CCNE Report on the public debate concerning end-of-life.

This is the National Consultative Ethics Committee’s report on the public debate concerning the end-of-life, initiated over two years ago, when the President of the French Republic created the French Commission for Reflection on the End-of-Life in France, chaired by Didier Sicard, in July 2012.

This report in no way implies that reflection on the subject has run its course. It merely marks a milestone.

It’s object is to gain a better grasp of the main points of convergence which are apparently emerging at this stage of the debate on an essential and complex subject which is of concern to us all, and of the shared recommendations which are their outcome; to identify the principal points of divergence; to revisit issues which were either left unformulated or were incompletely addressed during the discussions; to throw more light on certain ethical issues underlying the major differences of opinion; and to propose perspectives which could contribute to the more in-depth study of the subject which CCNE considers to be desirable.
Foreword

1. Over two years of public debate

The creation by the President of the Republic in July 2012 of the Commission for Reflection on the End-of-Life in France was the first step in a process of study and public debate on the end-of-life that has taken place, in various forms, over more than two years.

After organising debates in nine cities, holding a considerable number of hearings, proceeding with a qualitative enquiry involving people at the end of their lives and travelling to Belgium, the Netherlands, Switzerland and the State of Oregon in the United States, the Sicard Commission submitted a report at the end of 2012, under the heading of “Penser solidairement la fin de vie”.

As announced when the Commission was created, the President of the Republic then referred the subject to CCNE whose Opinion N° 121, The End of Life, Personal Autonomy, the Will to Die was published in July 2013.


As a conclusion to Opinion N° 121, CCNE proposed that reflection on the subject and public debate should continue and be extended in scope on the basis of two different, but complementary processes:

- On the one hand, the Committee recommended the organisation of a Citizens’ Conference, as prescribed by the July 7th 2013 law on Bioethics.

---


2 CCNE, Opinion N° 121, The End of Life, Personal Autonomy, the Will to Die. July 2013; http://www.ccne-ethique.fr/fr/type_publication/avis

3 Article L. 1412-1-1, Code de la santé publique (French Code of Public Health): “Plans for reform in connection with ethical problems and issues affecting society raised by advances in biological, medical and health-related subjects must only be formulated after public debate in Estates General has taken place. They will be organised at the behest of the National Consultative Ethics Committee for Health and Life Sciences, after consultation with the parliamentary commissions concerned and the Office parlementaire d’évaluation des choix scientifiques et technologiques (Parliamentary Bureau for the evaluation of scientific and technological decisions). Following the public debate, the Committee submits a report for evaluation to the Office parlementaire d’évaluation des choix scientifiques et technologiques. Article L. 1412-3-1: “The Estates General mentioned in Article L. 1412-1-1 convene Citizens’ Conferences, selected so as to represent the diversity of French society. After preliminary guidance, citizens hold discussions and draft an opinion and recommendations which are made available to the public. The experts participating in the briefing sessions for citizens and the Estates General are selected with reference to criteria of independence, pluralism and pluridisciplinarity.”
CCNE organised the Citizens’ Conference\(^4\), which took place over a period of four weekends in the autumn of 2013 and involved a discussion between some twenty participants from all walks of life, of which half were suggested by CCNE and the other half elected by the citizens themselves\(^5\). CCNE refrained from participating in any of the citizens’ discussions so as not to influence the debate. The opinion and the recommendations of the conference were made public at the end of 2013 at a press conference organised by the citizens themselves, after which they were posted on the Internet\(^6\).

- On the other hand, CCNE was in favour of broadening the scope of the public debate, involving in particular the Regional Forums for Ethical Reflection, one of whose mission’s being leadership on a regional basis for public reflection on subjects related to biomedical ethics\(^7\). In September 2013, at a meeting with the officials in charge of regional forums for ethical reflection, CCNE suggested that they might wish to organise discussions in their regions, if they cared to do so independently in whatever manner they chose, so that they could provide an input to the public reflection on end-of-life initiated in July 2012 on a scale appropriate to Estates General. These discussions took place, in various forms, up until the summer of 2014, and provided examples of the diversity of possible forms for public debate\(^8\). CCNE posted records of these debates received from the Regional Forums for ethical Reflection on its website\(^9\).

CCNE’s participation in the public reflection exercise then continued in another form. Early in 2014, the Conseil d’Etat (highest French administrative jurisdiction), ruling on the dispute in relation to the situation of Mr Vincent Lambert, invited the National Consultative Ethics Committee, the Academy of Medicine, the French Medical Council and Mr Jean Leonetti to submit “general observations in writing providing

---

\(^4\) The Bioethics Estates General that took place in 2009 and preceded the revision of the law on bioethics included three citizens’ conferences. But each of these conferences was on a different subject: stem cells and research on embryos for the citizens’ conference held in Marseilles; medically assisted reproduction for the conference in Rennes; harvesting and transplanting organs, tissues and cells for the Strasbourg citizens’ conference. CCNE therefore considered that on the single subject of end-of-life, one citizens’ conference should be convened.

\(^5\) Following a call for bids, CCNE chose IFOP (French Institute of Public Opinion) for the task of selecting a group of citizens. The recruitment phase consisted in a series of interviews throughout France for a period of five weeks managed by IFOP’s network of investigators. An panel composed of 18 people was recruited, with a view to representing as faithfully as possible the diversity of the French population and illustrating the variety of points of view that may be held by society on the subject of end-of-life. The group of citizens was evenly balanced for several socio-demographic criteria: gender, age, profession, education, place of residence and the type of urban centre. IFOP made sure that the spread conformed to the structure of the reference French population as defined by the latest INSEE census. Finally, in compliance with CCNE’s wishes, the citizens involved did not receive financial compensation.

\(^6\) http://www.ccne-ethique.fr/fr/actualites/avis-citoyen-et-video-de-la-conference-de-citoyens-sur-la-fin-de-vie#.USGq45R_vO4

\(^7\) Article L.1412-6 of the Code of Public Health: “The Forums participate in the organisation of public debates in order to further the information and consultation of citizens on bioethical issues”.

\(^8\) The various forms were: round table discussions on a specific theme or clinical situation, followed by a debate with the public, in some case initiated by a cultural event (theatrical performance, film); ethics lunch or coffee gatherings; organising controversial discussion between two specialists in the same discipline, followed by debate with the public; questionnaires and compilation of participants’ opinions; compilation of testimonies from individuals faced with end-of-life situations, followed by public debate relevant to the issues raised by the testimonies; etc. ... participation was either the public at large, or students and secondary school pupils, members of associations, members of ethical structures in hospitals, members of the medical professions, EHPAD senior officials (Etablissement d’Hébergement pour Personnes Agées Dépendantes - French care homes for elderly dependent persons), etc.

\(^9\) http://www.ccne-ethique.fr/en
constructive clarification on the concepts of “unreasonable obstinacy” and “artificial life support” as they relate to article L. 1110-5 of the Code of Public Health, and more specifically as they relate to persons in a minimally conscious state, such as Mr Lambert.

CCNE submitted its observations to the Conseil d’Etat on May 5th 2014 and posted them on line on its website after publication in the Revue française de droit administratif.

Other institutions made valuable contributions to reflection on this subject: the French National Observatory on End-of-Life Care, the French Medical Council, the French Academy of Medicine, the French National Council of Nurses, the French National Forum for Reflection on Ethical Issues and Alzheimer’s disease, the Cochin hospital Clinical Ethics Centre, the French Society for Terminal and Palliative Care (SFAP), the Association for the Right to Die with Dignity (ADMD), the Council of Europe Bioethics Committee (DH-BIO), the Bishops’ Conference of France, the Protestant Church of France, debates in the French Parliament and Senate, various symposia, enquiries by the French National Institute for Demographic Studies (INED) and a large number of surveys organised by various research institutes.

A number of debates, reflections and testimonies were heard in conjunction with various proceedings and court decisions over this same period of time, in particular numerous hearings at Docteur Bonnemaison’s trial.

In this way, several different and complementary kinds of contributions served to enhance reflection and public debate on this subject:

- debates in various regions involving citizens or members of the medical professions — verbatim accounts of debates in nine townships held by the Commission on Reflection on End-of-Life, for example;
- a Citizens’ Conference;
- opinions and reports, featuring recommendations, by various forums for reflection, some of which had previously organised hearings and surveys;
- public meetings with “experts”, followed by questions from the audience or questionnaires for the expression of audience opinions;
- hearings of people close to individuals approaching the end of their lives and enquiries on end-of-life situations;
- pronouncements on disputes regarding on the one hand the concept of unreasonable obstinacy and artificial life when someone who is not at the end of life is unable to express his or her wishes, and on the other hand on euthanasia.

10 The request was made “for the purpose of examining the submissions, ‘in view of the magnitude and difficulty of the scientific, ethical and deontological issues in dispute’.”
14Mainly concerned with jurisdictional procedures concerning Mr Vincent Lambert and Dr Nicolas Bonnemaison.
15 Not forgetting numerous books, documentaries and films.
This succession of debates helped to promote mutual understanding, dialogue and a gradual awakening of awareness that each end-of-life is a singular event unlike any other, that the various issues connected with end-of-life are complex and diverse. This increased awareness led to more extensive examination, or in some instances a new formulation of some of the issues.

2. After two years of reflection

CCNE wishes to draw attention to:

- A strong and unanimous expression of people’s determination to be heard, respected and have their autonomy recognised.

- The disgraceful situation constituted by the fact that for the past fifteen years there has been a denial of access to rights recognised by law, that the vast majority of people are abandoned left to fend for themselves at the end of their lives and the unbearable end-of-life conditions suffered by the overwhelming majority of our fellow citizens.

  - This leads to the need for:

    - Making known and enforcing currently applicable legal rights at the end of life to have access to palliative care, truly humane attention to needs and relief from pain and suffering.
    - Organising terminal care in the patient’s home which the vast majority of our fellow citizens have voiced a demand for.
    - Abolishing the dividing lines between curative and palliative care and integrate them both into a true culture of “care and taking care seen as one single process of care”, not only at the end-of-life but before the terminal phase begins.
    - Making a massive effort to train physicians and health carers, keeping ethical reflection in the prominent position it deserves and guaranteeing an authentic “public service” to that effect.

- The disgraceful social isolation and destitution which all too often precede the end of life.

---

16The way in which were organised and held the main investigations, conclusions and recommendations as a result of the various reflection initiatives and public debates can be viewed on line, as an appendix to this report, on the CCNE website: [http://www.ccne-ethique.fr/](http://www.ccne-ethique.fr/) CCNE will continue to post on its website any contributions received from the Forums for Ethical Reflection.

The main quotations included in this report are drawn from: the report by the Commission on Reflection on the End-of-Life in France *Penser solidairement la fin de vie*. (Thinking of the end-of-life in terms of solidarity) December 2012; CCNE’s Opinion N° 121, The End of Life, Personal Autonomy, the Will to Die, July 2013; the Citizen Opinion by the Citizens’ Conference on End-of-Life, December 2013; and the 2013 Report by the National Observatory on End-of-Life Care, *Fin de vie des personnes âgées. Sept parcours ordinaires pour mieux comprendre les enjeux de la fin de vie en France*. (End-of-Life of the elderly. Seven unexceptional case histories for a better understanding of end-of-life issues in France).
So that access to essential end-of-life care for everyone becomes a reality.

- The unfit for purpose organisation of the health care system which cannot respond appropriately to these key challenges.

- The expression of a general demand for new rights, the exact implementation of which is still the subject of debate:
  
  - To make advance directives expressing individual wishes binding on health carers;
  - The right — when people so request it and are in the terminal phase of end-of-life or when they decide to have life support discontinued — to have access to deep sedation\(^\text{17}\), leading to loss of consciousness, until they die;
  - A modification of the procedure described as collegial, in particular in cases where the issue arises of withdrawing treatment for patients who are not dying and are in a state of health rendering them incapable of expressing their wishes. The procedure should become a true deliberative process of collective decision, including to the fullest degree the views of loved ones regarding what they know to be the wishes of the patient, including also a procedure for mediation if a decision cannot otherwise be arrived at.

CCNE considers that this convergence of views represents a significant landmark in our society’s thinking on ethical issues related to the end-of-life, notwithstanding that a large number of points are still in debate concerning recommendations.

CCNE observes, conversely, persistence in the number of deeply divergent opinions on the subjects of assisted suicide and euthanasia\(^\text{18}\).

****

This report aims to draw attention to the wealth of contributions to this public debate and to submit an analysis of the ethical issues underlying the main points of dissent persisting in our society.

\(^{17}\) Deep sedation involves drug-induced sleep leading to complete loss of consciousness

\(^{18}\) These differences are not only due to different views on autonomy, respect for life and solidarity underlying the various standpoints, but also to the very different meanings attached to the terms: terminal deep sedation, assisted suicide and euthanasia.
I. An appallingly state of affairs

“To the extent that medical science can now alleviate pain, pain management is a right to which all patients are entitled and members of the medical professions are duty bound to provide it.” 19

A. Denial of the right to palliative care for the overwhelming majority of people at the end of their lives

- Despite the significant development of palliative care in France in recent years, “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.” 20
- “In 2009, IGAS (Inspection générale des affaires sociales - social affairs inspection department) noted that only 2.5% of people dying in hospitals had been identified in a GHS (groupe homogène de séjour - diagnosis-related group) corresponding to admission in a palliative care unit.” 21

B. Unbearable end-of-life for the vast majority

- “The study, Mort à l’hôpital (Hospital Death) in 200 French hospitals, published in 2008 by Edouard Ferrand et coll., says that over two thirds of the nursing staff stated that they considered the circumstances in which those they were caring for ended their lives would be unacceptable for themselves when they were dying. 22”
- “It is alarming that these situations of “forced indignity” are still frequent and that the issue of inequality of treatment in different parts of the country for people nearing the end of their lives is still as critical fourteen years after the adoption of the law guaranteeing access to palliative care and eight years after the adoption of the law on patients’ rights and the end of life, even though some significant progress has been made.” 23
- “Most sick and dying people feel either that they are helpless in the hands of a health system which is excessively concerned with technical performance to the detriment of the care and attention which they should be receiving; or that they are purely and simply left to their own devices [...]. The other disquieting

---

21 Report by the Commission for Reflection on the End-of-Life in France Penser solidairement la fin de vie, (Solidarity at the end-of-life) December 2012. CCNE emphasises that the activity-based financing system (T2A hospital reform) is particularly inadequate for the financing of palliative care.
22 CCNE’s Opinion N° 121. (The study quoted is: Ferrand E, et coll. Circumstances of Death in Hospitalized Patients and Nurses' Perceptions: French Multi-Centre Mort-a-l'Hopital Survey. Archives of Internal Medicine, 2008.168 :867-75
23 CCNE’s Opinion N°121.
image of death as we know it today, is death in intensive care with a feeling of total alienation in this ultimate moment of a person’s life.” 24

- “Death itself is not as frightening as the possibility of a ‘bad death’. Outrageous, intolerable, excruciating: the concept of a ‘slow death’ is above all synonymous with end-of-life beset by pain, suffering and discomfort.” 25

C. Wanting to be heard and respected

- “In end-of-life situations, if wishes can be expressed they must be heard and respected when decisions need to be taken.” 26
- “The patient’s wishes must take precedence over those of the physician.” 27
- “Decisions on end-of-life conditions must revert to being the prerogative of patients, not of physicians.” 28
- “A lack of ‘humanity’, of consideration, or even of common courtesy: in all circumstances the pain of not being treated as a person, of not being heard and recognised.” 29

As though the person who is dying fades away and is obscured by the use or non-use of technology and, more generally, of medicine.[…]
The primary consideration is, above all, to attach the greatest importance to what patients say and want as they are dying, and see to it that they are heard, in this extreme situation of vulnerability. […] Above all, the imperative of respecting the patient’s stated wants and autonomy. […] Autonomy, as the free appreciation of a patient’s wishes and appreciation of the value of life, is far removed from the concept of free and informed consent which should be replaced by the concept of freedom of choice.” 30

D. A law more concerned with defining the duties of health care professionals than with defining patient rights

The intention of the law dated April 22nd 2005 on the rights of patients and the end of life was to apply the rules set out in the law of March 4th, 2002 — on the rights of patients and the quality of the health care system concerning respect for an individual’s wishes — to end-of-life situations. And yet, it would appear from the thoughts expressed and the public debates that the April 22nd 2005 law is better at defining the duties of health carers than at defining the rights of patients.

- As regards advance directives:
  - although they are called “directives”, the law views them as the expression of preferences, the decisions being taken by physicians.

---

25 2013 Report by the National Observatory on End-of-Life.
28 Debate in Montpellier, Commission for Reflection on the End-of-Life.
29 Summary of the eight departmental conferences on issues arising out of end-of-life, organised by the Ethics Reflection Forum of Bourgogne/Franche-Comté.
Article L.1111-11 of the Code of Public Health states: “All adults may draft advance directives in case they should find themselves at some future time incapable of expressing their instructions. Such advance directives set out their wishes in an end-of-life situation for the conditions attached to limiting or withdrawing treatment. The advance directives may be revoked at any time. On the condition that they were written less than three years before the onset of unconsciousness, physicians will take them into account when making any decisions to investigate, intervene or treat.” And Article R. 4127-37 of the Code of Public Health: “The decision to limit or withdraw treatment takes into account the wishes that the patient may have previously expressed, in particular in advance directives if the patient had written any, the opinion of the trusted person the patient may have designated, as well as the opinions of the patient’s family or, failing that, the opinion of someone closely connected to the patient.”

• “It is probably because the possibility of drawing up the advance directives is mentioned too late in the day and that they are not binding that, most of the time, they are not formulated. And yet, drawing up advance directives is a responsible action and more deserving of appreciation.”31

• “What do you put into these advance directives? The advance directives require anticipating a situation at a time when you are not in that situation. Where should the advance directives be kept (with a person’s medical records, included in the information on the ‘carte vitale’ (French health insurance card), or elsewhere)? Currently, advance directives are not binding on the physician who is under no obligation to follow them but will in fine be taking the decision.” Designating a trusted person has also raised some issues: mostly unknown to the public at large and often mistaken for the person who should be called in an emergency; how do you designate a trusted person? Who? When? Who should be told? What is the right time to do it? What is a trusted person supposed to do?”32

• Concerning 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 terminal, 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

31 CCNE, Avis n°121.
32 Synthèse des huit rencontres départementales organisées par l’Espace de réflexion éthique Bourgogne/Franche-Comté.
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 effect (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.”

**E. Misapprehension and lack of enforcement of legal provisions guaranteeing the rights of sick people at the end-of-life**

The fact that neither citizens nor even a significant proportion of health care professionals have a full understanding of the law, and that its provisions are not applied (rights of patients, palliative care, advance directives, trustees, collegial deliberations, reflection on the meaning of unreasonable obstinacy or of sedation in the terminal phase, etc.) was brought up over and over again in the debates organised by the regional and inter-regional ethical reflection forums.

This lack of understanding applies to the June 9th 1999 law to guarantee that anyone in need of palliative care does indeed have access to it, is also the case for the provisions of the March 4th 2002 law on patients’ rights and the quality of the health care system, and is also true of the April 22nd 2005 law on patients’ rights and end-of-life.

- “...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. 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.”

- “Only a tiny number of people at the end of their lives have drafted advance directives: in the INED study published in 2012, only 2.5% of the deceased had done so.

---

33 Citizens’ Conference on the End-of-Life
34 Citizens’ Conference on the End-of-Life
It is a fact that the system is largely unknown to the medical profession although they are under “obligation to enquire as to the existence of directives, verify their validity, be aware of their contents and include the wishes that are expressed in them among the components supporting their medical decision”.

It can be seen that the law is not applied when patients’ wishes are not taken into account and when terminal care, and also alleviation of pain and suffering, are frequently deficient or even altogether missing at the end-of-life.

### F. Very inadequate commitment to making known and enforcing respect for the rights of people who are dying

There is largely general agreement that the authorities, the health care system, the hospital management, health caring establishments and retirement homes, as well as health care professionals are very insufficiently committed to the crucial action required to make known legal provisions and ensure that they are implemented.

- “The increased fragmentation of institutions and their lack of relevance to realistic situations is particularly disturbing. Institutions and structures are therefore answerable to a major degree — despite their commitment, their willingness, their financial contribution — for the lack of a coordinated healthcare circuit, in particular palliative care [...] The medical professions are hesitant to “let go”, because it is so difficult for a physician to refrain from attempting one more treatment, and even more difficult to withdraw on-going treatment and start a programme of supportive terminal care [...] It is a commonplace statement that the way in which the hospital system is evolving, or as some people claim, is even becoming a health care “business”, is not conducive to communicating with patients and being attentive to their needs. Hospitals [...] generally make the excuse that lack of time and beds, staff shortages, inadequate training and economic constraints cause these deficiencies, so that they cannot be held responsible and should not be blamed for the indifference of which they are accused”.

- “…although it will of necessity bring about considerable modifications in the management of patients at the end of life, it is hardly surprising that the law is misread and largely ignored or wrongly implemented because its adoption was not matched with an appropriate policy for the training of health carers. Furthermore, neither the authorities nor the media have given private citizens the information needed before they can sufficiently appropriate the changes.”

---

37 CCNE Opinion N° 121
G. Inappropriate organisation of the health care system

1. The sparsity and serious difficulty of supportive terminal care at home

- “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.”\(^{38}\)
- “It is mainly at home that palliative care has made the least progress. As emphasised by the National Observatory’s second report on the end of life, France is one of the European countries where the smallest number of people die in their own homes. Today, it is much more frequent to die in hospital than at home. In 2008, 58% of deaths were in hospitals, 27% at home and 11% in retirement homes. And yet, every successive survey reports that a vast majority of French citizens would prefer to die in the place they are most comfortable in: their home.”\(^{39}\)

It is a known and reported fact that some clinical teams of physicians and health care providers are committed to the highest standard of supportive terminal care, including in the home of their patients. But a demand for the development of palliative care at home and deep-rooted apprehension regarding the inequalities of care offers, depending on where people die, was constantly expressed by participants in the regional and inter-regional forums for ethical reflection\(^{40}\).

2. Death of the elderly and terminally ill in the emergency departments

- “All too often, at some point during the last few days of their lives, dying patients are transported from their homes or an EHPAD (Etablissement d'Hébergement pour Personnes Agées Dépendantes - French care homes for elderly dependent patients), to the emergency department of a hospital, where they die amidst shocking indifference. Eight thousand people sent by EHPADs die every year within hours of their admission to the emergency departments (2011 Report of the Commission for Reflection on the End-of-Life in France). The moribund patient’s condition is still, and far too frequently, a source of distress and uncertainty for emergency room doctors who are ill-prepared for dealing with the problem. This raises the following issues:
  o excessive disorganisation and lack of preparation concerning the management of such patients in an earlier phase (attendant physicians, emergency services - such as ambulances, fire brigades, call-out medical services, networks - HAD (hospitalisation à domicile - home hospital care) and hospital departments;

\(^{38}\) Citizens’ Conference on the End-of-Life  
\(^{39}\) CCNE Opinion N° 121.  
\(^{40}\) See Annex: ................ Summary of public thoughts and discussion organised by the Regional and Inter-Regional Forums for Ethical Reflection.
exhausted and anxious families but also on the part of far too many distressed and helpless health carers, a lack of understanding and appropriation of the legalities of the situation, sometimes a lack of empathy or of readiness to face a death situation responsibly.

In such circumstances, the absence of supportive terminal care for the dying then frequently leads to a tragic and paradoxical situation in which people die on a gurney in a hall or a corridor, much to the distress of their families, or alone amid general indifference."

• “Out of the 17,705 patients who died in 2012, 52%, i.e. 9,130, were aged between 75 and 89 years, while 3,990 (22%) were 90 years of age or more. This means that over 13,000 elderly people (≥75 years) die in the emergency departments every year.

Over 60% of them are admitted to hospital for a condition in which the foreseeable outcome and symptoms required palliative care. Over half of them die during the night following their admission to the emergency department.

On admission to the emergency room, over a third of these terminally ill patients undergo inappropriate intensive care. Very obviously, the circumstances of these deaths in the emergency room are unacceptable for patients and families alike. Emergency nurses and physicians feel isolated and helpless as they try to manage these end-of-life situations. The situation is indicative of the complete failure, at every level, of the system for the management of patients in the terminal phase of an active chronic pathology.

3. End-of-life in care homes for elderly dependent patients (EHPADs - Etablissements d'Hébergement pour Personnes Agées Dépendantes)

• “Over 90,000 people die every year in EHPADs.

25% of EHPAD residents die after being transferred to a hospital, and among those who die in their retirement home, 23% were admitted at least once to the emergency department of a hospital during the two weeks preceding their death.

85% of EHPADs have no night nursing staff. In those that do have at least one night nurse, the number of emergency hospital referrals is lower by a third.

One quarter of end-of-life residents experience significant physical discomfort during the last week of their lives and 7% suffer very severe pain in the last 24 hours before they die.

But no more than 8% of EHPADs call on HAD [Hospitalisation à domicile] (hospital services at home) in end-of-life situations. This is therefore a very rarely used option despite the fact that HAD provides for considerably reinforced nursing care if required and facilitates access to medical and paramedical equipment 43”.

41 Commission for Reflection on the End-of-Life.
42 2013 Report by the National Observatory on End-of-Life.
43 2013 Report by the National Observatory on End-of-Life.
• “Today, the vision of death before our eyes is mainly one in which very old people are gathered together (and so excluded from the rest of society) in institutions such as care homes for elderly and dependent patients (EHPADs). This concentration of very aged, sick or disabled people in this new kind of place in which to die, reinforces the “natural” anxiety about death that is every one’s lot […] (it is only natural to feel anxious about something that we know is bound to happen but of which no one has any experience…) and stigmatises extreme old-age."  

4. End-of-life of elderly disabled people

• “The life expectancy of disabled people is increasing faster than that of the population at large. And yet, this fact seems to be “invisible”: it has not been the point of departure of any public health policy, nor is it the subject of any nation-wide study and the media only rarely address it ... There are huge geographical inequalities [as regards medical and social establishments housing disabled adults, the Maisons d’Accueil Spécialisées (MAS) and Foyers d’Accueil Médicalisés (FAM), (special homes and hostels). At a national level, 31% of deceased residents had been given powerful analgesics as life ended, but only 16% in Lorraine or Poitou-Charente, as opposed to 50% in Brittany or the South of France. Only 16% of homes for adult disabled people actually have a duty nurse on the premises at night; 13% of them have a telephone standby system. The results are entirely comparable with those observed in the EHPADs. Interestingly enough, we can observe that the same causes produce the same effects: the actual presence of a night nurse reduces in-hospital death rates by 37% (55.5% versus 35%). A quasi-identical result to that recorded... in the EHPADs. On average, half of the residents die in a hospital. And we know nothing about disabled people’s end-of-life when they die in their own homes.”

5. Lack of training in palliative care for physicians and nursing staff

46 2013 Report by the National Observatory on End-of-Life. To which should be added that the statistical instruments required for an accurate record of the number of disabled people and their every day circumstances, and even less of their end-of-life circumstances, are not available in France.
• Initial and continuing training:

The training of members of the medical, nursing and allied professions devotes little or no time at all to the management, support and care that should be provided for people nearing the end of their lives. Despite repeated recommendations set out in various reports and the continuing demands of the National College faculty members for higher education in palliative care, progress in education on this subject is very limited. It is true that the subject of death and end-of-life was introduced into the first phase of university studies, but within a very broad curriculum. In the second phase, the number of hours set aside for the course on “pain, palliative care, anaesthesia” may vary from 2 hours to 35...
Later on, there is no further training except for complementary specialist studies. The majority of palliative care units are not accepted for training courses validating the DES diplomas for general practitioners or cancer specialists. Continuing education does not do any better. There is a university degree in palliative care, where according to ONFV, (Observatoire national de la fin de vie - National observatory for end-of-life) doctors represent only 28% of the total number of participants. In any case, there is no identification of action taken and it is estimated that 80% of doctors have no formal training on the management of pain. Out of 150, only 3 cancer specialists in the greater Paris region received training in palliative care in 2008 and 63% of doctors state that they have never received any training on treatment limitation.
As long as the training of health care professionals on the subject of palliative care remains so marginal, there is absolutely no likelihood of any improvement being derived from changing practices in France in end-of-life situations. Unless, defying conformism and tradition, the authorities decide to review the subject, there is no possibility whatsoever that medical institutions will take it upon themselves to propose changes since they do not appreciate the social importance of such changes for French citizens.

• This inadequate training is also distressing for people at the end of their lives, for their families and for health care providers themselves:

  o “What we hear from those who were present at such scenes, but also from participants in the debates, has borne witness to the sufferings of families and loved ones, of health care providers also, expressed as anxiety, anger and iatrogenic guilt as a result of defective communication and the feeling of having been neglected. The cruelty generated by defective communication transpires in all the testimonies and was singled out as being one of the central components of malfunction. The cruelty of uncertainty, inherent to the complexity of end-of-life situations, in the face of which patients’ loved ones felt helpless and friendless [...] The cruelty linked to the place where life ended, sometimes not chosen by themselves, which may reinforce this feeling of ‘inhumanity’.

The cruelty linked to the absence of any space provided for being heard, for speaking, for collective deliberation. The cruelty linked to the burden of making decisions or to being left alone to seek solutions, generating feelings of iatrogenic guilt."

- Insufficient attention is given to the suffering of health care providers which is part of the problem of pain management training."

- In EHPADs:

  “One care home coordinating physician in every five has had no training in terminal phase supportive care.”

- In medical and social establishments housing disabled adults, the Maisons d’Accueil Spécialisées (MAS) and Foyers d’Accueil Médicalisés (FAM), (special homes and hostels):

  “In one out of two of these establishments, neither the physicians nor the nurses have had any training on end-of-life supportive care. And yet training has a decisive impact on end-of-life circumstances. A comparison between establishments in which none of the medical professionals have had any training in terminal supportive care and those where the various categories of professionals have had this type of training shows that the proportion of residents who have been receiving powerful analgesics rises from 18% to 40%. The percentage of deaths in a hospital falls from 61% when none of the professionals have had any training in supportive care for end-of-life to 31% when all three categories of professionals have been trained.”

- In the patient’s home:

  - Nurses:

    “While the hospital care at home systems and the palliative care networks are better known to the general public for their activities in end-of-life and palliative care situations, free-lance nurses, home nursing services (SSIAD) and other services for care and assistance at people’s homes play an essential and irreplaceable role in providing terminal supportive care for elderly people at the end of their lives. This is evidence indeed of the involvement of neighbourhood professionals in providing both care and assistance. However, none of the support they need [initial training and continuing education, support, networking with hospital care at home and palliative care systems]is currently available: those professionals who are most deeply involved are in fact those who benefit from the least amount of training and assistance.

---

48 Summary of the eight departmental meetings on the issues arising out of end-of-life, organised by the Forum for ethical reflection Bourgogne/Franche-Comté.

49 Contribution from the Ethics Forum, Western Brittany.

50 2013 Report by the National Observatory on End-of-Life.

51 2013 Report by the National Observatory on End-of-Life.
A 2012 study by the Médéric Alzheimer Foundation reports that 34% of the home nursing services (SSIAD) had no professionals trained in terminal phase end-of-life care for patients with cognitive disorders, and that in 50% of cases, only some of their staff had been trained.” And yet, “…the detection and evaluation of pain in people with cognitive disorders is particularly difficult insofar as the traditional scales based on self-evaluation are not always pertinent.”

Home helpers:

“Home helpers are now a key resource for providing supportive care for the elderly. In fact, these professionals (of which 98% are women) most often look after these elderly people until they die. Studies and summaries by the National Observatory on the End-of-Life reveal the extent of their vulnerability; they often work alone over long periods of time. Often there to compensate for the scarcity of home nursing services — no more than 10% of the elderly are attended by professional nurses — they are in fact performing, without recognition, a delegation of tasks. The 2008 DREES enquiry “Intervenants à domicile” (IAD) revealed that 46% of home helpers are involved in end-of-life care for the people they are looking after and that this is a potentially difficult position to be in. And only a tiny number of home helpers have been trained in palliative care.

The Médéric Alzheimer Foundation conducted a national survey of home helper services to gain a better understanding of the various ways in which people with cognitive impairment were being looked after. Among the 911 services participating in the enquiry, 652 (72%) stated that they were attending cognitively impaired patients until “the very end of their lives”. And yet 38% of them have no programme for training their employees in terminal phase supportive care.”

H. Just before life’s very end, an end to life which is too often fraught with stress, not to say inhuman, because of impaired autonomy, whatever its cause

“What is almost always missing: human compassionate support continuing over time, not just in an emergency.”

1. Faulty support, not to say absence of support, for vulnerable people

This is a problem affecting a great many elderly people, sick or otherwise no longer autonomous due to their age. “The death of individuals begins with social death.”

---

52 2013 Report by the National Observatory on End-of-Life.
53 2013 Report by the National Observatory on End-of-Life.
In their home: “At the end of their lives, elderly people still in their own homes are frequently in very miserable circumstances. They are very often socially isolated and isolated from their families. They are very often extremely dependent. The existential suffering of elderly people at life’s end is a major public health issue.”

In EHPADs, despite the provisions in the February 11th 2005 law on equality of rights and opportunities, participation and citizenship of disabled people, in fact the defective accessibility of the homes of the overwhelming majority of elderly people with impaired autonomy, plus the lack of adequate support in their homes — scarcity of home helpers; lack of training and precarious tenure of home helpers; lack of assistance and therefore of any possibility of respite for family carers when there are any; lack of organised interaction between professional carers and family carers — means that more than often than not the old are obliged to go and live in EHPADs (Etablissement d’Hébergement pour Personnes Agées Dépendantes - French care homes for elderly dependent patients), and so to find themselves in a situation of “mass isolation of people gathered together because of their loss of autonomy, sometimes prevented from choosing where they wish to end their lives.

Paradoxically, our health system is premised on a logic that drives many elderly people to end their lives in a place where most of them would prefer not to be. While the number of older citizens living in EHPADs is constantly increasing, the decision to go there is rarely their own.

When the question was put to families of EHPAD residents in a survey by the National Observatory on End-of-Life, responses showed that in fact, in three cases out of four, the decision to live in an EHPAD was not taken by the elderly relative. It is more generally the only decision that families can come to in the face of limited possibilities for keeping their relative at home.

And yet there is a very strong correlation between the fact that residents are in an EHPAD at their own request and the way in which families perceive their physical and mental wellbeing: the probability that residents “have completely lost the will to live” is 64% lower when they themselves took the decision to move into an EHPAD.

The concept of being “put” into one of these nursing homes is also very revealing. It smacks of, as is the case of being put into guardianship, of something done contrary to the wishes of the person concerned for his or her own good and protection. It refers to situations where people are obliged to accept a move that some one else is proposing: and you never ‘put’ yourself into an institution, this is something other people do to you.

In an end-of-life context, this concept of “being put into an EHPAD” raises a fundamental issue: that of the degree of freedom and the

56 2013 Report by the National Observatory on End-of-Life.
choices that are on offer to people as regards the conditions in which they will be spending the end of their lives.

- Aggravated by the fact, as an ultimate paradox, that these same people will be paying for what they did not want...”57

- This is just as true, regardless of age, for the fifteen million people with chronic diseases, multiple pathologies or impaired autonomy whose lifestyles therefore make it necessary for them to be cared for by a number of health professionals and carers.

Such people and also quite frequently their families, suffer from the shortcomings of the health care, medical and social systems, among them first and foremost the absence of coordination between the various professions58.

- “Because these people are sometimes seriously disabled, the outward signs of their disease as well as the expression of their pain and suffering are not identical. Because the institutions they are put into are of a more social culture, their approach to sickness [and to end-of-life] in disabled people is deficient and sometimes lead to delays or flawed management. And yet, these people are alive, fall ill, suffer and die”59.

2. Inequalities in death are also the reflection of social inequalities

- “Conditions of death are probably one of the most far-reaching and unacceptable consequences of social inequality. It is a known fact that differences in socioeconomic levels lead to a significant gradient as regards life expectancy and the expectancy of life in a state of good health. A precarious socioeconomic level is the first cause of cancer-related mortality in this country, and is in itself a source of belated access to the health care system, delayed diagnosis and as a consequence, a greater likelihood of therapeutic failure. But this differential cannot be compensated for by a specific policy to cope with the death of those whose lifestyle is the most precarious, as though it was only when they are dying that we should start caring for them.

From the difference between the medical attention given to people who are well cared for, well acquainted with social and medical networks, living in a city centre, and the medical help provided for people in poor circumstances, deprived and living alone, far from any medical centre, it is easy enough to imagine the differences in attention they will be getting as they near life’s end. As the social position increases in vulnerability, the less choice there is in

59 2013 Report by the National Observatory on End-of-Life.
selecting one’s own end-of-life circumstances and how one will die. But even the expression of choosing one’s own death is reduced to a minimum, as though an acute and concrete awareness of existing resources was required to express access to a right or a freedom at the end of life. The most precarious situations are those that most need, at any time in life, a coherent and organised health care plan.”

- “Finally, the end-of-life issue touches upon more general problems: that of the cost of health care and economic constraints, of solidarity between generations, of the way in which ageing is regarded by society, be it the frantic youth culture of today’s society, the abasement of extreme age or of the value of experience. We have also found social and geographical inequalities in connection with end-of-life and the shortage of structures for looking after those who have reached the end of their lives.”

- The pricing system and the impact of the components entering into the calculation of what remains to be financed by the patients are the cause today of glaring inequalities: “the extension of life expectancy, the anxiety arising out of loss of autonomy, the dispersion of families, social isolation, ever growing individualism and the economic pressures that the community exercises over sick or disabled people in their old age and on their families — by demanding that they finance all of the cost of upkeep in health care institutions due to their loss of autonomy — all converge in today’s society, which is faced with budgetary restrictions, to turn the end-of-life and the sometimes extremely long period of time before the “end” into a time of steadily increasing anxiety and difficulty.

What do we mean by “end-of-life”?: the three weeks preceding death, as seems to be suggested by the time granted recently to families for being with someone whose life is ending, or the months or years following diagnosis of an incurable disease?

For the person whose life is ending, all this contributes to increase in some cases the feeling of being alone, of being a burden, even of being “superfluous”, of being unworthy of living in this way and of being an overly expensive and futile burden for loved ones.”

- For people living in EHPADs: “Over a million elderly people in this country are living in nursing homes and must contribute financially to their upkeep to the extent that they may exhaust their own resources or those of their families”.  

“This cost which remains to be borne by the person concerned (or the family) is a reason for worry by elderly inmates of EHPADs. The simple fact that the community is asking sick and elderly people in care homes to pay for the whole of the upkeep they incur due to their loss of autonomy (although the same is not demanded of younger people who are in the same circumstances) clearly signifies, in both the community’s “subconscious” and “conscious” perception, that

---

60 Commission for Reflection on the End-of-Life in France.
63 CCNE’s Opinion N° 121.
their fate is no longer of concern to the community. “Pay up, fend for yourselves, or let your families get on with it…” society seems to be saying to the sick, the aged and the disabled. Bad luck…”

- For aged and disabled people living at home: “The outstanding remaining cost of what the elderly and their families have to pay for when their lives are ending in their own home is considerable. This factual situation raises real issues in terms of social justice and equity within the health care system.” It should be remembered that the allowance for a disabled adult adds up to less than the poverty threshold, which reduces to nil any hope of quality care at home when the patient does not have sufficient financial resources to top up the personal assistance paid for by the disablement compensation allowance (prestation de compensation du handicap (PCH) and when their condition becomes more complex.

****

This appalling situation must not blind us to the reported fact that some clinical teams of physicians and health care providers are committed to the highest standard of supportive terminal care, including in their patients’ own homes.

But we must also underline, while deeply regretting that this is so, that many of the recommendations made in December 2012 by the Commission for Reflection on the End-of-Life in France have not had any effect, to begin with those concerning the enforcement of the provisions currently applicable, nor those concerning training for physicians and other health care providers, nor again those suggesting the Ministry of Health should draft in 2013 a form to serve as a model for writing advance directives. Were that to have been done, the findings on end-of-life in France today would have been very different as, indeed, would have been the public debate.

For CCNE, these findings add further emphasis to the need for public health and medicosocial reforms, as well as to the need for adopting different working models. We very much hope that these needs will be addressed during the parliamentary debates on laws concerning health and adapting to an ageing society, and that they will find expression in everyday life.

---

64 Commission for Reflection on the End-of-Life in France.
65 2013 Report by the National Observatory on End-of-Life.
66 The implementation of training programmes recently introduced into the various study cycles for future health care professionals did not gain sufficient pedagogical support from those in charge of this task. As a result, this is frequently still a marginal subject in medical schools; the least that can be said is that there are differences from one place to the other which would justify a new effort to raise awareness by the Conférence des Doyens (association of deans and senior members of medical schools) to the need for university identification of such teaching. It should be noted, however, that the recent reform of the second cycle of medical studies (decree dated April 8th 2013 concerning the first and second cycles) is beginning to integrate this missing aspect of training. Similarly, the draft reform of the 3rd cycle of medical studies, now being processed, includes mention of a need for specific training for staff working in palliative care institutions.
II. Shared recommendations

“First and foremost, the imperative: respect for patients’ wishes and their autonomy.”

A. Ending a fifteen-year old scandal: no access to rights recognised by law

“Because it is unacceptable that it is still not applied although it came into force seven years ago, society as a whole, physicians and other health care professionals should make major efforts to integrate the Leonetti Law into practice, in particular through regular awareness-raising campaigns and training programmes.”

This would involve at last giving everyone access to rights recognised by the June 9th 1999 law on palliative care, by the March 4th law on patients’ rights and the quality of the health care system and by the April 22nd 2005 law on patients’ rights and end-of-life.

Meaning in particular:

- ensure respect for the right of patients to make decisions concerning their own health “in consultation with a health care professional and taking into account the information and recommendations he or she provides”;
- ensure respect for the right of patients “in an advanced or terminal phase of a serious and incurable disease” to decide for themselves the withdrawal of treatment, nutrition and hydration and to receive compassionate care and alleviation of pain at the end of their lives;
- ensure that the right of “sick people whose condition so requires, to have access to palliative and supportive terminal care” is guaranteed;
- put an end to situations of indignity still occurring too often at the end-of-life “Supportive terminal care worthy of the name can only be meaningful within a society that demonstrates its solidarity, its readiness to hear and be respectful of the dying, but does not exclude them from decisions on their own behalf.”

---

70 The April 22nd 2005 law on patients’ rights and the end-of-life. Article L. 1111-10 al. 1 of the Code of Public Health.
71 The June 9th 1999 law on guaranteed access to palliative care.
72 Commission for Reflection on the End-of-Life in France.
B. Developing palliative care and improving training for physicians and other health care providers

The Commission for Reflection on the End-of-Life in France recommends:

- “making an evaluation of the financing and of the nursing staff required for everyone to have real access to all such palliative care. Ensure that financing is in fact allocated.
- “developing a positive policy in favour of palliative care at home, combined with ‘respite support’ for home carers.”

In Opinion N° 121, CCNE underlined the need to make palliative care accessible to everyone, to develop the provision of palliative care services in the home and to reinforce training for physicians and nursing staff:

- “Put an end to geographical inequalities, eliminating palliative care ‘deserts’.
- Put an end to palliative care segregation and promote a culture integrating terminal care, pain management and alleviation of suffering in every medical discipline.
- Make a determined effort to provide access to palliative care at home and for that purpose, in particular, authorise and train general practitioners to handle sedative medication.
- Make a determine effort to train — both initial training and continued education — physicians and nursing staff. Develop their capacities for attention and dialogue, provide education on the appropriate use of opiates and sedatives, understanding the meaning of “unreasonable obstinacy” and knowing how to associate terminal care with the absence of futile and aggressive therapy (“letting go”).
- Develop human and social sciences research on the circumstances of end-of-life.”

The Citizens’ Conference on end-of-life recommends:

- “Massive development of access to palliative care in proportion with demographic progress. 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.”
C. Giving access to both compassionate and palliative care before the very end of life and developing a medical and treatment “culture” combining “curative” and “palliative”

There is a convergence of views on the need for:

- ceasing to restrict palliative care to terminal care during the last three weeks of life,
- not confining palliative care to the final phases of end-of-life, but rather to elevate them to the rank of supportive care as well as end-of-life care, insofar as their objective is to prevent and relieve pain and suffering and preserve to the greatest extent possible the quality of life of patients and of their loved ones.

Doing so would also serve to lessen the all too frequent distinction between curative care and “taking care” 73:

- “...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. 74 .”
- “The Commission strongly emphasises the absolute necessity for a palliative care culture and the elimination of the dividing line between curative and palliative care.
- The final outcome of an excessively radical separation between palliative and curative care prevents the development of a “palliative culture”. Such a culture strives to integrate competence in palliative care into all clinical practices instead of confining it to a specialised activity.

In other words, while it is becoming apparent that a new specialist university discipline should emerge (to encourage training and research on end-of-life) this would never exempt other specialist courses from responsibility on the same subject. The fact that since the 2005 law was voted, more palliative care units are in operation — even though their number, about 120, is still limited — encourages health care professionals in other departments to feel that they are not really concerned. It seems to be particularly difficult in France to foster a common culture comprising consultation, enquiry, exchange of knowledge, that is a culture that instead of opposing “curative” to “palliative”, combines the two concepts 75 .”

This is why CCNE’s Opinion № 121 and the report of the Commission for Reflection on the End-of-Life both emphasise the need to put an end to all the situations of

---

73 See the thoughts expressed to that effect in the last few years, in particular in the North American continent, in the context, for instance, of the National Consensus Project for Quality Palliative Care, in particular the document entitled “Clinical Practice Guidelines for Quality Palliative Care”, May 2004, since quoted in several articles of medical literature.


75 Commission for Reflection on the End-of-Life in France.
indignity which still only too frequently prevail at the end-of-life. They recommend 76:

- developing compassionate care giving at any age in life so as to put an end to the isolation, deprivation and neglect of vulnerable people;
- developing an optimal relationship between care and “taking care”, between curing and caring, between curative care, supportive care and palliative care, between health care institutions and the patient’s home, between professional health carers and home caregivers.

“At every stage in the disease, it would appear necessary to seek out patients’ assent systematically and take account of their stated preferences 77.”

D. Developing information on advance directives and the trusted person

- “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 78.”
- “Organise major campaigns on a regular basis to inform citizens, physicians and other health care professionals on the subject of advance directives, on how important they are and the need for them to be carefully drafted and used effectively; and on the possibility of designating a trusted person and the tasks they may be asked to undertake 79.”
- “The designation of a trusted person is a matter that raised concern: the system is very largely unknown to the public at large and is often mistakenly thought to be the person who should be contacted in an emergency 80.”
- “The provisions of the 22nd April 2005 law on advance directives and the trusted person are still mostly misunderstood by the public. A campaign of information is needed with the participation of physicians. Not only should patients themselves be able to raise the question of advance directives with their attending physicians, the directives should also be recorded in a national registry or on media accessible to health care professionals in the clinical team. In compliance with the Code of Public Health, these directives can be modified at any time by the person concerned.

76 These recommendations converge with those of the Wise Men’s report in June 2013, to reduce the number of interruptions in the continuity of care — which are damaging for the quality and efficacy of care — by adopting a more systemic vision of action required and making assiduous efforts to find the most adequate method of reform.
77 Espace national de réflexion éthique sur la maladie d’Alzheimer (EREMA), (National forum for ethical reflection on Alzheimer’s disease) EREMA contribution to the national debate on end-of-life. www.espace-ethique-alzheimer.org
78 Citizens’ Conference on the end-of-life
80 Summary of the eight departmental meetings organised by the Forum for ethical reflection Bourgogne / Franche-Comté.
Physicians and members of the clinical team caring for the patient must take into account the advance directives and the opinion of the trusted person, these being the patient’s last conscious expressions of free will.\footnote{French Medical Council, « Fin de vie, « assistance à mourir » (End-of-life, assisted dying”), text adopted by the French Medical Council on February 8th, submitted to the General Assembly of Presidents and Secretaries General of the Departmental and Regional Councils on February 9th, 2013, together with a report on the IPSOS questionnaire addressed to practising physicians. www.conseil-national.medecin.fr/sites/default/files/sondage_fin_de_vie_fevrier_2013.pdf}

CCNE concurs with the requirement to have the authorities work on producing model documents to facilitate the drafting of advance directives and also with the need for information campaigns on the subject.

Some observers have underlined that in Germany advance directives are in more common use and consider that this is because they are not restricted to end-of-life situations: advance directives are not viewed as being a health concern, but rather as an expression of personal autonomy which extends over the full range of a person’s life experience.

**E. Making advance directives accessible to health care workers**

- “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. 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.”\footnote{Citizens’ Conference on the end-of-life.}
- “Create a nation wide computerised registry of these two document, making it in particular easily accessible in an emergency.”\footnote{Commission for Reflection on the End-of-Life in France.}

**F. Achieving a more useful allocation of economic and human resources**

- Staff shortages and, more generally scarcity of resources were emphasised in many of the regional debates (see for example the western Brittany ethical forum).
• The economic hardships of home carers were also emphasised, in particular by the Picardie ethical forum: “[To be able]to continue their professional activities from home for informal caregivers (flexible working hours, teleworking); encourage authorities to understand the benefits of tax inducements; think in terms of the productivity of a home carer or of nursing assistance, and of the particular assistance status of each case.”

• “The list of proposals made by the commission [on the need to develop palliative care] should be given priority in the allocation of financial support. They can be financed through a redeployment of resources currently allocated to curative services, disproportionately generously in view of excesses and the absence of critical review, so as to arrive at better management of “taking care” at the end-of-life.

The budget allocation for home care networks are constantly being reorganised, so that they are frequently short of funds. This is aggravated by the fact that the authorities allocating their funding do not base such decisions on an evaluation of how resources are used or of the quality of the service provided. It would seem that the often repeated encouragements in favour of palliative care are mainly incantatory. […]

It is understandable at a time when constraints weigh on the economy that the need for optimising management as a prime component of performance should make itself felt, particularly so when public funding is involved. “To do things properly” will always be a laudable objective. But the first consideration is “to do good things properly”! Performance is far from being only a financial matter. It is just as much a question of the quality of medical and caring practices. Caring activities will not be seen in the same light if the object of reform is reducing the cost of a therapy and, even more importantly, reducing the ineffectiveness of a therapy, or if the aim is to choose among therapies the one which is most financially rewarding and brings in the most resources! (See the issue on the activity based pricing system).

Operating as a multi-disciplinary team and thus sharing experience and competence, means that the various players involved in a complex situation can coordinate their working procedures, anticipate the possibility of further complications and limit inadequate but frequently very costly biomedical procedures which are a form of therapeutic obstinacy. Reducing inappropriate expenses and a reduction of suffering…

Would it not be better to take into consideration the time spent on shared reflection within a multidisciplinary clinical team’s in order to eliminate any form of therapeutic obstinacy, rather than seek refuge in what is easily quantifiable but always adds up to preferring more action, more technology and even more technology? Therapeutic obstinacy costs a great deal more than developing supportive care! And to the economic cost is added the cost of suffering… […]

The real issue is transferring some of the cost of curative medicine generating a futile consumption of resources, towards palliative medicine for which sustainable financing is always less of a certainty.”

---

84 Commission for Reflection on the End-of-Life in France.
III. A shared claim for two rights: make advance directives binding and have access to terminal phase deep sedation until life ends

A. Binding advance directives

One claim for respect is clear: when a person’s condition is such that wishes cannot be expressed, then respect for the wishes expressed in the advance directives is demanded.

On this subject, the public debate revealed two pressing needs:

- making the general appeal for everyone to draft advance directives more systematic,
- making the contents of the directives binding and making it compulsory for physicians to justify non implementation of the directives should the case arise.

CCNE stated on this subject “The Committee also considers that a change in perspective is needed regarding the value to be given to advance directives: the conditions in which they are recorded must be revised, medical support must be given to patients who wish to draft them so that they are as pertinent as possible to their state of health and can be effectively taken into account.

When advance directives exist, they should be presumed to be binding on health care providers and any deviation from what the directives prescribe should be justified in writing and included in the person's medical record.85”

B. The right to have access to terminal phase deep sedation until death

“Sedation is defined as using medication to reduce vigilance up to and including loss of consciousness. Its aim is to diminish or eliminate the perception of a situation the patients considers to be unbearable although all available and appropriate remedies have been suggested to the patient and/or administered without obtaining hoped for alleviation.

Sedation […] may be intermittent, temporary or continuous.”86

85 CCNE, Opinion N° 121.
See: http://www.sfap.org/pdf/Sedation-Phase-terminale.pdf
Terminal phase deep sedation, until the patient dies, can only be applied after other palliative care has been attempted.

There is a strong demand for patients’ right to receive deep sedation until death, if they so request when they are in the terminal phase of end-of-life or when they have decided to discontinue treatment, or nutrition and hydration.

- On this point, CCNE “considers that if patients request it, they should be provided with continuous sedation until death once they have entered the terminal phase of their disease.
  In this way, people whose existence is prolonged by life-sustaining equipment will be able, based on their right to refuse treatment, commence an end of life process with the benefit of palliative care and, if they so wish, die under sedation. So as to be sure that this right is in fact observed and that its implementation is not distorted, all decisions to apply deep sedation, either continuous or intermittent, in the final phases of disease, must be noted in the patient’s medical record.
  This would be a new right, to be added to the right to refuse treatment altogether and the right to obtain palliative care when there is an indication for it.”

- The same is true of the Citizens’ Conference on the end-of-life: “We... consider, however, that sedation is of primary importance 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.
  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.”

---

87 CCNE, Opinion N° 121.
88 Citizens’ Conference on the end-of-life.
IV. A certain number of points in these shared demands, however, are still under debate

A. Under debate, the binding nature of advance directives depending on the author’s circumstances at the time they were drafted

1. Binding only when they were drafted in the event of a serious disease or of a potentially risky surgical procedure.

- This is a recommendation made by the Commission on reflection on the end-of-life in France and in CCNE’s Opinion N° 121: “The Committee considers that the value granted to advance directives cannot be reinforced unless it is accepted that the capacities of those who are sick at the time they are writing down their wishes are evaluated. Evaluating the autonomy of those who are ill, means verifying their capacity of understanding, of appreciating, of reasoning, of expressing themselves and of settling on an opinion or a decision. It would be well if a doctor’s written statement were to certify the advance directives’ reliability
  - People, in sickness or in good health, thinking about the end of life, should be encouraged to draft “advance directives of their wishes” to set out preferences regarding where they want to be and how they want to be cared for.
  - All those suffering from a potentially serious disease should be informed by the attending physician of the possibility of drafting genuine advance directives. And it would be such advance directives which should be viewed as being binding, with any derogation from them to be justified in writing in the person’s case file.”

- The Commission on reflection on the end-of-life in France spells out a difference between two documents:\[89\]
  - the one, “proposed by the attending physician to consenting adults, without any obligation on their part and regardless of their state of health — and even if they are in good health — which would be regularly updated”;
  - the other, “in the event of diagnosis of a serious disease, or in the case of surgery potentially involving major risk”; “...this document dealing specifically with end-of-life treatment to be proposed in addition to the first document, in the context of a dialogue with the clinical and nursing team.”

---

89 Commission for Reflection on the End-of-Life in France.
2. Binding in all cases\(^{90}\) (except if inappropriate to the clinical situation of the patient\(^{91}\)).

- This was the recommendation of the Citizens’ Conference on the end-of-life: [The advance directives] “when they do exist they must be followed.”

- It is to be noted that over the year 2014, debates and thoughts in connection with the legal procedures and decisions regarding the case of Vincent Lambert raised public awareness on the extreme difficulty and complexity of appreciating, in the absence of advance directives, the concepts of unreasonable obstinacy and of artificial life support and to decide on whether it would be appropriate to withdraw artificial nutrition and hydration from a person unable to express wishes, severely disabled following a very serious accident, who was in good health before that accident.

- In their written general observations addressed to the Conseil d’Etat, CCNE underlined in this context, “...the need to encourage the use of advance directives” and to make these advance directives binding: “The existence of clearly worded advance directives (which, belying their name, currently are not really directives, since they are not binding and are only seen as a person’s wishes) are the best guarantee that can be hoped for that a request to withhold or withdraw treatment, including artificial nutrition and hydration — from someone who is severely disabled, unable to communicate and who is not at the end-of-life — was in fact formulated in advance by that person.

The duration of validity of advance directives is also a point of discussion.

**B. Under debate, the modalities of terminal phase deep sedation until death**

1. Should terminal phase deep sedation until death be used to alleviate pain and suffering, but without hastening death? Or could it intentionally hasten death upon a person’s request?

When death is imminent, either because of the spontaneous progress of disease or because the patient has decided to discontinue treatment, or even nutrition and hydration, the discussion is no longer concerned with the recommendation that people should have the right to ask for and be given deep sedation until their death, but on the meaning to attach to the adjective “terminal”, or to be more precise, to the words “terminal phase”.

- The differences of opinion bear on the time differentials between:

---

\(^{90}\) As is the case, for example, in Germany

\(^{91}\) In which case, the reason why advance directives were not complied with will need to be justified by the physician and noted in the patient’s case file.
sedation as palliative care until a person dies, alleviating pain and suffering, death occurring after a certain but indeterminate amount of time has elapsed, independently of the possibility that the treatment may, unintentionally, hasten death;92; and sedation which intentionally hastens death, at the person’s request, so that the unconscious state does not last overly long.

For the Commission for Reflection on End-of-Life in France, “the decision to take a lethal step in the last phases of supportive terminal care” “can equate, in the view of the Commission, the actual circumstances of deep sedation as it is written into the Leonetti law.”:

- “When patients are at the end of their lives, or when, in compliance with their advance directives included in the medical case file, they specifically request the withdrawal of possibly life-prolonging treatment, or even of nutrition and hydration in any form, it would be cruel to “let them die” or “let them live” without allowing them the possibility of a physician assistance hastening death.

The same is true:
- when such a request is expressed by family and loved ones while the patient is unconscious, and in the absence of advance directives included in the case file — which the Commission continues to stress the importance of. The request must necessarily be submitted for collegial discussion so as to verify that it does in fact meet the patient’s actual wishes;
- when the treatment itself is considered, after collegial discussion with the patient or his/her family and loved ones, to be unreasonable obstinacy and when supportive care would no longer have any other object than artificial life support.

This grave decision taken in all conscience by a physician, consigned to the case file, “can equate, in the view of the Commission, the actual circumstances of deep sedation as it is written into the Leonetti law.”:

---

92 This is, in particular, the position adopted by the Société française d’accompagnement et de soins palliatifs (SFAP): Recommandations de bonne pratique : Sédation pour détresse en phase terminale et dans des situations spécifiques et complexes (Recommendations for good practices: Sedation for distress in the terminal phase and for specific and complex situations.) Formal expert consensus, June 2009, validated by 28 expert societies and the Haute autorité de santé. See: http://www.sfap.org/pdf/Sedation-Phase-terminale.pdf

It was also the position taken in “Perspectives et propositions” as published after the Symposium on the end-of-life organised at the Collège des Bernardins in partnership with the Paris-Est Marne-la-Vallée University on February 2nd 2013: “Reconnaître la « sédation pour détresse en phase terminale » comme un acte de soin : objet d’une délibération, elle s’applique à des situations bien déterminées et s’appuie sur des recommandations de bonnes pratiques.” (Recognising “sedation for distress in the terminal phase” as a caring activity: object of deliberation, it applies to certain specifically determined situations based on recommendations for good practices.)

It could also be noted that certain associations object to terminal sedation for opposite reasons. For example, Alliance Vita, considers deep terminal sedation until death to be a disguised form of euthanasia which should not therefore, for that very reason be allowed. Whereas, the Association pour le droit de mourir dans la dignité (Association for the right to die with dignity) considers deep sedation until death as an inhumane practice leading to death by thirst and starvation that should be replaced, for that very reason, by the right to request assisted suicide or euthanasia.
In the Commission’s opinion, the criteria that a piece of legislation would seek to impose on this type of decision could never encompass all the complexity and diversity of real circumstances. But it seems clear to the Commission that, in the spirit of the Leonetti law, it would be a form of medical aggression to “allow to die” or “allow to live” a patient after all forms of treatment and supportive care have been withdrawn.

In the view of the Commission, this grave decision falls more within the scope of recommendations for good and responsible medical practices than that of new legislation. 93

In CCNE’s view, there is an essential need to make a clear distinction between the circumstances of those “who have reached an advanced or terminal stage of an incurable disease” and those “who are disabled, but are not in the terminal phase, and wish all life sustaining treatment to be stopped”:

- “As regards the specific question in the referral on sedation initiated in the terminal phase of disease, the Committee sees two different sets of circumstances.
  - Clearly in the advanced or terminal phases of an incurable disorder, Byzantine discussions on the doctor’s exact intentions when using substances which may contribute to, or hasten death, are no longer appropriate. Strict observance of the law must not lead to situations which are more distressing or violent than its non observance. The clinical team’s duty at this point and that of loved ones is to adapt as best they can to a unique situation, in a spirit of dialogue and respect.
  - Conversely, in situations other than end-of-life ones such as those described above, there is an essential difference between on the one hand, administering a lethal substance to someone who would not be about to die if that substance were not used, and, on the other hand, discontinuing treatment which the person concerned deems to be futile and has asked to be stopped, with as a result allowing death to occur earlier. If a person, either disabled or with an incurable disease, who is not in the terminal phase, wishes all treatment sustaining life to be stopped, than health carers must provide the support, with the help possibly of appropriate sedation, to act in compliance with the consequences of that decision. Death will happen sooner, it will be the consequence of the decision to cease treatment which the person considers to be futile, and doctors will respect this decision, as opposed to making the decision themselves. 94

2. The special case of discontinuing nutrition and hydration and providing terminal deep sedation until death in neonatal resuscitation

---

94 CCNE, Opinion N° 121
More than ever in such cases, some thoughts are unthinkable: “There is a contradiction between the birth of a baby and death”.

Decisions to cease neonatal nutrition and hydration for severely disabled neonates — decisions to deny the gift of life almost as soon as it was granted — raise some extremely difficult and harrowing ethical issues.

- “Palliative culture was adopted later in paediatric practice than in its adult counterpart although, in contradiction with adult practice, it has always been a subject on which neonatologists particularly have devoted much more attention to end-of-life issues. Paediatric palliative care should continue to be fostered for the same reasons as those which concern adult medicine, that is with a reinforcement of training programmes and the introduction of further thinking on unreasonable obstinacy, it being said that obstinacy is not always purely medical.

Decisions to withdraw treatment, or even withdrawing life support, must always be taken in association with parents and within the framework of a multidisciplinary collegial consultation. Working as team is always protective of children, families and health care professionals.”

- “CCNE wishes to draw attention at this point to a “borderline” situation arising sometimes in neonatal care. The issue of deep sedation of a kind that hastens the death process arises in a very specific way for new-borns with severe and irreversible brain damage. Before the law on patients’ rights and the end of life was voted, this was sometimes an occasion for lethal procedures. Now that the law has entered into force, a decision is made to cease treatment. When the neonate is receiving assisted ventilation, discontinuing ventilation and starting sedation is generally accepted, all the more so since the procedure itself generates discomfort and suffering.

Sometimes, these babies are breathing autonomously. At this point, the question arises of stopping nutrition and hydration and starting sedation. This is a very much more controversial situation. On the one hand, there is the fear that the child is being left “to starve to death”. On the other, there is the issue of the length of time which elapses before the child’s death, which is can be quite drawn out.

A study, as yet unpublished, by the Cochin Hospital’s Centre for Clinical Ethics, based on interviews with parents a short time after the death of a neonate and with the agreement of several neonatal departments, found that families retained a very positive impression when the child died only a few days after the decision was implemented as, during that time, they could hold the child in their arms without the encumbrance of all the medical apparatus, so that they experienced a sense of parenthood. Conversely, when survival persisted, sometimes over several weeks, it would seem that time had a destructive effect on parents witness to a steady physical deterioration of their new born child. They feel very guilty at not performing the parent’s role of feeding a child.

---

97 This study: Des pratiques à l’épreuve du réel (Practices put to the test of reality) has been made known to the public and the media and is about to be published.
These situations, which require of course deep sedation for the baby and attentive counselling for the parents, are still a subject for debate on the part of neonatologists and gynaecologist-obstetricians. CCNE’s opinion is that the law should be interpreted humanely so that, thanks to the management of sedation, the agony should not be prolonged beyond reasonable limits.98

C. Shared, but not altogether unanimous, demands

Some people are of the opinion that advance directives should absolutely not be binding and should just be considered as an expression of wishes.

- “A strong current favouring formalisation is now running through the medical world: setting up procedures and protocols, creating decision trees, standardising information. The aim is behavioural harmonisation, equitable access to health care and to information, but this comes at the price of standardisation which is ill suited to the consistently singular doctor-patient relationship. It would be a pity if the advance directives became just one more bit of paper. [...] Their main advantage and their only ethical justification is to extend this relationship to dialogue at the end of life. Some people do this spontaneously, others never manage it and some will be discovering a more significant and trusting way of establishing such a relationship through dialogue with their physician or another health care professional99.”

On the subject of recognising the right of patients to request — to obtain — deep sedation until death (in the terminal phase or after a request to cease life sustaining treatment):

- The French Society for Terminal and Palliative Care (SFAP), (Société française d’accompagnement et de soins palliatifs) points out that “…the law date 22nd April 2005 calls for a collegial decision which must, together with the conditions of implementation and the newly defined course of treatment, be set out in the patient’s case file100.”

---

98 CCNE, Opinion N° 121.
100 La sédation pour détresse en phase terminale et dans des situations spécifiques et complexes. (Sedation for distress in the terminal phase and in specific and complex cases. Formal expert consensus, June 2009, validated by 28 expert societies and the Haute autorité de santé.: http://www.has-sante.fr/portail
V. The situation of people “in an advanced [but non terminal] phase of a serious and incurable disease”, “unable to express their wishes” and who have not drafted advance directives

There is a radical difference between the following situations:

- that of conscious persons who “in an exchange with a health care professional and taking into account his or her recommendations, makes decisions concerning their own health” and that of persons “unable to express their wishes”;

- that of persons “in the final phase of a serious and incurable disease” and that of persons “in an advanced [but non terminal] phase of a serious and incurable disease”:
  - the persons “in the final phase of a serious and incurable disease” have reached the end-of-life,
  - the persons “in the advanced [but not terminal] phase of a serious and incurable disease” have not reached the end-of-life: it will be the decision to withdraw care or treatment which will cause death.

A. The Conseil d'Etat (decree dated February 14th 2014) clarified the interpretation of the law

The Conseil d’Etat put emphasis on a further fundamental right, besides the right to respect for life: the right not to undergo treatment based on unreasonable obstinacy.

The Conseil d’Etat considered that:

- the concept of “unreasonable obstinacy”, as defined in the 22nd April 2005 law also applies to people “in the advanced phase of a serious and incurable disease” who are “unable to express their wishes” and who are not at the end-of-life.

---

101 4th March 2002 law on the rights of patients and the quality of the health care system.
102 22nd April 2005 law on the rights of patients and end-of-life.
103 Unreasonable obstinacy concerns persons in an advanced or terminal phase of a serious and incurable disease, regardless of its cause, when in particular:
- acts of prevention, investigation or therapies may be viewed as futile, or disproportionate or having no other effect than artificial life support;
- there is a need to alleviate pain and distress, to safeguard the dignity of the sick, to give moral support to their families and loved ones;
- there is no other option for alleviation than to resort to a treatment which may have as a side effect the hastening of death;
- there is a need to let everyone live with dignity, until life ends.
• artificial nutrition and hydration are among the treatments which may be considered in such cases, as “having not other object (or effect) than the sole artificial prolongation of life”, therefore a demonstration of unreasonable obstinacy and so could be withdrawn.

**B. In their written observations to the Conseil d’Etat, CCNE underlined the particular nature of treatment by artificial nutrition and hydration**

“Artificial nutrition and hydration qualify as treatments which must be medically prescribed before they are put in place and pursued, and which require the use of medical techniques. Nevertheless, they differ from other treatments. CCNE considers that the characteristics that differentiate between treatments and care deserve, at the very least, to be reviewed in the case of artificial nutrition and hydration, in particular if the person concerned is unable to communicate but is not dying.”

CCNE also emphasised the extreme complexity of:

• “the difficulty in qualifying treatment as “futile” or “disproportionate”;”
• the difficulty in qualifying treatment as “having no other object than artificial life support”;”
• the difficulty in qualifying “obstinacy” as “unreasonable”;”
• the nebulous frontier between the concept of “an advanced phase of a serious and incurable disease, regardless of its cause, and the concept of “disability”;”
• the deep uncertainty inherent to any decision made in a situation of such radical singularity.”

For CCNE:

• “the sole fact of having to depend irreversibly, without any hope of improvement, on nutritional assistance to remain alive, is not in itself — emphasizing ‘in itself’ — sufficient to qualify for ‘artificial life support’ and ‘unreasonable obstinacy’.”

**C. How can an irreversible decision be taken in a situation of deep uncertainty? The issue of judging on some one else’s behalf**

1. A collegial procedure culminating in a decision taken by the physician alone
“I strongly object to the word ‘collegial’: the Leonetti law does not define any such entity; it would be a good thing to do so.”

In its written observations for the attention of the Conseil d’Etat, CCNE remarked: “The Code of Public Health stipulates that physicians can only decide to withdraw treatment after:

- consulting the patient’s advance directives, if there are any, or the trusted person designated by the patient, or should that not be possible, seeking the opinion of the patient’s family or a person close to the patient;
- setting up a collegial procedure.

Physicians can set up this collegial procedure on their own initiative if they hold the view that continuing treatment or certain treatments would be an instance of unreasonable obstinacy.

Furthermore, on being shown the advance directives, physicians must launch the procedure — that is if the patient had previously requested that some or all treatments be withdrawn in the particular prevailing circumstances — or at the request of a patient’s trustee, or of the family, or failing that, of a person close to the patient — that is if they testify that the patient had made that wish known to them or if they believe, knowing the patient personally, that he or she would not have wanted certain or all treatments to be continued.

As we can observe, when patients are not able to express their wishes, evaluation of the concept of “unreasonable obstinacy” is not unilateral; it is constructed on the basis of several different viewpoints:

- appreciation by the physician of the medical status of the patient under his or her care;

---

104 Citizens’ debate in Clermont-Ferrand, in the Report by the Commission on reflection on the end-of-life in France.
105 Article R. 4127-37 of the Code of Public Health: “The decision to limit or withdraw treatment is taken by the physician in charge of the patient, after consulting the clinical team, if there is one, and hearing the reasoned opinion of at least one other physician, called in as a consultant. There must not be any hierarchical connection between the physician in charge of the patient and the consultant physician. The reasoned opinion of a second consultant is requested by the first two physicians if one of them considers it appropriate. The decision to limit or withdraw treatment takes into account the wishes that the patient may have previously expressed, in particular in advance directives if the patient had written any, the opinion of the trusted person the patient may have designated, as well as the opinions of the patient’s family or, failing that, the opinion of someone closely connected to the patient. The decision to limit or withdraw treatment must be reasoned. The opinions heard, the nature and direction of the consultations which took place among the members of the clinical team as well as the reasons underlying the decision are set out in the patient’s case file. The patient’s proxy, if one was designated, the family or, failing their availability, a person closely connected to the patient are informed of the nature and reasons underlying the decision to limit or withdraw treatment. [...] the physician, even in the event that it is impossible to evaluate patient suffering due to cerebral dysfunction, initiates treatment to ensure patient comfort, including in particular the use of analgesic and sedative drugs. [...] The physician also ensures that the patient’s family and friends are informed of the situation and receive appropriate support.”

Article L. 1111-13: “after respecting the rules of collegial procedure as defined by the Code of Medical Ethics and consulted the trusted person referred to in Article L. 1111-6, the family, or failing availability, a person closely connected to the patient and, if they exist, the patient’s advance directives. The reasoned decision is set out in the patient case file.

...physicians preserve the dying person’s dignity and quality of end-of-life by providing the care described under Article L. 1110-10.”
• the wishes previously expressed by the patient, as they may be understood from the patient’s advance directives, if there are any, or as they may be reported or inferred by the trusted person, or failing availability, by the family or a person closely connected to the patient;

• and the appreciation by the clinical team and the reasoned opinion of physicians involved in the collegial procedure.

But in the current state of legislation, once this consultation has taken place, it is the responsibility of the sole physician in charge of the patient to decide whether a situation of “unreasonable obstinacy” prevails and, should that be the case, to decide on limiting or withdrawing treatment.

The wording used, collegial procedure, may give the impression of a procedure based on collective deliberation, but this is not actually the case. The procedure is based on consultation. The physician’s decision is not made with the trusted person when there is one, nor with family, nor with loved ones (nor with the clinical team, nor with the consulting physician): the decision is his alone, after consulting the various participants and having heard their opinions.

It ensues therefore, that in the current state of legislation, starting from a process of shared decision — in which when patients are lucid and capable of expressing their wishes, they make decisions regarding their own health106 with their physician — or in other words, a process of decision by the person107 concerned, whereas once patients are unable to express their wishes, we move on to a process of consultation and later decision where the physician is alone in making that decision.

And yet:

• if the treatment that is to be withdrawn is artificial nutrition and hydration, and the sick person is not in an end-of-life situation, withdrawing artificial nutrition and hydration will have the effect of causing death;

• and it is in such circumstances — where the decision is pending to withdraw definitely the artificial nutrition and hydration of persons “unable to express their wishes”, who have not left advance directives nor designated a trustee, who are in the “advanced or terminal phase of a serious and incurable disease”, but not at the end-of-life — that the physician’s appreciation of the concept of “unreasonable obstinacy” raises the most complex issues.

CCNE is pointing out in this connection the particular difficulties that the Code of Public Health’s present definition of a supposedly collegial procedure raises for physicians. It involves consulting another doctor, the clinical team, family and loved ones, but then going on to taking the decision alone:

• the physician must first decide whether a situation of unreasonable obstinacy is indeed occurring, clinically speaking, taking into account the patient’s

106 Article L. 111-4 of the Code of Public Health
107 Article L. 1111-10 of the Code of Public Health: When persons in an advanced or terminal phase of a serious and incurable disease, regardless of its cause, decide to limit or withdraw treatment of any kind, the physician must respect their wishes after informing them of the consequences of their decision.
specific medical condition and the actions prescribed by good medical practice,
• and then evaluate any available information on the patient’s wishes as they may have been previously expressed to family or loved ones.

The physician must therefore be both judge and party in passing judgment.

And yet, as discussed above, a decision made in a situation of such uncertainty cannot build on medical expertise alone, which is good reason why it should not be made by a physician acting alone.

CCNE, in its Opinion N° 121, recommended a modification of the collegial procedure so that it could become a true collective deliberation and “not seen as a collegial discussion among experts” and for it to be implemented on a “much broader basis as soon as complex decisions have to be made at the end of life, be it for medical reasons or following a patient’s request.”

In such a collective deliberation, the input of medical professionals will of course be extremely valuable as will that of non medical carers, those who are closest to the patient and to the patient’s physical reality and possible reactions, as will also be the opinions of the family and loved ones who have a different, more personal view of their relative’s possible reactions and alone are able to throw light on what they believe to be past wishes, hopes and fears.

Some people believe that the opinions of the spouse or of the life partner should predominate, since as far as anyone knows, the patient’s lasting decision was to choose the person sharing his or her life. Others, however, point out that such an option is frequently fraught with difficulty. A more generic word comes to mind, such as “loved ones” to take into consideration the fact that there are as many different responses as there are individuals involved108.

“In this extreme context, fraught with tumult and inequality, the decision cannot be subject to the sole arbitration of medical procedure [...]109.

2. A guide drawn up by the Committee on Bioethics of the Council of Europe

“Paying particular attention to the decision-making process regarding medical treatment at the end of life is a form of quality procedure, the main aim of which is to guarantee respect for patients who may be particularly vulnerable in an end-of-life situation.

In this context, it is essential to promote any measure that makes it possible to adhere as closely as possible to the patient’s wishes, which can be expressed either by the patient him or herself or by means of advance directives.

108 CCNE written observations for the attention of the Conseil d’Etat.
109 “Management of the vegetative or minimally conscious state until end-of-life”, Espace éthique Région Ile de France, CRFTC, Université Paris Sud.
The collective discussion process relates to the complex clinical situations in which patients find themselves at the end of life. In such situations, in which many ethical issues are raised, there is a need to discuss and compare arguments to enhance the response and formulate a decision that is geared to the situation and shows due respect for the patient.[...]

The decision-making process should in itself be the subject of:

- information for users of the health system, including their representatives from associations and their families. This information should relate to the tools enabling or facilitating dialogue between patients and doctors such as advance directives, the appointment of a person of trust and everyone’s role and responsibility in the decision-making process in end-of-life situations;
- training for health professionals. In addition to specific end-of-life related questions, training in the construction of individual thought processes and collective discussion is necessary so that each health professional can deal with the increasing frequency of complex situations involving many ethical issues in clinical practice. (...)
- specific studies, taking into account the complexity and singularity of the situations encountered (...). These studies on decision-making processes should foster interdisciplinary approaches combining human sciences and medicine.”

3. CCNE suggests: a collective deliberation and decision procedure, on a case-by-case basis, providing for a possible appeal to mediation

In its written observations for the attention of the Conseil d’Etat, CCNE suggested a collective deliberation and decision procedure.

“In such a situation of uncertainty, of limited knowledge and at life’s limits, it would seem right and fitting that the arguments contributing to this collective process of deliberation should be considered collectively, on a basis of equality, leaving hierarchy aside, and not in the belief that the medical point of view is the only one entitled to render a “verdict”.

In other words, CCNE considers that thought should be given to make this collective deliberation process evolve into a truly collective decision.

The first step is to consider the time required to reconcile the various viewpoints, those of family and loved ones as well as those of doctors and carers111. As is the case for informed consent, ensuring that dialogue takes as much time as is needed and is of the right quality will be much more useful than simply complying with

110 Guide on the decision-making process regarding medical treatment in end-of-life situations, Council of Europe, May 2014.
111 The time required for discernment in a conciliation is all the more necessary because more often than not, dissensus leads to prolonging treatment and care.
administrative obligations. This is particularly true when discussing a decision to withdraw treatment, but equally so when explaining the care required for life in a minimally conscious state, and its possible complications.

If a consensus does not emerge from collective deliberation, despite protracted attempts to reconcile divergent opinions and arrive at a consensual position, a second stage for mediation could be helpful.\footnote{A further advantage should this kind of procedure be adopted is that it would fulfil a role in the observation of complex, borderline and exceptional situations. In its Opinion N° 121, CCNE expressed the wish that some kind of observation system be implemented since rather surprisingly, no national nor even regional data is available to serve as a factual basis to analyse actual situations of unreasonable obstinacy in extreme or complex situations where the various participants involved disagree.}

Mediation, in the generally accepted meaning of the word, is an ethically motivated process supported by the sense of responsibility and the autonomy of participants, in which a third party — who must be impartial, independent, neutral, without power of decision, empowered only by the authority the participants to the collective deliberation process are willing to invest in the mediator — facilitates the opening of a dialogue or its resumption, the social interplay and the capacity to make a joint decision.

This process of mediation must necessarily be entirely independent of all the parties involved — meaning also independent of the hospital and other medical facilities.\footnote{The parliamentary evaluation report for the law on the rights of patients and on end-of-life recommended in 2008 (proposal 8) nominating appointees in each region who could step in to facilitate the law’s implementation in complex situations.}

It would probably be helpful if several people were part of the process.\footnote{Taking the matter to court would always be a possibility as a last resort so that the dispute could be settled by traditional judicial procedure.}

The thoughts set out above are anchored in the freedom of principled discernment which remains as the ultimate point of reference, on the condition that conscience is enlightened by confrontation with another’s understanding.

For this reason, rather than trying to establish a standard which could possibly apply to every conceivable case and which could give doctors a basis on which to construe a decision, CCNE considers that it would be preferable to set up a substantive process for deliberation and collective decision so that, in each case, in full awareness of the prevailing uncertainty, could emerge the best possible response to the radical singularity of each situation.\footnote{CCNE’s written observations for the attention of the Conseil d’Etat.}
VI. Concerning shared demands, modify the 22nd April 2005 law, or promulgate recommendations for good practices?

- For some currents of opinion, the right to deep sedation until death (however this is to be accomplished), the opposable nature of advance directives (whatever may be the decision as regards how they should be drafted), together with a possible modification of the so-called collegial procedure would require a modification of the 22nd April 2005 law on patients’ rights and end-of-life.

In its Opinion N° 121, CCNE recommends that it should indeed be adapted in these three respects while retaining the spirit of the law:

- As a first step, the process of collective deliberation which is beginning to be formalised in existing legislation should be reviewed so that there is a systematic involvement of the patient and the patient’s loved ones, so that it can be extended to all professional health care providers and not seen as a collegial discussion among experts and for it to be implemented on a much broader basis as soon as complex decisions have to be made at the end of life, be it for medical reasons or following a patient’s request.

- The Committee also considers that a change in perspective is needed regarding the value to be given to advance directives: the conditions in which they are recorded must be revised, medical support must be given to patients who wish to draft them so that they are as pertinent as possible to their state of health and can be effectively taken into account. When advance directives exist, they should be presumed to be binding on health care providers and any deviation from what the directives prescribe should be justified in writing and included in the person’s medical record.

- Finally, the Committee recommends the definition of a right to terminal sedation in the last days of a person’s life. In this way, people whose existence is prolonged by life-sustaining equipment will be able, based on their right to refuse treatment, commence an end of life process with the benefit of palliative care and, if they so wish, die under sedation. So as to be sure that this right is in fact observed and that its implementation is not distorted, all decisions to apply deep sedation, either continuous or intermittent, in the final phases of disease, must be noted in the patient’s medical record.

- Others consider that the steps to be taken “should preferably be in the form of recommendations for good and responsible medical practices, rather than requiring new legislation”\(^{116}\).

\(^{116}\) Commission for Reflection on the End-of-Life in France.
Another possible option might be, for example, to include in the law as one of the missions of the Haute Autorité de Santé the drafting of recommendations for good practices to that effect.

Some people consider that this debate — legislation versus good practices — is not the essential point:

- “In such a sensitive and complex human and medical context, the law alone cannot provide the answers which must, whatever the circumstances, be arrived at through consultation with due consideration for the higher interests of the person concerned”.  
- “The citizens of Picardie who were present did not discuss any form of overhaul of the Leonetti law since they considered the problems to be situated at a much earlier level. Their major concern was the absence of a social bond inevitably leading to a breach of the fundamental values which should prevail in life shared with loved ones.”

Regardless of which course of action is chosen, for CCNE the fundamental point is the commitment of health professionals and society to make humane care really available for vulnerable people before life’s end and for people at the end-of-life, whilst respecting their wishes.

117 “Management of the vegetative or minimally conscious state until end-of-life”, Espace éthique Région Ile de France, CRFTC, Université Paris Sud
118 Ethical forum, Picardie region, “Penser et vivre la fin de vie à domicile.” (Thoughts on end-of-life at home).
VII. A profound divide: the issues of assisted suicide and euthanasia

Out of public debates and reflection has emerged a profound divide on the decriminalization or not — or even need for authorisation or otherwise — of assisted suicide or euthanasia.

To which is added a substantial difficulty in working out definitions for the terms used which are acceptable to everyone.

Nor is CCNE itself free of both difficulty and division of opinion.

A. A profound divide on the issue of assisted suicide

Two very different kinds of recommendations have been put forward; they can be summarised as follows:

1. Recommendation that assisted suicide should neither be authorised nor decriminalised

   “The question of assistance in suicide for certain people who have reached an advanced or terminal phase of disease is still very sensitive, even though the Committee notes that the developments it is recommending would tend to make such requests even scarcer than they are at present.

   When other circumstances prevail, the majority of the Committee’s members consider that the answer should be clearly negative: particularly in cases where the disease has not reached an advanced or terminal phase as defined by the medical profession, i.e. people with disabilities, possibly mental, or with serious progressive diseases or severe depression.

   Certain CCNE members consider that assisted suicide and euthanasia should — at least in certain circumstances — be made legal. They consider that respect for individual liberties must extend this far and therefore that third parties who would be ready to provide that assistance should be authorised to do so, without this representing a major risk for solidarity within society.

   However, a majority in the Committee considers that such legislation is not advisable: apart from the fact that any development in that direction appears to be — particularly in the light of similar experience in other countries — very difficult to stabilise, there would be a significant risk of compromising the solidarity and fraternity which are the safeguards of life in a society marked by numerous individual and collective frailties and notable shortcomings in end-of-life policies.”

119 CCNE, Opinion N° 121.
• Without a doubt, even if it is “only” to assist suicide, deliberately causing death is not part of a physician’s mission. 120

2. Recommendation to legalise medically 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.

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.

In any case, medically assisted suicide must comply with procedures and be attended by health professionals. 121

3. Statement of the required conditions for medically assisted suicide — “were legislators minded to legislate [on this subject]”

• “For the Commission, assisted suicide can never be proposed as an alternative to the verified absence of palliative care or appropriate terminal care.

But for certain people in the throes of the terminal phase of a progressive and incurable disorder, the prospect of being compelled to live the end of their life, until the very last moment, enclosed in a medical environment, where loss of autonomy, pain and suffering can only be relieved by palliative care, may seem totally unacceptable. For that reason, they wish to end their life before their time has come and they are asking for help in committing suicide, in the form of medically prescribed drugs.

Such requests, which are rare indeed when there is a real possibility of attentive palliative care being provided, may owe more to wanting to have

---

The same position was adopted, in particular, by the Conseil national de l’ordre des médecins (the National Medical Association); the Société française d’accompagnement et de soins palliatifs (SFAP) (the French Society for attending the dying and palliative care), and by others...

121 Citizens’ Conference on End-of-Life.
This is also the position adopted, in particular, by a minority group of CCNE members, in Opinion N° 121; also by an association, Association pour le droit de mourir dans la dignité - ADMD. (Association for the right to die with dignity); and the overwhelmingly majority of responses to a large number of opinion polls.
available some ultimate last resort rather than to an actual decision to end life before the time has come.

Were legislators minded to legislate on assisted suicide, the following points should be considered:

- Ensure that those concerned explicitly and repeatedly state their wish to end their life with such assistance.
- Recognise the existence of an end-of-life situation by some form of collegial medical procedure.
- Ensure that the end-of-life patient’s decision is taken:
  - insofar as the patient is capable of autonomous movement.
  - insofar as the patient is fully informed and has freedom of choice.
  - insofar as the patient really has access to all other alternatives of palliative terminal care and relief of physical and mental distress.
  - insofar as the patient is informed of the practical conditions of assisted suicide.
  - in the context of a pluridisciplinary collegial discussion involving the patient, loved ones, the attending physician, another physician not participating in current treatment and a therapist providing assistance to the patient.
- Require the presence of the attending physician, or if he or she has conscientious objections, of the prescribing physician at the time when the deed is done and during the patient’s death agony.
- Guaranteering pharmacists’ conscientious objection option.
- Ensure that the medications used will comply with existing regulations as well as with health and pharmacological safety rules.
- Ensure that no pre-existing timetable has been set for the final step to be taken.
- Ensure that information (nature of the disease, reasons for the decision, circumstances of the procedure) is reported back by the physician to a national structure tasked with producing an annual report on all the information received.

Regardless of circumstances, of the wording of advance directives and even if a trusted person has been designated, the administration to the patient of a lethal substance by a third party cannot be defined as assisted suicide. This would be active euthanasia.

And when the request is made by conscious persons, unable to perform in any way the action required for assisted suicide, by definition the law could not be applied. But in that event, the medical profession would not be absolved from action and, at the patient’s request, would need to consider the possibility of a withdrawal of life-sustaining therapy while providing sedation.122

B. Profound divide on the issue of euthanasia

1. In extreme situations

In the view of the Commission for Reflection on the End-of-Life in France:

- “Confining palliative medicine exclusively to palliative care units would lead to mismanagement. For example, a medical team united by a very close relationship with its patients, might be unwittingly encouraged to strive for — in some instances unwanted — prolongation of life. Any request for euthanasia by the patient, forbidden by law, could be interpreted as an existential complaint to be dispelled by quality supportive care. Resigning itself to helping death along by some radical action is very difficult for a team of people who see their profession as essentially opposed to such an attitude which some consider to be positively “blasphemous”. This clearly understandable opposition can sometimes deny the deep-seated wishes of the person concerned. A doctor we spoke to said he had never heard a patient ask for euthanasia, but added: “but perhaps I was not really listening”. [...] “Since in this country the “palliative dimension” is only put forward when death is imminent, for certain patients and families it appears as a “bird of ill omen” and, for certain health professionals, it reinforces existing compartmentalization. The strongest impression in the minds of our fellow citizens is that health carers refuse euthanasia in favour of the notion that a good death is a slow death. It seems that citizens have a feeling that doctors find it difficult to understand that a patient may be tired of living. Does this rather anti-euthanasia attitude on the part of the medical professions protect patients or worry them? It ought to be possible to ask that question.”

In the view of the National Medical Association:

- “The law dated April 22nd 2005 prohibits forcing any kind of treatment on a patient who refuses it. It also prohibits any unreasonable obstinacy in examination or treatment. It authorises at the end of life the use of treatment at doses which effectively provide relief, with the patient’s agreement, even if those doses could also shorten the time before death ensues. However, the law offers no solution for certain very prolonged death agonies or for psychological and/or physical pain which, despite all attempts to alleviate them, remain intractable. Such situations, even though they may occur only rarely, cannot be left without remedy123.”

123 National Medical Association, op.cit.
2. Divergent stances on the existence or not of a difference between assisted suicide and euthanasia by request by the person concerned

In the view of the Commission for Reflection on the End-of-Life in France: “...euthanasia upon request by patients” “is totally different from assisted suicide in which the patients themselves commit the lethal action.”

For others, the dividing line between the two actions is complex (euthanasia in response to a request by a patient may be viewed as the equivalent of medically assisted suicide):

- Assistance in suicide goes a step further than not preventing someone from committing suicide. In its Opinion n° 63, the Committee saw no difference between this assistance and euthanasia. It is true that, just like euthanasia, an action which by definition is individual — suicide — in this case requires somebody else’s intervention. There is however a specific difference which is that with assistance in suicide, the person who asked for that assistance shoulders the responsibility for the final action — even though earlier, this responsibility was in fact shared with other people — and that the moral burden is not borne in the same way by anyone else but the person concerned. The distinction between assistance in suicide and euthanasia may however appear as rather specious and hypocritical to some people for whom there is a close connection between giving someone the possibility of committing suicide and being the author of the act that extinguishes that person’s life. The Committee nevertheless emphasizes that this distinction does at least confront those asking for assistance with the responsibility for their own actions. Furthermore, it does not give credence to the idea that it would be much easier for third parties, doctors in particular, to help someone die than for that person to commit suicide.

Assistance in suicide must of necessity involve third parties: the doctor who states that the sufferer’s disease will be lethal within six months, that the patient made a free and informed decision and who prescribes the lethal substance; the pharmacists who hands over the substance and, more generally, society as a whole which allows and organises this process.

The concept of assisted suicide refers to a different set of circumstances: when people who wish to end their life are not physically capable of doing so, for their decision to be implemented they need the active help of a third party to administer the lethal substance by ingestion or injection. The difference between that process and euthanasia is tenuous.

Assisted suicide therefore relies more heavily than assistance in suicide on the contribution of a third party, whose role raises serious issues: how much of such a contribution should be allowed? Facilitating the accomplishment of the suicidal action? Performing that action? Is there not a risk that a third party could impinge on the personal autonomy of the patient? To what extent, given the right to wish to put an end to one’s life, could someone in this situation oblige a third party to “put them to death”?

Some people consider, however, that there is a genuine difference between assisted suicide and euthanasia: there is on the one hand the settled and independently stated will of people who wish to die and take whatever steps —
such as refusing treatment — under their control, but are physically incapable of killing themselves. They therefore ask a third party, possibly a doctor, to do what they cannot do for themselves. According to all commonly accepted definitions, euthanasia is the act of deliberately ending the life of a person who is seriously and incurably sick, at that person’s request, with the aim of putting an end to a situation that person considers unbearable. Following the logic of what we have just said, this concerns people who do not wish to commit suicide, even with assistance. In effect, some people may express simultaneously the wish to die and their refusal — or their psychological incapacity — of putting themselves to death by suicide — there being no involvement of a physical impediment to such action in this case — or their preference for a doctor to put an end to their life at their own request, rather than doing it themselves. 124.

- “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 participants), once a third party was brought in to administer a lethal substance and death ensued immediately, this was defined as euthanasia.”

3. Radically different recommendations

Three very different kinds of recommendations have been put forward and they can be summarised as follows:

- A recommendation that neither euthanasia nor assistance in suicide should be authorised because, generally speaking, they raise the same ethical issues since “there would be a significant risk of compromising the solidarity and fraternity which are the safeguards of life in society.”

- A selective recommendation not to authorise euthanasia because the ethical issues it raises are very different from those raised by assistance in suicide: “The act of euthanasia, at the request of patients, as it is only authorised in the Benelux, is a medical action which, by its radical achievement and its precise programming in time, suddenly and prematurely ends a life. This is a totally different decision from the one quoted above of a lethal action in the final phases of terminal care. It is also totally different from assistance in suicide when the lethal action is performed by the person concerned.

124 CCNE, Opinion N° 121.
125 Citizens’ Conference on End-of-Life.
126 CCNE, Opinion N° 121. This is also the position adopted inter alia by the National Medical Association, the Académie Nationale de Médecine, the (SFAP) (the French Society for attending the dying and palliative care), and by others...
Euthanasia is a deep commitment to a society’s concept of what its medical services’ missions should be, so that there is a significant changeover from universal duty of humane care and support to an act which is so universally controversial. The Commission cannot see how clear legislation in favour of euthanasia, formulated in the name of individualism, could fail to bring about this changeover. The Commission also points out that whenever a limit to what is allowed is extended, other borderline situations are created and they are always unforeseen initially and likely to trigger repeated demands for further legislation.  

- A recommendation, formulated by a minority within CCNE, to authorise euthanasia, “Nor is there any convincing ethical reason for continuing to relegate to secrecy the so-called “active” exception for euthanasia which was formally accepted by CCNE in its Opinion no 63; it is up to the law to state when and how death could be inflicted; obscurity is always dangerous and we cannot continue to tolerate it as is sometimes suggested it should be; it is dangerous for doctors who will never be able to know in advance if their action is acceptable and will be recognised as such, since there is no legal definition to go by; it is no less dangerous for patients who will be deprived of the protection of precisely defined, organised and supervised procedures.”

- This is also the point of view of the Association pour le droit de mourir dans la dignité - ADMD, (Association for the right to die with dignity): “Over 90% of French people are in favour of this law for freedom (Ifop for Pèlerin Magazine), 60% of doctors in favour of this law for freedom (Ipsos for the Conseil National de l’ordre des médecins), await to have the long-awaited right - as is the case for our friends in the Netherlands since 2001, in Belgium since 2002 and in Luxembourg since 2009 - in conscience and in liberty, to choose the conditions of their own end to life.”

4. The particular case of persons unable to express their own wishes

When the person concerned has drafted advance directives or designated a trusted person:

- Quite obviously, for all those who would recommend that euthanasia should not be authorised for people who actually request it, the same recommendation applies a fortiori to the case of people who are unable to express themselves, regardless of whether or not they have drafted advance directives to that effect or designated a trusted person.

---

128 Minority opinion of CCNE members in Opinion N° 121. This is also the position held by the Citizens’ Conference on the End-of-Life and of an overwhelming majority of views expressed in opinion polls.
129 Open letter to the Prime Minister, May 5th 2014.
People recommending that euthanasia be authorised because they consider that the dividing line between assistance in suicide and euthanasia on request is hazy, feel that euthanasia should also be authorised when people have drafted advance directives or designated a trusted person:

- “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.)

When the person concerned has not drafted advance directives or designated a trusted person:

- Any form of euthanasia in such circumstances is firmly condemned by almost all expressions of opinions, reflections and recommendations:

  o The definition of euthanasia in CCNE’s Opinion n° 63, dated 27th January 2000, “End of Life, Ending Life, Euthanasia” was the following: Euthanasia is the action of a third party deliberately putting an end to someone’s life with the intention of terminating a situation which is considered to be unendurable. It is commonly accepted, particularly in countries having already adopted legislation favourable to euthanasia, that this term must be reserved for situations where a request is formulated by the sick person. This is what distinguishes euthanasia from homicide which is the name for putting to death someone who did not ask for this to be done.”

- However, the Citizens’ Conference recommends, without going into any further detail, the possibility in certain cases of an “exception for euthanasia”:

  o In view of the existence of the procedures contained in the Léonetti Law, the advances of palliative care and the possibility of turning

---

130 Citizens’ Conference on the End-of-Life.
131 CCNE, Opinion N° 121. In Opinion N° 63, CCNE emphasised: “CCNE is unanimous in condemning such action which is planned and executed without any request being made or consent being given by individuals concerned or their representatives. Without consent, no act of euthanasia could even be considered. The patient’s autonomy would require formal recognition and expression by authentic petition (free, repeated, expressed orally at the time, or previously in a document).”
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.\(^\text{132}\)

C. Assistance in suicide and euthanasia requested for extremely varied circumstances

The circumstances put forward differ considerably:

- terminal phase of a serious and incurable disease;
- or an advanced, but not terminal, phase of a serious and incurable disease;
- or in a non active phase of a seriously debilitating disease or disability;
- or in case of a future incurable disease being diagnosed, including cases when the disease is not fatal.

The diversity of legislation in countries where assisted suicide or euthanasia are authorised is evidence that there is no one single solution to the problem.

Those who are opposed to assistance in suicide or euthanasia being authorised or decriminalised underline that whenever a limit to what is allowed is extended, other borderline situations are created and they are always unforeseen initially and likely to trigger repeated demands for further legislation.\(^\text{133}\)

D. A fact: euthanasia in the absence of any request from those concerned or from their families, when they are unable to express themselves

\(^\text{132}\) The expression “exception for euthanasia” was submitted by CCNE in 2000 in its Opinion N° 63, End of life, Ending life, Euthanasia, but with an altogether different meaning. On the one hand, as emphasised above, CCNE condemned any act of euthanasia affecting a person without expression by authentic petition (free, repeated, expressed orally at the time, or previously in a document). And furthermore, this was not a recommendation to legalise euthanasia. As CCNE recalled in Opinion N° 121, “While it [the Committee] emphasised in the strongest terms the essential and constructive value of prohibiting the act of taking away a life, it noted that although strict enforcement of the law led to euthanasia being qualified, as wilful homicide, murder or failure in the duty of rescue, when such cases were brought to trial, they were judged with great leniency. Reiterating the central value of setting a limit through the prohibition of taking a life, it went on to consider as legitimate the proposal for the insertion in the Code of Criminal Procedure of an “exception for euthanasia” giving judges the possibility of putting an end to all further legal proceedings, depending on the circumstances of, and the motivation for, the act of euthanasia.”

\(^\text{133}\) Commission for Reflection on the End-of-Life in France.
A recent INED document reports that 0.6% of deaths in France, i.e. some
3,300 deaths per year, appear to be due to euthanasia.134

“The same study considers that 0.4% of deaths could be the result of an
injection of a lethal substance by a health care provider without the person
concerned having requested it. Such situations, which are in fact homicides,
are unacceptable. Here again, the study gives us absolutely no
enlightenment on the nature of situations leading to such actions. Obviously, they need to be examined.”135

E. Another fact: suicide by elderly people as an indicator of
distress and social violence

Observations have been made of people committing suicide when they are compelled
to move into a care home (EPHAD) and desperate acts when suffering situations of
indignity.

“The existential distress of the elderly at the end of their lives is one of public
health’s major problems. According to figures in Dr Jean-Pierre Aquino’s report in February 2013
“Anticiper pour une autonomie préservée : un enjeu de société” (Planning for on-going autonomy: a challenge for society), depression affects 15 to 20% of
people over the age of 65 and 40% of those in institutions.
One suicide out of three concerns an elderly person.
Suicide is one of the main causes of death of elderly people, together with
cancer and cardiovascular disease. In France, in 2010, 2,873 people over the
age of 65 took their own lives. This represents almost 30% of suicide in
France although the over-65s only make 20% of the French population.
Out of these suicides, a majority (1,816 in 2010) were committed by people
aged 75 or more. In the over-85s, the prevalence of suicide is twice that of
25-44 year olds.”136

134 Pennec S, et coll. Les décisions médicales en fin de vie en France. INED 2012 (End-of-life medical decisions in
France).
135 CCNE Opinion N° 121
136 2013 Report by the National Observatory on End-of-Life.
VIII. More in-depth reflection on the ethical issues underlying the main divisions of opinion

A. Issues related to assisted suicide and euthanasia

1. The fundamental debate regarding the dividing lines — radical for some but more blurred in the mind of others — between “allowing to die”, “helping to die” and “making die”, upon request by the person concerned

In some minds, the borderlines are radical:

- It is of importance to “be clear on the terms of the discussion” by defining “euthanasia as “a deliberate action by a third party leading to the death of a patient’”, by recognising the “distinction between suicide which may be allowed but is not a right, and assisted suicide which is the instrumentalisation of a third party.”

- Those who object[ to euthanasia] only exceptionally do so for religious reasons and moreover also ask the State to ensure equality of rights, pointing out the risk of discrimination against the most vulnerable who would no longer benefit from a priori protection.

Although they recognise the liberty of requesting death, they express:

- the fear that it would become an obligation on physicians because, in practice, conscience clauses would never be accepted;
- that expressions such as “self deliverance” and “compassionate death” are only used to soften the violence implied by the word “euthanasia”;  
- that evaluation commissions seem to have given up on evaluating the cogency of the criteria used, as they are restricting them to a posteriori consideration. The situation is therefore paradoxical in that there is a reinforcement of medical empowerment that is not subject to any rigorous evaluation procedure or at least, never to prior evaluation before action is actually taken;
- that to consider loss of autonomy and ageing as synonymous with degradation may naturally point the way to thinking of euthanasia, encouraged in this by resigned acceptance on the part of the people concerned.

137 Perspectives and suggestions from the discussions on end-of-life by the collège des Bernardins in partnership with the Paris-Est Marne-la-Vallée University, February 2nd 2013.

For others, the dividing lines are still of vital ethical value, although they are “sometimes tenuous”:

- “This article [in the 22nd April 2005 law on patients’ rights and the end of life] is very important in ethical terms: it implies, if the patient’s wishes are to be respected, not only ceasing to provide treatment, food and fluids by artificial means (to “allow to die”), but also if the case arises to extreme steps and actions, such as switching off a device, which in themselves are likely to put an end to the patient’s life. […]”

Nevertheless, the interpretation of the law raises a certain number of queries. To begin with, there are doubts regarding the solidity of the distinction on which it is based between “allowing to die” and “causing to die”. The difference is sometimes very tenuous. For patients and those close to them, the concrete difference in the terminal phase of a serious and incurable condition between, on the one hand, discontinuing treatment considered to be futile, an action which may hasten the advent of death, combined with palliative care — including pain control which may have a double effect — and on the other hand, administering a substance with the aim of bringing about the death at the patient’s behest (act of euthanasia) may lead to ethical issues on two counts […]”

However, a majority in the Committee considers that such legislation [on assisted suicide or euthanasia] is not advisable.139.

- “The Commission strongly emphasises:
  o the absolute need to develop a culture in favour of palliative care and to abolish the frontier between curative and palliative care;
  o the imperative need for collegial decision making;
  o the absolute need to apply with determination existing legislation rather than unceasingly think up new laws;
  o that trying to legislate for the great complexity of end-of-life situations is utopian140.
    o that breaking down a barrier of prohibition is dangerous141.

For other thinkers again, these dividing lines have already been crossed by current legislation:

- “French law necessarily accepts acts of euthanasia since withdrawing treatment has the direct effect of causing death. Some thinkers consider that to proceed from “allowing” to “causing” death would be an ethical “leap” into the unknown; if that is truly the case, they should accept that the law as it stands has already done that; the law should not therefore be an insurmountable obstacle preventing other actions of the same nature to be authorised also.”142.”

---

139 CCNE, Opinion N° 121.
140 Ne légiférez qu’en tremblant, ou bien, Entre deux solutions, préférez toujours celle qui exige le moins de droit et laisse le plus aux mœurs ou à la morale » (Make law with trepidation or Between two solutions, always prefer the one with the least law and the most morality). CARBONNIER, Jean. Flexible droit, Librairie Générale de Droit et de Jurisprudence, EJA, Paris, 1998
141 Commission for Reflection on the End-of-Life in France.
142 As expression by a minority of CCNE members in Opinion N° 121.
Finally, for yet another body of opinion, the essential issue is not so much the nature of the act, but rather the right of a dying person to request it.  

2. Various possible reasons for expressing a request for assistance in suicide or euthanasia

- The request may be essentially based on fear of being denied access to palliative care or a horrified reaction to witnessing outrageous and disgraceful end-of-life circumstances when loved ones die.

- It may be a desire for an alternative to palliative care, consisting in anticipating the ultimate phase of life’s end:
  - the public debate did in fact reveal that for some people, the prospect of having to experience end-of-life, until the ultimate terminal phase, in a medical environment where loss of autonomy, pain and distress would only be relieved by palliative treatment or even loss of consciousness due to deep sedation until death ensues, simply seems unacceptable.
  - the desire for assistance in suicide may also essentially correspond to a deeply felt need to retain a degree of autonomy until the end. The Commission for Reflection on the End-of-Life reports: "fierce determination ("a particularly marked cultural characteristic of the people concerned") on the part of a very small number of people in the State of Oregon ("0.2% of deaths in the State of Oregon) [...] to be allowed to exercise their autonomy [...] by requesting assistance in suicide.

- It may be a desire for a possible complement to palliative care: to have, as a last resort, the possibility of protecting oneself, with help from the community, from the imposition of a situation which could become unacceptable.

- It may be the wish to shorten the unpredictable length of the final agony, either because the person concerned cannot endure the thought or to spare loved ones.

- It may be a desire to be allowed to choose the place and time of death and to make sure that all loved ones can be present in that final moment.

---

143 This was in particular the opinion expressed by the Citizens’ Conference on the End-of-Life.
144 Some people analyse this as being the reason for the overwhelmingly large majority of responses in opinion polls.
3. Assistance in suicide or euthanasia versus deep sedation until death

The debate may focus on:

- differences in the method: how will life end?
- differences in length of time: how long will the end-of-life last?
- differences on the time chosen for the ultimate end of life: choosing the time of death.

Differences in the method:

- One of the essential differences between assistance in suicide or euthanasia, on the one hand, and deep sedation until death, on the other hand, is that the latter option can only be requested by a person in an advanced and terminal phase of a serious and incurable disease, after that person has requested that treatment or even artificial nutrition and hydration be discontinued.
- This issue of differences in method is related, therefore, to the essential issue of the point in time when someone may decide to cease living.
- There are at least two important differences between assistance in suicide and euthanasia which relate them to some extent, but in different ways, to some of the characteristics of deep sedation until death:
  - like deep sedation, assistance in suicide is more frequently practised, in those countries that have already authorised or decriminalised it, by taking strong barbiturates with lethal effects. And, unlike deep sedation until death which is managed by physicians, assistance in suicide is an action taken by patients themselves;
  - like deep sedation until death, in countries that have already authorised or decriminalised it, euthanasia is managed by physicians. And, in contrast to deep sedation, it is more often than not administered by injecting an immediately lethal substance.

Differences in the length of time of dying moments:

- Very short in the case of euthanasia.
- With assistance in suicide, the Commission for Reflection on the End-of-Life made the following observations in the State of Oregon: there is a certain element of violence involved, both symbolically and in factual terms.\(^\text{145}\) In

\(^{145}\) *The medical professions are still very much divided. Even among those who are not opposed to prescribing a lethal substance, many are not clearly in favour of this action which they describe emotionally and even angrily. For example, Dr Widmer, a specialist in internal medicine who does not refuse to prescribe lethal substances, was very disturbed by several death agonies by assisted suicide that he had attended.* Observation in Switzerland by the Commission for Reflection on the End-of-Life.
Oregon, most deaths due to the ingestion of veterinary barbiturates, occur within three hours with extremes varying from one minute to forty-eight hours — and not almost instantaneously.

- In the case of deep sedation until death, after discontinuing treatment and artificial nutrition and hydration, the death agony may last several hours and up to two weeks.

This matter of the duration of the last phase of life’s end is conditioned by the expectations of the person concerned and of those loved ones who will be present to provide solace to the patient during this time. They may be either disturbed and exhausted in the extreme by long-drawn-out death throes, or be deeply shocked by abrupt death. These differences in the appreciation of time will in fact condition the experience of separation, acceptance of bereavement, and closure.

On this question of the duration of the ultimate phase, in the event of a request by the person concerned to discontinue treatment which may be prolonging life or even to discontinue nutrition and hydration, or if that request was written into previously drafted advance directives, the Commission on End-of-Life remarks: “...the decision to take lethal action in the final phases of end-of-life support” “... could equate in the eyes of the Commission to the actual circumstances of deep sedation as it is defined in the Leonetti Law”, and would avoid prolonging the final moments of a life which, to quote the Commission, may be cruel, and constitute a “form of obstinacy to “allow to die” or to “allow to live”.

Differences on the time chosen for the ultimate end of life: choosing the time of death.

- The Leonetti Law (dated 22nd April 2005 on patients’ rights and end-of-life) chose to use the concept of “…the terminal […]phase of a serious and incurable disease” to define the end of life, but they also consider the case of a person who is “in an advanced [but not terminal]phase of a serious and incurable disease” meaning the circumstances in which a person has not reached the end of life and it is in fact the decision to discontinue care and treatment which will be the cause of death.

Two issues arise out of the above:

- If anyone, in an advanced or terminal phase of a serious and incurable disease (but not necessarily undergoing essential life-supporting treatment), taking the decision to cease absorbing food and drink, could ask for deep sedation until death ensues, this difference regarding the choice of the time of death would be largely attenuated.

---

146 In the State of Oregon, barbiturates with marketing approval for human use cannot be sold for the purpose of medically assisted suicide.

147 The Commission for Reflection on the End-of-Life noted that in Oregon, “The questionnaire to be filled in by the patient is precise and clear on this question of how long the death agony lasts since it explicitly mentions the following: “I further understand that although most deaths occur within three hours, my death may take longer and my physician has counselled me about this possibility.”
perhaps the same is true for some one to whom a diagnosis of a serious and incurable disease has been imparted? It may be that the problem of legislation to edict a non arbitrary time limit in such circumstances cannot be solved (in Oregon, the terminal phase of a disease during which it is possible to request assistance for suicide is identified as the last six months of life. This conforms with federal law which recognises the shift from curative treatment to moving into a phase of compassionate care with access to palliative treatment, without for instance, the use of chemotherapy).

For CCNE:

- “The debate on the management of life’s end cannot be confined to the extreme end of life, to the final phase of an incurable disease, since this may well be the situation in which resorting to voluntary death is the least likely and the demand for it the least pressing.
- “The Committee further underlines the absolute need for a better understanding of “borderline cases” in which patients or their loved ones, as well as the health care providers concerned consider that neither palliative care nor sedation are sufficient to make the last moments of a person’s life acceptable. Once and only once this has been thoroughly investigated can the current situation made up of contradictory rumours be put behind us so that some further truthful light can be thrown on the end of life debate."  

B. Assisted suicide: a special problem?

Three points of view are put forward in public debates:

- for some, assistance for suicide and euthanasia are not fundamentally different. In both cases, on the part of the sick person there is a request for assistance with the aim of ending that person’s life. However, stemming from this observation:
  - some people consider that assisted suicide and euthanasia on request should both be authorised,
  - while others are of the opinion that both should be prohibited.
- And in yet other opinions, assisted suicide, because the lethal action is performed by the person concerned, it is radically different from euthanasia by request. Euthanasia should continue to be prohibited, even if assisted suicide were to be authorised.

In those few countries where assisted suicide or euthanasia have been authorised or (conditionally) decriminalised, there is often a big difference in the way the two

---

148 CCNE. Opinion N° 121.
practices are viewed\textsuperscript{149}. Switzerland, and the States of Oregon, Washington, Montana and Vermont in the United States, have decriminalised or authorised assisted suicide, but are still strictly forbidding euthanasia. Conversely, Belgium has legalised euthanasia but not assisted suicide. Only the Netherlands and Luxembourg have (conditionally) decriminalised both practices.

In the opinion of the European Court of Human Rights, “…an individual’s right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention.”\textsuperscript{150}

\section*{1. Assisted suicide or assistance in making suicide possible}

There are two radically different forms of assistance with suicide:

\begin{itemize}
  \item Assistance in actually committing suicide: this is in particular the case in Switzerland.
    The point in common with euthanasia is that the person sets a date and must keep to it. Indeed, one of the conditions to obtain assistance in committing suicide is the expression of firm and reiterated determination. If the person subsequently decides to defer to a later date, the firmness of his or her original decision will be subject to question.
  \item Assisted suicide without setting a date: this is the case in the States of Oregon, Washington, Montana and Vermont in the United States.
    \textit{“The situation in the state of Oregon is interesting in this connection: people with a disease diagnosed as incurable are allowed to ask a doctor to prescribe a lethal substance. In Washington State, where assistance in suicide is also legal, according to a recently published study, over a third of the people who could obtain the lethal substance, do not do so; just under a third of them get the substance but do not use it (because they die first or decide not to commit suicide); just over a third of them use the substance — of which 60\% ingest it — and die generally within 24 hours. These suicides correspond to 0.2\% of deaths. It would seem that the fact of knowing that the possibility is available to them, perhaps because they find that reassuring, frequently inspires people to refrain from the final step.”}\textsuperscript{151}
\end{itemize}

A point of debate:

\begin{itemize}
  \item Some people are inclined to believe that the possibility of assistance for suicide, if it is authorised, may have a paradoxical effect: for those who decide
\end{itemize}

\textsuperscript{149} It must be emphasised that in all of these countries, only a tiny minority of deaths are due to the (authorised or decriminalised) practice of euthanasia or assisted suicide.

\textsuperscript{150} Judgment, 20 January 2011, Haas v. Switzerland, n°31322/07, §51

\textsuperscript{151} CCNE, Opinion N° 121.
not to commit suicide, this is an unfettered decision to play out to the full the situation in which they find themselves. Instead of being the unwilling victims of their end-of-life, they are deciding not to end their lives. In a way, they deliberately decide to live, to live additionally the weeks or months they decide to keep.

- For others, the possibility of being assisted in suicide, and the decision not to have recourse to it, is an act for which not only the sick person must take responsibility, but also a commitment on the part of the patient’s human environment, in particular the medical team but also that of society as a whole. Paradoxically, there is an imperative need to provide access to palliative care and to offer a quality of care and solace worthy of the decision taken by those who decide not to put an end to their lives.

- Finally, for yet another body of opinion, the most formidable risk is that of possible manipulation of the patient to go ahead with suicide so that those who would have wanted to live to the end, even in the most harrowing circumstances, are prevented from doing so.

2. Two special problems

What kind of medical environment for physician-assisted suicide?

- For the Commission for Reflection on the End-of-Life, amid the large number of considerations that should be taken into account “...were legislators minded to legislate on assisted suicide”, there is “an imperative need to involve primarily the responsibility of the State and of the medical profession”, and in particular as mentioned above:
  o “making sure that the dying person’s decision is taken within the framework of a pluridisciplinary collegial discussion involving the patient, loved ones, the attending physician, another physician not participating in current treatment and a therapist providing assistance to the patient;
  o requiring the presence of the attending physician, or if he or she has conscientious objections, of the prescribing physician at the time when the deed is done and during the death agony;
  o ensure that the medications used will comply with existing regulations as well as with health and pharmacological safety rules.”

- In the view of the Citizens’ Conference on End-of-Life, who were recommending that physician-assisted suicide be authorised: “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).”
However, there is the question of where this should take place: should medical assistance for suicide be allowed within a hospital environment? Or should it, on the contrary, take place outside hospitals? The stark contrast between a hospital’s mission to heal and this activity is very obvious. The Commission for Reflection on the End-of-Life in France observed that in the Swiss Canton of Vaud, there was an obligation on all health caring establishments, hospitals and care homes alike, to accept within their walls persons who wished to end their lives in this way. This had finally been considered as acceptable and agreed to, but the only allowable procedure was admission of the patient to the hospital and the absence of the health caring teams on the day of the suicide. That being said, only two such cases have arisen over a period of twelve years.

The primary problem would be the compatibility of such expectations with current deontological obligations on clinical and health caring teams.

The person’s age

- Particular attention to the issue of the person’s age would be necessary because the high incidence of suicide by the elderly, adolescents and young adults is one of the major causes for concern by the health care system and is the subject of preventive measures.
- The matter would be of particular concern as regards younger people, since:
  - one the one hand, suicide is currently the primary cause of mortality for young people aged 15 to 25;
  - on the other hand, there is the issue of whether sick minors, despite the maturity beyond their years they often display as a result of their painful ordeal, are really capable of authentic, truly free and informed consent in such circumstances.
  - And there is also the whole and essential issue of the parents’ role in the decision and of the competence of sick minors to decide on their own, without parental intervention of any kind.

3. Legislation on failure to assist a person in danger

Non assistance to a person in danger is a criminal offence and carries penalty for indifference to the plight of others. There is a requirement for legislative clarification, as previously stated by CCNE, when its occurrence is precisely owed to non indifference to the plight of others:

- “Not attempting to rescue someone who is in mortal peril, including in the case when the person in danger is actually the source of that danger, may be severely punishable, as much as a five-year prison sentence.” However, the following question comes to mind in some circles: in the name of what principle should persons suffering from a serious and advanced incurable disease be forced to continue on a path they no longer wish to follow? Not preventing persons in such circumstances from taking their own life, seen from that angle, is not a form of non assistance to someone in danger, but rather a manifestation of respect for that person’s freedom to act.
This is not the case of pharmacological suicide, where a person supplies a substance. It is even less the case of actual assisted suicide, where a third party helps to administer the lethal substance: it is simply a matter of how to consider someone who is present at the time of a suicide. It so happens that French law does not distinguish in any way between two categories of people who do not intervene directly to administer the lethal substance, that is between a person who is giving assistance and one who simply is present. As a result, someone who wishes to die is condemned to total solitude which raises an ethical issue and leads to considering the possibility of the law taking into account the specific character of this particular situation.  

4. The issue of the demand for medical involvement

The public debate reveals an expectation that society and the medical professions commit to assisting people at life’s end whilst respecting their needs, their wishes and their autonomy.

This expectation is also in evidence — this being particular to our country — in the demands of those who want assisted suicide to be authorised or decriminalised.

This request for medical involvement in every form of end-of-life assistance and care expresses — in addition to very numerous criticisms aimed at the medical professions — massive expectations addressing health carers and the health care system.

But what is still a subject for debate is the compatibility of such expectations with the current deontological obligations of the medical and nursing professions.

---

152 CCNE, Opinion N° 121.
IX. Measuring the complexity

Over and above an attempt to summarise the findings, the queries and the recommendations expressed in this process of public reflection, and aware that any legislation will need in any case to satisfy constitutional and traditional safeguards for the protection of health and the right to life, this report seeks to throw light on some of the ethical issues underlying the main lines of division and emphasise their complexity with the aim of encouraging further thought on the subject and a firmer grasp of these issues.

A. From what standpoint are we speaking and who do we speak of when we speak of people at the end of their lives?

We are all concerned and each of us at various times in our lives has experienced various attitudes, or sometimes all of them simultaneously:

- The vantage point that each of us has concerning our own end-of-life
  - when we are in good health
  - when we are facing the threat of serious ill health or incapacitating disability
  - when we are suffering from a serious and incurable disease or from an incapacitating disability
  - when we are dying
- The vantage point of our individual and collective responsibility to others, be they autonomous or highly vulnerable.
- The vantage point of our individual and collective responsibility to others when they are unable to express their wishes.
- The vantage point of family and loved ones.
- The vantage point of health care providers.

- "The Coma Science Group at the University Hospital of Liege, headed by Steven Laureys, published recently the results of an extensive survey questioning 2,475 medical and paramedical professionals in 32 member states of the Council of Europe, on the subject inter alia of attitudes towards people in a minimally conscious state for more than a year. Less than a third of the respondents considered that withdrawing artificial nutrition and hydration for people who were minimally conscious was acceptable, whereas two thirds of health carers would not have wished to be kept alive themselves in that condition.

This discrepancy is all the more thought provoking because it is evidenced in a population, that is health care professionals, who are responsible by law for evaluating the “reasonable” or “unreasonable” dimension of continuing or withdrawing life supporting treatment 154, 155.

B. Taking into account the existence of multiple implicit or explicit philosophies underlying the various attitudes

In particular this is the case for:

- The importance attached to personal autonomy, depending on whether it is held to be a founding principle or if it is understood as being primarily born of a relationship in otherness — a person being perceived by others insofar as that person acts in his or her own right.
- The attitude to a person’s vulnerability and fragility.
- Individual dignity, emphasising that legislation comprises an obligation “ensure that dignity is preserved throughout a person’s life” and “to preserve the dignity of sick people” 156. CCNE therefore remarked in Opinion N° 105: From the start, it had been noted that the principle of respect for the dignity of the human being could appear as having a “variable composition”. It demands that people should never be considered simply as means towards an end, but an end in themselves, and should never instrumentalised. For some, dignity is inherent to human nature whereas for others, it should be recognised that it is contingent on a more subjective assessment. 157 The Committee also emphasised just as forcibly, in Opinion N° 121, the convergence of views denouncing the unacceptable: that is abandoning the most vulnerable members of society to a life, or an end-of-life, of indignity 158.
- The sufferings of the person concerned and of loved ones, in their multiple dimensions, keeping in mind that legislation provides for the need to “alleviate physical and psychological pain” and for “their families to be given support” 159. Coping with pain has consequences on decision making, all the more since emotion is an intrinsic part of the process. In this connection, contemporary neuroscientific thinking views decision making as following a pattern: decision arising from emotion with rationalisation only emerging later, retrospectively 160. The role of emotions must be included in the ethical debate on decisions affecting life and death — and all the more so

154 Steven Laureys’ comment on this study was that medical professionals needed to review their stance since “It is neither moral nor ethical to deny to others rights that we grant to ourselves”.
155 CCNE Observations for the Attention of the Conseil d’Etat (Council of State, highest French administrative jurisdiction).
157 CCNE, Opinion N° 105, Questions for the Estates General on Bioethics.
158 CCNE, Opinion N° 121, The End of Life, Personal Autonomy, the Will to Die.
159 Art L. 1110-5 of the Code of Public Health.
because such decisions are taken in a situation of profound uncertainty, conducive to subjective and divergent interpretations.

- The actual view that we have on solidarity. In its Opinion N° 108, CCNE wrote: “Ethical concern in matters related to the life and death of human beings touches upon the permanence of the social bond.”

- The meaning of life. The question probably has less bearing on the meaning of life, a question to which there is probably no other answer than an individual one, than to the meaning of respect for life — in the absolute, or in relation to another’s need — and on the purpose of the form of care and solace requested by the person concerned and provided by his or her physicians, carers and loved ones.

- The connection to the passing of time brings into focus the problem of individual prognosis when knowledge of the situation is necessarily only statistical and probabilistic. It is linked to consideration of life expectancy in terms of quality as much as in those of a span of time, or also to the major distinction to be made depending on whether death is, or is not, imminent. Finally, it is related to the different meanings that each of us attaches to time, a simple measurable time span or the mark of infinity on the finite.

- The reality of care. However qualified the clinical team, however devoted the family and loved ones, there are times of exhaustion when a condition is not evolving, when the difficulty of preventing complications such as bedsores, tendon retraction, intercurrent infections, all combine to bring about feelings of utter hopelessness or realising that adequate care and comfort can no longer be provided.

- The impossibility of integrating death, be it one’s own or someone else’s, when attempting to enter another person’s mind. Death borders on the boundaries of what it is possible to think of. It borders on what the psyche is fundamentally incapable of representing. How can decisions be taken in such a context? This is the central question arising when anyone participates in a decision to discontinue the life of another person, in particular when that person can no longer express his or her wishes.

### C. Autonomy and solidarity

CCNE perceives three different kinds of fear as underlying or contained in most of the debates:

- In the case where terminal care is not forthcoming and there is no possibility whatsoever for a person to request an end to life: the fear of being condemned — or be witness to a loved one’s plight — to be subjected, with no possible alternative, to an end-of-life racked with pain and deserted, or in an emergency setting.

- In the case where terminal care is provided but without any opportunity whatsoever of requesting an end to life: the fear — for oneself or for a loved one...

---

161 CCNE, N°108, Opinion on ethical issues in connection with the development and funding of palliative care
one — of being in a situation where there is no alternative to gradual painless death, possibly unconscious, without knowing how long it will take for death to arrive.

- In the case where terminal care is being given and it is allowable for the person concerned to ask for his or her life to be ended: the fear in a position of vulnerability or of social or economic precariousness of being subjected to pressure — or to see a loved one subjected to pressure — to put a premature end to his or her life instead of being allowed to live it to the full, with the benefit of terminal care. This fear being exacerbated by the knowledge that terminal care requires human and financial commitment on the part of the community.

The necessary conciliation between autonomy and solidarity — solidarity at autonomy’s service and autonomy at solidarity’s service — helps each of us to think of ourselves alternatively, as in an end-of-life situation, cared for by others or as a carer or someone involved in the end-of-life of others.

The border line fluctuates constantly, including each of us among those who are caring for others or responsible for others, or, suddenly including us in those whose lives are ending, expecting that others will do their best to care for us.

Being able, individually and collectively, to embrace these two apparently contradictory (and yet complementary) situations is probably one of the difficulties and one of the challenges and essentials of ethical reflection which, quoting Paul Ricoëur, consists in seeing “oneself as another”.

Respecting the autonomy, offering solidarity and protection for the most vulnerable among us is all the more difficult to reconcile in our time because care in the twilight years and care at the end of life are still tragically and profoundly inadequate.

The outcome of public debate on assisted suicide and euthanasia illustrates the very considerable ethical and philosophical difficulty of thinking in unison, or even attempting to reconcile two very ancient cultural or perhaps anthropological traditions: on the one hand, a timeworn tradition based on the principle of autonomy and, on the other hand, a timeworn tradition prohibiting the deliberate ending of another’s life.

The two traditions confront each other in a dimension which exceeds the sole field of legality. Law cannot on its own cope with all of the ethical considerations, in particular because of the radical singularity of each life as it ends.

“The purpose of ethical reflection is not to establish a more or less satisfactory legal solution” wrote CCNE in Opinion N° 87 on April 14th 2005, “Treatment Refusal and Personal Autonomy”, “but rather to analyse and understand the value judgments which have been expressed and the involvement of all participants: the persons concerned, their families, society and the medical profession, with full respect for the dignity and beliefs of everyone.”
<table>
<thead>
<tr>
<th>Table of contents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Foreword</strong></td>
</tr>
<tr>
<td>1. Over two years of public debate</td>
</tr>
<tr>
<td>2. After two years of reflection</td>
</tr>
<tr>
<td><strong>I. An appalling state of affairs</strong></td>
</tr>
<tr>
<td>A. Denial of the right to palliative care for the overwhelming majority of people at the end of their lives</td>
</tr>
<tr>
<td>B. Unbearable end-of-life for the vast majority</td>
</tr>
<tr>
<td>C. Wanting to be heard and respected</td>
</tr>
<tr>
<td>D. A law more concerned with defining the duties of health care professionals than with defining patient rights</td>
</tr>
<tr>
<td>E. Misapprehension and lack of enforcement of legal provisions guaranteeing the rights of sick people at the end-of-life</td>
</tr>
<tr>
<td>F. Very inadequate commitment to making known and enforcing respect for the rights of people who are dying</td>
</tr>
<tr>
<td>G. Inappropriate organisation of the health care system</td>
</tr>
<tr>
<td>H. Just before life’s very end, an end to life which is too often fraught with stress, not to say inhuman, because of impaired autonomy, whatever its cause</td>
</tr>
<tr>
<td><strong>II. Shared recommendations</strong></td>
</tr>
<tr>
<td>A. Ending a fifteen-year old scandal: no access to rights recognised by law</td>
</tr>
<tr>
<td>B. Developing palliative care and improving training for physicians and other health care providers</td>
</tr>
<tr>
<td>C. Giving access to both compassionate and palliative care before the very end of life and developing a medical and treatment “culture” combining “curative” and “palliative”</td>
</tr>
<tr>
<td>D. Developing information on advance directives and the trusted person</td>
</tr>
<tr>
<td>E. Making advance directives accessible to health care workers</td>
</tr>
<tr>
<td>F. Achieving a more useful allocation of economic and human resources</td>
</tr>
<tr>
<td><strong>III. A shared claim for two rights: make advance directives binding and have access to terminal phase deep sedation until life ends</strong></td>
</tr>
<tr>
<td>A. Binding advance directives</td>
</tr>
<tr>
<td>B. The right to have access to terminal phase deep sedation until death</td>
</tr>
<tr>
<td><strong>IV. A certain number of points in these shared demands, however, are still under debate</strong></td>
</tr>
<tr>
<td>A. Under debate, the binding nature of advance directives depending on the author's circumstances at the time they were drafted</td>
</tr>
<tr>
<td>B. Under debate, the modalities of terminal phase deep sedation until death</td>
</tr>
<tr>
<td>C. Shared, but not altogether unanimous, demands</td>
</tr>
</tbody>
</table>
V. The situation of people "in an advanced [but non terminal] phase of a serious and incurable disease", "unable to express their wishes" and who have not drafted advance directives

A. The Conseil d’Etat (decree dated February 14th 2014) clarified the interpretation of the law

B. In their written observations to the Conseil d’Etat, CCNE underlined the particular nature of treatment by artificial nutrition and hydration

C. How can an irreversible decision be taken in a situation of deep uncertainty? The issue of judging on some one else’s behalf

VI. Concerning shared demands, modify the 22nd April 2005 law, or promulgate recommendations for good practices?

VII. A profound divide: the issues of assisted suicide and euthanasia

A. A profound divide on the issue of assisted suicide

B. A Profound divide on the issue of euthanasia

C. Assistance in suicide and euthanasia requested for extremely varied circumstances

D. A fact: euthanasia in the absence of any request from those concerned or from their families, when they are unable to express themselves

E. Another fact: suicide by elderly people as an indicator of distress and social violence

VIII. More in-depth reflection on the ethical issues underlying the main divisions of opinion

A. Issues related to assisted suicide and euthanasia

B. Assisted suicide: a special problem?

IX. Measuring the complexity

A. From what standpoint are we speaking and who do we speak of when we speak of people at the end of their lives?

B. Taking into account the existence of multiple implicit or explicit philosophies underlying the various attitudes

C. Autonomy and solidarity
Documents quoted in this report can be consulted on the CCNE website

http://www.ccne-ethique.fr/