework**” is of prime importance in any reflection on this subject. What laws should apply? Should current legislation, i.e. the Léonetti Law, be replaced or even abolished, amended, or left as it is?

In practical terms, should society adopt a stance on euthanasia and assisted suicide? And is it possible to anticipate all the consequences?

What difference does the French population see between “allowing to die” and “causing to die”? Were euthanasia to be authorised, what would people be afraid of? How should French public opinion on the subject be made known before any action is taken?

How could euthanasia and assisted suicide be authorised and governed?

And were that be done, how would it be possible in a single legislative framework, to set up safeguards and take into consideration all the special cases?



Palliative Care

To our thinking, palliative care is one of the considerable advances of medicine and represents a possibility of responding to human aspirations to lessen the pain of sickness and psychological distress. In recent years in France, palliative care has progressed significantly.

There are, however, problems to be solved regarding its availability and quality:

- No more than 20% of people who should be receiving palliative care do in fact have access to it and this is compounded by severe geographical inequalities as regards palliative care facilities and the number of hospital beds reserved for this purpose.
- Because of the barrier between curative and palliative care and the importance in France attached to technical excellence, palliative care is still the system's 'poor relation' for which financing provisions do not match demographic prospects in the next twenty years. As a consequence, palliative care is not entirely integrated into the health care system.
- Finally, this slow development of palliative care contributes to public opinion's misconceptions on the subject. The public knows little of what it involves. This lack of information generates anxiety: to many minds palliative care is synonymous with imminent death.

In view of the above, we recommend and/or express the following proposals:

- Palliative care must be elevated to the dignity of a national cause with the stated objective of providing access for everyone. The 'economic' development of such care must be encouraged and the population as a whole reassured regarding its objectives: alleviating pain. In this way it should be possible to disconnect it from the idea of a death sentence.
- Training on palliative care must be provided as an integral part of both basic and continuing education for all members of the medical professions: hospital doctors, general practitioners, students, clinical and paramedical teams.
We consider that such training must essentially include practical courses based on actual passing on of experience by doctors who have themselves provided palliative care.
- More generally, we would suggest that courses on palliative care could be included in the teaching of all medical disciplines. This could help to narrow the gap between curative and palliative care and even allow patients to benefit from more integrated care services.



Advance directives and trustees or proxies

We have found that the general public knows very little about advance directives, i.e. the possibility for individuals to express in writing their wishes and desires as regards the health care they receive at the end of their lives (burdensome medical treatment to be withheld or continued, resuscitation, feeding, etc.) and naming a trusted person as their proxy decision-maker tasked with ensuring that their wishes are respected.

We are in favour of this principle of advance directives. Even though they are not compulsory, when they do exist they must be followed. Individuals must remain free to modify the directives and the name of their proxy, should they wish to do so. In which case, the current three-year validity limit for advance directives is pointless.

Apart from the lack of information on the subject provided to the public at large, we also observe the absence of a central register for advance directives, endowing them with an official status and making them enforceable for families and physicians.

We therefore propose the creation of a nation wide electronic repository. Such a centralised system, governed by CNIL rules (*Commission nationale de l'informatique et des libertés* - French data protection authority) would be accessible to professional health care providers (in particular emergency and resuscitation room doctors) so that they would be informed of, and could comply with patients' wishes.

In parallel, the existence of a patient's advance directives should be part of the information contained in the '*carte vitale*' (electronic health insurance card).

Were such a repository to be set up, the authorities could write to those listed every five years to remind them of the existence of their advance directives and of the possibility of modifying them.

Finally, we feel it necessary to task the authorities with organising a nation-wide communications campaign with the object of increasing public awareness on the possibility of writing advance directives and of naming a proxy and how to go about doing this. Special provision must be made for the relationship between general practitioners and their patients to be incorporated in the implementation of this campaign.



Sedation

Despite a large number of presentations on the subject, our group found sedation to be a particularly difficult subject to comprehend in the end-of-life context since it is essentially relevant to medical technology and therefore a subject over which patients have no control and no responsibility.

We understand that different kinds of sedation coexist, from progressive to terminal¹, and that there is also a difference between simple sedation for pain relief and much deeper sedation modifying the state of consciousness.

We also understood that sedation is widely dependent on the various practices of different medical teams and departments. This finding may be reason to fear the possibility of patients under sedation being treated inequitably due to geographical disparities or health carers' degree of competence or beliefs.

This feeling that patients were being treated inequitably was particularly pronounced when we considered examples of different kinds of control over the double effect² (difficulty in controlling the opioid doses).

To the above considerations should be added serious misgivings regarding our perception of the legal framework — as defined by the Léonetti law — which is not sufficiently clear and is rarely applied because it gives excessive leeway for interpretation by members of the medical professions and excludes patients and the population as a whole from its implications.

Furthermore, this legal constraint may have had the effect of hindering the clinical team's freedom of decision as regards deep sedation in the terminal phase.

Some medical teams are afraid of over-sedating a patient and then being accused of having intended to cause death.

We still consider, however, that sedation is of primary importance insofar as it is inseparable from patient care when seeking to relieve pain.

The possibility of being adequately sedated, in proportion to a patient's needs, is in our eyes a right to which terminally ill patients are entitled, or those suffering from an incurable disease, even if the effect may be to shorten life.

We recognise the right for physicians to freely practice sedation as soon as there is any reason to suspect patients are suffering, even if they are unable to make their pain known.

¹ Terminal sedation has two meanings: terminal phase sedation (chronologically speaking) and sedation with a terminal effect.

² Double effect should be understood to mean that it is initiated to relieve the pain of a dying patient with the unintentional effect of also shortening the patient's life.



Sedation must, however, be the outcome of discussion with patients themselves when that is possible and when it is not, with those who are close to them (trustees, families, medical consultants).

In the terminal phase, the objective of alleviating the patient's pain and distress must take precedence over the risk of death which could be the end result of deep sedation.



Assisted suicide

The possibility of committing physician-assisted suicide and of receiving help to commit suicide is, to our thinking, a legitimate right for end-of-life or incurably ill patients, based necessarily on informed consent and full awareness.

Our group was in two minds on this subject:

- Medically assisted suicide is involved once the will to die is expressed by the person concerned (expression of will medically certified, with or without assistance and drug administration by a third party); (12 members of the group)
- Medically assisted suicide excludes drug administration by a third party. (6 members).

In these circumstances there are two possibilities: people who are capable of acting of their own volition, or people needing assistance. In the latter case, patient consent will be based on the advance directives that may have been written or the decision that was made known to a third party (a trusted person, a doctor, etc.).

In any case, medically assisted suicide must comply with procedures and be attended by health professionals. It must not, in any circumstances, become a commercial operation (such a demand must not create a market), nor should it be a part of any private structure (neither commercial concerns nor associations).

The medically assisted suicide procedure must be imbedded in an institutionalised medical environment (in particular *via* a dialogue with the patient's consultant physician).

A medically assisted suicide must necessarily comply with a number of mandatory conditions. It must exclusively concern people who are at the end of their lives or who are suffering from a condition that is incurable or irreversible, who have expressed the will to die and whose state of consciousness has been formally certified by a panel of at least two physicians.

On this subject, we would point out that the law does not incriminate all those who have helped a consenting person to put an end to his or her own life, on the absolute condition that the patient's consciousness is a proven fact. Nevertheless, and to prevent any possibility of abuse, we insist on the vigilance that must be exercised in cases where medically assisted suicide concerns people who are not capable of committing the deed without assistance.

Euthanasia

Following on the hearings held in our working group sessions, we noted the following facts:

- As of now, there is no legal framework authorising euthanasia.
- The implementation of the Léonetti Law has not put an end to clandestine euthanasia.
- The failure to respect advance directives is a contributing factor to placing the burden of decision on families, leading in turn to conflict.

Several interpretations of what is meant by euthanasia existed within our group: some members (12 participants) defined euthanasia as a medically assisted death when the person's direct consent could not be given. When consent was given, it became medically assisted suicide, including cases where a third party administers the lethal substance.

For another sub-group (5 participants³), once a third party was brought in to administer a lethal substance and death ensued immediately, this was defined as euthanasia.

Apart from this divided perception on the definition of euthanasia, our group was of one mind on the concept of the respect for human life which is one of the essential principles underpinning society as we know it. No one has the right to decide on another person's life without his or her consent: this is a fundamental principle, at both national and European level.

We consider this fact to be entirely coherent with our previous point regarding the importance of respect for the dignity and wishes of individuals.

In view of the existence of the procedures contained in the Léonetti Law, the advances of palliative care and the possibility of turning to assisted suicide as we recommend in our Citizens' Opinion, we consider that euthanasia can be ruled out as a solution for end-of-life situations.

We are, however, in favour of an exception for euthanasia.

Euthanasia would be admissible in special cases which cannot be dealt with by a procedure for assisted suicide and when there is no other possible solution (no direct patient consent).

Such strictly regulated cases would be left to the collective appraisal of a local ad hoc commission which should be set up.

So as to reflect the plurality of views, the composition of each of these commissions would be jointly made up of members of the clinical team concerned by the particular case, the patient's consultant physician, a physician not working in the same hospital as the one in which the patient was treated and a representative of the hospital's ethics committee.

For each case, the commission would be convened within a reasonable time lapse, not exceeding eight days.

³ One person in the group did not adopt a position on this point.



Finally, with respect to the points of view and thoughts contained in our Opinion, we wish the Léonetti Law to be adjusted on the following points:

- Massive development of access to palliative care in proportion with demographic progress;
- Authorising sedation in the terminal phase;
- Legalisation of medically assisted suicide (incorporating the very delicate distinctions noted in our Opinion);
- Creation of an exception for euthanasia.

We would like to see enacted regular assessments of the implementation and enforcement of all laws concerned with end-of-life.