Foreword to CCNE's Opinion N°121

Following submission at the close of 2012 of the report by the French Commission for reflection on "Solidarity in France at the end of life", the President of the French Republic referred three questions to the National Consultative Ethics Committee for Health and Life Sciences (CCNE):

- How and in what circumstances should advance directives expressed by persons in good health or when a serious medical condition involving the end of their life is made known to them, be recorded and applied?

- How can the final moments of patients whose treatment has been discontinued following a decision taken at their own request or that of their family or by health care providers, be made more dignified? ".

- According to what procedures and strict conditions should conscious and autonomous patients suffering from a serious and incurable disease, be authorised to obtain support and assistance in their decision to put an end to their own life?

Over the last twenty years, CCNE has more than once had occasion to reflect on these matters. In the first Opinion the Committee published on this subject in 1991, CCNE "expressed its disapproval of legislation or regulations that legitimise the act of taking the life of a patient" (Opinion N°26). In 1998, it declared itself in favour of "discussing publicly and with serenity the problem of care at the end of life, including in particular the subject of euthanasia" (Opinion N°58). In 2000, CCNE suggested the concept of "joint commitment, a plea of exception for euthanasia". (Opinion N°63).

Opinion N°121, "The End of Life, Personal Autonomy, the Will to Die", sets out CCNE's current thinking, taking into consideration developments in law and in practice over the last ten years on the subject of the rights of patients and of people at the end of their lives, as well as the Sicard Commission's report.

Several recommendations, in particular the following six, were unanimously agreed by the members of the Committee:

- the need to put an end to all situations of indignity which, still all too often, are prevalent at the end of life;

- the need to make the right to palliative care accessible to everyone — a right which legislators recognised fourteen years ago;

- the need to develop access to palliative care at home;

- the need to associate fully the person concerned and loved ones to all the end of life decision making processes;

- respect for advance directives given by the person concerned. Currently, despite the name “directives”, the law considers them simply as an expression of wishes, with decisions in fact taken by physicians. The Committee requests that, when they are drawn up in the presence of attendant physicians and in circumstances where the existence of a serious condition has been made known, advance directives should be binding upon health care providers, save for exceptions duly accounted for in writing;

- respect for the right of those nearing the end of their lives, if they so request, to deep sedation until death, once treatment and possibly nutrition and hydration are withdrawn at the patient’s request;

- the need to develop the training of health care providers, their capacity for attention and dialogue, as well as research in human and social sciences on the circumstances surrounding people at the end of life.

- the need to put an end to the social isolation and deprivation to which, all too often, the sick, the disabled and the elderly are subject before they die, and to give them access to the support which is essential for their welfare.

As regards the right of a person at the end of life to access, at his or her request, medical action for the purpose of accelerating death and/or the right to assisted suicide, the Committee did not arrive at unanimously shared thoughts and proposals.

The majority of the members of the Committee expressed major reservations and recommends that the law as it stands should not be modified. They consider that it makes an essential and useful distinction between “allowing to die” and “causing to die”, even if in certain circumstances the difference may seem blurred. They consider that continuing to forbid doctors to “induce death deliberately” protects people at the end of their lives and that it would be a danger for society if doctors could participate in “taking away life”. As regards more specifically assisted suicide, they consider “that such legislation is undesirable”, and are very reticent on the indications for assisted suicide and/or euthanasia in countries where the procedure has been decriminalized or authorised. They further are concerned as regards extensions of the indications in some of these countries. Finally, they consider that any development in the direction of authorising active assistance in dying could be experienced by vulnerable people as a risk of no longer receiving attention and medical help if they express the wish to continue their life until its end.

For some members of the Committee, who have expressed their viewpoint in a contribution which follows the text adopted by the majority of CCNE, the borderline between “allowing to die” and “causing to die” has already, in effect, been abolished; the 2002 laws on patients’ rights and the 2005 ones on the end of life — since they recognise the right for a person to ask the doctor to cease vital treatment or nutrition and hydration — have already recognised the right for doctors to “cause to die” or help people who so request, to “bring their life to an end”. For these members, the question that now arises is why, in these circumstances, certain forms of “requests for help to put an end to life” can be allowed and other forms cannot be.

It is hardly surprising that members of CCNE have not arrived at a unanimous opinion on this subject since these issues are so complex that our predecessors wrote in Opinion N°63: "...the dilemma itself raises ethical issues ; ethics are born and thrive less through categorical certainties than through tension and refusals to settle once and for all questions which are recurrent and irksome and thereby express one of the fundamental aspects of the human condition".

Opinion N°121 represents a juncture in the Committee's thinking, that was finalised in its present state due to the constraints of time connected to the renewal of a portion of its members every two years, i.e. on June 15th. But CCNE as a whole considers that the subject of life's end is not settled once and for all and deserves further consideration in the form of public debate.

Since the President of the Republic mentioned in the referral the introduction of draft legislation on these matters in the near future, this public debate should include the convening of Estates General of "conferences of citizens chosen to represent the diversity of society," as set out in the law on bioethics."

CCNE will be continuing to reflect on matters concerning the end of life and will report after the public debate which it is proposing.

June 30th, 2013

Jean Claude Ameisen
President of CCNE

National Consultative Ethics Committee for Health and Life Sciences

Opinion N° 121
The End of Life, Personal Autonomy, the Will to Die

Members of the Working Group:

Régis Aubry (rapporteur)
Michaël Azoulay
François Beaufils
Ali Benmakhlouf
Alain Claeys
André Comte-Sponville
Anne-Marie Dickelé
Frédérique Dreifuss-Netter
Jean-Pierre Kahane
Xavier Lacroix
Claire Legras (rapporteur)
Claude Matuchansky
Francis Puech
Louis Schweitzer
Jean-Louis Vildé
Bertrand Weil

Personalities heard:

Jean Leonetti, *Former Government Minister*
Didier Sicard, *Chairman of the End of Life presidential consultation Group for France (2012), Honorary President of CCNE*
Yves Kagan, M.D., *internist, gerontologist, Fondation gériatrique de Rothschild, Paris*

The End of Life, Personal Autonomy, the Will to Die

Following submission of the report by the end of life presidential consultation Group for France[1], the President of the French Republic referred three questions on the expression of individual autonomy concerning the end of life to the National Consultative Ethics Committee for Health and Life Sciences: *"How and in what circumstances should advance directives expressed by persons in good health or when a serious medical condition involving the end of their life is made known to them, be recorded and applied? According to what procedures and strict conditions should conscious and autonomous patients suffering from a serious and incurable disease, be authorised to obtain support and assistance in their decision to put an end to their own life? How can the final moments of patients whose treatment has been discontinued following a decision taken at their own request or that of their family or by health care providers, be made more dignified?"*

In the past, the Committee had already considered the issues of care at the end of life and of euthanasia.

In its first and brief Opinion on the subject[2], in 1991, CCNE went no further than the formulation of several fundamental principles on the basis of which it expressed disapproval of legislation or regulations legitimising the act of taking away the life of a patient. In 1998[3], it called for public and serene discussion on the problem of care at the end of life, including in particular the subject of euthanasia and insisted on the importance of collective reflection on the subject of the circumstances prior to death.

In 2000, it reflected on the subject in more depth[4]. Noting that the question of euthanasia as such cannot be isolated from the broader context of dying today in a world which is profoundly influenced by medical technicality and its obvious advantages, but also its limitations, it recommended the resolute implementation of a policy of palliative care and rejected excessive and futile therapy. While it 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,

---

[1] « Penser solidairement la fin de vie », Commission de réflexion sur la fin de vie en France, La Documentation française, December 2012. ("Solidarity in France at the end of life". Report by the presidential consultation Group for France on the end of life.)

[2] Opinion n°26 of June 24th, 1991 concerning a draft resolution on assistance to the dying, adopted on 25th April 1991 by the Commission for the Environment, Public Health and Consumer Protection of the European Parliament.

[3] Opinion n°58, Informed consent of and information to persons accepting care or research procedures

[4] Opinion n° 63, January 27th 2000, "End of life, ending life, euthanasia".

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.

As regards the current Opinion, CCNE of course builds on its previous reflections which also considered the issues of neonatal resuscitation, treatment refusal and ethical issues in connection with the development and funding of palliative care[5]. Be it in the present day or in the past, a request for assistance in dying raises conflicts in outlooks and moral values which can only be resolved with the greatest of difficulty. However, thirteen years later, the issue is set in a comprehensively revised legislative framework.

Drawing on the strength of a large number of recent studies and reports in various countries and well aware of the extreme singularity of each individual end of life, the Committee thought fit to begin with a consideration of the origins of the current debate on the issue of the wish to die to understand why it seems to be topical and critical, but also to measure the scope of the changes it conveys. The Committee then examined the theoretical and practical advances brought about by recently adopted laws in France on patients’ rights and the rights of the dying to support. Finally, it considered possible further developments in law and attempted to throw some light on the questions arising in the event of legalisation of assisted suicide.

---

[5] Opinion n° 65 of September 14th, 2000, “Ethical considerations regarding neonatal resuscitation”; Opinion n° 87, April 14, 2005, “Treatment refusal and personal autonomy”; Opinion n°108 of November 12th, 2009 on “Ethical issues in connection with the development and funding of palliative care.

Part One
Origins of the current debate on voluntary death

I- A context marked by three salient points

The issue of being allowed to end a life arose in a context marked by three salient developments: medical and sociological changes, how the practice of medicine relates to life, the decision by certain countries to tolerate or legalise euthanasia or assisted suicide.

I--1- Medical and sociological changes.

• Increasing longevity and the consequent ageing of the population[6] addresses the health care system and more generally, our society at large, with some crucial problems: how do we cope with the loss of independence and autonomy of very old people, without overtaxing the strength of their loved ones, but also without letting solicitude and protective feelings restrict the freedom of those concerned? How, and how far should we go in caring for and assisting particularly vulnerable sick or disabled people, suffering from clinically complex and poly-pathological conditions? How do we cope with the growing numbers of people suffering from neurodegenerative diseases?

Another consequence — long disregarded — of technical and scientific clinical advances is the possibility of extended periods of time living with a disease for which there is no cure. Giving, as it does, more attention to chronic diseases, modern medical practice often results in longer life expectancy, but at the cost of extreme dependence on constant health care, sometimes accompanied by a huge degree of discomfort or pain.

Major medical progress, for example through intensive care, also has a downside when it leads to inextricable situations. What should be done when survival comes at the cost of very severe motor, sensory and cognitive consequences?

• These extreme situations, as well as the circumstances surrounding people who are either demented or totally dependent, are sometimes described or experienced as a kind of social or "incomplete" death, at the risk of losing sight of the individual and collective advances they represent.

And yet, life expectancy without infirmity grows at a faster rate than life expectancy itself; since the 1970s, the average number of months of dependence per person has dropped from 12 to 9[7]. Life can be lived to the full for longer, even though the *tempo* of life of the

---

[6] In the space of fifty years, the number of people aged over 85 years has grown from 200,000 to 1.4 million.

[7] Cf Jean de Kervasdoué, « *Les vieux et l'argent : vrais problèmes et lieux communs* », (Old people and money: real problems and truisms) *in* Médecine et vieillesse, seven public debates leading to invalidating some popular misconceptions. September 2012, publication by the Clinical Ethics Centre of the Cochin Hospital.

elderly is obviously not that of younger people. Life's end is simply life at a different rhythm, not just the last lap.

But such fears are also fuelled by the relegation that seems to be the fate of so many people nearing the end of their lives, in particular those who are very isolated or who end their days residing in institutions which are sometimes seen by people in good health as little more than a dreaded place to die in. And yet, this impression does not lead our society to grant more importance and provide more for the assistance of the very old or those that age or infirmity have deprived of much of their resources.

• Those close to the sick or the very old already have, and will have in the future to face sometimes very lengthy and even exhausting stretches of time caring for them, despite the already excessive burden of the tasks and stresses of daily life and not always having access to adequate caring facilities and services at home. Often, the next of kin no longer can, or no longer wish, to take on a burden which used to be more confined to the family circle in times when much of life was very different. The increasing onus of such situations — reflect for instance on the plight of those caring for someone with Alzheimer's disease or some other cognitive disorder — the fact that children almost never live under their parent's roof any more, that both spouses usually have a job: everything combines to make the so-called "natural" carers' task more difficult.

The concept of a "right to a respite" for carers must be made a reality in a more satisfactory way than is the case at present, for instance by the creation of structures able to provide relief for the family circle. Furthermore, the welfare of the elderly deserves more understanding: they do not just need health care; they need to be looked after as nearly as possible according to their own aspirations, they need others to interact with them apart from the purely medical aspect of caring.

• Sociological change in the relation to death.

Certain critical episodes such as the heat wave in the summer of 2003 revealed both the extreme isolation of some elderly people and the damaged image of them conveyed by the media's crude assumptions: ruined bodies, faces long past the "reference appearance" of individuals in their prime.

Furthermore, management of the end of life and of death has become institutional and professional. In France, the norm is to die in a hospital or a retirement home: according to the data collected by the *Observatoire national de la fin de vie*[8], (National Observatory for the end of life), today 58% of French nationals die in hospitals, 27% in their homes and 11% in retirement homes or some similar establishment. In the same way as prisons are no longer situated in city centres, people no longer die at home, sheltered accommodation

---

[8] End of life: state of affairs. 2011 report of the O*bservatoire national de la fin de vie*, Paris, La Documentation française, 2012.

housing dependent elderly people or the disabled are frequently situated outside towns, sometimes quite far away from them, so that death happens at a distance from our daily lives.
As a result of these changes, there is a progressive withdrawal of death from the community’s culture, with the rituals that used to surround this event and made it both visible and more acceptable, either disappearing entirely or undergoing profound change and a general move in the direction of total control, including that of life and of death.

In this context, many people confronted with frequently novel situations brought about by medical progress and its complement of new reasons for being fearful, ask for euthanasia and assisted suicide to become legal.

These developments may be related to those of biases on the definition of a good way to die: once, it was dying conscious, with loved ones present, ready to face up to one’s last moments on earth; now, it is dying without pain, with faculties intact, if possible suddenly and without being aware of it. Today, our relationship to death is very much determined by the way we now live, by our relationship to body and mind.

The experience of death has therefore changed considerably: while death has become institutionalised, and its attendance has become more professional, the modern relationship to death has become private and individual, hovering between putting death at a distance and a wish to keep it under control, to make death subject to individual choice.

I-2- The amount of space that health care occupies in our interrelations with life contributes to the importance now attributed to this issue

The wish to be in control of the way they die expressed by a number of people has two sources: it is the result of the hopes that they pin on health care and the recognition of a new role for patients in the way they think about their health.

Medical expansion has a mythical presence: health carers and patients often share a common faith in medicine; they see the struggle against disease as battles, that are sometimes fought to the point of becoming a form of unreasonable obstinacy. The unrelenting pursuit of treatment must not, of course, be caricatured because it is entirely consubstantial with medical vocation and the possibility of medical progress. Nor should we forget that before the development of palliative care, initiated in Great Britain in the 1970s, modern medicine was largely inclined to ignore pain and the solitude of those of its patients it was unable to “save”.

In this context, where much was expected of health care providers and there was growing awareness of unacceptable situations in which people at the end of their lives were left unassisted by medicine, doctors themselves were given a central role to play in decisions concerning life or death, sometimes to the detriment of personal autonomy even though recent legislation, in 2002 and later in 2005, has attenuated that role.

Our relationship with medicine is also witness to how difficult it is for each of us to live with our personal assortment of threats and fears — pain, age, sickness, death — and perceive our mortality as a form of freedom and not solely as a burden. The quest for health can be the source of morbidity when it stands in the way of confronting our finitude and that of other mortals. Disease is always seen as something that needs to be fought; sometimes it needs to be accepted.

Although faith in medicine and in doctors may have evolved in recent decades towards a demand that medicine should learn to adapt to the will of those it addresses, no doubt as a result in the last fifteen years or so of the claim to patients' rights. The sick are now very much involved in the management of their health problems — sometimes due to social pressures to take proper care of one's health so as to age "well" — and all the more so since they now have easy access to a great deal of information and their rights have been recognised by law makers seeking to reinforce their autonomy and give more weight to the expression of their wishes.

The current of opinion in favour of the right to "choose one's own death" is in part the result of these development as it is also of medical boundaries to the possibility of attending to the sufferings of those whose lives are ending. The dividing line is often very thin between demanding medical treatment at any cost and its violent rejection and denunciation of burdensome excessive medicalization at the end of life. In this way, our society which is inclined to refuse death and expect answers from medical technology, may at the same time wish to dismiss medicine when it seems excessively invasive. Since my doctor must tend to my sufferings without losing sight of what, I the patient want, then in the final analysis it is again I the patient who is the legitimate prescriber, when beyond treatment as such, we are in fact organising and managing the end of my own life.

These developments fuel the legislator's determination to recognise people's right to choose the circumstances and the time of their death. This determination is no stranger to western culture: mastering one's life until it comes to an end and deciding how and when that end must come is thought to be more honourable and less unacceptable than to wait passively. It would also testify to the full awareness of our transience. The issue of where suicide fits in to this attitude emerges at this point and, in a context where people are confronted throughout their lives with demands for good performance, it is sometimes presented as the ultimate expression of individual determination and freedom. However, the request to authorise assistance in dying comes also in another guise: it corresponds on the part of many people to the wish to avoid pain and situations of indignity.

I-3- In certain countries, euthanasia or assisted suicide are legal or tolerated.

In recent years, several countries — Switzerland, the Benelux countries and three American states (Oregon, Washington and Montana) — have elected to tolerate or legalise euthanasia or assisted suicide. Others, Canada and the United Kingdom for instance, are currently reflecting on making changes to their existing legislation (Cf. Annex 1). This current in favour of liberalising assistance in dying, although undeniable, is however still very much in the minority world wide.

The first laws on the subject go back about twenty years. Furthermore, the cultural context was in each case rather exceptional. Oregon, the first state to move in that direction, legalised assisted suicide in 1997. The overriding reason for it to be accepted is because it responds to a very strong cultural demand for autonomy. Conversely, euthanasia is still prohibited. The idea of dying at the hand of another person is profoundly shocking to the prevailing mind set since it is too far from the usual standards of autonomy. For that matter, this is one of the remarkable characteristics of practices in this American state: the wish to retain autonomy is higher on the list of reasons motivating the decision to choose assisted suicide than the intolerable nature of the suffering which must be borne, the latter being a more frequent motive for decision on the old continent.[9]

The second oldest law, in the Netherlands, also saw the light of day in a particular cultural context: it in fact did no more than give formal structure to a thirty-year old practice. In the early 1970s, Dutch society had already begun to practise euthanasia. In 1984, the Royal Medical Association drafted the precise details which today are part of the law adopted in 2001. Euthanasia, therefore, was gradually introduced into Dutch culture and the law simply gave formal shape to an already widespread practice, thereby causing no fracture in collective thinking. Euthanasia now figures significantly in Dutch statistics, as can be seen by the figures reported for causes of death.[10]

Furthermore, euthanasia has sporadically come to the notice of public opinion in this country through the media prominence given to cases which were very different in nature but converged to fuel the claims for a right to die and a right to be assisted in dying.

II- The scope for reflection on the right to active assistance in dying

The issues raised by the debate on voluntarily hastening death are very far reaching. Boundaries need to be carefully defined.

II-1- The debate is not limited to the extreme end of life

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.

---

[9] The Sicard report, p.76

[10] 2,8% of deaths in the Netherlands are by euthanasia (Sicard report, p.74)

Those in favour of assisted suicide or euthanasia are expressing claims which differ widely in their scope: some are claiming active assistance in dying to be limited to people who are suffering from incurable diseases and who are asking for that assistance because they wish to spare, either themselves or their loved ones, an end of life that they find unacceptable; for others, it is a form of the “right of control over one’s own body”. But these claims converge in their identical sensitivity to the issue of the quality of life, to the concept of life that is no longer worth living, to the will to retain a certain level of control over one’s physical and intellectual status.

The request for assisted suicide is possibly less particular to situations where death seems imminent than to the period of time that comes before. The “real” end of life, as plentifully documented, is a time of uncertainty, a phase during which decision is often sluggish and the will is hesitant. This factual situation is in conflict with the liberal model based on the right to choose and the supremacy of individual right of decision.

Other circumstances than the extreme end of life enter into the discussion, in particular those of people who suffer from serious chronic conditions or who are gravely disabled, or those of who must face up to the prospect of impending degradation of their mental faculties when they have been diagnosed with a neurodegenerative disease. The issue also arises here of the acceptance by our society of differences, deviations from a norm, ultimate otherness and therefore to that of the meaning of certain forms of continuing life, and this is an issue which may well inhabit patients themselves when they no longer have a sense of their rightful place. Certain medical practices are also concerned, resuscitation in particular, which cannot elude the issue of what limits can be set, but which must also consider the specificity of each particular clinical and human condition.

As a background to any reflection on shortening lives, there is also the economic context in which individual and collective decisions on health are made. Some people wonder whether we should do our utmost to prolong life into extreme old age if we are not able to provide the elderly with “acceptable” living conditions although they are a burden on collective resources. Those concerned themselves frequently tend to accept this line of thought and to express concern over the human and financial burden they impose on loved ones or society as a whole.

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. The effort of solidarity which is required to alleviate this factual situation is often represented as being beyond realistic expectations. CCNE, however, feels there is a need to inject clarity and truth into this debate. Frequently, the figures quoted are erroneous as to the cost of caring for old and vulnerable people. In this respect, an Opinion adopted by the *Haut conseil pour l’avenir de l’assurance maladie*, « *Vieillissement, longévité et assurance maladie* », (Higher Council for the Future of Sickness Insurance) on April 22nd, 2010, on Ageing, Longevity and Sickness Insurance, refutes a number of popular misconceptions and demonstrates that better management of loss of autonomy — specific needs and treatment — could go a long way towards limiting sickness insurance expenditure for dependent people.

II-2- Physical pain is not the sole concern

Still only too frequently the demand for legalising assistance in suicide or euthanasia is related to the physical pain which dominates the consciousness of those who are dying or whose quality of life has deteriorated beyond relief. It is sometimes based on the fact that life is no longer perceived as anything but unrelenting pain. Such a demand raises at least two questions: exactly what are we referring to and how do we respond to such suffering?

Pain is not easy to define for an outside observer: it can be a symptom of an encroachment on the integrity of the body, which can be objectivised and evaluated, or it can be without rational explanation but real nevertheless since it is pain that someone feels, or it can be the expression of moral, social or existential suffering.

Experts agree on the fact that all pain can now be attenuated by a whole range of remedies which can extend to using anaesthetic techniques or surgical pain relief. When suffering stems from depression, in the great majority of cases there are medical solutions to the problem, although it must be said that only too often, they are not adequately dealt with. Therefore, neither physical pain nor depression should be the reason for the demands to hasten death if good quality palliative care were available throughout the country: this is a point on which our fellow citizens very obviously need convincing reassurance.

For some of us, choosing our own time of death seems to be the only valid response to suffering of a more existential nature. Such distress is obviously not the sole prerogative of the very old in the terminal phase of a serious disease. It is a human reality which has its origins in our relation to others, to oneself, to life, to one's own life.

Certain people want assistance so that they can die serenely and no longer experience this existential suffering. At which point the daunting question of the scope of this response arises: should this assistance be given only to those whose death is very imminent?

This question leads, as an absolute priority, to more thought being given to the efforts which must be made in order to ensure that relief can be forthcoming more efficiently. For instance, all requests for assisted suicide or euthanasia must be explored to determine their motive. When the case is accessible to palliative care and counselling, they must be provided, while remembering that palliative care does not simply aim to assist the dying once curative treatment can no longer be expected to help; palliative and curative care must be fully integrated in the effort to alleviate suffering; they are never mutually exclusive.

The question arises then of what needs to be done when a request for assisted suicide or euthanasia does not seem to be caused by anything accessible to treatment or palliative care, and seems to be related to distress of an existential nature, to a wish for death or a rejection of the obligation to end one's life with no other option than sickness, in the clutches of an increasingly medical care environment.

II-3- Response cannot be purely medical

The limitations and deficiencies of end-of-life care are clearly expressed in a large number of testimonies heard by the Sicard Commission and in many studies by Edouard Ferrand[11],, inter alia, emphasising the major difficulty of access to palliative care. They convey an assortment of quasi-obsessive grievances related to a lack of attentiveness on the part of doctors, to condemnation of the "nothing but curative" attitude to care, even to defective medical management, to serious practical failures in the implementation of palliative care, to the impossibility for families to cope with the multiple clinical teams they have to deal with and to communication breakdowns between clinical teams among themselves and in dealing with families. These testimonies also reveal dissatisfaction, the meaning of which is not entirely clear, on the length of time and the way in which the final agony takes place. They are also indicative of the unease with which the medical professions discharge the task of coping with death given to them by society.

It is a fact that the practical experience of a large proportion of the dying and their loved ones reflects an extremely negative perception of the assistance provided by health care providers. The study, *Mort à l'hôpital* (Death in hospital) in 200 French hospitals, published in 2008 by Edouard Ferrand et coll. [12], 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. Much still remains to be done, in all medical services throughout the country to make sure that members of the medical professions are ready to really hear their patients and to be fully attentive to their pain and suffering, failing which medical practice will lose its humanity. Certain situations, lacking in respect and dignity, as reported by the Sicard mission must be remedied as an absolute priority.

Concurrently, the Committee wishes to underline the need to protect the specificity of medicine. The dominant part which it is taking or which it is made to take in the support of those who are dying or those who are highly vulnerable is not entirely self-evident.

---

[11] See, for example: Ferrand E, *et coll.* Evolution of requests to hasten death among patients managed by palliative care teams in France: a multicentre cross-sectional survey. *European Journal of Cancer*, 2012, 368-76.

[12] Ferrand E, et coll. Circumstances of Death in Hospitalized Patients and Nurses' Perceptions: French Multicenter Mort-a-l'Hopital Survey. Archives of Internal Medicine, 2008,168 :867-75

The global management of the very aged, of those who are entering the final phases of their disease, of the disabled, the support that must be given to them over a length of time, are not solely the concern of the medical professions, nor are they entirely within the purview of public action. To support these people is a manner of expressing both individual and social solidarity by an acceptance of their singularity and respect for their individual liberty. The attention they are given cannot be exclusively in the hands of the medical world. To be attentive means to be ready to hear their needs and their diffident aspirations to a degree of autonomy. It means sustained presence and concern. The object of that attention — beyond its testimony to our shared humanity — is to ease the life of those whose life is ending and facilitate the giving of care to satisfy the needs both of the person concerned and of the community. It aims to retain singularity within the acceptance of the whole.

III- The demand for euthanasia and assisted suicide to be made legal involves principles whose scope and compatibility are disputed

III-1- Dying with dignity?

Through surveys responding to frequently overly simplified questions — and it is worth noting that they almost never address people who are "at the end of their lives" — and an overly sketchy description of the arguments put forward in the debate by the media or activists, has emerged a kind of axiom to the effect that to authorise euthanasia would meet the wish to guarantee that, whatever the circumstances, everyone could "die with dignity". And yet, the principle of dignity is also put forward by those who oppose euthanasia and assisted suicide.

In fact, as the Committee has already had occasion to point out, there are two widely divergent interpretations of this expression.

- The supporters of choosing your own death refer to a subjective or personal concept of dignity: dignity is in this case held to be the way in which individuals view themselves in relation to the values they hold dear, their aspirations, their bonding with loved ones, all of which may therefore differ considerably from one person to another and may change when old age or ill health become more intrusive, depending on the image which is reflected by others. In this case, dignity corresponds to a normative dimension (to a way of existing, to a satisfactory self-image which is presented to oneself or to the outside world, or to being 'presentable' in the light of standards which vary enormously in different times or places, to a concept of decency). Dignity is also the stoic virtue of being able to control ourselves and spare others the sight of our discomfort.

In this acceptance of the term, the right to die with dignity means the right that everyone should have of deciding on the acceptable limits of deterioration of their autonomy and quality of life. This demand must above all be mindful of the objectively recognised indignities which are all too often, as we have remarked above, the lot of many disabled or dependent people. For others, the demand for a the "right to die with dignity" is more an affirmation of a claim for personal autonomy; it is in fact the expression of individual liberties and the possibility of opposing one's will when it is disputed.

- In another concept, which is that which modern tradition situates in the foundations for human rights, dignity has an ontological meaning and is an intrinsic quality of human beings: humanity itself is dignity, so that it can not depend on someone's physical or psychological circumstances. Dignity is understood in this instance as being that which expresses the fact of each person's belonging to human kind, as the deep-seated attribute of equality, a moral reality which characterises the existence of human beings and qualifies them for the recognition of certain rights.

The problem is not so much ranking these concepts of dignity, as of measuring what each of them intends to convey in the debate on choosing when to die. The differences between the two concepts are very significant at this level.

In the absolute, dignity is inalienable and not quantifiable. Those who are mentally or physically impaired do not lose their dignity. In that respect, all men are not only born equal, they also die "equal in rights and dignity". To state that assisted suicide or euthanasia can bring about, in certain circumstances, a "more" dignified death is meaningless.

We are all able, however, to link our sense of dignity to the possibility of comprehending, thinking, making decisions or to a quality of life. When a person considers his or her life is no longer worth living — this being an entirely natural and easily understood sentiment in a certain number of situations, but it is also tragic in that our sense of our own dignity is related to how others see us — should this person be given the option of dying prematurely?

The Committee emphasises that the concepts of dignity express very different meanings of the word and, *a priori,* are not mutually exclusive. It also emphasises that what the community and the authorities should be fighting against are circumstances of clearly recognised indignity: lack of systematic access to palliative care, isolation of certain people at the end of their lives, poor living conditions and defective support for the sick and the disabled so that it becomes impossible for them to end their lives in their own home. The ultimate in indignity would be to consider that people have lost their dignity, have become unworthy, because they are sick, different, alone, inactive, costly... But the transition from dignity-decency to dignity-freedom which is operated by some currents of opinion does some damage to the concept of dignity as a guarantee of the equality of value of all human beings, regardless of their circumstances. To consider assistance in suicide or a lethal injection by a doctor as a possible response to a personal sense of indignity or to the fear of losing one's dignity, meaning losing the full command of faculties or even of the capacity to be sufficiently happy and autonomous, may lead to inducing in vulnerable people a feeling of “indignity”. And this fear may also be expressed by the option that is now open to the sick to refuse any life-saving treatment and thus choose to cut short their lives.

There is clearly a degree of tension between the need to give a personal sense of dignity its rightful place and the risk of allowing that dignity to be confused with the inalienable dignity which family and care providers must respect in those who are extremely vulnerable, when they are providing them with support, solace and affection. As for the community, it must strive to avoid marginalising any of those in its midst who are vulnerable because of their health or because they have difficulty, or are even incapable, of finding a rightful place for themselves within society or among those close to them.

Since prevailing culture proclaims that the value of human beings resides in the capacity to act, to be productive and profitable, as well as to the capacity to flourish, it is essential never to lose sight of the fact that dignity is also the inalterable value which can, without destroying it, enter into conflict with individual liberty.

III-2-The demand for the legalisation of euthanasia or assisted suicide lays claim to a vision of liberty which questions the relationship between individual resolve and the tenor of the law.

The emergence of patients’ rights, with its legal consecration, has contributed to taking ethics out of purely medical confines. It has also encouraged citizens to assert their individual demands whenever their health or their body, or that of their loved ones, are in question.

These changes have come about at a time when there is a deep-seated modification in the relationship between the individual and the collective; they are also now one of the major drivers of this modification. As in other matters, there is a need to define how far individual preferences can inspire, on the most intimate level, new rights drawing on the assets of national solidarity.

Claiming the right to get help in ending one’s own life impinges on the equilibrium between individual liberties and concern for the common good so that it may be the subject of a democratic consensus.

Liberty is of course the value which draws together the members of our society. Not only is it of primary importance for the individual, it is also the basis for the life of the community. The principle of liberty implies that all those who are of legal age and competent can make their own decisions about what concerns them. They should not have to comply with some external decision regarding their behaviour for the sole reason that it would be objectively in their best interest. Each individual is sole judge of his or her interest, including the decision to disregard that individual’s best interest. Individual liberty would be devoid of meaning if the irrational nature of behaviour were to be a reason for it becoming illegal.

It is true that this logic is not absolute: compulsory wearing of seat belts and strict rules governing live organ donation are two examples among many others of a limitation.

Nonetheless, it is now accepted that the right of a person to receive treatment cannot be read as an obligation to submit to treatment[13]. In the past, this obligation may have been viewed as being mainly an obligation to the community, an obligation on the physician, but also on the patient. The community had, at the time, rights over the health of its members, rights of which physicians were the custodians.

The postulation of authorising assistance to put an end to one's own life, or even of a right to euthanasia goes much further; it opposes a concept of autonomy understood as individual sovereignty and its implications, both personal and social.

Euthanasia and assisted suicide are not only sought as a solution to the feeling of indignity, suffering or extreme existential lassitude which affects certain people. They are also a different or more extreme claim on principle by some sectors of opinion aspiring to have autonomy become the primary reference so as to disempower nature or a third party (particularly the doctor) from deciding when life is to end.

A certain number of points do not apparently spark debate. First of all, liberty means of course the possibility for each individual to make decisions according to his or her own personal concept of what is right. The doctors must therefore respect the liberty, the beliefs, the decisions and the wishes of their patients, even if in the doctor's view they are contrary to common sense or to the patient's interests (take unreasonable risks, take drugs, refuse blood transfusion or essential treatment) and even if, in so doing, the doctor clearly incurs a moral liability and compromises his dedication to the values forming the basis of his vocation.

Secondly, if caution is to prevail in situations involving seriously ill people or those undergoing several forms of severe discomfort in their extreme old age, particular attention must be paid on two counts: the difficulty of evaluating their independence of judgment which is always subjective to a large degree; and the possibility that those concerned are making a decision under influence exercised by a third party. Nevertheless, no one is entitled to presume that the free will of sick or elderly people is absent or too compromised to be a fair expression of their wishes.

And yet, thinking along other lines, to link the exercise of freedom to the right to choose when and how to die, and to be assisted in this, is not an easy option, for at least three different reasons.

---

[13] CCNE's Opinion n° 87 of April 14th 2005, "Treatment Refusal and Personal Autonomy", includes in Annex an historical analysis of the rights and autonomy of individuals explaining where and why this has not always been the case.

First of all, there is the fact that in the name of freedom, I am encroaching on the freedom of others if I ask them to help me in a way which they may consider to be at variance with what is owed to fraternity or which they find to be cause for dismay[14].

Then there is the fact that it is never possible to be certain that the wish of the person concerned to exercise that freedom is in fact a total and persistent commitment. Those who support or care for patients with severe diseases or who are in their extreme old age are witness to the great variability of requests for anticipated death. The demand for a death of one's choosing is therefore a great challenge to our conception of liberty and its connection to the common good.

Finally, liberty interpreted as the sovereignty of free will is, according to some thinkers, the fruit of a defective concept, in that it is forgetful of the relational dimension of all beings. They emphasise that the heart of the matter when life ends is not solely concerned with aspirations, rights, or even individual ordeals: it is rather the meaning of the bond, of the interpersonal relationships and also of the social bond. The end of life or a period of ill health are, for many people, a time when the bond with others is particularly important. It may be a time of pain, but it is also a time for emotion, an essential time for passing, for handing on words or deeds or family lore... A time for attempting to reflect on the human condition, that of solitary individuals belonging wholly to a social group.

---

[14] This is already the case for withholding treatment, food or fluids, but is also true for elective or therapeutic termination of pregnancy, the destruction of spare embryos, preimplantation diagnosis, etc. So the problem is not limited to suicide, even though it may be exacerbated in the case of suicide.

Second Part

Existing law and its limitations as regards the end of life: improvements to legislation and public policies are needed

I- In the last fifteen years, legislators have particularly focused on the subject of the end of life

For a long time, the law's treatment of the subject of life's end was mainly negative; the prohibition of homicide was complemented by clauses in the code of professional ethics requiring physicians to "*abstain from any form of unreasonable obstinacy*". In the last fifteen years or so, legislators have made a number of amendments to the law which do not fundamentally overturn the principles underlying the existing ethics and case law, but can be said to have had a very striking impact, even though the law's enforcement is regrettably patchy. The law dated March 4th, 2002, on patients' rights and the quality of the health care system, together with the April 22nd, 2005 law also on patients' rights and the end of life, in fact represent major steps towards the specification of the rights of people suffering from ill health and the consideration of the complex issues prevailing at the end of life. In depth debate presided over the drafting of this legislation; the statements of health care professionals testify to the significant effect the law has had, in particular in the hospital environment, towards a more respectful approach to people at the end of their lives. The April 22nd 2005 law, called the Leonetti Law, in particular served as a signal leading a certain number of hospital department to reconsider their practices in the light of the principles they formally declared — or reaffirmed — to be those they upheld.

This changed perspective, however, is still not clearly perceived as such by the public and is far from being fully effective in the medical environment.

I-1- *Patients are now entitled to a large number of rights.*

The June 9th 1999 law on palliative care guaranteed the right of any sick person in need of it to have access to palliative care; it is now a right which patients or their relatives can claim for in court. Furthermore, the March 4th 2002 law on patients' rights and the quality of health care gave all patients the right to free and informed decision on any subject connected to their health.
To patients' rights correspond doctors' duties.
In its present form, medical ethics impose three duties on doctors: alleviate suffering, shun any unreasonable therapeutic obstinacy, respect a patient's wishes. These duties have long been stated with absolute clarity in articles 36, 37 and 38 of the Code of Medical Ethics before being reaffirmed in the laws dated March 4th 2002 and April 22nd 2005.

The first of these duties, alleviate suffering, implies in particular the extension of the palliative care to which the discussion raised by the 2005 law gave undeniable impetus.

According to the latest version of legislation, the determination to alleviate pain and suffering authorises the use of techniques and products with the possible side or indirect effect of being conducive to death. In this instance, the law integrates under the name of the "principle of double effect" a doctrine which gave rise to considerable discussion: a risk is considered justifiable if the benefit of the action which produced it outweighs the secondary effects, if these secondary effects are not an end in themselves but are only the indirect and involuntary consequences of that action, even though they may be foreseeable and, finally, if there is no other way of caring for and alleviating the patient's sufferings.

The second of these duties, that of abstaining from "*any form of unreasonable therapeutic obstinacy*", was reiterated in the same terms as those of the Code of Medical Ethics. However, the 2005 law, introduced the possibility of withholding treatment if it seemed to be futile or disproportionate. While it would theoretically seem obvious, in practice this duty is complicated by the complexity of certain situations and because doctors, patients and loved ones are reluctant to cease trying. The difficulty can be related to the fact that there are two very different kinds of "futile or disproportionate" treatments which are often mistaken one for the other: on the one hand, those that medical practice has objectively dismissed as not indicated and, on the other, those that the patient considers to be futile, disproportionate or unreasonable. In the first case, this is a standard; in the second, this is the patient's perception and choice.

The April 22nd 2005 law went on to stipulate that artificial prolongation of life could be considered unreasonable, which is a clarification of the principle. An important point should be noted: in its very definition, the prohibition of unreasonable obstinacy authorises or even imposes if necessary, acts and measures (for instance disconnecting a device) which, in themselves contribute directly to the person's death. This is well beyond what is implied by the sole aspiration to alleviate suffering.

The law has also modified the balance which the Code of Medical Ethics expressed, by giving doctors the possibility of deciding on their own initiative to stop or limit treatment for patients who were "*unable to express their wishes*": such a decision has to be taken only after a collective process of discussion has taken place, taking into consideration "*the wishes that the patient had already expressed, in particular in an advance directive if there is one, the opinion of a trusted proxy the patient had designated, as well as those of family or, in the absence of family, a person close to the patient*".

The third duty was the one most formally reaffirmed in both the 2002 and the 2005 laws: individuals, together with health care professionals, "*make decisions concerning their health*". The doctor must respect the "*determination to refuse any form of treatment*"; if such a determination puts the patient's life in danger, the doctor must attempt to persuade the patient to accept treatment and at least ensure "*quality at the end of life*". The 2005 law reiterates that it is the person concerned who "*decides to limit or stop any form of treatment*" that he or she considers to be unreasonable and who therefore may be voluntarily entering a path leading to the end of life.

Just like the preceding article, this is very important in ethical terms. As the previous article does, 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 take extreme steps and actions, such as switching off a device, which in themselves are likely to put an end to the patient's life.

Finally, the 2002 and 2005 laws make a further important contribution to the protective measures and procedures to be followed for patients who are not able to express their wishes: the doctor must follow a collegial procedure, enquire after and take into account any advance directives and request the opinion of the patient's proxy (if such a person has been designated) or, failing the existence of a designated proxy, consult family and loved ones. The doctor must limit or cease treatment if it is considered to be "*futile, disproportionate or having no other effect that keeping the patient alive artificially*". The reasoned decision must be entered into the patient's case file.

It can therefore be said that since the publication of CCNE's Opinion N° 63, the rights of patients at the end of their lives have been considerably extended.

While patients may not claim the right to treatment unless it is scientifically pertinent, they are entitled to refuse pertinent treatment even if that decision will hasten the time of their death. They may write advance directives which remain valid for three years and which can be modified at any time to take care of the possibility that they become incapable of expressing their wishes. Doctors are obliged to enquire whether such directives exist and take account of them if their patients are unable to express their wishes. But these are directives in name only: they are not binding and at this point, there are no special rules regarding the way in which they are recorded and kept safely.

Finally, anyone attaining the legal age of majority can designate someone they trust — relative, loved one or attendant physician — who will be consulted if they are themselves in no fit state to express their wishes or comprehend what is being said to them on the subject. The opinion of the proxy takes precedence over any other non medical opinion, except for what is stated in the advance directives.

This set of legal provisions is still not entirely known to the public at large and insufficiently known even to practitioners. And yet, it has led to similar steps being taken in other countries and it is undeniably very coherent. In particular, the law dated April 22nd 2005, was adopted unanimously by Parliament and has inspired similar legislation in a number of countries.

I-2- 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.

Do a few extra hours or a few extra days in a psychological state akin to coma make any sense? It is true that in the first case, that of ceasing futile treatment, the primary intention is to alleviate pain or suffering, while in the second case, the intention is to extinguish a life. In point of fact, withdrawing vital treatment or administering a treatment whose side effects may contribute to hastening the time of death has the same consequences as administering a lethal product. The important issue in this case is not so much questioning intentions — actual intentions being difficult to appreciate — but rather to posit the demand for an ending to a life with a minimum of discomfort and with as much respect as is possible for the person concerned and his or her loved ones. Between these two circumstances, the time element differs with death advancing more slowly and *a priori* more peacefully when withdrawing treatments that seem to be futile — providing of course that palliative treatment and the support of loved ones contribute to those merciful intentions — than in the case of assisted suicide or euthanasia.

However, the question now arises of whether patients are entitled to claim treatments that may hasten their death, the decision to be taken by the doctor, or even treatments inducing death.

As legislation translates into practice, the emphasis seems to be on adopting the most consensual path: alleviating suffering even at the risk of hastening death and loss of consciousness. But this should not lead us into losing sight of the fact that to "allow to die" according to the Leonetti law, is not simply allowing nature to take its course. The concept is complex, with boundaries that tend to get blurred, involving a difficult task, requiring labour-intensive support and multiple decisions to determine with as much precision as can be mustered what to withdraw or not withdraw, limit or not enter into, what to administer and its dosage.

Furthermore, while it is clear that the law now presented as finely balanced did bring about a reduction in the number of acts of euthanasia still practised today in a medical closed-doors environment, as many health carers have told us, it has also moved the boundaries of what is commonly held to be acceptable. Following the fluctuations of successive legislative developments, various practices have crossed a line: withdrawal of treatment at a patient's request, including, according to the Committee[15], withholding artificial nutrition and hydration[16], or the administration of powerful analgesic or sedative drugs, all of which may hasten the patient's death.

Although palliative care is essential, it would be illusory to believe that it can always respond effectively to suffering and that its presence suffices to eliminate every aspiration to voluntary death. Palliative care, therefore, does not remove the need for debate: it is intended to alleviate the difficulties and discomforts of the end of life, but it does not and cannot throw any light on the issue of whether advancing the time of death is a legitimate undertaking.

II- Making progress in understanding and enforcing the law: much remains to be done

As the law dated April 22nd 2005 is still largely misread[17], it was enacted too restrictively by members of the medical professions: although it in part is stating over again a number of well-established principles, in some hospital departments its impact is strong while it is hardly discernible in others or outside public hospitals, possibly because of the very deep-seated modifications in medical practices and in the relationship between doctors and patients that would be needed for it to be fully implemented.

The information given to patients and families, both as regards the pertinence of curative treatment and palliative support strategies becomes a crucial issue. It is, however, not an easy task to strike a happy medium between the duty of providing information which will be necessary for patients to be able to express their wishes and the duty to do so with tact and restraint, without despairing them with unpalatable truths. And yet, this is at the very heart of the process of free and informed consent which is one of the founding principles of modern medical ethics.

Stating and recording advance directives is no simple matter: both health carers and patients must face up to the possibility of the worst of all outcomes, of no possible cure and of a harrowing end-of-life experience.

---

[15] CCNE's Opinion N°87 "Treatment Refusal and Personal Autonomy", (2005).

[16] Unlike assistance with eating and drinking, considered to be part of basic care, artificial nutrition and hydration (by intravenous infusion or enteral tube) are treatments for which the patient's consent must be secured.

[17] At the time of the evaluation in 2008 of the law dated April 22nd 2005, as well as in the National Observatory's first report on end of life in 2012, and again when INED's study on medical decisions at the end of life was published.

Medical practitioners are not accustomed to collegial decision-making. They are generally trained to decide on their own.

CCNE notes, however, that 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.

While patients and their loved ones generally know little about the legal situation, this is even more true of people who have so far not had to cope with serious ill health and the end of life.

Most of those who demand that assisted suicide or euthanasia should be made legal base their claim on personal experience: frequently, these are people who have witnessed the death of a loved one suffering intolerable or prolonged physical or mental distress, isolation and failing physical functions. With this in mind, they reject the possibility of suffering a similar fate, either for themselves or for another person they care about. Palliative care was not provided, or was of poor quality. Fear of excessive medicalization at the end of life and the rejection of artificial and prolonged efforts to maintain vital functions fuel some of the stances regarding euthanasia, as CCNE had already emphasised in its Opinion N° 63 and again in Opinion N° 108 published on November 12th 2009 on ethical issues in connection with the development and the financing of palliative care.

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[18].

Most assuredly, palliative care has made great progress in France in the last fifteen years. But this has been possible mainly in hospitals and particularly in “acute” care departments. Considerable improvement is desperately needed in follow-up care and long-term care units, as well as in medico-social institutions, although a considerable amount of effort is being deployed in homes for elderly dependent patients.

---

[18] In hospitals, at the end of 2011 there were 117 palliative care departments, totalling 1314 beds; 5057 beds were identified as available for palliative care (with reinforced staffing and special training in departments where the end of life is a distinct possibility) and 418 mobile palliative care units which are essential for the development of a palliative care culture to become more familiar to health carers who are confronted with difficult end-of-life circumstances, in health caring institutions but also in medico-social structures where a large number of deaths occur.

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[19].

III- Improvements are therefore really necessary

This Opinion will not be covering the question of training health carers and multi-disciplinary research on the end of life; on this point, it agrees with the recommendations made by the Sicard Commission, referred to in Annex 3. It also refers, on the subject of steps and reforms which are required to make it possible and to one's liking to die at home, to the National Observatory's 2012 report on the end of life "*Ending life at home".*

Three sets of improvements would seem to be appropriate: redefining the conditions for collective interdisciplinary debate; reformulate the purpose and value of advance directives; revaluate the practice of terminal phase sedation.

III-1- *Changing over from a collegial procedure to collective and interdisciplinary deliberation.*

Today's rules stipulate that the "collegial procedure" is to be restricted to the cases of patients "*whose condition prevents them from expressing their wishes*". It is true that the collegial procedure's scope has been extended following the November 2008 report on the evaluation of the law dated 22nd April 2005 covering patients' rights and end of life[20]: physicians must comply with the procedure if they are considering a decision to limit or withdraw "futile, disproportionate treatment, or that has no other purpose but to prolong artificially the life of the patient", but also once they have been shown the patient's advance directives, by anyone in possession of these documents, or if requested by the proxy or the family, or in the absence of the above, by loved ones.

CCNE considers that the collegial principle should be extended even further and more stringently for any decision involving the end of life. The way in which it is thought out and implemented, and also the circumstances in which it enters into play must be set out precisely.

---

[19] Ending life at home. National Observatory on the End of Life, 2012 Report, Paris, La Documentation Française, 2013.

[20] Article 37 of the modified Code of Deontology. Article 5. 4127-37 of the Code of Public Health. Decree dated January 29th 2010 on the conditions for implementation of the decision to limit or withdraw treatment.

- This “collegial procedure” must be made systematically available to patients (with the care and precautions which may be needed to take into account cultural and psychological specificities), even if their state of health makes it difficult for their wishes to be expressed, or should that be impossible, to proxies, families[21], or loved ones. No efforts should be spared to enable ailing persons to make a decision or if they are unable to do so, to participate in the deliberation.

- The “collegial procedure” must also evolve in the direction of becoming more exacting. Rather than a procedure, it should be a process of collective deliberation between a group of people with various reasoned opinions; its objective is to eliminate, by the very fact that they are made known to others, non pertinent reasons for action (the clinical team’s weariness, rampant emotion, staffing considerations, lack of resources).

- This collective deliberation should not be limited to discussion between members of a gathering of doctors. It must be interdisciplinary or meta-disciplinary. Generous access must also be granted to non medical professionals involved in managing the patient’s case. In particular, the non medical professionals involved must be able to decide on the need for collective deliberation. Currently, it can only be initiated by the doctor, of his own volition or on being presented with the patient’s advance directives by whoever has custody of the document, or at the request of the proxy, of family, or if the above are unavailable, of loved ones.

- This deliberation process must be used in situations where the person concerned is no longer able to communicate: it is necessary before any decision is made to resort to sedation and in any situation of extreme uncertainty, regardless of where and how the end-of-life situation is being managed.

- The implementation of this collective deliberation procedure should be an item included in the assessment of health care establishments. Its should be highly rated for its “effectiveness” value.

III-2- *Rethinking the purpose and the value of advance directives.*

Regardless of how they are drawn up or of what they are called, which varies from country to country — advance directives, life care advance directive, living will or power of attorney given to a proxy — wishes expressed in advance may help patients “participate without being present” in the discussions which precede decisions regarding treatment and management of their end of life.

---

[21] An interim ruling in summary proceedings of an administrative tribunal in Châlons-en-Champagne, on May 11th 2013, on the subject of an end-of-life situation in the University Hospital in Reims, raises this issue of the rank and value of the opinions — which may be divergent — of various members of the family and the physician’s obligations before taking a decision.

"Advance directives" formulated in writing, are probably the most direct expression of the wishes of the person concerned, at the time those wishes were formally set out.

So far, very little use is made of them: according to a recent INED[22] study, advance directives were used for 1.8% of patients for whom an end-of-life decision was made although "*they were no longer able to participate in the decision*". This raises very obviously the issue of the adoption of this practice, both by patients and by members of the medical professions.

Taking into account the proposals made on this subject by the French Commission for reflection on "solidarity in France at the end of life", the Committee considered the subject on two levels.

III-2-1- Context, content, how the directives are recorded and archived.

The first time thought is given to the directives is when they are drafted. What value can be attributed to directives written at a time when the person concerned is, admittedly, fully aware and competent but is still in good health or only just beginning to experience ill health?

CCNE considers that two kinds of advance directives are possible depending on circumstances.

- One first kind, which it would be better to call "advance statement of wishes" that anyone considering their end of life, be they in good or poor health, would be invited to write. The purpose of this document would not be to hasten death, but to reflect on one's own end of life: wishes concerning where to spend the end of life or the kind of care to be preferred.

- The second kind would respond to situations where people are seriously ill or suffering from a potentially lethal condition. The intrinsic value of the "advance directives" is different in this case: they are in fact an instrument for dialogue with the patient. They must therefore be drafted with the help of a health care provider whose support would be proposed to the person concerned, so that this very sensitive episode can be dealt with tactfully and soberly and a document drafted which will be really effective. Such "advance directives" could anticipate the decisions that will have to be taken as and when the disease progresses and various options unfold. Such a document would also be useful, very obviously, for both patient and doctor, in the event of chronic or degenerative disease.

---

[22] Pennec S, Monnier A, Pontone S, Aubry R. "*End-of-life medical decisions in France: a death certificate follow-up survey 5 years after the 2005 Act of Parliament on Patients' Rights and End of Life*". BMC Palliative care 2012; 11 (25) ; survey made in cooperation with the Observatoire national de la fin de vie (End of Life National Observatory).

With this second kind of document, the scope and content of the advance directives must be measured with care: if they are too general, they will not ensure that the wishes as expressed will cover the situation. They can only of course choose possibilities which are legally permitted. They should at least be allowed to bear on the choice of treatment to be preferred, but also on possible requests for a limitation or withdrawal of treatment in certain predefined situations. Furthermore, they should be able to broach other subjects concerning the end of life: organisation of health care, conditions and whereabouts of residence.

Clearly, regardless of which legal system is applicable, for advance directives to be followed and effective, they must meet certain conditions of validity: authenticated author, the author's legal competence, precise contents, among others.

Another question to be addressed is the duration of their validity, the current limit being three years, and also of how they would be renewed if the case arises. In conditions like Alzheimer's disease, however, in the course of which the deterioration of the patient's cognitive capacities may be slow but then worsen, there would be a need to refer to wishes expressed much earlier, before deterioration of the patient's cognitive skills had reached the point where any reiteration of directives would cease to be valid.

Finally, they must be made accessible to the doctor in good time, which requires some consideration of how and where they would be kept. If at all possible, they should also be communicated to the attending physician, and to the proxy. They should also be an integral part of the computerised medical record and even registered in a national register.

III-2-2- Should advance directives be given mandatory status?

Is there any certainty that the advance directives written by someone who is suffering from a serious disease express that person's free and informed opinion? We should not however presume that being seriously ill makes it impossible to express preferences. And yet the value of advance directives written by someone who is in the early stages of cognitive impairment may be open to question.

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...

Is it desirable that an advance statement of wishes be seen as legally binding at a time when the issue of the possibility of unreasonable obstinacy is under consideration? In other words, should we want to have — as the name implies — real "directives"?

In certain countries, advance directives are binding for the doctor so that the responsibility of the decision is the patient's; they are not any more frequently resorted to as a result. In other systems, they are not binding on the doctor and are only considered to be an indication of their author's wishes at the time they were written, so that the doctor takes them into consideration but is not obliged to follow them. This is the case in France: the doctor retains a degree of appreciation of the current situation and of possible medical advances at the time a decision must be made; the doctor is responsible for the decision — hence the usefulness of a process for collective deliberation before any decision is taken, as defined in the previous paragraph. While advance directives state the wishes of the person concerned at the time they were written, they are without prejudice regarding the possible changes in those wishes during the process of advancing disease — changes which are regularly noted in the wishes of patients who are still capable of expressing them. In fact, as the time of death draws nearer, it is increasingly found that sick people change their minds and revise their advance directives. In any event, the revocable nature of advance directives is accepted everywhere.

Germany[23] provides a particularly interesting example. The law gives patients the possibility, in the event they are not able to express themselves, of listing in advance, in writing, the treatments they would accept and those they would refuse, even though at the time they are expressing these wishes, no treatment or operation is in the offing. Based on that written statement, when patients can no longer make their wishes known, their assistant or proxy must check whether the arrangements previously made are pertinent to the current situation as regards quality of life and treatment. If that is indeed the case and there is no indication that might lead one to suppose that the patient now thinks differently, the patient's representative makes those wishes known and sees to it that the clinical team adheres to them. The rule applies regardless of the nature and degree of advancement of the patient's condition. Should the patient's previously listed preferences not correspond to the current life and treatment circumstances, the assistant must determine the wishes regarding treatment or the presumed wishes of the patient and decide on that basis if a medical procedure should be authorised or specified, it being understood that the rule also applies if the patient has not made his wishes known. In this way, when the wishes expressed are too divergent compared to the actual circumstances of the sick person, the advance directives are no longer binding. At that point, an analysis of the presumed wishes of the patient takes precedence, and the law specifies that the patient's presumed wishes must be based on concrete data such as the patient's written or oral statements or known ethical or religious beliefs.

---

[23] Dominique Thouvenin: « *La loi n° 2005-370 du 22 avril 2005, dite loi Leonetti : la médicalisation de la fin de vie* », (Law n° 2005-370 dated April 22nd 2005, the 'Leonetti Law': medicalization at end of life, *in* " Fin(s) de vie – Le débat ", coordinated by Jean-Marc Ferry, PUF, 2011, p. 303-368.

In order to achieve even more compatibility between respect for the patient's wishes and respect for the doctor's freedom of action, to give all our fellow citizens who wish to do so the possibility of making preparations for the end of their life so as to preserve what seems in their eyes to be essential, for themselves and for their loved ones, and to contribute to a discussion ahead of time on the end of life and the role of medicine, the Committee believes that the value of advance directives should be reinforced, on the condition that the way in which they are recorded and their contents comply with certain criteria. Very clearly, it is difficult to imagine that the futility of this instrument in our country at the present time could be remedied unless respect for what is said in it receives more protection.

At the very least, ignoring advance directives at any level should be justified in writing, with reference to the collective debate duly recorded in the patient's medical record.

III-2-3- Proposals

The Committee considers that the authorities should initiate a new phase in favour of the significant instrument that advance directives could become. 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.

- 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. On this subject, a specific interdisciplinary discussion should be initiated in order to develop a model form, based on the most convincing examples in other countries. Far from being exclusive, it would provide space for personal reflection.

- For advance directives to become a real instrument for dialogue, people suffering from a serious disease or entering an EHPAD (*établissement d'hébergement pour personnes âgées dépendantes* - home for elderly dependent people) should be given the opportunity, as early as possible in the course of the disease, of benefiting from the support of a professional health carer in order to draw up such a document if they so wish. The directives would help to anticipate the decisions to be taken in the event that the disease takes a downward course, both for the choice of treatment and the organisation of care or of accommodation.

- In both cases, advance directives must be made an integral part of the computerised medical record, or even recorded in a national register. Rules currently limiting the

> duration of validity could be made more flexible together with measures to encourage their renewal within a reasonable lapse of time.

When advance directives do exist, they should be presumed to be binding for health care professionals. This presumption of being mandatory would be invalidated in only three types of circumstances: they could not be followed because of an emergency; the directives were not compatible with the patient's clinical status; there are sufficiently precise, supported, and agreed (if there are several) testimonies by the patient's loved ones that the directives no longer correspond to the latest wishes of the patient. In these three situations, the fact that the directives were not followed should be the subject, on a mandatory basis, of written justification to be included in the patient's medical record. Even in certain emergencies, it is possible to take the advance directives into consideration; in particular they can help to decide on the choice of treatment. An example could be an ALS[24] patient refusing intubation.

III-3- Reassessment of the practice of sedation in the terminal phase

"Sedation is seeking by medication to reduce vigilance to a degree which may go as far as losing consciousness. Its aim is to diminish or abolish the perception of a situation which is felt to be intolerable by the patient, although all the means available and appropriate for the situation have been proposed to the patient and have failed to provide relief"[25].

Sedation may be intermittent or continuous. Deep and continuous sedation is the most controversial form and a large number of authors[26] agree that it should be reserved for use with patients with an imminently terminal prognosis, that is "a few hours or a few days", the "terminal phase" according to the agreed definition of the term by professional health carers.

Situations and the type of decisions to be made in connection with sedation are not all of the same kind and ethical issues are of more consequence when the clinical status has not attained the terminal phase, when the refractory[27] nature of the symptoms is not clearly defined or when suffering is essentially psychological. The ethical dilemma is also compounded when sedation is concomitant with limiting or discontinuing a treatment maintaining a vital function or with the withdrawal of nutrition and artificial hydration.

---

[24] Amyotrophic lateral sclerosis (ALS) also referred to as motor neuron disease or Lou Gehrig's disease in the US and Maladie de Charcot in France, is a neurodegenerative condition leading to progressive paralysis of voluntary muscles.

[25] Formal expert consensus. Sedation for distress in terminally ill patients and in specific and complex situations. Blanchet V, Viallard ML, Aubry R. Sedation in palliative care: recommendations for adults and specificities for death at home and for geriatric medicine. medpal.2010 ; 9 :59-70

[26] Idem

[27] *"Is defined as refractory a symptom that is perceived as unendurable and cannot be adequately controlled despite obstinate efforts to identify a tolerable therapy that does not compromise consciousness".* Cherny NI, Portenoy RK. Sedation in the management of refractory symptoms: guidelines for evaluation and treatment. J Palliat Care 1994; 10(2):31-38.

When sedative treatment is given to relieve symptoms, it compromises vigilance or even consciousness, modifies cognitive processes and the ability to communicate, which may be seen as contrary to the expectations of patients receiving palliative care. But in other cases, on the contrary, this reduced consciousness is what is hoped for. This is particularly true for diseases where the process of dying may be associated with exceptionally severe pain, anguish and distress for patients or family members (death by asphyxia in ALS for example).

The Committee considers that the possible effects of the administration of sedation in the terminal phase are such that its implementation should be the subject of collective debate — in the same way as the decision to limit or cease treatment supporting life — with the participation of the patient if at all possible. Currently, this is not always the case.

Taking the subject one step further, the Committee debated on the need to modify the law so that, should the patient request it, the doctor would be bound to continue sedation until death ensued. The Committee considered that, depending on which of four clinical situations prevailed, the matter appeared in a very different light.

1) Terminally sick people, suffering from a serious and incurable disease, and able to express their wishes.

It seems fitting that a sick person whose clinical status combines an imminently fatal prognosis and immediate danger of death (cataclysmic haemorrhage, particularly external, from ENT, pulmonary or digestive systems), or asphyxiating respiratory distress (feeling death by suffocation to be imminent together with panic reaction) should be given the benefit of continuous sedation until death.

When terminally ill patients present with a refractory symptom or are suffering unendurably, the Committee considers that “preference for reasons of conscience” cannot be opposed to their wishes and that their requests must be satisfied. But it notes that this decision can only be subsidiary: in the circumstances, patients must be given sufficient time before the terminal phase, to be firm in their decisions and doctors the time to explore the possibility of improving treatment management, possibly by requesting expert advice. Collective deliberation, as defined below, is of course required if the patient’s demand appear to be sufficiently steadfast and informed. The time can be spent usefully by all concerned to consider whether sedation should be light and intended to relieve discomfort and facilitate a degree of communication and contact with loved ones, or, following the patient’s wishes, deep and continuous until death. It is also in the course of this collective deliberation that would be discussed the possibility of discontinuing any treatment serving to prolong life in a way which is considered excessive or artificial.

In both circumstances — light or deep sedation — it would be the serious and incurable disease and also the discontinuation of life support treatment that are causing the person’s death. Continuous sedation itself does not cause death and has as its sole purpose to prevent unendurable suffering or symptoms from invading the entire consciousness of people about to die.

2) Terminally sick people unable to express their wishes

The same reasoning as above must prevail. The Committee is of the opinion that a close watch for perceptible signs of suffering and strict compliance with advance directives if they exist and feature a request for continuous terminal sedation, as well being appropriate for the circumstances which the patient is currently experiencing. The opinion of the surrogate or proxy, or if there is none, of the family and loved ones, should obviously be taken account of.

3) People suffering from a serious and incurable disease, who are not terminally sick and are unconscious or unable to express their opinion and whose life support treatment has been discontinued.

These are people who are seriously ill whose survival depends on the continuation of intensive care, or people who are seriously and irremediably brain-damaged[28] (Persistent Vegetative State or severe Minimally Conscious State following concussion, intra-cranial haemorrhage or the consequences of cerebral anoxia) whose survival is totally dependent on nursing care and artificial nutrition and hydration.

The problem in these cases is to discover whether these people are, or are not, being treated with futile obstinacy and whether the treatment providing artificial life support should be continued or withdrawn. When the decision is made to cease measures which may be contributing to life support, there is an obvious case for providing benefit-of-the-doubt terminal sedation to alleviate possible pain or discomfort arising out of the discontinuation of treatment. Such is the case for instance of extubation, decannulation, or the withdrawal of artificial nutrition and hydration.

In this situation also, cessation of treatments contributing to life support is the cause of a hastening of death. Continuous sedation is not, therefore, the cause of death. Its indication, as is the case for prescribing analgesics, is solely consistent with wishing to avoid having possible symptoms or suffering overwhelming the last moments of a person’s life.

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

---

[28] The Persistent Vegetative State (and the Minimally Conscious State) are defined by the absence (or the severe paucity) of self and environmental awareness, and of wakefulness-sleep cycles. Survival is totally dependent on nursing care and artificial nutrition and hydration.

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. 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[29] 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.

Furthermore, it is undeniable that, in certain cases, such situations only arise because previously — at birth or even before birth — clinical teams were unable to abstain from, or reject, unreasonable obstinacy in cases where such a course would have been preferable. Such difficult decisions give rise, and cannot fail to continue giving rise in the future, to professional differences of opinion.

4) The issue of continuous terminal sedation, at the request of certain sick people suffering from a serious and incurable disease, but who not in a terminal phase.

A refractory symptom appearing in a non terminal palliative phase can be an indication for sedation which, *a priori,* would be intermittent or transient. Resuming sedation or even initiating continuous sedation is only justified if attempts to deal with the patient's discomfort prove unsuccessful.

---

[29] *Cf* "The French Society of Neonatology's Proposals for Neonatal End-of-Life Decision-Making", C. Dageville, P. Bétrémieux, F. Gold, U. Simeoni, for the Working Group on Ethical Issues in Perinatology. Neonatalogy Sept. 2010 et "A Time to Be Born and a Time to Die: Ethical Challenges in the Neonatal Intensive Care Unit Commentary on C. Dageville et al.: The French Society of Neonatology's Proposals for Neonatal End-of-Life Decision-Making", Ola Didrik Saugstad, Neonatology April 2011

If, as the disease progresses, dominantly psychological or existential suffering becomes refractory to appropriate management, there again transient sedation can be acceptable if the patient requests it, after repeated pluridisciplinary assessments, including the participation of a psychologist or a psychiatrist. Resuming sedation or even initiating continuous sedation is only justified if attempts to deal with the patient's discomfort prove unsuccessful and after collective deliberation including a written record of the reasons for making such a decision.

With these non terminally ill patients suffering from a serious and incurable disease, but in the absence of any refractory symptom or suffering, it does not seem justifiable to use continuous sedation over several weeks or months. Clinical experience has demonstrated the degree to which such demands fluctuate over time; palliative care and adequate support, generally speaking, have a positive impact. Conversely, acceding to a request for continuous and terminal sedation until the person dies, when there are no symptoms or suffering deemed to be refractory and the terminal phase is not yet reached, would put the person concerned in a state of consciousness which does not allow for the expression of possible changes of mind. There is, however the possibility of temporary sedation, or more prolonged milder (conscious) sedation titrated to permit a possible expression of opinion while making life more bearable for the sufferer.

In the case of sick or disabled people, suffering from a serious and incurable disease, who are not terminally ill, who are well informed and repeatedly request that essential treatment or medically administered nutrition and hydration be discontinued, possibly combined with a request for sedation to attenuate the consequences of such a decision, there may indeed be an indication for sedation. Clearly, such a decision can only be made after the matter has been fully and collectively discussed on numerous occasions by the sick person and all the people involved in care and treatment.

Is there any real difference between continuous sedation and euthanasia?

Sedation means treatment aiming to attenuate the perception of refractory symptoms or suffering, or else to induce altered vigilance or consciousness until death for people with a serious and incurable disorder. The doses are titrated and appropriate to the intention. When sedation is continuous, death does ensue, but in a lapse of time that cannot be predicted and in a context of relative comfort that may facilitate the support of families.

If the sedative is used to terminate a person's life, at his or her request, this is euthanasia. Doctors proceed entirely differently. The sedative doses are often used *crescendo* until death.

In order to avoid ambiguity, the same term should not be used to designate practices with different intentions[30]. The risk of confusion would be significant if very different realities were to be covered by the same word. Euthanasia and sedation do not share the same clinical approach nor the same support, and they differ as regards the decisions made by patients and their loved ones.

This difference between continuous terminal sedation and euthanasia is an essential one, which does not mean that, in practical terms, it is always entirely obvious.

In the final phases of a serious illness, the distinction between terminating life-sustaining treatment combined with sedation, on the one hand, and using sedatives at the request of the person concerned to hasten death, on the other hand, can be disputed.

Withdrawing life-sustaining treatment — medication or nutritional — or to cease using technical appliances (such as for example mechanical respirators) equates to the hastening of death. It can therefore be said that, in certain circumstances, shortening the time before a person dies, at his or her request, may be legitimate.

This raises questions in people's minds. If it is considered acceptable in ethical terms to hasten death at the sick person's bidding, by discontinuing treatment or technical support, why should administration of a substance — be it intrinsically lethal or made lethal by the dose used or by the context of a disease which has advanced to the point of functional organ failure — not be acceptable?

From a consequentialist approach, the result is identical, i.e. hasten the death of someone who is already close to death.

To some thinkers, a great deal of importance should be attached to intentions, which are not identical: they consider that to allow death to happen when that which maintains life artificially is withdrawn is not of the same nature as administering a substance which causes death.

Others are more inclined to highlight that the time factor is different when futile treatment is discontinued or with euthanasia. They consider that time plays a significant role. When death is not brought about speedily with the help of a lethal substance, the time before death may serve to allow one last occasion to be together with loved ones so that the process of mourning may be facilitated.

Yet others feel that this distinction serves no useful purpose in the advanced phases of disease: they consider that when someone asks for death to be hastened, the difference is

---

[30] Anquinet L, Raus K, Sterckx S, Smets T, Deliens L, Rietjens J.AC. Similarities and differences between continuous sedation until death and euthanasia – professional caregivers'attitudes and experiences: a focus group study. Palliative medicine 2012; 27(6): 553-561

not radical between disconnecting a ventilator, ceasing nutrition and hydration and injecting a sedative substance which, in this context and depending on how it is used, may hasten death, on the one hand, and on the other hand, injecting a lethal substance with the intention of bringing about the death of the person concerned.

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 one 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.

In conclusion, 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. 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.

Part Three

Legalising assisting suicide?

The President of the French Republic asked CCNE the following question: *"According to what procedures and strict conditions should conscious and autonomous patients suffering from a serious and incurable disease, be authorised to obtain support and assistance in their decision to put an end to their own life?"*

This question's field of reference relates to people with a serious and incurable disease, not necessarily only those who have reached an advanced or terminal phase of that disease. Also of note is the fact that the question is confined to people who are conscious and autonomous and have expressed the will to put an end to their own life.

Before considering the procedures that might apply to organise assistance by a third party to someone who is in this situation, the Committee considers that the first issue to be examined is the nature of such assistance, and then how extensive it should be.

I- Distinguishing between two concepts: assistance in suicide, assisted suicide and euthanasia.

When someone with a serious and incurable disease asks for help in dying, the request is always charged with significance, which must be discovered as a first priority.

The first step whenever such a request is motivated by inadequately controlled symptoms or suffering that would be accessible to treatment or support, must be to offer palliative care to the sufferer.

When, nevertheless, the request is persistent, there is an obligation to make sure that it corresponds to the patient's free, informed and reiterated wishes.

The nature of the request must then be analysed: there are clear differences between asking for help in dying and ending life, asking for help in committing suicide, asking for assisted suicide and asking for euthanasia.

Two situations will not be specifically addressed at any length in this Opinion: requests for help in dying which reflect a request for palliative care and requests made by a third party for putting someone to death.

The first of these situations is probably the most frequent. It is often the result of indignity suffered by a person who is no longer being given proper consideration — to which an offer of palliative care and support must be the response, although this is not, of course, the sole responsibility of palliative care teams.

Requests for death formulated by a third party for someone with an advanced, serious and incurable disease, who has not personally expressed a wish to die, is another matter entirely. Such requests must be viewed with the greatest circumspection since, on the one hand, the persons for whom such requests were made are so vulnerable that they cannot express their own wishes and, on the other hand, there is a grave risk of a decision being made based on an overly subjective approach to benevolence or as a consequence of ambivalent motivations. The process of collective deliberation, as defined in the previous chapter, should then be launched to decide whether it is appropriate to continue with life-sustaining treatment. At the end of this process, when it has been decided to discontinue treatment that is considered to be futile, the question of terminal sedation may arise.

Some further clarification is required, however, on the concepts of assistance in suicide on the one hand, and assisted suicide and euthanasia on the other hand.

There is an *a priori* obvious difference between suicide and euthanasia: while suicide is an action by the person concerned, euthanasia requires action causing death by a third party. But the difference is not so sharp in the case of assistance in suicide. In certain situations, persons wishing to end their own life may not be physically capable of doing so because of a serious and incurable disease.

Two distinct situations can then be defined, assistance in suicide on the one hand, and assisted suicide or euthanasia on the other. The rationale is that giving someone the possibility of taking their own life does not equate with taking the life of someone at their own request.

I-1-Assistance in suicide

Assistance in suicide consists in giving someone the wherewithal to commit suicide. In this case, the persons concerned do what is needed to commit suicide by absorbing a lethal substance that was provided to them. The only resolve generating the lethal action is that of the person concerned, who may, as a private act, put an end to his or her life. A person in possession of a deadly substance is at liberty to decide not to absorb it.

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. Assistance in suicide also is different in that it is no more than a possibility given to someone to put an end to their life instead of being, like euthanasia, an action terminating another's life.

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.

The situation in the state of Oregon is interesting in this connection: people with a disease that is assessed as being incurable and fatal within the next six months 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[31], 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.

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.

This could be called pharmacological assistance in suicide, which seems preferable to calling it medical assistance in suicide, since in fact the doctor's presence is not essential. The procedure allows, in very strictly defined conditions, the delivery and safekeeping of a lethal substance which, when voluntarily absorbed, leads to a rapid and non violent death.

I-2-Assisted suicide and euthanasia

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.

---

[31] Loggers E.T, Starks H, Shannon-Dudley M, Back A.L, Appelbaum F.R, Stewart F.M. *Implementing a Death with Dignity Program at a Comprehensive Cancer Center*. N Engl J Med 2013;368:1417-24

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 and 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[32] 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.

II- Issues raised by assistance in suicide

The actual principle of this major modification to legislation, mentioned in the President of the Republic's referral, must be discussed at a first step since the issue of the legitimacy of the act of assistance in suicide does not depend, or at least not primarily, on the nature of the conditions in which it is performed.

I-1-Non assistance to a person in danger

Although a person may wish to die, the community's first duty is to hold out a helping hand to those of its citizens who need support to get on with their lives or overcome despair, and indeed it has always sought to improve its performance in that domain. The concept of assistance in suicide is therefore rather shocking, in so far as it seems to signify that, contrary to our determination to respond to those who wish to bring their life to an end, we see suicide as an acceptable alternative solution to their problems.

---

[32] 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.

This concept finds expression in the Criminal Code in the form of an offence: non assistance to someone in danger[33]. 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.

II-2-Assistance in suicide and the prohibition against killing

Hardly any principle is as solidly established as this prohibition, starting with the wording of the Hippocratic oath: "*I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect.*" It is also transcribed in the physicians code of ethics in France in the following terms : "*The physician must support the dying patient up to the last moments of life, ensure by appropriate care and measures the quality of a life at its end, protect the patient's dignity and provide solace to the patient's family and loved ones. The physician is not allowed to cause death deliberately*"[34].

The only exceptions to this prohibition against killing someone are connected to the obligation of preventing someone from harming others in a violent situation.

---

[33] As set out in article 223-6 of the Criminal Code: "Anyone who could by immediate action and without risk to himself or herself or for third parties, prevent either a crime or an offence against the corporal integrity of another person, and who voluntarily abstains from doing so, will incur a five-year prison sentence and a €75,000 fine. The same penalty is incurred by anyone voluntarily abstaining from helping someone in danger if he or she could do so without risk to self or to third parties, either by personal action or by calling for help."

[34] Article L. 4127-38 of the Code of Public Health.

This prohibition is of course a component of the trust each of us can place in society and is therefore very important for our collective faith in society. It is expressed in strong and simple words.

While suicide today is no longer prohibited, as it was in earlier times or in other civilisations, it is still almost always seen as the final phase of despair, of not finding any meaning in one's life — but refusing treatment is legal although it may be motivated by the very same reasons.

It is difficult to claim that suicide is always the result of a form of freedom since it is often rooted in pain, a feeling of uselessness or loss of meaning, of guilty feelings of having failed those we love, even though there is such a thing as an altruistic suicide, as Durkheim presented it but in a broader context: frequently elderly people in poor health say that they do not wish to be a burden on their children and that they want to preserve the heritage they wish to bequeath to them, which would be largely dilapidated by medical costs in old age.

It is thought by some, furthermore, that to reverse the ban on assisting someone to commit suicide could considerably modify the relationship between those who are sick and those in close contact with them, health care providers in particular. The basic trust in benevolence could be shaken. There is a certain degree of ambivalence in the minds of those close to a sick person, as there is also in the sick person's own mind, albeit a different kind of ambivalence[35]. The desire to help hasten death may be felt by carers, family and loved ones, particularly if the end of life is characterised by suffering and a host of discomforts. The people in attendance may project onto the sick person their own anxieties or their difficulty in providing support.

The prohibition against killing other people as formulated by law firmly sets a boundary. It often prevents family members from feelings of guilt regarding a dire decision they would have to make or ratify.

The demand for legalising assisted suicide, that is help given to someone so that they can exercise their "liberty" to commit suicide, leads to a significant change in perspective — even though there is some contention that there is a form of continuity between this development and doctors withdrawing vital treatment at the request of the person concerned or as the outcome of a collegial procedure when there can be no expression of his or her wishes.

Giving someone nearing the end of life the possibility of committing suicide to respect that person's wishes is still, and always will be, an act of extreme gravity and society, when it leaves this in the hands of doctors, burdens them with the most onerous task that can be

---

[35] As underlined by one of the person's heard by the Committee, Dr. Kagan.

imagined. No reform of the text of the law, of any kind whatsoever, will ever be able to ignore this fact.

However, there should not be an equation of homicide which is prohibited by every civilised society, this being the action of taking away somebody’s life, with the situation of a someone in the presence of a patient who has decided to die, who persists in that intention by refusing treatment and nutrition and who furthermore asks for active assistance in order to achieve the death which he or she seeks (assisted suicide or euthanasia); the two situations and therefore, the two actions are situated in two radically different worlds.

Assistance in suicide could be likened, for some, to the possibility given by lawmakers to physicians to act in a manner which will lead to death, in order to conform to the bon on futile medical obstinacy or to respect the wishes of a patient refusing treatment.

Furthermore, some people consider that a distinction must be made, in serious and incurable diseases, between the non terminal and the more advanced “terminal” phase. When life expectancy is assessed at just a few days, or even a few weeks, and the person concerned asks for assistance in suicide, the distinction between cessation of life-sustaining treatment with the possible adjunction of sedation until death and assistance in suicide may appear tenuous.

To allow death to happen is of course not at all the same thing as administrating a substance that causes death, nor is it the same as giving someone after discontinuation of the treatment they considered to be futile, a substance with which to commit suicide. Some people think however that this distinction is not convincing in an advanced or terminal phase of the disease and that there is no radical difference between disconnecting a ventilator, withdrawing artificial nutrition and hydration, giving someone a lethal substance or injecting a lethal substance if the sick person’s request is sufficiently free and informed.

Another argument that is brought up is related to a question of equity: why should suicide which an autonomous person can commit, should cease to be possible for people for the sole reason that they no longer command the physical autonomy to accomplish the deed? To which some people reply that the law is not intended to reinstate on all counts inequalities resulting from natural causes.

II-3-“Borderline situations”

While the prohibition set up by the law and its value as a boundary are the object of a particularly broad consensus, there are complex situations in which choices are made to transgress, for compassionate reasons or by conviction, or for other more unfathomable reasons.

Those in favour of legalising assistance in suicide consider that this factual situation is justification enough for moving the boundaries of the prohibition. They emphasise that assistance in suicide is a reality and that it is simply hypocrisy to allow this to remain in the shadows and the unsaid in the name of the purity of ethical principles and to shroud it in the vocabulary of compassion while letting those who practise it run the risk of criminal proceedings.

The Committee would first of all observe that it is very difficult to ascertain the reality and the number of these so-called extreme or borderline cases for which doctors or the patient's loved ones accept such a risk, a risk furthermore of which they may be more or less aware.

Although it would be essential to gain enlightenment of the factual reality of such cases, there is no pertinent study available, except for the recently published INED[36] report. On such a subject, it would be necessary to distinguish between rumour and fact. INED's publication shows that euthanasia is rare: it represents 0.2% of deaths if are combined the intention of causing death, the patient's request and the injection of a lethal substance by a health care provider, i.e. some 1100 of the 550,000 annual deaths in France. But this interesting study does not throw any light on the facts of situations leading to assistance in suicide.

The same study considers that 0.4% of deaths could be the result of an injection of lethal substances by a health care provider without the person concerned having requested it. Such situations, which are in fact homicides, are unacceptable[37]. Here again, the study gives us absolutely no enlightenment on the nature of situations leading to such actions. Obviously, they need to be examined.

When they are confronted with a situation they consider to be borderline or extreme, for which strict enforcement of the law seems to be unsatisfactory, doctors or other health care professionals should be able to choose an intermediate course of action between leaving patients to their own devices on the grounds that the response they are considering is illegal, and acting in solitude and concealment to avoid criminal proceedings. In this particular situation, it is on the contrary essential that they engage in a process of collective deliberation — in the direction proposed in Chapter II above. As the outcome of this deliberation, some written record should show all the possible alternatives that were explored — in particular sedation until death — and be capable of justifying and providing the motives for the decision that was made, making visible all that so far is shrouded in opaque obscurity... Proceeding thus represents above all the possibility of arriving at a more equitable decision in the patient's bests interest; it could also limit or eliminate the risk for

---

[36] Pennec S, Monnier A, Pontone S, Aubry R. "*End-of-life medical decisions in France: a death certificate follow-up survey 5 years after the 2005 Act of Parliament on Patients' Rights and End of Life*". BMC Palliative care 2012; 11 (25); study made in cooperation with the "*Observatoire national de la fin de vie*" (National End of Life Observatory).

[37] In its Opinion n° 63 "End of Life, Ending Life, Euthanasia", CCNE underlined that "Without consent, no act of euthanasia could even be considered."

professionals who had acted with competence, diligence and humaneness to run the risk of prosecution. The arguments set out in CCNE's Opinion n° 63 regarding "joint commitment", "solidarity" and "plea for euthanasia" would also apply here[38].

The Committee notes that it would be essential to obtain more information on this subject through extensive and prolonged studies, taking into account the quality of support, the benefit of palliative care and the possibility of being given deep sedation at the extreme end of life; when all these components are present and effective, the number of borderline cases should be considerably reduced.

At this point, it is therefore not possible to state with confidence that the will to preserve the sacrosanct nature of certain principles is accomplished at the cost of an ambiguous and occult, but accepted, practice nor that more "realistic" legislation would permit clearer treatment of the subject.

The Committee also notes that to move the boundaries of prohibition would not eliminate boundaries: whatever is set as the limit, there will always be extreme situations which touch the limit and challenge it. If the prohibition against killing were to be displaced, the problem would arise of the risk of its delimitation being achieved by the use of a movable cursor, with re-evaluation as a result of a balance drawn up between the advantages and drawbacks of various categories of situations. The risk already exists, quite obviously: the greatest vigilance must be exercised whenever withdrawing treatment is being considered, but also as regards access to treatment and, in particular, to resuscitation. It is particularly sensitive in a society where economic realities may considerably encroach on respect for the individual. Extreme caution is required therefore when active assistance is to be given to someone in committing suicide; this all the more so because it would be very difficult to define and limit efficiently the possibility given by law of putting an end to one's own life to resolve a situation which is felt to be unbearable, in particular because it is exceedingly difficult to codify realistically the limits of what is bearable.

Finally, certain thinkers believe that to base a system of ethics — and *a fortiori* a legal system — on compassion would be perilous. To sympathise with someone's suffering is undeniably a respectable sentiment; but to make compassion an ethical or legal determinant would be hazardous. Unalloyed compassion can lead to the worst excesses through overly intense bonding. It can be a projection of our own fears. A balance must be reached

---

[38] "... what cannot be accepted at the level of principles and discursive reason, human solidarity and compassion may well adopt. Faced with such distress that all hope of alleviation is lost, and suffering becomes intolerable, there can be a need to take into consideration the fact that a human being transcends rules and that plain solicitude may sometimes appear as the only remaining route to take to face the inevitable in a spirit of solidarity. Such a position could be then designated by the expression : joint commitment." "Although in a concrete situation, the decision to end a life may in borderline cases appear acceptable, this action cannot rest upon clear ethical evidence. Such a decision cannot, and never should become routine practice. This practice, based on respect for unalienable personal rights, should only strive to contain firmly end of life, and possibly ending of life, within the embrace of life itself, so as not to exclude from a humane world the last moments of a given existence."

through other principles. A moral doctrine, excluding reference points from its scope, or with empathy as its sole reference, could absolve itself of the need for discursive reason and of the primary requirement of reinforcing solidarity in favour of those who are vulnerable.

But it is also true, inversely, that the request for assistance in suicide is not always formulated as a request for compassion, but rather as an appeal for solidarity so as to be "free of the obligation to be an object of compassion"; it would thus express more respect for autonomy and personal freedom.

II-4- The outcome of systems adopted in other countries would be an invitation to prudence, in particular when euthanasia is authorised

The outcome, as detailed in Annex 2, differs from country to country among those that have been practising active assistance in dying for some length of time; the data regarding the Benelux countries, where euthanasia is allowed, raise some complicated issues, according to both the Committee and the Sicard Commission. Numbers in those countries are increasing considerably faster than is the case elsewhere. Whereas Oregon and Switzerland only record several dozen assisted suicides every year, the number of recorded euthanasia episodes has increased by 18% between 2010 and 2011 in the Netherlands, and has almost trebled in Belgium since 2006, where today, 1200 cases of euthanasia are recorded every year.

In the other countries, figures are more stable. There is, however, some evidence of a risk that patients who might change their mind and want to continue living could be in danger of not getting the medical care they are entitled to. According to Oregon's annual reports on medically assisted suicide[39], the frequency of assistance in suicide increases regularly, albeit slowly, while numbers are dropping of patients being offered medical treatment for depression at the end of their life. Nevertheless, a recent study demonstrates that this evaluation by psychiatrists is stricter than when associated with the much more frequent decisions to limit or withdraw vital treatment[40].

Is the law's scope properly observed?

- Even though there is more to it than the question of euthanasia, experience in the Benelux countries shows that it is rather illusory to fix stable eligibility criteria for euthanasia. In these countries, euthanasia is legal for sick people in the terminal phase of their disease and capable of making a decision. In practice, the target population has gradually been extended and now applies to vulnerable members of society. In Belgium, several adult incompetent people were euthanized, as were people suffering from neurodegenerative conditions at a fairly early stage of the

---

[39] See: http://www.oregon.gov/DHS/ph/pas/index.shtml.

[40] Prokopetz J.J.Z, Soleymani Lehmann L. Redefining Physicians' Role in Assisted Dying.n engl j med 2012; 367: 97-99

disease. As indicated by the thirty or so draft laws with the purpose of extending the scope of the 2002 law, demand is far from being fully satisfied as yet in this country. An amendment to the law intended to extend the right of euthanasia to the insane and those under legal age is even now being submitted to Parliament. This intention to broaden the law's scope for euthanasia shows that the principle is now well imbedded and accepted by a majority of Belgian citizens, despite considerable disparity between Walloons and Flemish. It is also evidence that euthanasia is seen as a personal right of which in principle certain categories of citizens should not be deprived.

- In the Netherlands, euthanasia is generally performed by a family doctor who knows the patient and usually in the patient's home. Globally, it seems well accepted. However, it has been pointed out that solidarity is waning to a certain extent as euthanasia becomes more commonly practised. There is also a tendency to continue extending the interpretation of the existing legislation: for instance, the creation of "mobile teams" specifically for the practice of euthanasia is under consideration.

- In Switzerland, assisted suicide, tolerated by virtue of an *a contrario* interpretation of criminal law, did not stay strictly confined to people at the extreme end of their life. According to a study, the Swiss association Exit Deutsche Schweiz has given assistance between 1990 and 20000 to 748 suicides: 21,1% of the people concerned were not suffering from any fatal disease[41].

As the Sicard Commission's report noted, legalising euthanasia does not eliminate violations of the law: in Belgium, it would seem that three times as many cases of euthanasia in dubious circumstances are now occurring compared to the situation before the law was adopted — which is not as paradoxical as it may appear as it can be explained by the relative ease with which such practices are implemented.

Some thought should also be given to the particular difficulty of coping with bereavement following active assistance in dying. Some of those in favour of assisted suicide argue that families supporting their dying relative are relieved. But reality is more complex and not so systematic. Induced death does not always bring serenity to families and it is not always "peaceful" for the person concerned. The process may take a long time — several hours — and some of the external signs, such as the death rattle and the respiratory interruptions may greatly distress those who are in attendance. The role often given to loved ones is not an easy one: help a relative to commit suicide, be present, carry that burden...

Nor is the act entirely devoid of violence, in symbolic terms and in fact. It is to be noted that doctors are relatively reluctant to get involved. In Switzerland, the medical profession is very much in two minds on this matter. The illusion that euthanasia is a simple task for a

---

[41] Bosshard G, Ulrich E, Bär W. 748 cases of suicide assisted by a Swiss right-to-die organization. Swiss Medical Weekly 2003. 133.:310–317·

doctor who has been asked to participate should be dispelled. It is probably no easier to dispense death, however it is done, than to commit suicide. Many health carers, including some members of the Committee, have testified to the extreme difficulty with which they had endured the practice of administering “lytic cocktails” to patients at the end of life, which is not very much in use any more, although, as we have seen, it has not entirely disappeared.

Finally, the practice of assistance in suicide or euthanasia seems to resist any effective form of control. Although laws include supervisory procedures, checks are made *a posteriori* and in a declarative form, based on the clinical experience and good faith of the doctor reporting the facts. As a result, there is a quasi systematic absence of prosecution (none so far in Oregon, Luxembourg and Belgium; just a few per year in the Netherlands).

III- Conclusion

At the close of its reflection on the subject, the Committee has six groups of comments to formulate.

1. Entering into a new phase is essential in order to guarantee that at the end of life people’s aspirations are taken into account. In this connection, the Committee recommends three major developments in existing legislation.

- 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 note in the patient’s medical record.

The Committee considers that such changes could satisfy the great majority of requests made by people at the end of life. It should then be possible for responses to be diverse and adaptable, which is essential since each case is very different from any other, and to be as accommodating as possible to individual wishes, which are frequently difficult to foresee and tend to fluctuate.

2. And yet, there is still a long way to go before the task is done. The circumstances in which people end their lives in France are not globally satisfactory. While in the present state of the medical art, physical distress and, theoretically, suffering due to depression can be adequately relieved, in practice pain is still not always appropriately treated. More generally, the Committee insists that the more pressing issues in this respect should not be eluded: financial management and human support for the sick and the disabled, equitable access to palliative care, not only at the end of life, but every time some relief is requested, organisation of palliative care in the home, development of physician training and research on the subject of the end of life, attention to the conditions in which elderly people find a place in today’s society and vigilance as regards their rights, help for family carers and loved ones.

Putting an end to some situations of indignity must be an absolute priority in health care policies. The Committee notes that such situations may generate a feeling of indignity which is expressed by some people at the end of their lives, or that is feared by our fellow citizens. It also remarks that legalising assisted suicide or euthanasia is not going to solve some of the acute and urgent problems which have just been listed.

3. 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. The authorities should then launch an initiative with the aim of allowing professional health carers, magistrates and patients to share and attempt to harmonise their views on such situations so that criminal justice can be equitably enforced.

4. As regards assistance in suicide, several points of view were expressed within the Committee.

It should first of all be remarked that the referral is not limited to the issue of assistance in suicide for people at the end of their lives and that the debate covers broader issues, as is confirmed by the situations in other countries to which reference can be made.

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.

5. Certain CCNE[42] 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.

6. The current debate on the end of life and the support owed to the aged and the disabled should continue and deserves to attract more public attention. The Committee considers that a genuine public national debate on the end of life and voluntary death should be organised. In point of fact, Article 46 of the law dated July 7th 2011 on bioethics provides that any reform project on ethical and societal issues raised by advances in biology, medicine and health should be preceded by public debate in the form of States General to be organised on the initiative of the National Consultative Ethics Committee.

Public debate is an instrument for associating civil society with public decision. It helps to progress beyond merely finding that two irreconcilable positions are in confrontation. Instead, the debate could highlight common concerns, thus integrating individual preferences that cannot be otherwise incorporated, and reveal the complexity of issues. It also helps to advance beyond the finding that there are deep-rooted differences in approach, and so reach a point where agreement can be found on values in which we concur: personal autonomy, protection of the weakest, freedom of thought.

Paris, June 13th 2013

---

[42] See infra "Other Reflection"

Another reflection submitted by certain members of the Committee:

Besides the proposals concerning the collective interdisciplinary deliberation process, advance directives and the practice of terminal phase sedation on which all the members of the Committee are of the same mind as regards the text adopted on June 13th 2013 by a CCNE majority, the undersigned members of the Committee subscribe to the two following contributions.

Yves AGID, Joëlle BELAÏSCH-ALLART, André COMTE-SPONVILLE, Patrick GAUDRAY, Jean-Pierre KAHANE, Alice RENE, Michel ROUX, Michel VAN PRAËT

Choosing the exception

Patrick Gaudray

The recurrence of the debate on the end of life is a clear illustration of the fact that we stand in the undecidable ground of a domain where values which are all as entirely fundamental as each other enter into confrontation, where applying strict rules all too often adds yet another measure of violence to the intimate violence of the last moments of a life, where vulnerability commonly dominates, the stigma of individual fragility and of a certain strength, if it can be said that the strength of humanity is held together by the sum of these individual vulnerabilities.

In reply to the three questions referred to the Committee by the President of the French Republic, following collective reflection and discussion, CCNE chose to submit an Opinion with a three-part structure: (i) The origins of the current debate on voluntary death, which could be seen as a certain perception of society and of death, (ii) The current status and limitations of legislation regarding the end of life: the law and public policies need improvement, establishing an appraisal of the legislation in action, and (iii) Legalising assistance in suicide? Meaning, should or should not the law be changed?

While the recommendations in the second part of the Opinion (collective and interdisciplinary deliberation, advance directives and terminal phase sedation) are a common platform for the full range of CCNE reflection, the third part, which reports on the Committee's thoughts in reply to the President of the Republic's last two questions, reveals irreconcilable opinions, both within CCNE and in society at large. Presenting only one of these would have the Committee moving away from the approach based on openness adopted in 2000, when it drew up its Opinion N° 63[43]. Noting that *"Although in a concrete situation, the decision to end a life may in borderline cases appear acceptable, this action cannot rest upon clear ethical evidence. Such a decision cannot, and never should become routine practice."* At the time CCNE considered that: *"Both the positions in this debate*

---

[43] CCNE, Opinion N° 63: "End of Life, Ending Life, Euthanasia", (January 27th 2000).

represent weighty values and are worthy of attention and respect. The Committee taken as a whole recognises and emphasises this. However, they appear to be irreconcilable and their opposition seems to lead to an impasse. Should that be accepted with resignation and any hope of further progress forsaken?"

In this same Opinion N° 63, CCNE contributed a complex and open reflection, in which the concept that is mainly remembered is the *"plea of defence for euthanasia"* in the legal acceptation of the term. The Committee gave as justification for it the observation that *"it is never healthy for a society to experience a situation where discrepancy between rules as they are laid down and real life is too glaring",* referring to euthanasia's reality: clandestine, hypocritical, inegalitarian and anarchic. But CCNE also emphasised, beyond purely legal considerations, that certain situations were not within the bounds of normality and should be perceived and treated as exceptional[44].

Enforcing, as it should be, the law introducing the prohibition of "unreasonable obstinacy", recognising and taking account of the rights and wishes of patients, as well as intensifying the role of palliative care in hospital departmental clinical policies, to all of which a useful complement would be the proposals put forward in the second part of the Committee's majority Opinion, together with more genuine regard for and emphasis on the trustee's task, make up a coherent whole which should not be put forward as an alternative to the possibility of a request for euthanasia. This is an altogether different matter and denial of this fact would lead to considering euthanasia as a substitute for the implementation of the measures outlined above. This is absolutely not the case.

Palliative care does exist and is gaining more ground in this country, even though it is commonly experienced as still being substantially inadequate. This is also true, more generally, of support for people at the end of life or in cases of therapeutic deadlock. Nevertheless, assistance in suicide or putting an end to life cannot conceivably be accepted as an alternative to filling these gaps.

Choosing to hasten death must remain an exception, and not the last resort solution to an absence of the capacity to limit suffering, be it physical or psychological. Furthermore, such a choice should be only be considered once quality palliative care has been tried and has failed. However exceptional, however, such a choice must not remain covert.

"We refuse to believe that in the presence of sickness, suffering and death, there can be a rigid framework defining dignity, individual freedom or collective responsibility", states a document produced by the United Protestant Church of France[45]. The right that therefore must be upheld is, apart from the right to be free of suffering, physically or mentally, is the right to die without indignity. Such a right should even become enforceable.

---

[44] *"Certain situations can be considered extreme or exceptional and appear from the outset as not fitting into the "standard". "Standard" in this case means that a health care provider provides health care, come what may, and that the patient has the will to survive. But that will may not just be missing, it may in fact be reversed and replaced by a will to end it all and die." (*CCNE, Opinion N° 63).

[45] *Eglise protestante unie de France*, Lyons Synod 2013: « *A propos de la fin de la vie humaine* » (On the subject of the end of human life).

Leaving a human being alone with a decision (expressed and demonstrated clearly and repeatedly) to put an end to his or her own life, failing to provide access to a relatively humane and "gentle" way of doing so, amounts to desertion, to failing in solidarity and fraternity, the fraternity that the French national motto advocates. There is a semantic frontier between suicide, assisted or otherwise, and euthanasia. It is therefore difficult to achieve an uncomfortable fusion between the two by the use of a subtle distinction between "assistance in suicide" and "assisted suicide". Once we are in a situation where a person wishes life to be ended, but is unable to do so unassisted[46], we are faced with choosing to induce death, to proceed with euthanasia, and no euphemism can lighten that burden. "Allowing to die" instead of "causing to die" does not lessen the burden.

---

[46] Albert Camus begins the Myth of Sisyphus with the words: *"There is but one truly serious philosophical problem and that is suicide. Judging whether life is or is not worth living amounts to answering the fundamental question of philosophy"*

Ethics for suffering and death

Michel Roux

For a long time, society bowed to the dual inevitability in the face of death: that of unavoidable suffering, that of an end that could only be awaited. Fundamental medical developments have drastically modified these certainties and offer the possibility of perhaps doing away with suffering altogether, when death is imminent and when death is upon us; no less fundamental developments have brought about the acceptance of the idea, which has been defended since antiquity, that all men are entitled to do away with their own life, and that there exist extreme situations when death could, or even should, be dealt out. Today, society asserts its demand for solidarity by recognising that there is a duty to relieve suffering and the right, in certain cases, to cause death to happen.

I- The duty to relieve suffering

This has always been a fundamental obligation placed by society on its physicians; it is even imperative in the event that patients refuse treatment of any kind and doctors are obliged to respect their will to die.

This duty must be accepted with all its consequence; it makes it possible, in the advanced phase of an incurable disease, for treatment with known and potentially lethal side effects to be initiated. In cases of extreme and intractable suffering, there is a duty to allow sedation until death; the battle against suffering must be fought to the extreme of risk to the patient’s life and consciousness. But this duty does raise two ethical issues.

- The first of these issues is due to the fact, that in the present state of legislation, decisions can never be taken by the sick person; it is up to the doctor, and the doctor alone, with appropriate advice, to decide; this is one of the too flagrant expressions of medical empowerment that the law still preserves. As we shall see, if it is up to individuals to decide what becomes of their own life, necessarily, it is also up to individuals to decide how much suffering they are willing to endure.

- The second issue is related to the way in which palliative care is viewed. Thanks to such care, death is no longer the only escape from the most extreme suffering attending the end of life. Would it then become an alternative opposing a request for voluntary death? Why would anyone want to die if there is to be no longer any suffering? Would there still even be any demand for death once all suffering can be appeased?

Such questions are, by their very nature, difficult to entertain; however widespread palliative care becomes, it will not completely eliminate every request for voluntary death, and this, even though it may be less frequent, must continue to be received with respect. The existence of an ethical debate and its importance cannot, in any fashion, depend on the number of people concerned. And while palliative care does not do away with the need to debate, it does not make any contribution to clarifying the issue: it is designed to make the time when death is imminent more bearable, but it has nothing to say, nor can it have anything to say on the legitimacy or absence of legitimacy of hastening death.

II/- The right to cause death

Contrary to popular misconceptions, French law recognises, in certain conditions, a right and even a duty to bring about a death; measuring exactly the scope of legislation on this subject is absolutely essential, in particular in the light of the prohibition of causing death to another person. Possibilities of further change also need to be examined.

1) Current legislation

The possibility of causing death is connected to two of a physician's fundamental duties, as has been stated for a long time in the medical code of ethics: the duty to abstain from unreasonable obstinacy, and that of respect for any decision to refuse treatment (Articles 37 and 36, incorporated and in part added to in two laws in 2002 and 2005).

a) To abstain from any "unreasonable obstinacy" implies in particular the rejection of disproportionate treatment; the law makes it clear that this duty can go as far as authorising artificial life-sustaining treatment to be discontinued; by its very definition, the prohibition includes therefore, and may even prescribe, actions which will be the direct cause of death — for example, the disconnection of vital devices; it therefore goes much further than simply the duty to relieve suffering.

b) Refusal to accept treatment obliges the doctor to discontinue any treatment even if the consequences are that the patient's life will be in danger; the doctor must inform the patient of these consequences; if the patient confirms the decision, it must be respected, including the action of disconnecting vital equipment; the doctor's duty includes providing the dying person with support until life is over.

These rules are stated, and even stated twice over, in the Code of Public Health; their importance as regards their impact on principles cannot be ignored: they imply necessarily the right to take directly lethal action; they constitute in themselves, the recognition which is not to be found in any other legal document, that there is an authentic right to suicide and a duty to provide active medical assistance for it.

For these various rights and duties to be exercised, the laws include procedures for the protection of patients: consulting a trustee or proxy, a collegial decision-making procedure and also the possibility of formulating advance directives in the form of "wishes" that the doctor must "take into account".

2)- The prohibition against inflicting death

This is, very obviously, one of the most fundamental prohibitions of free societies; it is echoed in the prohibition of "deliberately causing death" that the law imposes on all doctors and that is part of the oath they take.

But this prohibition must be interpreted in the only meaning and scope that it can be allowed to have. It is one thing for society to protect the lives of its members and, for that reason, to repress homicide which is the action of taking someone else's life; another is to define the duty of a doctor with a patient who is doomed to die; or who refuses nutrition and treatment and requests the assistance of health care providers to achieve the death he or she is calling out for. These are two radically different worlds, entirely foreign to each other: one is a crime against a person, the other, an act of ultimate solidarity as a personal service, the conditions of which are defined by the law itself.

Reiterated as one of the fundamental medical duties, respect for the prohibition cannot, furthermore, be considered independently from other fundamental requirements which are demanded of a doctor and with which it must necessarily be reconciled; it is the law, and only the law, that must accomplish this supremely complex reconciliation, as it already had to do for borderline cases when any form of treatment is rejected or when continuation of treatment is impossible; in these cases, as in other extreme instances that the law may need to deal with in the future, legislators have the duty to define the boundaries that can safeguard the essential components of the contradictory demands that they need to reconcile; this is what legislators have always done so far and the oath taken by members of the medical professions, an oath that is itself a component of the law, cannot stand against the law.

3) The law under ethical scrutiny

The debate on inducing death requires two different concepts to be combined: that of the nature of the action that can legally cause death and that of the cases where the law allows those actions to be legally performed. Although these two concepts are obviously connected, they do not entirely overlap.

One thing is clear in the French law: it is exclusively related to a concern for public health: with as its starting point a definition of the physician's duties, it now tends to put more weight on the rights of patients. But in the main, the Code of Public Health adopts a prudently implicit attitude: it defines the cases which are authorised, it mentions the actions recognised by law; but it does not reveal the close doctrinal link which connects them.

a) The nature of the actions which may cause death

The law is entirely confined within the contours of a definite doctrine: "allowing to die", the only ethical course, as opposed to "causing to die", which is not ethical and never will be. But, neither in fact nor in principle, can the situation be described in such simple terms.

This is evidenced when considering the most dire action that the law currently allows: that of disconnecting life-sustaining devices, which is also classified as the ultimate stage of "allowing to die". But can it still be reasonably claimed that we are on a logical path of simply waiting for death in the presence of an action whose unique object and unique effect will be to bring about a death that we cannot and do not wish to delay any longer and which, if that action were not performed, would not be happening?

There is clear artifice in trying to classify such action where some people would like it to be, in the convenient category of passive attitudes. There is truly no difference in kind and, consequently no ethical difference between such an action, which brings death but is nevertheless authorised, and a lethal injection which, on the contrary, must remain prohibited in all cases and all circumstances.

Do forbidden actions vanish altogether as a result of being illicit? Everyone knows well enough that this is not so, be it euthanasia or refusing treatment. To preclude, as a guiding principle, any transgression of current rules, is probably a way of ensuring a kind of ethical "purity" for legislation, by turning a blind eye if necessary to the fact that it implies in reality a real right to cause death; but in fact and above all, it adds up to condoning without even trying to know and understand them all the forbidden actions and decisions although they may be inspired by the same humane considerations as actions which are authorised.

Finally, supposing even that such a doctrine could be considered rightful, would it keep ethics safe? This seems highly unlikely. Apart from the exceptional situation when life-sustaining devices need to be switched off, "allowing to die" is simply delivering someone into death by depriving them of treatment and food, with the risk and sometimes the certitude, of thus bringing about dramatic or totally unbearable circumstances, as has been found in any number of healthcaring establishments, even and including neonatal departments where the dreadful distress of parents doomed to watch over new-borns who can neither live nor die is manifest. It would seem very doubtful that a doctrine which allows for practices of this nature, even with the assistance of palliative care, can claim that it is based on authentic ethical reflection.

The frontiers for "allowing to die" are generally uncertain and arbitrary; it is therefore very difficult to draw the dividing line between what should be prohibited and what could be allowed. Even the law that tries to impose that frontier does not respect it; nor can it do so since if it allows withdrawal of treatment, it necessarily allows everything that is associated with it, including the sometimes inevitable action of switching off a device and thereby causing death.

If truth be told, it is the very concept of "allowing to die", imperfect in both principle and its consequences, which is directly questionable.

b) Cases when death can be induced

French law, therefore, only accepts induced death in the strict framework of two medical situations which it defines. This evolved from ancient beliefs regarding the duties of a physician when confronted with an impossible situation: the case when any form of treatment is found to be definitively hopeless or when care would have to be forced upon the patient. There was no denying that although withdrawing treatment was indeed a very serious matter, in the two cases above, it had to be allowed. What was then accepted was entirely justified. But the consequences that were drawn from that acceptance in matters relating to public health and in other situations were not justified.

1- We cannot be content with false pretences: withdrawal of nutrition, to consider but one example, does not require any specific action and does not immediately manifest all its effects. It therefore seems easy to accept. And yet it kills. And it makes waiting for death unavoidable, whereas a lethal action would not. The waiting itself can be an unbearable and endless source of distress, for patients and loved ones, while health carers can only look on, powerless to relieve it.

Ethics are first and foremost a duty of coherence; the law clearly defaults on that obligation: the fact that it authorises certain actions inducing death and forbids other actions with the same effect does not follow any logical justification. But we are obliged to go one step further and say that the law defaults on ethic itself in that it accepts and allows to prolong some of the most unendurable circumstances leading to death.

2- If, as is the case today, withdrawal of treatment is the only possible action, it is obviously inconceivable in any other sequence of events but one in which treatment is already being provided; the law therefore excludes necessarily, without needing to explain, to justify, nor even consider, all the other circumstances, however serious they may be as long as they cannot be included in such a sequence of events.

c) Possibilities for reform

If truth be told, there is no convincing ethical reason for limiting assistance in suicide to the sole case of treatment refused, and even less so to the even more limited case of imminent end of life; the very spirit inspiring this duty of assistance implies on the contrary that it should include all the cases where a conscious and authentic wish to die is established, where the state of health of the requester is objectively recognisable as being extremely serious, where, finally, all the conditions are respected and all the detailed guarantees ensured in procedure and in substance, following the example of practices abroad.

Nor is there any reason why the right of all to take decisions regarding their own life cannot be given due respect when they set out their wishes in advance directives; doctors have, without dispute, the right and even the obligation, to ascertain that such wishes expressed in advance are genuine and this is without doubt a difficult task for which they need the benefit of advice of a not exclusively medical nature; they should not, however, be given the right to choose between following and not following these directives: if people all have the inalienable right of decision over their own life, then directives must be binding on physicians.

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 n° 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.

Finally, it is the duty of society to deal humanely with major, irremediable infirmities when death is requested; to forgo the denial which is the response today in such cases, would simply be honouring a duty: that of hearing the expression of extreme suffering and to bestow, quite literally, the gift of death on those who ask for it.

These proposals and possibilities must be assessed as regards their exact reality. 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.

***

Would a move forward in legislation present the danger of "trivialising death", of changing the attitude of society towards death, or even, as is sometimes claimed, undermine the cause of palliative care? Such fears rest on the very disputable postulate that the essential gravity of death would cease to be recognised solely because it is spoken of openly; and that conversely it would be more worthy of respect in places where it is not mentioned. Some go as far as supposing that liberalising the law would be detrimental to the respect that health carers owe to life; such suspicion, which is not always expressed frankly, is clearly unjustifiable. Finally, there is no confirmation that in countries who have chosen openness there has been any loss for palliative care; there is even reason to believe that, on the contrary, it has progressed in some of these countries.

There is also some controversy regarding reports from these countries. Various deviations concerning the law and practices are made much of; we are even told that they are inevitably the consequence of any liberalisation of the law. It is however perfectly possible to discuss the legislation of a country without this leading finally to a reform of the law; a law can also be added to, more precisely defined, or even modified without incurring the suspicion of laxity for that reason alone. As regards international comparisons of actual practices, they deserve a reservation in principle. In France, all forbidden actions remain concealed; it is therefore impossible to measure any kind of deviation, and in consequence to make any pertinent comparison with countries where these same actions are recognised, reported and supervised.

Nor is it therefore possible to assert that an increase in the number of actions reported in these countries would be particular to these countries and non existent elsewhere; in the circumstances, there can be no possible justification for stating that the increase, generally small, of the number of such actions which has been noted in some of these countries, is *a priori*, abnormal.

ANNEXES

ANNEXES
Annex n°1
Foreign legislation on assisted suicide and euthanasia

Country	Euthanasia	Assisted Suicide
Switzerland *Articles 114 and 115 of Criminal Code, 1942*	***Penalised***	***Tolerated according to an a contrario interpretation of the Criminal Code*** In the absence of federal and canton legislation, the directives of the Medical Sciences Academy of Switzerland (Académie Suisse des Sciences Médicales - ASSM[47]) are considered to be additional rules. In practice, assistance in suicide is organised by associations in certain Swiss cantons. → Physicians are not central to the process, ASSM considers that assistance in suicide is not a medical activity. → The only federal requirement is that the action should not have any selfish motivation.
OREGON *The Oregon Death with Dignity Act, October 27th 1997* **WASHINGTON** *The Washington Death with Dignity Act, March 5th 2009*	***Penalised***	***Legalised*** → Physicians are not central to the process. → The patient must be at least 18 years old and resident in the state of Oregon. → The criterion is "terminal disease" (incurable and irreversible condition with a life expectancy of no more than 6 months). → The patient must ask for medications twice orally and once in writing. At least 15 days must elapse since the first request and 48 hours between the written request and the delivery of the drugs. → The patient must be deemed competent to take health-related decisions (not suffer from psychiatric or psychological disorders, nor depression). → The palliative care alternative must at least be considered.
NETHERLANDS *Law on the regulation of interruption of life on request and for assisted suicide, April 12th 2001*	***Legalised***	***Legalised*** → Physicians are central to the process. → Physicians must be convinced that there is no reasonable alternative for the patient. → Suffering must be unbearable without any possibility of relief. -For people to be deemed competent to express their wishes, they must be aged at least 12 and the request must be voluntary and well settled. -For people unable to express their wishes, patients must be at least 16 and the request must be made as "advance directives".

---

[47] *Medical and ethical directives on the medical support to be given to patients at the end of life or suffering extreme cerebral disorders, by the* Académie Suisse des Sciences Médicales (Medical Sciences Academy of Switzerland).

Country	Euthanasia	Assisted Suicide
BELGIUM *Law on euthanasia, May 28th, 2002*	***Legalised*** → Physicians are central to the process. → Physicians must mention therapeutic and palliative possibilities. → Request must be in writing. → The patient must be of legal age or an emancipated minor. -For persons competent to express their wishes, the medical status must be intractable and patients must complain of unbearable continuous physical or mental suffering as a result of serious and incurable ill health due to accident or disease. Request must be voluntary, settled, repeated and free of any external pressure. -For persons unable to express their wishes (unconscious) patients must be suffering from an accidental or pathological condition which in the present state of medical science is serious, incurable and irreversible. The request must be in the form of "advance directives".	***The law is silent***
LUXEMBOURG *Law on euthanasia and assistance in suicide, March 16th 2009*	***Legalised*** → Physicians are central to the process. → Patient must be of legal age. → Request must be in writing. -For persons competent to express their wishes the medical condition must be intractable and patients must refer to continuous physical or mental suffering, unbearable and without any prospect of improvement, as a result of accident or disease. Request must be voluntary, settled, repeated and free of any outside pressure. -For persons unable to express their wishes (unconscious persons) patients must be suffering from an accidental or pathological condition which is serious, incurable and irreversible in the present state of scientific knowledge. Request must be made in the form of "end-of-life directives".	***Legalised*** → Physicians are central to the process. → Patients must be of legal age. → The request must be made in writing. → The medical status must be intractable and patients must complain of unbearable continuous physical or mental suffering as a result of serious and incurable ill health due to accident or disease. Request must be voluntary, settled, repeated and free of any external pressure.

Status report on the situation in the United Kingdom

In the United Kingdom, current discussion is on assisted suicide. In fact, the British attitude to autonomy seems to be having an influence on end-of-life issues and is more readily inclined to tolerate help in committing suicide than it is to accept taking someone else's life.

Euthanasia

Since euthanasia is not criminalised as such[48], the law takes the view that it is homicide and punishes it quite severely. In fact, the law takes account of the deed itself and the intention to kill but does not concern itself with the patient's suffering, nor repeated requests for help, nor with the doctor's compassion. Recently for example, the courts sentenced a woman who had killed her son to life imprisonment with a minimum term of nine years, which was later reduced to five years in November 2010. The son had reversible brain damage and his mother decided to give him a lethal heroin injection. The Court stated: "*We must underline that the law on murder does not distinguish between murder committed for malevolent reasons and murder motivated by familial love....mercy killing is murder.*[49]

Assisted suicide

In 1961,[50] suicide and attempted suicide were decriminalised. Today, only assisting suicide is still a criminal offence, the penalty being a maximum of fourteen years imprisonment. However, the concept of assisted suicide is more easily acceptable to the British way of thinking than that of euthanasia.

The Purdy case heard by the House of Lords (2009)

The Purdy[51] case reopened the subject once again in the United Kingdom. Debbie Purdy, was suffering from multiple sclerosis and applied to the High Court of Justice to make sure her husband would not be prosecuted if he accompanied her to Switzerland where she wished to die with the help of the *Dignitas* association. The Court held to the letter of the law. The House of Lords, however, ruled that the Director of Public Prosecutions, who decides on whether to prosecute should clarify his policy regarding prosecution for assisted suicide so as to remove the risk of arbitrary decisions.

Director of Public Prosecutions (DPP) directives (2009-2010)

DPP Keir Starmer then published directives on September 23rd 2009, modified on February 25th 2010 after a public consultation exercise. While making it clear that assisting suicide was in no way being decriminalised, as the references to "suspect" and "victim" indeed suggest, the DPP listed sixteen factors in favour of prosecution and six mitigating factors against. The main points to be noted in the criteria for not prosecuting, are, first and

---

[48] *Homicide Act,* 1957

[49] *Frances Inglis* case, January 21st 2010, Court of Appeal judgement, November 12th, 2010

[50] *Suicide Act* 1961

[51] *R. v. Director of Public Prosecutions, July 30th* 2009

foremost that the person concerned took a perfectly autonomous decision (no external pressure, no mental deficiency, taking the initiative...) and that the person who assisted was acting for purely altruistic reasons. Strangely enough, no reference is made to the physical status of the person committing suicide. However, the DPP went on to say that the list of criteria was not exhaustive and that he was not giving anyone the assurance that they would not be prosecuted. Decisions are made on a case by case basis. This position was disputed by the Commission on Assisted Dying, a private organisation composed of experts, who argued that the uncertainty was a cause for anxiety for doctors and families.

Legalisation of assisted suicide proposed by the Commission on Assisted Dying (2012)

Set up to keep a close watch on issues related to assisted dying, the Commission published a lengthy report in January 2012. After interviewing over 1,300 people, it came to the conclusion the 1961 Act was “inadequate and incoherent”.

As a consequence, the *Commission on Assisted Dying* pronounced itself in favour of legislation for assisted suicide. The model it proposed was very close to the Oregon model in the United States. Those eligible would be terminally ill, over the age of 18, with less than a year to live, but would not include the seriously disabled. They would be in sound mental health, meaning that their judgment was not in any way impaired by depression or dementia. Were that the case, the doctor’s duty would be to ensure that the patient was put in the way of receiving appropriate care. The Commission rejected the criterion of unbearable suffering which they considered to be overly subjective and not very clear. It also rejected the legalisation of euthanasia. Since only patients themselves could use the lethal substance, the respect of their wishes was protected and they would be in sole charge until the very end. Doctors should not in any circumstances be allowed to administer a lethal substance. So far, no draft legislation is under way, based on these proposals.

Status report on the situation in Canada

In Canada, the debate on euthanasia and assisted suicide began in earnest in the 1990s, with various proposals for new legislation being unsuccessfully submitted to parliament. As a result, current legislation still prohibits any active assistance to put an end to life. And yet, debate is even more topical now than it was then. Because of the governmental structure, the question is addressed at two different levels, i.e. the Federal State (competent in criminal matters) and the provinces (competent for public health). At federal level, there is a refusal to accept legislation but some of the provinces are trying to find a way of overcoming this hurdle.

I- Federal resistance

I-1- Legislation in criminal matters

At the present time, there is no formal prohibition of suicide. Although it was a criminal offence only a few decades ago, attempted suicide was decriminalised in 1972. Currently, only assisting suicide is still unlawful. Article 241 of the Criminal Code categorically forbids counselling, aiding or abetting another person to commit suicide. As for euthanasia, it is punishable under Article 222 of the Criminal Code which prohibits murder. Generally, Canadian law distinguishes between two degrees of homicide, depending on whether it was premeditated (1st degree) or not (2nd degree). Rather paradoxically, euthanasia is frequently qualified by the law as 2nd degree homicide although the intention to kill is generally not in doubt.

Since the 1990s, parliamentarians have submitted more than a dozen draft bills on voluntary death[52]. The latest of these, in favour of decriminalising assistance in dying, was submitted in May 2009[53]. It proposed an authorisation procedure for euthanasia and assisted suicide. The person concerned had to be at least 18 and be *suffering acute physical or emotional pain without any prospect of alleviation,* or be in the *terminal phase of disease.* The law was not voted, however, because of a large number of criticisms and was rejected by a massive vote of 228 votes against 59 on April 21st 2010.

I-2- The jurisprudence of the Supreme Court of Canada

Canada's Supreme Court confirmed the prohibition of assisting suicide in the notorious *Rodriguez* case in 1993[54]. A woman with amyotrophic lateral sclerosis asked the judges to recognise that Article 241 of the Criminal Code was unconstitutional, but did not win her case. The judges based their decision on the fact that the Criminal Code was intended to protect vulnerable people and that only complete prohibition was acceptable.

The Supreme Court also confirmed the prohibition of euthanasia in the *Latimer* case. In November 1994, Robert Latimer was convicted of 2nd degree homicide by asphyxia on the person of his severely disabled daughter, Tracy, aged 12. He was sentenced to life imprisonment without any possibility of release on parole for 10 years.

II- Rifts in the provinces

While the Federal Government does not seem at all eager to legalise euthanasia and assisted suicide, the provincial law courts are not as fiercely opposed. Generally speaking, the provincial courts are fairly lenient in end-of life-cases. Firstly, there seems to be a certain degree of impunity, since people accused of assisting suicide mostly receive suspended sentences or probation periods. Furthermore, first degree murder accusations are frequently reclassified during the trial to second degree murder, or even to no more than administration of a harmful substance.

Recently, two provinces have specially drawn attention to their disagreement with federal policy: British Columbia is attempting to gain recognition for the legitimacy of assistance in dying through the unconstitutional nature of the provision of the federal criminal code, while Quebec prefers to elude the issue via health care legislation.

---

[52] Since 1991, 8 draft bills were submitted to the House of Commons (C-351, C-203, C-261, C-215, C-385, C-407, C-562, C-384) and 3 to the Senate (S-13, S-29, S-2).

[53] Lalonde bill C-384 (May 13th 2009)

[54] Rodriguez vs British Columbia, Sept. 30th 1993.

II-1- British Columbia: the constitutional battle

The *Carter* case in 2012[55] attracted a great deal of attention: British Columbia's Supreme Court did not follow the example of the *Rodriguez* case and judged that the total prohibition of assisting suicide was not constitutional because it was disproportionate. It further considered it to be discriminatory: the fact that suicide was not forbidden by law whereas assisting suicide was, put people who could not commit suicide unaided at a disadvantage. According to the Court, suicide and assisting suicide cannot be treated differently by the legal system. The case is still pending a decision on appeal, forthcoming shortly.

II-2- Quebec: the legislative battle

Recently, Quebec has been coming to terms with the idea of euthanasia. In a June 2007 survey, out of all Canadian provinces, it was the one most in favour (87% of Quebec citizens). The Royal Society of Canada then issued an opinion rather in favour of legalisation in November 2011[56], followed by an identical position reported in March 2012 by a Commission specifically tasked by the Quebec National Assembly, after a survey throughout the province and a large number of public consultations. The Ménard Committee, composed of legal experts, was asked to reflect on how such legislation could be implemented, and reported in January 2013[57]. A draft bill is to be proposed in June 2013.

The report suggests a way in which the federal obstacle could be circumvented. Medical assistance in dying would be designated by the wording "care at end of life". The consequence would be that assisting suicide would come under health care for which competence is provincial and the Federal Government has little power.

Both the Ménard and the Commission's reports, start off with defining the scope of a possible law: which is medical assistance in dying at the end of life. However, under closer examination of the text, while the medical aspect is indisputable, the end-of-life criterion is not clearly outlined: "*The Committee subscribes to the idea that de facto medical assistance in dying is necessarily situated at the end of life, but does not express a requirement for terminal disease.*"[58] There would be therefore a degree of confusion, insofar as there is a requirement for serious and incurable disease… Concerning the medical conditions for assistance in dying, there must be on the one hand the existence of a serious and incurable disease, and on the other hand, the medical status of the persons concerned must be characterised by advance degradation of their capacities, without any prospect of improvement. Finally the persons concerned must be experiencing continuous, unbearable physical or psychological torment, with no possibility of alleviation. The Commission judged physical and psychological pain to be of equal importance. Rolling out the logic of qualifying assistance in dying as "care", it adds: "*the decision to ask for medical assistance in dying*

---

[55] Carter v/ Canada, June 15th 2012 (2012 BCSC 886)

[56] SOCIETE ROYALE DU CANADA, *Prise de décision en fin de vie,* (End-of-life decisions) November 2011

[57] MENARD, GIROUX and HEBERT, « Mettre en œuvre les recommandations de la Commission spéciale de l'Assemblée nationale sur la question de mourir dans la dignité » (Implementation of the recommendations of the National Assembly's special Commission on the subject of dying with dignity), *Report by legal experts, January 2013.*

[58] *Ibid*, p. 357

must not require a greater degree of competence to consent than for any medical treatment[59]. It would seem therefore that the Committee is not recognising any specificity for end of life decisions.

The Committee does not, however, wish the possibility of assistance in dying to be proposed to people suffering from *"a mental disorder, such as depression".* When that is the case, the physician must advise his patient to seek appropriate treatment. In the same way, "*the existence of some form of cognitive deficit is not sufficient to make a person incapable of consent. [...] Therefore, people who have been diagnosed with dementia or Alzheimer's disease, in the early phases of their condition, are still generally capable of consent and it is only as the disease progresses that they become incompetent to consent to treatment"*[60].

Although the Committee is of the opinion that the possibility of medical assistance in dying should only be open to competent people of legal age, the question of extension to minors does arise. In fact, if the law accepts that this assistance can be qualified as "care", existing law recognises the capacity to consent to, or refuse treatment to minors over the age of fourteen. It is true that this is not a real "medical legal coming of age" since a minor's decision may be reversed by parents or even in court. However, the question is not clearly settled.

The Committee proposes an *a posteriori* verification by a coroner and also an *a priori* verification by a court in the event of difficulties arising over competence and acquisition of admissibility criteria.

---

[59] *Ibid.* p.359

[60] *Ibid.,* p.360

Annex 2
Outcome of systems adopted in other countries for assisted suicide and euthanasia

Beyond French borders, several other countries have already begun to deal with the problems raised by euthanasia and assisted suicide, either by choosing to accept one or the other of these two practices, or by accepting both. While some countries are debating today on the subject of following suit, as is presently the case in Quebec and the United Kingdom, others on the contrary are reversing course. Such an example is to be found in Australia, in the Northern Territory, where euthanasia and assisted suicide had been legalised in 1995 but the Federal Government then overrode the decision in 1997.

I- The legalisation of assisted suicide (Oregon and Washington state)

Some fifteen years ago, Oregon made assisted suicide legal. The state of Washington followed suit in 2009 and the Supreme Court of Montana recognised these rights in the same year, in its ruling on *Baxter vs Montana* of December 31st 2009. Since the entry into force of its *Death with Dignity Act*, Oregon has reported about a thousand cases of assisted suicide. Figures are increasing year by year but not at an alarming rate[61].

The principal condition required by these two quasi-identical legislations is that the patient be terminally ill, i.e. that not only disease be involved (infirmity or extreme old age are not sufficient as made additionally clear in 1999), but that there must also be an end-of-life situation (with a life expectancy of under six months). Contrary to the situation in the Benelux countries, lawmakers did not include suffering as a criterion, which is difficult to evaluate and much more subjective than sickness.

The law goes on to prohibit explicitly the administration of lethal medication to someone suffering from psychiatric or psychological disorders, or depression, since such conditions could impair the faculty to consent. For this reason, the physician can seek advice from a colleague specialising in psychological conditions. However, in the last few years, there has been a drop in such psychiatric consultation: in Oregon up to 2005, 14% of assisted suicides were preceded by expert psychiatric referral, whereas in 2010, the percentage fell to 1.5%, and 3% in Washington state[62].

Regarding the public health care insurance in these American states, very different from the system in France, it seems that legislation on assisted suicide was designed with access to palliative care in mind. The law only allows assisted suicide for people whose life expectancy is thought to be less than six months. According to a 2007 report by the *Oregon Health Services Commission,* it is only during that time period that people under the protection of

---

[61] In their annual reports, the figures were 71 cases in Oregon and 94 in Washington state for the year 2011.

[62] LEGROS B., *Euthanasie, arrêt de traitement, soins palliatifs et sédation,* (Euthanasia, withdrawal of treatment and sedation). Les Etudes Hospitalières, 2011, p.248

Medicaid (health care insurance for people with a low income) are admitted to palliative care under the Medicare programme[63].

So as to curb any tendency to abuse, the two laws provide for supervisory bodies. However, on reading various reports, it would seem that their task is more closely involved with recording statistics than with censure.

II- Tolerance for assisted suicide in Switzerland

In Switzerland, the state is competent at two levels: federal and cantonal. At federal level, the Criminal Code clearly bans euthanasia but tolerates assisted suicide when it is practised for unselfish reasons. It is then up to the cantons, whose competence covers health care, to legislate on the subject or refrain from doing so. If there is no legislation, the authorities follow the rules set out by the *Académie suisse des sciences médicales* (Medical Sciences Academy of Switzerland).

This absence of legislation has sometimes led to abuse on the part of certain associations concerned with assisting suicide. For instance, some suicides were organised in incongruous settings, such as in cars or caravans on parking lots (autumn 2007). Methods were sometimes changed, with helium replacing NaP (in the spring of 2008). One rumour went as far as saying that the ashes of suicides had been cast into a lake in Zurich (October 2008) [64]. Leaving aside the subject of sometimes questionable methods, associations providing assistance with suicide generate a feeling of unease because of the “business” slant on their activities. Several marketing and advertising campaigns (advertisements in the media: radio, public transport, etc.) were launched and the turnover of some associations is rapidly expanding, as much as doubling in just a few years[65]. Finally, in recent legal proceedings, an assistant who had herself turned on the tap allowing the lethal substance to infuse, thus performing an action resembling euthanasia which is banned, was acquitted[66].

But what attracts the most adverse comment is the broadness of the selection criteria the associations use. There is no obligation to be a resident of Switzerland for candidates to suicide, so that certain associations, like *Dignitas*, accept foreigners (33% of the assisted suicides in 2007). This also gives rise to “death tourism” which does no credit to Switzerland’s image and disturbs legal order in neighbouring countries. Furthermore, the associations frequently accept the applications of people who are not nearing the end of their lives. In the figures for assisted suicides supplied by *Exit Deutsche Schweiz* for the years 2001 to 2004, 34% of the people committing suicide were not suffering from life-threatening

---

[63] *Ibid.,* pp.242-244

[64] DFJP, *Assistance organisée au suicide : examen approfondi des solutions envisageables et de la nécessité d’une nouvelle règlementation fédérale,* (Organised assistance for suicide: in depth examination of possible solutions and of the need for new federal regulations). 2009

[65] This is the case for Dignitas. Turnover was 770,000 Francs in 2004 and 1.4 million in 2008.

[66] DREYFUS A., « Notre mort nous appartient », in *Marianne,* April-Mai 2013

diseases[67]. These organisations also sometimes help people with psychological diseases or disorders. On that score, on November 3rd 2006, the Federal Court recognised a right to suicide for people suffering in this way, on the condition that they be competent to express their judgment freely (Hass case). Finally, in the last few years, some associations have opened their doors to people in good health. This policy was announced by *Dignitas* in June 2008[68] and by *Exit Deutsche Schweiz* in September 2008[69]. Jérôme Sobel, the president of *Exit ADMD* in Suisse Romande, however, recently stated that all requests for suicide are not necessarily valid[70]. ASSM also considers that certain criteria, such as loss of the will to live or poor quality of life are not sufficient to give rise to the right of assisted suicide[71].

Between 2003 and 2007, the number of assisted suicides has increased by 52%[72], after which there was a lull in their progression. The authors of the 2009 report express with caution the idea that the lull might be connected to a reinforcement of palliative care, which the associations do not always offer[73].

In recent years, the *Conseil fédéral* preferred to maintain a *statu quo* because they did not wish to bestow state status on the practice of assisted suicide. The Federal Court, in the Hass case, refused to accept as a constitutional right the handing over of a lethal dose of prescribed NaP. Nevertheless, the strict application of the law by public authorities has sometimes given rise to abuse by organisations assisting suicide. For example, it was because surplus doses of NaP illegally stocked by one of these associations were confiscated, that it turned to helium to satisfy earlier commitments[74]. But this tendency to the *statu quo* was questioned in June 2012 when the Vaud canton decided to draw up legislation on the subject, a first for Switzerland.

III- Legalisation of euthanasia and assisted suicide in the Benelux

After several decades of the practice being accepted, the Netherlands legalised euthanasia and assisted suicide in 2001. In 2002, Belgium followed suit for euthanasia but remained silent on assisted suicide. Finally, in 2009, Luxembourg accepted both. At a time when the outcome in Luxembourg is not yet very clear and only involves a few cases per year, progress in the Netherlands and Belgium is, to say the least, alarming. In recent times, there has been an 18% annual progression in the number of cases for euthanasia (2010-2011) [75]. Already in

---

[67] DFJP, *Assistance organisée au suicide…,(* Organised assistance for suicide...,) op. quoted above, p.7

[68] http://www.blick.ch/news/schweiz/todes-service-jetzt-auch-fuer-gesunde-id163490.html

[69] DFJP, *Assistance organisée au suicide…, (*Organised assistance for suicide*)...,* op. quoted above, p.7

[70] "There is no intention to follow the wishes of someone in good health who makes an emotional appeal because they have lost their job or their spouse has left them. In that respect, we can also be a good safeguard against suicide for futile reasons". in DREYFUS A., « Notre mort nous appartient », in *Marianne,* April-May 2013

[71] ASSM, *Problèmes de l'assistance médicale au suicide,*(Problems concerning medically assisted suicide) 2012

[72] DFJP, *Assistance organisée au suicide…,(* Organised assistance for suicide...,) op. quoted above

[73] LEGROS B., *Euthanasie…*, (Euthanasia..., quoted above, p.233 ; Sicard Report, pp.67-69

[74] DFJP, *Assistance organisée au suicide…,(* Organised assistance for suicide...,) op. quoted above

[75] Sicard Report, p.75

2009, when the annual rise was 13%, the UN had made it known that they considered it a reason for concern[76]. In Belgium, for euthanasia, numbers have almost trebled since 2006[77].

III-1- Extensive interpretation of the text of the law

In Belgium, the text of the law stipulates as admissibility criteria the presence of unbearable and continuous physical or psychological suffering as a result of serious and incurable accidental or pathological conditions. In just a few years, the interpretation of this concept has been considerably distended as evidenced by the various reports from the supervisory commission.

It is probably the concept of suffering which has been mostly revisited by the Belgian supervisory commission. First of all, as regards the characteristics of suffering, the Belgian commission considered, in its first report (2002-2003) that the unbearable nature of suffering was "*mainly subjective and depended on the patient's individual personality, ideas and values*"[78], making it difficult to evaluate by a doctor. Similarly, "*as regards the intractable nature of the suffering, the fact that the patient has the right to refuse treatment for suffering, even palliative, must be taken into account*[79]*".* In its third report, the Commission decided that the unbearable and intractable nature of suffering should sometimes take into account the patient's age and that "*the expectation of dramatic developments (coma, loss of autonomy, progressive dementia) was considered to be unbearable and intractable psychological suffering".* [80]

Furthermore, the law requires the source of the suffering to be pathological or accidental. In fact, the Belgian supervisory commission accepts the applications of people who are solely suffering the effects of extreme old age[81]. In its fourth report (2008-2009), several members of the Commission (a minority) were unable to agree to this extended interpretation of the law, considering that suffering and the request for euthanasia in this case were not connected to illness but to the consequences of old age[82].

---

[76] HUMAN RIGHTS COMMITTEE, Report, Vol.I, General Assembly, United Nations, Official Documents, 64th session, supplement n°40, 2009, p.69. Available at http://ccprcentre.org/doc/ICCPR/AR/A_64_40(Vol I)_Eng.pdf.

[77] There were 429 cases in 2006 and 1133 cases in 2011.

[78] *Commission fédérale de contrôle et d'évaluation de l'euthanasie*, (Federal Commission for the control and evaluation of euthanasia) First report to the houses of parliament, September 22nd 2002-December 31st 2003, p.16

[79] Ibid.

[80] Commission fédérale de contrôle et d'évaluation de l'euthanasie, (Federal Commission for the control and evaluation of euthanasia)*Third report to the houses of parliament,* (2006-2007), p.24

[81] For example, in March 2011, a couple's application for euthanasia was accepted although only the husband was terminally ill with cancer. His wife's sufferings were due to extreme old age. See http://www.ieb-eib.org/fr/bulletins/bulletin-de-lieb-14-avril-2011-56.html#sujet131

[82] Commission fédérale de contrôle et d'évaluation de l'euthanasie, (Federal Commission for the control and evaluation of euthanasia) *Fourth report to the houses of parliament* (2008-2009), p.22

Similarly, the Commission is increasingly receptive to cases of psychiatric disorders. In its second report (2004-2005), some neuropsychiatric disorders were already present: 6 cases in 2004, 3 in 2005[83]. Following on from the third report and its broad interpretation on the subject of psychological suffering, it can be seen that in the category of euthanasia for people whose death is not thought to be imminent, the number of neuropsychiatric conditions rose from 8% to 24% over two years[84], thus contributing to the confusion between psychological suffering and psychiatric disorders.

The sole criterion in the Netherlands is that of unbearable suffering with no prospect of improvement. However, the Supreme Court is very lenient with physicians who have accepted a request for euthanasia from a person who has simply lost the will to go on living (Brongersma case, December 24th 2002)[85].

III-2- Claiming for the right to euthanasia and assisted suicide for the most vulnerable

The issue of opening these rights to minors is currently being debated in Belgium. With respect to the various draft bills already submitted, the debate is between keeping an age-limited threshold or eliminating that threshold in favour of the capacity for discernment (which some situate as being present as early as around 7 or 8 years. The Netherlands, for their part, already recognise the right for minors of 12 years onwards. This was one of the new items that the 2001 law added to existing practices at the time. For the 16-18 year olds, parents must participate in the decision making process and for 12-16 year olds, double consent is required, that of the child and of his or her parents.

In Belgium, the question of allowing euthanasia for people who are insane was also considered[86], in particular for those who had expressed their wishes in non time-limited advance directives. Today, the discussion also touches on the subject of people with Alzheimer's disease, although several cases have already been mentioned in reports. In the Netherlands, twelve cases of insanity were noted in 2009. In their report, the Dutch supervisory commissions simply recommended that doctors should exercise more caution as regards the person's capacity of discernment. They added that the presence of another doctor was essential for psychiatric disorders with the exception of dementia and depression[87].

Finally, there is still the case of new-borns. Belgium's influence is visible on the Groningen Protocol, launched in the Netherlands. This agreement was reached between the Groningen

---

[83] 1 case of Creutzfeldt-Jakob disease, 3 cases of Alzheimer's, 1 case of Huntington's, 4 of intractable major depressions. (Federal Commission for the control and evaluation of euthanasia) *Second report to the houses of parliament* (2004-2005)

[84] LEGROS B., *Euthanasie…,* (Euthanasia) op. quoted above, p.276

[85] The physician was found guilty on the principle, but incurred no penalty. LEGROS B., *Euthanasie….,* (Euthanasia) op. quoted above, p.266

[86] Submission 53 0498/001, October 28th 2010

[87] COMMISSIONS REGIONALES DE CONTROLE DE L'EUTHANASIE, (Regional commissions supervising euthanasia) *2009 Report.*

Academy hospital and the Courts to allow shortening the lives of severely disabled neonates. Paradoxically, the practice is illegal but is officially supervised.

III-3- Ineffective supervision of practices

First, there is a noteworthy downward trend in the consultation of other physicians at the time of determining the eligibility to assisted suicide or euthanasia. As remarked above, the Belgian Commission does not consider it essential to obtain the opinion of another doctor when dealing with dementia or depression. In the Netherlands, before the 2001 law, the doctor needed to consult with at least two independent experts, one of which had to be a psychiatrist. Since that law was passed, the doctor need only consult with one colleague, without any specification regarding medical speciality. As in Oregon, psychiatric referrals are becoming rarer. Sometimes even, with the excuse of urgency, Dutch doctors do not consult a colleague. It is true that this attitude is criticised by the Dutch Commissions, but only *a posteriori*[88]. Finally, in Luxembourg, the doctor's opinion only concerns the serious, incurable and hopeless nature of the disorder, as well as the continuous and unbearable physical or psychological suffering, but not the question of consent[89].

Moreover, in these three Benelux countries, the supervision system is declaratory and *a posteriori*, which allows for some doubt regarding the safety of supervision: for which reason the number of sanctions is close to zero. In ten years of practice, not one case was referred to the Public Prosecutor in Belgium[90]. In the Netherlands, only a few cases per year are penalised[91]. In Luxembourg, every case of euthanasia has been pronounced legal[92].

III-4- Is there an alternative?

In Belgium, the Health Commission had unanimously agreed to the insertion of an *a priori* palliative care filter into the euthanasia procedure, but this was eliminated when the law was drafted. And yet, people undergoing palliative care seem to be less demanding of euthanasia than others. For the year 2010-2011, 10% of euthanasia requests were formulated by doctors trained in palliative care, whereas 50% by general practitioners and 40% by specialists[93]. Belgian doctors seem to be increasingly less trained in palliative care. Of the practitioners consulted for euthanasia, 19.5% were trained in this discipline according to the first report in 2002-2003, while in 2009 there only remained 10%[94].

---

[88] CRCE, *2009 Report*

[89] COMMISSION NATIONALE DE CONTROLE ET D'EVALUATION DE LA LOI DU 16 MARS 2009 (National commission for supervising and evaluating the March 16th 2009 law), *First report,* (2009-2010)

[90] IEB, Dossier, *Euthanasie : 10 ans d'application de la loi en Belgique, (*Euthanasia: 10 of years of law enforcement in Belgium), April 2012

[91] CRCE, Annual Report

[92] CNCE, First Report, (2009-2010)

[93] IEB, Dossier…, op. quoted above

[94] LEGROS B., *Euthanasie…,* Euthanasia..., quoted above, p.282

Similarly, there appeared to be an improvement in palliative care in the Netherlands. However certain studies show that, although undeniably the number of palliative care units has grown, the quality of their services is not always equal to the task. The most symptomatic evidence of this trend is the excessive amount of sedation in the terminal phases. In fact, pain, dyspnoea and confusion, habitually the realm of palliative care, are frequently managed with sedation by Dutch doctors. It is often resorted to without investigation by the practitioner that the symptom is refractory, nor that suffering is unbearable, nor that life is at an end (life expectancy of one or two weeks)[95]. A study showed that a specialist palliative care team was not in favour of sedation in the terminal phase in 42% of cases. This negative vote was motivated in 96% of cases by the absence of refractory symptoms[96]. Sedation in the terminal phase tends to become routine although it should normally be exceptional.

III-5- Access to death made increasingly easier

Euthanasia and assisted suicide are becoming increasingly routine in the Benelux countries. In Belgium, it is becoming less and less rare to see nursing staff practising euthanasia although in theory they are not allowed to[97]. In the same direction, since 2005 Belgian pharmacies have been offering a “euthanasia kit” for sale[98].

As for the Netherlands, the “Uit wrije wil”, (i.e. “Willingly”) association, is actively militating for greater accessibility to euthanasia. For instance, they demand that anyone over the age of 70 who is simply tired of living be given this right. It is this association which launched the idea of mobile euthanasia teams and clinics specialising in end of life.

---

[95] MATTELAER X., AUBRY R., *« Pratique de la sédation aux Pays-Bas : preuve du développement des soins palliatifs ou dérive euthanasique ? »* (Practising sedation in the Netherlands: proof of an extension of palliative care or an abuse of euthanasia?), in *Médecine Palliative,* Vol.11, June 2012

[96] DE GRAEFF A., JOBSE AP., VERHAGEN EH., MOONEN AAJ., *De rol van consultative bij palliative sedatie in de regio Midden-Nederland,* Ned Tijdschr Geneeskd 2008 ; 152 : 2346-50

[97] LEGROS B., *Euthanasie…,* op. quoted above*,* p.280-281

[98] http://lci.tf1.fr/science/2005-04/kit-euthanasie-dans-pharmacies-belges-4895910.html

Annex 3

INSUFFICIENT TRAINING AND IMPOSSIBLE JURISDICTIONAL DIVISION

Extract from the report by the French Commission for reflection on "solidarity in France at the end of life, submitted on 18th December 2012 to François Hollande, President of the French Republic

In the training of members of the medical, nursing and allied professions, little or no time at all is devoted to management, support and care 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* (diploma) 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.

Recommendations

Ask the Conference of Deans, as of 2013:

- To create in each university a higher education course specifically on the subject of palliative care.
- To reconsider medical studies exhaustively so that curative stances cease to confiscate the entire educational scene:
- Make palliative care training compulsory, including an in-depth examination of the various clinical situations.
- Develop training on the correct use of opiates and sedative medications..
- Initiate university and continuing education on the meaning of "*unreasonable obstinacy*".

- Provide training throughout the university degree courses of medical students on the need for good human relationships in end-of-life situations, with the help of the human and social sciences, and encourage these students to reflect on the excesses of medicalization.
- During their internship, make training courses in a palliative care unit compulsory for students, general practitioners and specialists particularly concerned by the treatment of serious diseases.

Similar steps must be taken in institutions training other health care providers.

- For the continuing education of physicians (*Développement Professionel Continu*), require that one of the annual training courses for practising physicians, at least once every three years, should be devoted to palliative care and the attitudes that should be adopted when caring for sick people nearing the end of their lives.

- Similar steps should be taken in the continuing education of other health care providers.