OPINION 139

ETHICAL ISSUES RELATING TO END-OF-LIFE SITUATIONS: AUTONOMY AND SOLIDARITY

COMITÉ CONSULTATIF NATIONAL D'ÉTHIQUE
POUR LES SCIENCES DE LA VIE ET DE LA SANTÉ

Note for the English translation:

In France, a 2016 law:
- confirmed the importance of the right to palliative care,
- strengthened the role of the “trusted person”,
- increased the authority of advance directives and offered the possibility of continuous deep sedation until death to people suffering from a serious and incurable disease, who are expected to die in the short term and who are experiencing suffering that is refractory to treatment.

However, a request in our society for voluntary assisted dying is expressed through legislative proposals, opinion polls, and NGOs. This request is most often based on the claim to the right to self-determination and the right to define the limits of a dignified life for oneself.

If it should be stressed that the anguish of death will never be alleviated by medicine alone and that, in the words of the CCNE in its Opinion No. 129 of the 18th of September 2018, "ethical questions will never be resolved by law", the CCNE decided, in 2021, to look again at the end-of-life issues.

OPINION 139

ETHICAL ISSUES RELATING TO END-OF-LIFE SITUATIONS: AUTONOMY AND SOLIDARITY

The Council voted on the text of this Opinion during the 30th of June 2022 Plenary Session.
Some members of the Council have wished to express a “Reservation” in a contribution completed on the 8th of September 2022.
This Opinion was made public on the 13th of September 2022.

This Opinion follows a self-referral by the French National Advisory Ethics Council on Health and Life Sciences (CCNE) in June 2021. It is based on the discussions held in a dedicated working group and during the plenary sessions devoted to it.[1]

It begins by recalling the work carried out by the CCNE and the legislative developments that have taken place over the last twenty years concerning the support of people at the end of their lives. It then examines the ethical issues relating, on the one hand, to the implementation of the current law (2016 law) and, on the other hand, to the situations of people suffering from serious and incurable diseases who are expected to die not in the short term, but in the medium term.

Finally, the CCNE makes a number of recommendations, presented in two parts:

- The strengthening of public health measures in the field of palliative care.
- The unavoidable ethical requirements in the event of the decriminalisation of voluntary assisted dying.

The CCNE considers that there is indeed a way to ethically apply voluntary assisted dying, but that it would not be ethical to consider a change in legislation if the public health measures recommended in the field of palliative care are not taken into account.

As in its previous works on end-of-life issues, the CCNE emphasises two fundamental principles in this Opinion: the duty of solidarity towards the most vulnerable people, and respect for personal autonomy. The reconciliation of these two principles remains the guiding principle of this Opinion in all its components.

The purpose of this Opinion is to inform public debate, the practices of health professionals and the legislator.
It has been the subject of debate among the members of the CCNE and has led the Council to publish, together with the majority opinion, a different opinion expressed by a number of its members.

This Opinion is presented in a context marked by the current alarming situation of the health system, and in particular of the public hospital system, following the health crisis. The worrying shortage of health professionals and their suffering once again underline the essential nature of their role in supporting people with serious, advanced illnesses and the duty of solidarity towards them.

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[1] The CCNE was renewed on the 22nd of April 2022.

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Some members of the CCNE have wished to publish an associated text entitled “Reservation”.

INTRODUCTION

Since its creation in 1983, the CCNE has examined ethical issues relating to the end of life on several occasions, culminating in Opinion No. 121 of the 30th of June 2013, in which it presents its most reasoned reflections on the subject. In his foreword, the President of the CCNE stated that this Opinion represented a stage in the council's reflection, specifying further that: "reflection on the subject of the end of life is not yet closed...".

Ten years have passed, during which important legislative developments have occurred both in France and in other countries.

The law No.2016-87 of the 2nd of February 2016, known as the Claeys-Leonetti law, confirmed the importance of the right to palliative care, strengthened the role of the "trusted person", increased the authority of advance directives and offered the possibility of continuous deep sedation until death to people suffering from a serious and incurable disease, who are expected to die in the short term and who are experiencing suffering that is refractory to treatment.
In other countries, several states have developed their legislation in the direction of legalising or decriminalising assisted suicide. This is the case in Austria as well as in about ten states in the United States, following the pioneering legislation in this direction in the state of Oregon in 1997. In Germany, following the Federal Constitutional Court's ruling of the 26th of February 2020 declaring the provision of the German Criminal Code prohibiting assisted suicide to be unconstitutional on the grounds of freedom of self-determination, three bills have been tabled in parliament to regulate such assistance.[2] Similarly, over the past decade, several states have passed legislation allowing both assisted suicide and euthanasia.[3] These include Spain, Canada, several Australian states and New Zealand. Various drafts are in preparation or under consideration in Italy, Portugal and Ireland.[4]

Numerous studies show that the apprehension of the end of life still raises deep questions or concerns among our fellow citizens. Believing it necessary to provide them with a new response, several members of parliament tabled a bill on the 19th of January

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[2] They were discussed at first reading on the 24th of June 2022 by the Members of the Bundestag.

[3] Belgium, the Netherlands and Luxembourg adopted such legislation in the early 2000s. Switzerland, which does not allow euthanasia, had, as early as 1937, limited the scope of the criminal law to assisted suicide carried out with a "selfish motive", thus leaving assistance carried out with an altruistic motive out of scope.

[4] In Ireland, after a draft was adopted on the 7th of October 2020 by the lower house of Parliament, the legislative process was halted following the conclusions of a "Joint Committee on Justice" composed of MPs and Senators, which reported "serious technical and legal shortcomings" in the text under consideration.

2021, No. 3755, "aimed at affirming free choice at the end of life and ensuring universal access to palliative care in France".

In the light of all these developments since its last Opinion in 2013, and in accordance with the wishes of President Jean-François Delfraissy as expressed in a letter of mission sent to the rapporteurs on the 21st of May 2021, the CCNE has decided, by means of a self-referral in June 2021, to examine in greater depth certain ethical issues in the debate, relating to:

- Ways of improving the implementation of existing legislative and regulatory provisions;
- Ways of dealing with the complex situations of people who are expected to die not in the short-term, but who are nevertheless faced with the inevitability of imminent death, either as a result of a serious, progressive and incurable disease, or as a result of a decision to stop life-sustaining treatment.

In its previous works on end-of-life issues, the CCNE emphasised two fundamental principles: the duty of solidarity towards the most fragile people and the respect for personal autonomy. The reconciliation of these two principles remains the guideline of this Opinion in all its components.

I. THE CCNE'S ETHICAL REFLECTION AND THE LEGISLATIVE DEVELOPMENTS THAT HAVE TAKEN PLACE OVER THE LAST TWENTY YEARS CONCERNING THE SUPPORT OF PERSONS AT THE END OF THEIR LIVES

A – The characteristics and paradoxes of our contemporary relationship with death

Contemporary Western societies are marked by a painful paradox: death is both exposed everywhere, in the media, newspapers, films, literature, video games, etc., and deeply feared to the point of often being avoided, even denied, disavowed.[5] At the same time, the omnipresence of injunctions to beauty, health, performance and the search for perpetual youth feed a thanatophobic culture, complicating or even obscuring the approach to the end of life.

The end of life is no longer perceived as an essential time in the human experience. Illness, disability and ageing are sources of marginalisation. Rites of passage are disappearing, secularisation is progressing, and symbolic and spiritual representations are gradually disappearing. Because of its medicalisation, sometimes its over-medicalisation, the end of one's life is increasingly taking place in healthcare settings,[6] and death is still often seen as a failure by medical teams.

A certain fantasy of "dying well" or "good death" is increasingly developing. Many of the doctors interviewed for the purpose of drafting this Opinion stressed the danger of allowing this hope to persist: no death is, strictly speaking, *gentle*, whether it occurs naturally or following voluntary assisted dying. Whether sudden or prolonged, accompanied or solitary, natural or induced, it remains a physical and metaphysical ordeal, which medicine cannot always alleviate to any great extent.

The lockdown and severe constraints linked to the Covid-19 health crisis (restrictions on visits by relatives of palliative care patients, very strict burial conditions, etc.) have further altered the quality of end-of-life conditions, giving rise to a major collective awareness of the need to accompany people to the end of their lives and to respect our duty not to abandon them.

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[5] According to the terms of the "Sicard report". Commission de réflexion sur la fin de vie en France. Penser solidairement la fin de vie. 18/12/2012. https://www.vie-publique.fr/sites/default/files/rapport/pdf/124000675.pdf

[6] More than one in two deaths occur in a hospital, about one in four at home. See : Deaths in 2018 in France. INSEE. 01/10/2019, https://www.insee.fr/fr/statistiques/4218743

B – The previous reflections of the CCNE on the accompaniment of people at the end of their lives

Since its creation, the CCNE has devoted a great deal of work to ethical issues relating to the end of life. In particular, two Opinions have been devoted entirely to this subject:
- Opinion No. 63, "End of life, cessation of life, euthanasia" of the 27th of January 2000;
- Opinion No. 121, "End of life, personal autonomy, wish to die" of the 30th of June 2013.

To these two Opinions should be added the reflections shared in Opinion No. 128, "Ethical issues of ageing" of the 15th of February 2018, as well as the chapter on "Support at the end of life" included in Opinion No. 129 of the 18th of September 2018 published on the occasion of the revision of the bioethics law.

The major ethical principles that permeate French legislation in this area have been informed by this work as well as by several other notable contributions. In particular, we would like to mention:

- The information report No. 1287 of the 28th of November 2008 produced by the parliamentary mission to evaluate the law of the 22nd of April 2005, chaired by Mr Jean Leonetti;
- The report "*Penser solidairement la vie*" of the 18th of December 2012 produced by the *Commission de réflexion sur la fin de vie en France*, chaired by Prof. Didier Sicard;
- The Opinion of the Citizens Committee[7] expressed during the Estates General on bioethics in 2018;
- The Opinion of the Economic, Social and Environmental Council "*End of life: France at a time of choice"* presented by Mr Pierre-Antoine Gailly, rapporteur on behalf of the Temporary Committee on the End of Life, 10/04/2018;
- Surveys by the French Society for Palliative Care and Support (SFAP), current and past.

This work recalls the importance of initial and ongoing training of healthcare professionals in the recommendations of good practices, and the development of palliative care[8] throughout the country, in healthcare and medico-social institutions as well as in people's homes. In particular, they call for the integration of a palliative culture into all healthcare acts, including the refusal of unreasonable obstinacy.

The CCNE's previous reflections have been built on the search for the right articulation of the principles of freedom, dignity, equity, solidarity and autonomy.

In 2018, in its Opinion n° 129, the CCNE stressed that all persons are worthy, whatever their status, condition, degree of independence or self-determination; that dignity is intrinsic to being, that we can only lose the feeling of it, recognising moreover the extent of the suffering involved. This position is not universally shared, we suffer from the failure to formulate a collective definition of dignity: "*this word is a trap because it is both very fashionable and very confusing (...). Today, this concept is invoked rather than de-*

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[7] https://www.ccne-ethique.fr/node/521?taxo=93
[8] Palliative care is intended to manage the physical and psychological suffering of people with a lethal disease in its various stages. It is not limited to the terminal stage of an illness.

fined, used rather than understood".[9] The CCNE nevertheless reaffirms that the ethical dilemma that characterises the complexity of end-of-life situations does not concern the question of dignity.[10] It considers that the ethical tension at stake mobilises, on the one hand, the question of freedom to determine one's own degree of tolerance for suffering and the contours of one's personal destiny and, on the other hand, that of our duty of solidarity towards people at the end of their lives.

Some people in extreme suffering question the fine line between solidarity and abandonment in the face of great vulnerability. What ethical requirements should guide the accompaniment of people at the end of their lives? How can we respect the individual's freedom to set the limits of physical and psychological suffering for themselves, without abandoning the medical, social and ethical requirement to do everything possible to relieve and respond to pain and distress by means of care, support and concern?
Two expressions of fraternity are put in tension here: one that expresses itself in voluntary assisted dying,[11] the other in assistance in living until death in conditions that allow the relief of suffering and respect for the autonomy of the person.

C – The intensification of ethical questioning as a result of recent societal and medical developments

The first part of the CCNE's Opinion No. 121 of the 30th of June 2013 describes the context of the debate on voluntary death. It touches on, in particular, the increasing longevity of individuals and the inherent ageing of the population, the development of chronic diseases and the complexification of certain end-of-life situations. It also recalls the recent affirmation of patients' rights,[12] within which the idea of the right to "choose one's own death" is increasingly being promoted by certain advocacy groups. Opinion No.121 notes that "these developments are fuelling the request that the legislator take into account a right to choose the circumstances and time of one's death", and stresses that this request is two-sided: on the one hand, a request for control over one's life until the end, and on the other, a request for the prevention of suffering and situations of extreme vulnerability.

Since this Opinion was published, certain developments have become more marked:

- *An increased tendency to medicalise the end of life*. Medicine has become the main framework for the end of people's lives, and the social and family dimensions have

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[9] See Eric Fiat, « La notion de dignité est très à la mode, mais très confuse », (Le Point, avril 2021 : https://sfap.org/system/files/euthanasie_et_dignite_eric_fiat_-_le_point_avril_2021.pdf)

[10] See André Comte-Sponville, "La dépénalisation de l'euthanasie n'est pas une question de dignité, mais de liberté, face à sa propre vie ou à la souffrance", (Philo magazine, 08 avril 2021. Voir : https://www.philomag.com/articles/andre-comte-sponville-la-depenalisation-de-leuthanasie-nest-pas-une-question-de-dignite)

[11] Like the National Centre for Palliative and End-of-Life Care in its Panorama of Legislation on Active Assistance in Dying around the World, we choose to use the term "voluntary assisted dying", which encompasses the notions of euthanasia and assisted suicide, rather than "medical assistance in dying", a concept introduced in Quebec as part of the discussions leading up to the End-of-Life Care Bill, which refers to euthanasia - as distinguished from assisted suicide.
(https://www.ethique.gouv.qc.ca/fr/ethique/qu-est-ce-que-l-ethique/aide-medicale-a-mourir-et-suicide-assiste/)

[12] The law of the 4th of March 2002 entitled "Patients' rights and quality of the health system" is a major step in this evolution.

been progressively neglected. Even more than medicalisation, the technicalisation of the end of life and the valuing of action, of "doing" at all costs, have increased, at the expense of accompaniment and ethical reflection, thereby contributing to the neglect of the subject.
For several years now, our health system has been going through a structural crisis that is responsible for a moral uneasiness. The quality and safety of care given have been altered by the lack of staff and equipment, the spread of "medical deserts" and the inadequate organisation of care pathways. The human dimension of the care relationship is not taken into account in the methods for financing hospital and medico-social activity. These multiple economic, structural and organisational contingencies, aggravated by the health crisis linked to Covid-19, have contributed to the devaluation of the *care* ethics[13] (or 'solicitude ethics'), which refers to caring for others, for the benefit of *"cure"*, the main aim of which is to treat in order to heal through technical power. Caregivers are thus increasingly forced to devote their time primarily to technique, at the expense of listening.

- As a result of technical and scientific advances in medicine, *the time at the end of one's life has become longer and new forms of end of life have appeared* (living with a disease that will not disappear but whose evolution is slowed down by treatments; living with several synchronic diseases; living with severe impairment of cognitive functions; living with major functional dependence...). End-of-life issues can no longer be reduced to the very end of life, nor to sick people who are expected to die in the short term. This new temporality of the end of life, which is becoming longer, pushes us morally to deepen our reflection on the responses provided by society and our health system.
  At the same time, the lengthening of the end-of-life period provokes and/or is accompanied by a temptation to die *in a hurry*, a feeling of the "*urgency of dying*" and a loss of recognition of the value of the time spent on accompaniment and rituals, which nevertheless have a meaning and a function, both from the point of view of the dying person and of those around them. The neglect or denial of the last exchanges weakens or even hinders the psychological and physiological processes at work in the time of grieving, i.e. the human creativity that enables the radical nature of suffering to be faced and overcome.

- *A trend towards increasing loneliness and social isolation, particularly among older people*. Several recent reports[14] show a worsening of the situation of isolation of the elderly (about one in three today). As these studies point out, the end of social existence precedes physical death, which is, therefore, often desired.

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[13] "Cure" refers to the curative, essentially technical; "care" refers to "taking care", more precisely to the concern for others, for the Other in their suffering, according to Emmanuel Levinas, in a holistic approach to care. See: Morvillers, Jean-Manuel. "Le *care*, le *caring*, le *cure* et le soignant", Nursing Research, vol. 122, no. 3, 2015, pp. 77-81.

[14] On this matter, see: Enquête de La Fondation de France : « 7 millions de français confrontés à la solitude », 29/04/2021. https://www.fondationdefrance.org/fr/les-solitudes-en-france/7-millions-de-francais-confrontes-a-la-solitude-decouvrez-notre-enquete-annuelle
Enquête des petits frères des pauvres , 30/09/2021 : https://www.petitsfreresdespauvres.fr/informer/prises-de-positions/mort-sociale-luttons-contre-l-aggravation-alarmante-de-l-isolement-des-aines, 30/09/2021

- *Increasing importance is attached to psychological autonomy, to the "modernity of the body",*[15] *and to functional independence* in a "society of the individual" (Norbert Elias)[16] which promotes good health and individual performance, and which is deeply concerned with the question of the individual "to the point of often making it (its) reference value".

  In such a context, people who are seriously ill or who have an impairment of their independence or autonomy are more likely to develop the feeling of being a burden to others, of living "in fear of failure" and of being powerless.[17]
  The promotion of autonomy in care is also ambivalent: it serves the interests of the patients and highlights the importance of listening to their needs - in this sense it is certainly beneficial - but it can also present the risk of authorising or causing steps that are close to abandonment, a disinvestment in support, and delinking. The caregiver's action must therefore not succumb to either of the two temptations that can arise in the care of a person at the end of their life, namely paternalism consisting of taking the decision in the patient's place, or formalism[18] giving respect for autonomy the guarantees of form but ignoring or despising the incompressible part of subjection that the experience of extreme suffering entails. This, in part, jeopardises our capacity for free thought, or even confiscates it.

- *A request in our society for voluntary assisted dying*. This request is expressed through legislative proposals, opinion polls, and NGOs. Admittedly, opinion polls do not always accurately reflect the characteristics and real strength of societal requests. Nevertheless, in 2021, 270 Members of Parliament from different political backgrounds expressed a public stance on this subject that deserves attention.[19]
  This request is most often based on the claim to the right to self-determination and the right to define the limits of a dignified life for oneself.

  While for some this request is a genuine aspiration for emancipation and self-determination, for others it may be more of an expression of the fear of death, of dying, of dying badly, of suffering, of causing suffering to those around them.[20] The request for voluntary assisted dying reflects in particular the fear of ageing badly: of suffering from isolation, loneliness, disability, dependence or lack of access to palliative care. Finally, requests for death can also be the expression of a deep anxiety

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[15] David Le Breton, Anthropologie du corps et modernité. PUF, Quadrige, 2008

[16] Erik Neveu. Norbert Elias, *La société des individus*, Paris, Fayart, 1991. In: *Politix*, vol. 4, n°16, Quatrième trimestre 1991. Causes entendues - Les constructions du mécontentement (1) sous la direction de Annie Collovald et Brigitte Gaïti. pp. 98-100.

[17] See: La Société du malaise, Alain Ehrenberg, https://laviedesidees.fr/L-autonomie-aspiration-ou.html

[18] SCHAERER René, « Le « principe d'autonomie », ses ambiguïtés et ses illusions », *Jusqu'à la mort accompagner la vie*, 2014/1 (N° 116), p. 37-45. DOI : 10.3917/jalmalv.116.0037. URL : https://www.cairn.info/revue-jusqu-a-la-mort-accompagner-la-vie-2014-1-page-37.htm

[19] Article published on the 3rd of April 2021, Le Journal du Dimanche : « *Nous voulons débattre et voter* ». Voir : https://www.lejdd.fr/Societe/lappel-de-270-deputes-sur-la-fin-de-vie-nous-voulons-debattre-et-voter-4036064

[20] Hearing of Aline Chassagne, research engineer, CIC - CHU Besançon.

syndrome (which needs to be assessed and treated) in a situation where loss of function and autonomy follow one another, leading to a loss of self-esteem.[21]

These fears may explain a desire for legislative change in favour of authorising voluntary assisted dying. However, it should be stressed that the anguish of death will never be alleviated by medicine alone and that, in the words of the CCNE in its Opinion No. 129 of the 18th of September 2018, "*ethical questions will never be resolved by law*".

D – The strengthening of patients' rights in recent legislative developments

In the past twenty years, four essential laws have been adopted by Parliament. They have in common the concomitant reinforcement of the autonomy of the person and the duty of solidarity in accompaniment:

- Law No.99-477 of the 9th of June 1999 aimed at guaranteeing the right to access to palliative care;
- Law No.2002-303 of the 4th of March 2002 on patients' rights and the quality of the health system, enshrining two closely related principles: the right to information and the right to consent (and refusal to consent);
- Law No.2005-370 of the 22nd of April 2005 on patients' rights and the end of life;
- Law No.2016-87 of the 2nd of February 2016 creating new rights for patients and people at the end of life.

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[21] See Hearing of François Salachas, neurologist at the Pitié Salpêtrière Hospital, specialist in amyotrophic lateral sclerosis (ALS).

These laws have radically changed the approach to the end of life by introducing notions that appear fundamental. Here are the main inputs:

- Since the law of the 9th of June 1999, "*any sick person whose condition requires it has the right to access palliative care and support*". Article 7 states that "*public or private health establishments and medico-social establishments shall implement the appropriate means to manage the pain of the patients they receive and to provide the palliative care that their condition requires, regardless of the unit and the care structure in which they are received*".
- The law of the 4th of March 2002, and in general the numerous texts in the health and medico-social field, reinforce the rights of people in care and accommodation. Any investigation or treatment must be preceded by the patient's free and informed consent: the patient must therefore be informed about their state of health. The right to refuse treatment is recognized. This law has brought about a paradigm shift in the relationship between doctor and patient by positioning the latter as the main actor in their health.[22]
- Since the law of the 22nd of April 2005, unreasonable obstinacy (previously referred to as "futile medical care") has been prohibited by the obligation not to prevent death from occurring when treatment appears to be "useless, disproportionate or having no other effect than the artificial maintenance of life". However, while treatment can be stopped, or not undertaken, care and support are a duty and must be continued.
- In 2005 and then in 2016, measures were written into the law to guarantee respect for the person when they are no longer able to express their will:

  ✓ Option of writing advance directives which are, except in the case of an emergency or inappropriate to the situation experienced by the person, since 2016, binding on the doctor.

  ✓ Incentive to designate a "trusted person" likely to be the spokesperson for the person who can no longer express their will.

  ✓ Need for a "collegiate procedure", i.e. a discussion between health professionals, based on the advance directives if they exist, or taking into account the opinion of the "trusted person", or failing that, that of the family of the relatives, to base and argue any decision to stop treatment.

Finally, the 2016 law created a right to continuous deep sedation until death for patients who are expected to die in the short term, with all treatments stopped.

The CCNE observes a positive evolution of the right of persons at the end of their lives over the last 20 years. However, it notes a gap between the appropriation of this right and its application. The reality on the ground reveals, in some cases, a lack of knowledge of rights or their implementation, and in others, critical situations with no solution under the law in force.

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[22] On this matter see Opinion No.136 of the CCNE: "The evolution of ethical issues relating to consent in care", published on the 7th of July 2021.

Based on the expertise of the personalities heard,[23] the written contributions sent to it and the rare data available concerning the evaluation of palliative care in France,[24][25] the CCNE endeavours in this Opinion to consider the greatest number of end-of-life situations. It seeks to grasp the recurrent, sometimes new, ethical issues, and questions the two societal requests that coexist today: the need for equitable access to palliative care anywhere in the country, and the need to be able to decide on one's own death.

It wishes to emphasise that it regrets the absence of reliable data and significant statistics on the subject, even though the Minister of Solidarity and Health had announced a study mission on this subject in April 2021.[26]

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[23] See Appendix 1.

[24] Data from the CNSPFV: https://www.parlons-fin-de-vie.fr/

[25] IGAS Report: "Evaluation of the application of the law of the 2nd of February 2016 on the end of life 2018", available at https://www.igas.gouv.fr/spip.php?

[26] "The state of knowledge on the application of this law is far too weak and we do not have any recent scientific study on end-of-life decisions. I will therefore launch a new mission in the next few days to find out how the law is actually applied". Speech by O. Véran, Minister of Health, National Assembly, 08/04/2021. See: https://www.dalloz-actualite.fr/flash/loi-sur-fin-de-vie-deputes-pressent-gouvernement#.YrRoid86-Uk

II. ETHICAL ISSUES RAISED IN END-OF-LIFE SITUATIONS

All of the CCNE's Opinions recall the need to improve the quality of the attention and assistance given to the most fragile people, whatever the cause of their vulnerability. In doing so, the CCNE draws attention to the most widespread and dangerous threat to the debate on support for people at the end of life or wishing to die: indifference. The suffering and the requests for voluntary assisted dying that follow it invite us to firmly oppose the trivialisation of indifference, to establish a *ban on indifference*. Resignation in the face of the suffering of people at the end of their lives in France is not tolerable. The person who is indifferent to the suffering of the person at the end of their life is the first to die, morally, *internally.*[27]

The CCNE considers that any change in the law or in practices that would encourage the weakening of relational care and the weakening of the duty to accompany would not be ethically admissible. Similarly, any change in the law that would suggest that certain lives are not worth living or saving (in a context of crisis or health tension, for example) would be unacceptable.

At the end of life, respect for the human person cannot be the result of an ideological, formal, fixed approach, whether it is to accept voluntary assisted dying or to reject it. No systematic truth is tangible in the search for solutions for the appeasement of dying people; the search for the most appropriate accompaniment requires, each time, the courage and discomfort of a singular face-to-face meeting with the patient, and calls for a unique response every time.

In this Opinion, the CCNE has endeavoured to identify elements to help make decisions that are fair, or as fair as possible, in borderline situations and situations of great uncertainty.
Beyond the analysis of specific cases, and following the example of its conclusions in Opinion No. 129 published on the 18th of September 2018, it wishes to reiterate the following remarks:

- Medicine and the health care system must absolutely avoid initiating treatments or resorting to medical techniques (especially resuscitation practices) likely to lead to

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[27] Emmanuel Lévinas, in the name of ethical responsibility, evokes the "impossible evasion" in the face of the distress of the other. See: Durante Massimo. La notion de «subjectivé» dans la phénoménologie d'Emmanuel Lévinas. In: *Revue Philosophique de Louvain*. Quatrième série, tome 104, n°2, 2006. pp. 261-287.

these "borderline situations", which constitute new forms of end of life[28] marked by extreme vulnerability. These *borderline situations*, creating real ethical dilemmas, give rise to great uncertainty as to what is or is not the right thing to do in the interest of the suffering person.

- To date, there are no prognostic criteria that allow us to predict with certainty the extent of the handicap, the future quality of life and to facilitate decision-making in a situation of uncertainty. Caregivers' understanding of the boundary between unreasonable obstinacy and cessation of active therapies, the systematic development of collegiate procedures, and acculturation to the implementation of "therapeutic de-escalation" when necessary, are likely to optimise the accuracy of medical decisions. Therapeutic de-escalation contributes to the prevention of difficult vulnerability or end-of-life situations and avoids that medicine generates them. The patient must never suffer from the inability of caregivers and family members to understand and accept that the curative project is unreasonable. It is essential for caregivers to learn *not to do* certain things in certain care situations, just because they know how to do them.

- The will of the patient is a matter of their freedom of decision, as solemnly established by the law of the 4th of March 2002 on patients' rights. If accompanying care and treatment of symptoms of discomfort until the end of life remain unchanged, any refusal of treatment must be thoroughly analysed and respected (law of 2005).

Part II will deal successively with the ethical questions generated by the application of the current law, and then those relating to the situation of people suffering from serious and incurable diseases, causing refractory suffering, who are expected to die not in the short term, but in the medium term.

II.1. ETHICAL ISSUES RELATING TO THE IMPLEMENTATION OF CURRENT LEGISLATIVE AND REGULATORY PROVISIONS

A. The development of palliative care: insufficient academic and financial recognition

Since the law of the 9th of June 1999 aimed at guaranteeing the right to access palliative care, five plans for the development of palliative care and support at the end of life have been defined and implemented.[29] Like the Conseil d'Etat,[30] the IGAS[31] and the

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[28] For example: the end of resuscitation of adult patients or premature newborns for whom the question of stopping active therapies may then arise, the possibility of a long end of life in total dependence, or of an end of life with a major alteration of consciousness, situations of serious and incurable diseases chronicled by heavy treatments, etc.

[29] The 5th plan covering the period 2021-2024 was announced on the 22nd of September 2021 by the Minister for Solidarity and Health.

[30] Conseil d'Etat, Révision de la loi de bioéthique : quelles options pour demain ?, 11 juillet 2018, p.116. Consultable sur https://www.conseil-etat.fr/ressources/etudes-publications/rapports-etudes/etudes/revision-de-la-loi-de-bioethique-quelles-options-pour-demain

Economic, Social, and Environmental Council (ESEC),[32] the CCNE deplores the modest resources allocated to these plans and the persistence of inequalities in access to palliative care: territorial situations remain inequitable and heterogeneous depending on the structures, the medical density, and the human and financial resources. The development and implementation of the decision to limit or stop active therapies and the prescription of continuous deep sedation until death are complex in units where the quality and continuity of care are perfectible and very limited. Finally, the CCNE regrets the absence or inadequacy of a palliative culture integrated into the practice of health professionals.

A university degree in palliative care was set up in 2016, but it has remained in a fictitious state, as no professor has been appointed to date. The lack of teaching and research in this field makes it impossible to build a solid and thorough palliative culture.

Interdisciplinary research between the humanities and social sciences and the biomedical sciences has certainly been encouraged through the creation in 2018 of the National Platform for Research on the End of Life, but the training of researchers in the interdisciplinary approach requires time and resources. In addition to its lack of development, teaching the approach to death, palliative care and support remains difficult to access for all healthcare staff, and is confined to a siloed, monodisciplinary training programme, whereas it is a question of learning to work together in consultation. This teaching should also be part of a reflective, epistemological approach, aimed at developing critical analysis and not limited to the acquisition of knowledge derived from science. Palliative care is therefore not yet recognised at university level and is therefore not widely used by health professionals.

The T2A fee-for-service pricing system in hospitals provides a specific fee for palliative care, a sign of its recognition as an integral part of the care process. This is an improvement on the past situation where the specificity of this care was not recognised. Nevertheless, the lack of staff in many departments does not allow care providers to give it the time it needs to be provided under good conditions. In addition, it is important to remain vigilant about the level of tariffs themselves, as the growing and sometimes staggering costs of technical medicine are likely to put pressure on other hospital budget lines.

The medico-social sector and private medicine do not set aside any specific fees for palliative care. An essential part of care is thus undervalued. Its relational components, support for patients as the disease progresses and the question of the end of life and death arises, interprofessional ethical deliberation to establish relevant care and treat-

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[31] IGAS, *Évaluation du plan national 2015-2018 pour le développement des soins palliatifs et l'accompagnement en fin de vie.*

[32] CESE, Fin de vie : la France à l'heure de ses choix, 10 avril 2018, pp.19-23. Consultable sur https://www.lecese.fr/travaux-publies/fin-de-vie-la-france-l-heure-des-choix

ment plans, and respect for good practice at the end of life are all dimensions that contribute to good care that are too often neglected.

B. Strengthening the effective role of the “trusted person”

The role and place of the “trusted person” must be more widely recognised and decisive, as recently recommended in Opinion No. 136 of the CCNE.[33] The hearings and debates held on this occasion showed that the “trusted person”, once they have fully understood and accepted the delicate task of expressing the wishes of a patient deprived of their capacity to express themselves, assumes this role in a unique and concrete way, and genuinely helps in the medical decision. Decisions to limit or stop the treatment based on non-medical factors and more in line with the values of the dying person must be particularly attentive to the testimony of the “trusted person”.

C. Valuing advance directives

The law of the 2nd of February 2016 makes advance directives binding. They take precedence over any other opinion (including that of the doctor, the “trusted person” or relatives), except in a life-threatening emergency or where the advance directives are manifestly inappropriate or do not conform to the medical situation.[34]

The law provides that these directives are "at any time and by any means, revisable and revocable".[35] It is therefore desirable that they are part of a process to help the patient, that they are not written in a solitary manner but rather as part of an accompaniment of the patient, so that the latter can reflect as calmly as possible on what they wish for the end of their life.[36] Even when they are drawn up by a healthy person wishing to express their wishes (in the event that an accident or the sudden onset of an illness deprives them of their faculties to express themselves), it is desirable they be the result of a process of reflection with one or more members of the nursing staff who can help ensure the clarity and relevance of the words chosen.

The methodological conduct of the collection of the expression of advance directives must be better mastered by healthcare staff. They must have dedicated time and places

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[33] The evolution of ethical issues relating to consent in care https://www.ccne-ethique.fr/fr/publications/avis-136-levolution-des-enjeux-ethiques-relatifs-au-consentement-dans-le-soin. 07/07/2021.

[34] Articles L. 1111-11 and L. 1111-12 of the Public Health Code

[35] Article 1111-11 of the Public Health Code, second paragraph

[36] See on this point the Opinion of the ethics committee of the Fédération hospitalière de France (FHF): Opinion on the ethical constraints of binding advance directives concerning a person with a serious illness https://www.espace-ethique.org/sites/default/files/201602_FHF_avis%20Directives%20anticipe%CC%81es%202.pdf

to reassure patients of the trust they place in health professionals, and to assure them that their wishes will be respected during deliberative decision-making processes.

The low number of advance directives drawn up by French citizens is problematic. It underlines the slow appropriation of this legislative device, partly due to the fact that it is often reduced to the expression of the patient's wishes at the very end of their life. The possibility of thinking about the proportionality of care throughout the illness, in the image of what is practised in Anglo-Saxon and Scandinavian countries, would make it possible to better anticipate decisions and avoid therapeutic escalation or even unreasonable obstinacy. Advance care planning is particularly well suited to situations of long-term chronic illness. It corresponds to a process of consultation, a pathway between the patient, the “trusted person” or their relatives and the care providers, aimed at defining a common orientation of care and treatment to be implemented or not throughout the patient care. The values and priorities of the patient, whether they are able to express their wishes clearly or not, are thus determined at the end of a proactive and anticipatory process that facilitates decision-making in emergency situations.[37]

The low take-up of advance directives probably also reflects the inadequacy of efforts to promote this tool among the public and healthcare professionals called upon to advise or accompany patients. The public must be better informed of the possibilities of traceability offered by digital technology, via "my health space”[38] (which includes the shared medical record (DMP)), where advance directives can be accessed and saved. It would be appropriate to extend and diversify the media for advance directives - currently limited to a signed and dated written document - to its equivalent in an audiovisual form.

D. Respect for the deliberative dimension of the collegiate procedure in the event of the limitation or cessation of treatment

The "collegiate procedure" provided for by the law[39] is conducted in particular when the question arises of limiting or stopping active therapies for people at the end of their lives who are not/no longer able to express their wishes, or the implementation of continuous deep sedation until death, requested or envisaged.

The decision to limit or stop treatment is taken by the doctor in charge of the patient at the end of this collegiate procedure.[40] In accordance with the "good practices" formulated in this respect with the aim of guaranteeing the most appropriate decisions possible

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[37] Walloon Federation for Palliative Care, see: https://www.soinspalliatifs.be/acp.html/

[38] https://esante.gouv.fr/mon-espace-sante

[39] Article L. 1110-5-1 of the Public Health Code

[40] Article R. 4127-37-2 of the Public Health Code

in complex situations,[41] the "collegiate procedure" must always consist of a deliberative process[42] and not be reduced to its procedural dimension.

In this spirit, each participant in this collegiate procedure must be able to argue and then debate within an interdisciplinary consultation, without prioritising the arguments according to the role of the professionals present. Each person's position must be able to evolve under the influence of the arguments of others in order to arrive at a fair and proportionate assessment in the interest of the person being cared for. This process requires multiple skills,[43] time and availability. It must be mentioned in writing and argued for in the patient's medical file.

E. Insufficient use of continuous deep sedation until death at home and in medico-social establishment

The law stipulates that continuous deep sedation until death can be implemented, at the patient's request, not only in hospitals but also in medico-social institutions or at home.[44] Recent regulations[45] have been introduced to facilitate the implementation of this pharmaceutical and human support. However, its application remains too heterogeneous depending on the structures, the number of doctors, and the human resources present.[46]

It seems necessary to give private practice doctors the opportunity to discuss the implementation of continuous deep sedation until death, to monitor it, to trace it and to ensure that it is carried out correctly, in order to provide the best possible *comfort* for the person at the very end of their life and to support their relatives.

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[41] https://www.has-sante.fr/jcms/p_3151633/en/sedation-profonde-jusqu-au-deces-une-decision-collegiale#toc_1_1_2

[42] On this point, see Opinion No.121 of the CCNE: "End of life, autonomy of the person, will to die", published on the 30th of June 2013. https://www.ccne-ethique.fr/node/181

[43] On this point, see Opinion No.84 of the CCNE: "Training in medical ethics", published on the 29th of April 2004, which was inspired by the report "Ethics and the health professions" submitted on the 19th of May 2003 to the Minister of Health by Mr Alain Cordier.

[44] Article L. 1110-5-2, penultimate paragraph, of the Public Health Code

[45] Order of the 14th of June 2021 applying part of the narcotics regulation to medicinal products for human use composed of midazolam, administered by injection.

HAS. Commission de la transparence. Opinion of the 20th of October 2021. Midazolam. Extension of indication. Availability in town. https://www.has-sante.fr/plugins/ModuleXitiKLEE/types/FileDocument/doXiti.jsp?id=p_3303977

Order of the 15th of December 2021 modifying the list of pharmaceutical specialities reimbursable by social security

[46] Dr Elisabeth Hubert, Former Minister of Public Health, President of the Fédération Nationale des Etablissements d'Hospitalisation à Domicile (FNEHAD), hearing on the 4th of November 2021

Drawing on the work undertaken in 2018 by the National Centre for Palliative and End-of-Life Care,[47] which showed that "*continuous deep sedation until death is a provision that is struggling to be implemented on the ground*", a regular quantitative and qualitative assessment of the use of this provision of the law, as well as the reasons for non-use, must be undertaken.

II.2. ETHICAL ISSUES RELATING TO THE SITUATION OF PEOPLE SUFFERING FROM SERIOUS AND INCURABLE DISEASES, CAUSING REFRACTORY SUFFERING, WHO ARE EXPECTED TO DIE NOT IN THE SHORT TERM, BUT IN THE MEDIUM TERM

A. The scope of the proposed reflection

At the end of the hearings conducted by the CCNE, it appears that the current legal framework is satisfactory when the patient is expected to die in the short term,[48] offering arrangements that respect the dignity of people suffering from serious and advanced diseases. This is the case, for example, for cancer patients who are expected to die in the short term. The cessation of treatment deemed unreasonable, the continuation of palliative care and the possibility of resorting to continuous deep sedation until death generally allow for a relatively safe and peaceful end of life.

Nevertheless, quality palliative care does not always lead to the eradication of the desire to die: a recent study[49] conducted on the basis of more than 2,000 medical records of patients admitted to palliative care services revealed that 9% of patients expressed a wish to die and 3% a request for euthanasia. Some people suffering from serious and incurable illnesses, causing intractable suffering,[50] who are expected to die not in the short term but in the medium term,[51] do not find a solution to their distress within the scope of the legislative provisions. The same applies to situations of dependence on life-sustaining treatments whose cessation, decided by the person when they are con-

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[47] Continuous deep sedation until death in France, two years after the adoption of the Claeys-Leonetti law, Les cahiers du Centre National des Soins Palliatifs et de la Fin de Vie, 11/2018.

[48] That is, according to a definition of the European Association for Palliative Care and the French Society for Accompaniment and Palliative Care, adopted by the High Health Authority, when the patient is expected to die within a few hours to a few days.

[49] Guirimand, F., Dubois, E., Laporte, L. *et al.* Death wishes and explicit requests for euthanasia in a palliative care hospital: an analysis of patients files. *BMC Palliat Care* 13, 53 (2014). https://doi.org/10.1186/1472-684X-13-53

[50] The notion of refractory suffering is considered in this Opinion in the same way as the notion of refractory symptom. "Refractory is defined as any symptom whose perception is unbearable and which cannot be relieved despite persistent efforts to find a suitable therapeutic protocol without compromising the patient's consciousness". See: Cherny NI, Portenoy RK. Sedation in the management of refractory symptoms: guidelines for evaluation and treatment. J Palliat Care 1994; 10:31-8.

[51] The medium term could be understood, as in some foreign legislation, as covering a period of a few weeks to a few months.

scious, without altering their cognitive functions, does not lead to death in the short term.

These situations raise serious ethical questions, particularly when the patient is expected to die within a few weeks or months. The present reflections focus on the situation of these people who present a medical picture very similar to that of patients covered by the current legislative provisions, with the difference that they are not expected to die as quickly.

B. The limits of the practice of sedation allowed by the current law

However, such a broadening of the temporality in the assessment of the vital prognosis has its own medical limit. In the current state of science, beyond several days of continuous deep sedation, the patient may present signs of awakening associated with a deterioration of his physical state, due to the tachyphylaxis[52] of the drug indicated and prescribed for this purpose. The patient's situation thus continues to deteriorate without death occurring within a reasonable time. While it is possible, in this situation, to resort to other molecules in a specialised hospital environment (resuscitation units, of which there are a limited number), this is not possible in all end-of-life settings, particularly at home.

Some people thus believe that the temporal limits of any strategy of continuous deep sedation invite reopening the debate on voluntary assisted dying. This could be aimed at people suffering from serious and incurable diseases, causing refractory suffering, who are expected to die not in the short term, but in the medium term. A number of foreign legislations have opened the way to voluntary assisted dying for people who are expected to die within *a few months*.

For example, with regard to *assisted suicide*, the American states of Oregon, Washington, Vermont, California, Colorado and New Jersey have adopted legislations setting a six-month deadline for the estimation of death within which assisted suicide is legal.

With regard *to euthanasia and assisted suicide*, some Australian states have also adopted a six-month time limit, which can be extended to twelve months in the case of neurodegenerative diseases (e.g. Victoria, Western Australia, South Australia and Tasmania). In the Australian state of Queensland, the time horizon is uniformly twelve months, while it is six months in New Zealand.

C. Between respect for the right to life and non-existence of the duty to live: the imperative search for a meeting point between solidarity and autonomy

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[52] Tachyphylaxis is the process of habituation of the body to a treatment or pathogen. See: https://www.larousse.fr/encyclopedie/medical/tachyphylaxie/16450

The prospect of legalising one or both of these two forms of voluntary assisted dying (assisted suicide and/or euthanasia) in France raises major questions that the CCNE has already discussed in previous Opinions, in particular in its Opinion No. 121 of the 30th of June 2013.[53]

It is worth emphasising today the points that guided Opinion No. 121:

- In the continuation of Opinion No. 121, we recall that assisted suicide consists of "*providing the means for a person to commit suicide themselves*", while euthanasia is "*an act intended to deliberately end the life of a person suffering from a serious and incurable disease, at their request, in order to put an end to a situation that they deem unbearable*". Both acts involve the intervention of a third party but with a very different degree of involvement. In the case of assisted suicide, this intervention may be limited to the medical prescription of a lethal product, whereas in the case of euthanasia, a doctor administers the product themselves.

- In anthropological terms, the prohibition of death is a founding principle for the whole of society. With regard to the medical profession, this prohibition is enshrined in its code of ethics, which states that the doctor "has no right to deliberately cause death"[54] and is recalled in the Hippocratic Oath.

  The right to life is enshrined in Article 2 of the European Convention on Human Rights (ECHR) and Fundamental Freedoms.[55] Article 8 of the same Convention also enshrines the right to respect for private and family life, which may be restricted by interference from public authorities only on the grounds listed exhaustively and in particular to protect the rights and freedoms of others.[56] The signatory states of this Convention and their jurisdictions deduce from this Article 8 a right to autonomy and freedom of self-determination.
  The ECHR recognises other fundamental rights and does not establish a hierarchy between them. These rights recognise everything that contributes to human dignity and makes it possible to give effect to the values of freedom, security and equality that are the foundations of our democracies. It is sometimes difficult to reconcile these rights. The principle of autonomy and individual freedom can conflict with the values of equality, equity and solidarity. In such cases, the best possible compromise between competing rights must be sought, accepting that one right should be infringed, to the greatest extent possible, in order to prevent its intransigent asser-

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[53] Available at ccne-ethique.fr

[54] Article R. 4127-38 of the Public Health Code

[55] Art. 2 Right to life - The right of every person to life is protected by law. Death may not be inflicted on any person intentionally, except in execution of a sentence of death passed by a court of law in cases where the offence is punishable by law.

[56] "Art. 8 Right to respect for private and family life - 1° Everyone has the right to respect for their private and family life, their home and their correspondence. 2° There can be no interference by a public authority in the exercise of this right unless such interference is provided for by law and constitutes a measure which, in a democratic society, is necessary for (...) the protection of the rights and freedoms of others."

tion from causing a more serious infringement of another fundamental right. These assessments must be made on a case-by-case basis, in a concrete manner.

We consider that ethical deliberation is about the value of the right to life. Some believe that the right to life is a supreme value that cannot be compromised. Compromise is therefore impossible and it is unthinkable to undermine it by changing the law. However, it should be emphasised that respect for the right to life does not mean that a person *has a duty to live* a life that they find unbearable. There is no obligation to live.

We can therefore also consider that the right to life can be weighed against other values, in particular that of respect for freedom of self-determination. When a person is in a situation where, objectively, no alternative can be offered, and when they lucidly and unambiguously request and reiterate a request for assistance in dying because they consider that their condition is no longer compatible with their own dignity, they want their right to self-determination to take precedence over their right to life.

D. A plurality of opinions within the CCNE

Listening to the testimonies of health professionals highlights the coexistence of different conceptions of care in situations of unrelievable and unbearable physical pain and/or mental suffering:

- Some health professionals argue that they are obliged not only to care for and respect life, but also to relieve suffering *unconditionally*. Their medical ethics could, according to them, justify, when the conditions are met, putting an end to the intolerable, even if this decision to relieve suffering would result in the shortening of life.[57]

- Others express the view that in such a situation voluntary assisted dying would be desirable, under strictly defined conditions.

- Others still, consider that the medical mission cannot, under any circumstances, be to help bring about death. Among them, some claim that opening up a right to die would constitute a danger both for the patient and for society. For the patient, because it could be an inappropriate response to an ambiguous request, and the risk of misapplication of a new law (errors of judgment on the request and the patient's situation, etc.) seems to them to be major. For society, in that this right could stigmatise certain patients with disabilities or suffering from chronic illnesses, whose

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[57] Hearing of Dr Jean Leonetti at the CCNE, on the 7th of October 2021. "Non-suffering is therefore a complicated objective to achieve. Should it go so far as to put the patient's life at stake? I think we were clear on this point in 2005 and perhaps even more so in 2016: we must strive to relieve all suffering at the end of life, even if this means shortening life. At the end of one’s life, it is the quality of life that takes precedence over the length of life.”

lives could be considered as not worth living or no longer worth living. This right would then be counterproductive for the development of palliative care, as the prescription of a kill-pill would be simpler and less expensive.

The CCNE also notes the existence of a plurality of opinions among its members:

- For some, inducing death by means of one of the forms of voluntary assisted dying mentioned above would constitute a break with a history, a culture, and the moral references on which our society is based. The proponents of this position also call on us not to ignore the risks of abuses that such a possibility could generate.[58] They also believe that voluntary assisted dying in all its forms would commit doctors to perform acts that are resolutely contrary to their vocation and to the sense of medical duty and care. For them, these acts would represent an abdication, a collective incapacity to really take charge of the end of life. They would confront health professionals with value conflicts leading to professional exhaustion, and would risk aggravating the disengagement of carers already fed by the moral crisis that the health system, and in particular the hospital, is currently experiencing.

  Finally, they note the ambiguity of the coexistence of suicide prevention policies and a demand for the right to assisted suicide for certain people, even in exceptional situations.[59]

- Some did not express any opposition in principle to the decriminalisation of voluntary assisted dying, but felt that the time had not come to legislate on the subject, given the current crisis in the health system.

- Others consider that certain situations of extreme suffering justify aiming for the sole ethical goal of relieving the patient, even if this results in accelerating the occurrence of death, within timeframes that seem reasonable to them. They consider that "*there may be a 'worse than death', which may lead to the painful (and staggering) choice of death itself as the 'lesser evil'*".[60] Refusing what appears to be "worse than death", i.e. relieving people who ask for it of suffering so intolerable that it becomes for them "an argument against life/their life",[61] appears to them as the ultimate way of defending life and resisting the scandal of suffering, even if it means risking the scandal of freedom, an ethical value, but also a republican, legal or spiritual one.

  They also maintain that the decriminalisation of strictly controlled voluntary assisted dying would in no way call into question the generality and power of the ban on killing.

  Finally, they assert that opening up a right to voluntary assisted dying would in no way undermine suicide prevention policies, which must be carried out by the health authorities on an ongoing and active basis. This right would not lead to the develop-

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[58] See Appendix 5

[59] Hearing of Dr Jean Léonetti at the CCNE, on the 7th of October 2021. "Suicide in France is a freedom-right: I have the right to decide that my life is not worth living and to end it. However, is it an entitlement, like the right to life, that can be claimed from society as an enforceable right? This is a question of law, but also of ethics."

[60] Frédéric Worms, April 2022, in Libération : https://www.liberation.fr/idees-et-debats/opinions/affirmer-contre-le-pire-20220415_EUNNOUPUIJCRNMC72ERQUDVHCA/

[61] Expression taken from the works of Nietzsche

ment of abuses, as has sometimes been observed in other countries, if the legislator strictly, ethically and subtly regulates the practices.

- If the objective of relieving suffering were to be translated into legal terms by simply decriminalising assisted suicide, some people question the ethical soundness of a new framework that would leave this heavy decision to the patient alone. The omission of the doctor's role with regard to a person in deep distress would, in their view, be tantamount to the doctor's ethical disengagement. This is why, in this respect, they consider that the act of euthanasia is more acceptable than assisted suicide.

- For others still, on the contrary, assisted suicide would be the manifestation of an acceptable compromise between respect for a form of personal autonomy at the end of one's life, the duty of solidarity towards them and the maintenance of the prohibition on disposing of the life of others.

  Although these concepts are debated within the CCNE,[62] it nevertheless considers that it is for it to specify, in the event that a change in the law is envisaged by the legislator, the conditions that should be laid down to meet ethical imperatives.

  The ethical issues are set out in the following sections of this chapter.

E. Ethical issues relating to assisted suicide

The question of assisted suicide generally arises upstream of the field covered by the law in its current state. It concerns persons suffering from serious and incurable illnesses, causing refractory suffering, who are expected to die not in the short term, but in the medium term. These may be progressive diseases or diseases causing a profound alteration in functional independence or autonomy. In these circumstances, the cessation of treatment deemed unreasonable does not lead to death in the "short term", which is the scope of the law of the 2nd of February 2016.

The wish to accelerate the occurrence of death may be a reaction to physical and/or psychological suffering. All requests for assistance in dying require empathic listening, exploration of their origin and meaning, evaluation and expect a response. The first response is to pay attention to the pain and suffering expressed, and to make a constant effort to alleviate it, in accordance with patients' rights.

The request for assisted suicide falls within the philosophical framework of human autonomy and the legal framework of the right to respect for private life as affirmed by Article 8 of the European Convention on Human Rights. As was pointed out earlier, this principle of autonomy, which entails respect for private life, must be reconciled with the right to life, protected by Article 2 of the Convention. In a recent judgment, the German

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[62] See also the "Reservation" text at the end of this Opinion, which some CCNE members would like to see published as a supplement.

Federal Constitutional Court assessed the terms of this reconciliation and concluded that the freedom of self-determination rendered unconstitutional the provision of the German Criminal Code that makes assisted suicide a criminal offence.[63] The European Court of Human Rights has so far refused to rule on this issue, considering that Member States have a wide margin of appreciation in this area.[64]

If France were to move towards a legal analysis comparable to that undertaken by Germany, personal autonomy should not be retained as an absolute notion:

- Some consider, on a theoretical level, that autonomy diminishes or disappears when the suffering person asks someone else to help them access a lethal product insofar as they request the intervention of a third party. Others emphasise that, pragmatically, these people who express the wish to benefit from assisted dying, because of their illness and deteriorating condition, are no longer able to exercise this vision of autonomy, which consists of being able not only to *decide for oneself* but also to *do so oneself*. What remains for them is the possibility of experiencing autonomy through the accomplishment of their will, made possible by the intervention of a third party.

  A request for assisted suicide may also be uninformed if it is the expression of a request, not to die, but to no longer suffer, to be relieved of irrepressible anguish. It can be difficult to express an informed will under the effect of a serious illness, confronted with the question of one's own finiteness, prey to existential anguish and suffering that modify one's relationship with oneself and one's entourage.

- Promoting a person's autonomy requires taking into account not only their present needs, but also their entire journey over time. It is necessary to ensure that this request is firm and consistent, beyond what may be a one-off response to a period of crisis. Requests for voluntary assisted dying evolve over time and change, or sometimes fade or disappear.[65] Medical pain control helps to reduce, and sometimes even eliminate, requests for voluntary assisted dying. All requests must therefore be listened to, received and analysed over time to ensure that they are free, informed and permanent.

F. Assisted suicide and the role of the doctor

Assisted suicide requires the intervention of a physician. Before prescribing the lethal product, the doctor's role is to confirm that the person is suffering from a serious and

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[63] BverfG, Second Chamber, 26 February 2020. See for an analysis of this important judgment, Laurie Marguet, Du droit d'exiger de mourir en France et en Allemagne (obs. à propos des évolutions de l'encadrement juridique de la fin de vie), Europe des droits et liberté, September 2020/2 p. 349-369

[64] ECHR, 20 January 2011, Haas v Switzerland, no 3132207

[65] Leboul D, Bousquet A, Chassagne A, Mathieu-Nicot F, Ridley A, Cretin E, Guirimand F, Aubry R. Understanding why patients request euthanasia when it is illegal: a qualitative study in palliative care units on the personal and practical impact of euthanasia requests. Palliative Care & Social Practice. 2022, Vol. 16: 1–11.

incurable pathology, which causes refractory suffering,[66] with a repeated request for assisted suicide, and that they are expected to die in the short or medium term.

In order to avoid any trivialisation or drift, the doctor must be able to explain in writing that the request for assisted suicide is not the manifestation of an anxiety-depression syndrome that could be treated and would require an adapted therapy. They must ensure that this request does indeed come from a person who is in a situation of intolerable and irreversible suffering. Indeed, the desire to die may include a major depressive component, which, in a certain number of cases, is reversible. It is also important for the doctor to ensure that any pain or other major source of discomfort has been treated to the best of the medical art.

To limit the possible impact of the doctor's subjectivity, their decision to prescribe the lethal product should be preceded by an interprofessional deliberation within the framework of a collegiate procedure of the same nature as that provided for in Article R. 4127-37 of the Public Health Code. This approach would make it possible to ensure that the request corresponds to the wishes of the person, that it is free and not determined by external pressure, that it is constant and that assistance in suicide is justified by the person's state of health. The traceability of this collegiate procedure should be ensured. It seems important to us that the collegial procedure should include the participation of a psychiatrist and, if appropriate, of a specialist in pain treatment.

This would allow access to a lethal product that the person could then purchase (or not) and administer (or not) to themselves. These vagaries of the decision or non-decision appear in foreign experiences of assisted suicide. These show that the mere possibility of having legal access to such a product sometimes has a calming effect and that a significant proportion of people who have obtained the product do not use it in the end.

Any legal development towards decriminalisation of assisted suicide should be accompanied by the introduction of a conscience clause, together with an obligation to refer the patient to a practitioner who can perform the procedure.

G. Ethical issues relating to euthanasia

The ethical issues raised above in relation to assisted suicide are all the more valid in relation to euthanasia, which also implies the existence of a free, informed and reiterated request. We cannot therefore accept the administration or injection of a product that

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[66] As a reminder, we refer to the following definition for this term: "A refractory symptom is defined as one that is unbearably perceptible and cannot be relieved despite persistent efforts to find a suitable therapeutic protocol without compromising the patient's consciousness." Cherny NI, Portenoy RK. Sedation in the management of refractory symptoms: guidelines for evaluation and treatment. J Palliat Care 1994; 10:31-8.

would lead to the death of a person who has not asked for it, even if prolonging their life may seem meaningless.

It should also be remembered that the representations we may have of a person's quality of life are largely conditioned by our life trajectory, our social environment, our beliefs, our cultural references, in short, our subjectivity. For example, the disability paradox,[67] described by Albrecht and Devlieger, concerns patients with extremely severe disabilities who nevertheless sometimes consider that they enjoy a good or even better quality of life than healthy people. This is notably the case for certain people suffering from "Locked-in syndrome"[68] (see CCNE Opinion No.138: L'eugénisme, de quoi parle-t-on? published on 16 February 2021).[69]

Finally, present and future economic difficulties, coupled with the growing demographic burden of the elderly or even the very old, may lead society to be tempted not to prolong the lives of people perceived as "useless" because of their advanced age and great dependence. This devaluation of human life can be integrated by the elderly themselves and lead them to exclude themselves from society. The duty of solidarity and fraternity towards all members of society must absolutely counteract this ethically intolerable trend.

Certain "borderline situations" that had already been mentioned by the CCNE in its Opinion No. 129 lead us to question once again the hypothesis of decriminalising euthanasia. This concerns the situation of people suffering from a serious and incurable disease, which is progressive, but who retain their capacity for discernment, and who are expected to die not in the short term but in the medium term, and who are not physically capable of committing suicide, but who constantly express the desire to do so; how can it be justified that the relief of suffering - if it were permitted to others, who are physically able-bodied, by means of assisted suicide - should be refused to them on the grounds of their handicap? The discrimination that such a refusal would generate for non-abled but mentally autonomous people would be ethically questionable.

The degree of involvement of the doctor and their team in the act of euthanasia is major, since they administer or inject the product that will directly cause death. Any legal development towards the decriminalisation of euthanasia, as well as for assisted suicide, should be accompanied by the institution of a conscience clause, with an obligation to refer the patient to a practitioner likely to perform the procedure.

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[67] Fellinghauer B, Reinhardt JD, Stucki G, Bickenbach J. Explaining the disability paradox : a cross-sectional analysis of the Swiss general population. BMC Public Health. 2012; 12:655. Published 2012 Aug 15. doi:10.1186/1471-2458-12-655

[68] Locked-in syndrome is a state of arousal and consciousness with tetraplegia and paralysis of the lower cranial nerves resulting in an inability to show facial expression, move, speak or communicate except through co-dependent eye movements. https://www.msdmanuals.com/fr/professional/troubles-neurologiques/coma-et-troubles-de-la-conscience/locked-in-syndrome-syndrome-enfermement

[69] https://www.ccne-ethique.fr/node/470

At the end of these reflections, the CCNE is also aware that it has not dealt with certain complex issues. These will have to be addressed at a later date.

- This is the case of the ethical issues relating to voluntary assisted dying when requested by a minor or by a person suffering from mental or cognitive disorders that impair but do not prevent their capacity to express their opinion.

- Similarly, complex issues arise with regard to persons unable to express their wishes and dependent on life-sustaining treatment. When the cessation of such treatment is decided on the basis of unreasonable obstinacy and at the end of a collegiate procedure, it may happen that death, which is expected, does not occur within a legal timeframe corresponding to the notion of the short term, and that the person shows signs of discomfort or even suffering, refractory to the treatments implemented.

- Lastly, the CCNE will have to examine the ethical issues raised by the development of digital technology in the management of the end of life, and even after death.

III. RECOMMENDATIONS OF THE CCNE

If the legislator wishes to take up this subject, the CCNE considers that there is a way to ethically apply voluntary assisted dying, subject to certain strict conditions, with which it seems unacceptable to compromise, as presented below.

The CCNE would not understand the lack of political commitment to public health measures in the field of palliative care, nor the limitation of the debate to them. The CCNE's proposals are thus developed in two equally important parts, and their complementarity should guide the legislator's thinking.

They are based on the reconciliation of two fundamental principles: the duty of solidarity with the most fragile people and respect for personal autonomy.

A. Strengthening public health measures in the field of palliative care

1. Make palliative care one of the priorities of public health policies. The CCNE notes that current legislation is very poorly implemented. It recommends a resolutely proactive policy that does not call for legislative reform, but commits to measures that will enable palliative care to be integrated into the practice of all health professionals and in all care settings as soon as possible.

2. Ensure the effective development of an academic discipline (ideally interdisciplinary) dedicated to palliative care with the appointment of an academic in each faculty of medicine. Strengthen initial and ongoing training in palliative care, support for patients, relationships and communication, ethical questioning and deliberation. Palliative care modules could be integrated and made compulsory in each medical speciality (oncology, neurology, etc.).

3. Support interdisciplinary research on the end of life.

4. Promote relational care, support for the sick and their families, and practices that respect patients' rights, within the required timeframes, in dedicated places, with effective, interdisciplinary human resources. Establish and enhance the deliberative processes necessary to reach fair decisions when major ethical issues arise. These measures presuppose a reform of the pricing system in the hospital, medico-social and private sectors.

5. Strengthen palliative care at home and in medico-social institutions. In this respect, recognise and value the role of volunteers, family and professional carers; develop “support leave”[70] and the right to respite for family carers.

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[70] As a reminder, there is a family solidarity leave, or "support leave", which allows employees to assist a seriously ill relative. In principle, this leave is not paid for by the employer, but the health insurance

6. Include palliative care in regional health programmes (PRS) and in the medical projects of health and medico-social institutions. Make it compulsory for health professionals (public and private) in each French department to set up a palliative care team within a short timeframe.

7. Carry out a rigorous evaluation of the law of the 2nd of February 2016 as soon as possible in order to determine the extent of the needs mentioned in the following points and to take measures to meet them.

8. Supporting an early expression of the will.

   - Encourage our fellow citizens to appoint a “trusted person” in health and medical-social establishments and at home.

   - Strengthen the role of the “trusted person”, particularly in decisions to limit or stop treatment for a person who is not able to express their wishes.

   - Include the drafting of advance directives in the support process for patients who are about to die. Deploy effective means of communication (dedicated day, advertisements in medical cabinets, health centres and hospitals, etc.) to make their interest known to the general public.

9. Promote the interprofessional nature of the collegiate procedure, including if necessary the consultation of experts, for any decision to stop treatment.

10. Make access to continuous deep sedation until death more effective, in hospitals, in all medical and social establishments and at home.

11. The public health measures mentioned in the above points must be taken. Indeed, the CCNE insists on the fact that the vast majority of distressing, even unacceptable, end-of-life situations are the result of inadequate, or even faulty, implementation of the legislative and regulatory provisions in force. Before any reform, French society needs to speed up the efforts made in recent years to promote palliative care and train health professionals in its use.

12. Encourage everyone to take ownership of end-of-life issues by developing specific conferences, training courses or workshops in secondary schools, colleges, universities, the media, care facilities, etc. Everyone should be able to consider the end of life in an informed way, to be accompanied in their reflection by adapted and accessible media, to know their rights and the extent of existing solutions to alleviate suffering. In no way should the prospect of dying become a duty to die: society's view of vulnerable people must evolve

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scheme may pay a daily allowance for accompanying a person at the end of their life for 21 days during this leave. This measure is a form of recognition of the value of this time. We very much hope that it will be better known and used.

and learn to guess and recognise the subtle fecundity inherent in the experience of vulnerability, however difficult it may be to live.

13. Encourage all health professionals to become more aware of end-of-life issues in order to ease their relationship with death and help them to stop confusing it with failure. Finiteness is not a failure, but an absolute and unavoidable fact of human existence. Only the inability to welcome and accompany it in a way that respects the vulnerable person is a regrettable weakness. The goal of medicine is not to save life "at all costs" if its preservation is at the cost of intolerable physical and moral suffering. It must not contribute to the development of extremely painful and seemingly meaningless survival situations.

14. The government must pursue major suicide prevention campaigns in parallel. The Covid-19 crisis has also weakened certain vulnerable populations or those exposed to risks or difficult working conditions: young people (including those under 15), carers (especially medical interns) and the elderly. Effective and ambitious public health policies must be implemented to combat suicide and facilitate care and psychiatric support.

B. What are the ethical guidelines in the event of the decriminalisation of voluntary assisted dying?

15. If the legislator decides to legislate on voluntary assisted dying, the possibility of legal access to assisted suicide should be opened up to adults suffering from serious and incurable illnesses, causing refractory physical or psychological suffering, and who are expected to die in the medium term.

16. Leaving those who are no longer physically capable of such a gesture outside the scope of the law would raise an issue concerning equality amongst citizens, which in itself constitutes a major ethical difficulty. This is the reason why some people propose these patients should have legal access to euthanasia under the condition that they are expected to die in the medium term. Others consider that the law should not establish exceptions to the prohibition on giving death and would like medical decisions in exceptional cases to be left to the discretion of the judge. The CCNE leaves it to the legislator, should they take up the subject, to determine the most appropriate approach to these cases.

17. A request for voluntary assisted dying should be expressed by a person with autonomy of decision at the time of the request, in a free, informed and reiterated manner, analysed in the context of a collegiate procedure.

18. The decision to grant a request for voluntary assisted dying should be documented and argued for and would be taken by the doctor in charge of the patient at the end of the collegiate procedure defined in Article R. 4127-37 of the Public Health Code. This procedure would make it possible, in particular, to ensure that the person's physical and/or psychological suffering is refractory.

19. The doctor in charge of the patient and the other health professionals participating in the collegiate procedure should be able to benefit from a conscience clause, accompanied by an obligation to refer the patient to a practitioner likely to follow up on the patient's request.

20. The law as reformed by the provisions envisaged in the preceding points should be evaluated within a maximum of five years after its implementation and subsequently re-evaluated.

C. The need for a national debate

With this Opinion, the CCNE is helping to inform the public debate. Article 38 of the law of the 2nd of August 2021 on bioethics states that the Council "*shall lead public debates each year on one or more of the ethical problems and societal issues mentioned in Article L. 1412-1, in conjunction with the ethical discussion forums*". It stresses the need for a national debate on this issue before any new legal reform is undertaken in the end of life field. The CCNE prefers public debate to a referendum because of the extreme complexity of the subject and the importance of the nuances behind each possibility analysed. The CCNE can organise these public debates in the regions, in collaboration with the Regional Ethical Reflection Centres (ERER).[71] The National Centre for Palliative and End-of-Life Care could organise a stakeholder conference, and the Economic, Social and Environmental Council (CESE) could organise a citizens' convention to ensure that all citizens have a better understanding of the measures provided for in the laws enshrining patients' rights and of the complex ethical issues relating to support for people at the end of their life.

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[71] https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000043884384

Some members of the CCNE wanted the following text to be published along with it:

Reservation

We share the observations made in the text of this Opinion regarding ways of improving support for end of life situations in France. However, these observations lead us to express reservations about the very possibility of accompanying any legislative change. The shared observation that "we die badly in France" leads us to question the roots of this problem and the human resources that need to be developed to respond to it, rather than first considering a legislative change in favour of voluntary assisted dying.

From our point of view, **this development could only be discussed on the sine qua non condition that a certain number of prerequisites are already in place:**

- knowledge, application and evaluation of the many existing legislative provisions;

- access to palliative care and comprehensive and humane support for all persons at the end of their life;

- a precise analysis of requests for voluntary assisted dying,[72] in order to evaluate their motivation and their impact on relatives and on society as a whole, in France but also in countries where such assistance is authorized.[73]

These prerequisites are a guarantee that recourse to voluntary assisted dying is neither a failure of care nor a lack of knowledge and thus preserve the integrity of the fundamental ethical principle of free and informed consent. Developing voluntary assisted dying at a time when access to palliative care is very unevenly distributed throughout France and very inadequate in relation to needs[74] leaves open the possibility of resorting to such assistance for lack of appropriate support.

In addition, we wish to **raise several concerns**:

- **What message would a legislative change send to society?** Claiming recourse to voluntary assisted dying commits oneself and others, not only in the private field of one's relationship with others, but also in the societal field. We are concerned about a claim to autonomy on the part of the subject that would tend to deny that this development, at the junction of the intimate and the collective, concerns us not only as individuals but as

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[72] The testimonies of health and palliative care professionals during our hearings underlined the uncertainty and complexity that characterise these requests and the difficulty of assessing them and distinguishing between the wish to die or the wish to end unrelieved suffering and/or a poorly supported disability.

[73] There is very little knowledge about the effects (on patients, their families and carers) of legislation allowing assisted dying in countries where it exists.

[74] IGAS, Évaluation du plan national 2015-2018 pour le développement des soins palliatifs et l'accompagnement en fin de vie. https://www.igas.gouv.fr/IMG/pdf/2018-140r_tome_i_soins_palliatifs.pdf

parts of a social body and questions more broadly the relationship of this body to death and life.

- **What message would such a legislative development send to seriously ill, disabled or elderly people?** Is there not a risk that it will be perceived as a sign that some lives are not worth living? We are concerned that this law will create a form of guilt, or even a life complex for people already suffering from social exclusion. Furthermore, how can we reconcile a legislative change in voluntary assisted dying with the necessary prevention of suicide and policies to support old age?

- **Finally, what message would a change in legislation send to healthcare workers today?** In the context of the major health crisis we are experiencing and a crisis in the vocation of care and medicine, at a time when healthcare workers are experiencing unprecedented ethical suffering, it seems inappropriate to us to prioritise this legislative development over the urgency required by the alarming situation of our health care system. Moreover, for many carers, assisted suicide and euthanasia are acts that are contrary to the vocation and sense of medical duty and care, and contradictory to the Hippocratic oath. The introduction of voluntary assisted dying would risk representing for them an abdication signifying the collective incapacity to really take charge of end of life situations.

Precisely because we share the observation that "we die badly in France", it seems to us ethically unavoidable that every effort should be made to remedy the difficulties of the health system, to promote a medical culture appropriate to the particular issues at stake at the end of life, and to question society's relationship to old age and death. The introduction of voluntary assisted dying, for a few exceptional cases, would not on its own significantly improve the conditions of the end of life in France. In the current context of an unprecedented crisis in the health system, it could, on the contrary, contribute to worsening them, especially if it were an opportunity to overlook the prerequisites that we identify as priorities.

Thus, from our point of view, a legislative evolution on voluntary assisted dying could only be discussed if these prerequisites, recommended for several decades by the CCNE, made real and important progress. Taking this legislative step without these prior efforts would present a risk of renunciation that we do not wish to take.

<u>Signatories:</u>
Gilles Adda
Michel Badré
Sophie Crozier
Annabel Desgrées du Loû
Emmanuel Didier
Sylvie-Anne Goldberg

Marion Muller-Colard
Dominique Quinio

APPENDIX

This Opinion, and in particular the proposals that we have formulated, have been adopted by the CCNE in its composition following its partial renewal, as recorded by the decree of the 22nd of April 2022.

The preparatory work for this Opinion had included members of the CCNE in its previous composition and in particular Mrs Florence Gruat, who was co-rapporteur of the working group until the end of her mandate on 26 December 2021.

These people, who were no longer members of the CCNE at the time of the adoption of this Opinion, did not take part in the vote.

Appendix 1 Composition of the Working Group

A letter of mission from the President of the CCNE was sent to the rapporteurs on the 21st of May 2021. The working group held 38 hearings between September 2021 and January 2022. The Opinion was discussed by the Technical Section on the 5th of May 2022, the 19th of May 2022, the 16th of June 2022, in the President's Meeting (Council members' renewal period) on the 27th of January 2022, the 17th of February 2022, the 24th of March 2022, the 21st of April 2022, and by the Plenary Session on the 16th of December 2021, the 2nd of June 2022, and the 30th of June 2022.

Mounira Amor-Guéret
Régis Aubry (Rapporteur)
Alain Claeys (Rapporteur)
Sophie Crozier
Marc Delatte
Pierre Delmas-Goyon
Claude Delpuech
Fabrice Gzil
Florence Jusot
Claude Kirchner
Karine Lefeuvre
Alain Léon (Reims University Hospital, Director of the Espace de Réflexion Ethique Grand Est (EREGE); external expert)
Dominique Quinio

Members until the end of their mandate on 26/12/2021:
Pierre-Henri Duée
Florence Gruat (Rapporteur)

With the organisational and editorial support of Louise Bacquet (CCNE), Ingrid Callies (CCNE), Lucie Guimier (CCNE), Marguerite Schweizer (Sciences Po Paris, CCNE), Olivia Guilbert-Charlot (EHESP, CCNE), Pierre de Branche (CCNE trainee lawyer).

Appendix 2 List of People Interviewed

Jacques Bringer and Claudine Esper: President and Vice-President of the Ethics Committee of the Académie Nationale de Médecine
Marion Broucke, Nurse in the mobile palliative care team, AP-HP - GHU Paris-Saclay; MSc Research in palliative medicine
Alexis Burnod, Emergency doctor, Support Care Department, Institut Curie
Aline Chassagne and Danièle Leboul, Research Unit, Maison médicale Jeanne Garnier and CIC CHU Besançon
Anne-Claire de Crouy-Chanel, Physician in physical medicine and rehabilitation, CHU Kremli-Bicêtre
Sarah Dauchy, President of the Strategic Orientation Council of the National Centre for Palliative and End-of-Life Care (CNSPFV), Medical and University Department of Psychiatry and Addictology, AP-HP Centre-University of Paris
Claire Fourcade and Elise Perceau-Chambard, Palliative care physicians, Presidents of the French Society of Accompaniment and Palliative Care (SFAP) and member of the Scientific Council of SFAP
Véronique Fournier, Public health physician and cardiologist, Centre for Clinical Ethics, Cochin Hospital
Norbert Ifrah, Professor of haematology and oncology, Angers University Hospital; Chairman of the Board of Directors of the National Cancer Institute (INCa)
Claude Jeandel, Geriatrician, Montpellier University Hospital; President of the National Professional Council for Geriatrics; Fondation Partage et Vie
Olivier Lesieur, Hospital practitioner in intensive care, Groupement Hospitalier La Rochelle, president of the ethics commission of the Société de réanimation de langue française (SRLF)
Didier Sicard, Professor of Medicine, Paris-Descartes University, Honorary President of the CCNE
Sophie Moulias, Hospital practitioner in internal medicine, geriatrics, CHU Ambroise Paré
Lionel Naccache and Marie-Germaine Bousser, Neurologists, members of the CCNE
Fabrice Michel and Pierre-François Perrigault, Anaesthetists, members of the ethics committee of the French Society of Anaesthesia and Intensive Care (SFAR)
François Salachas, Neurologist, Peripheral Nerve Unit, Amyotrophic Lateral Sclerosis (ALS), Pitié Salpêtrière

Marie de Hennezel, Psychologist, psychotherapist, writer
Emmanuel Hirsch, Professor of medical ethics, University of Paris Saclay, Director of the Espace éthique de la région Île-de-France
Corine Pelluchon, Philosopher, Professor of philosophy, University of Paris-Est

Sadek Beloucif, President of the Orientation Council of the Fondation de l'Islam de France, Head of the Anaesthesia-Resuscitation Department at Avicenne Hospital.
Mgr Pierre d'Ornellas, Archbishop of Rennes
Haïm Korsia, Chief Rabbi of France
Jean-Gustave Hentz, Emeritus hospital practitioner at the University Hospitals of Strasbourg and President of the Ethics and Society Commission of the French Protestant Federation.

Jonathan Denis and Anne Vivien, President and Vice-President of the Association for the right to die with dignity (ADMD)
Tugdual Derville, Caroline Roux, Jeanne Bertin-Hugault, General Delegate and members of the association Alliance Vita; SOS Fin de vie
Elisabeth Hubert, President of HàD France, President of the Fédération nationale des établissements d'hospitalisation à domicile (FNEHAD)
Olivier de Margerie, President of the Federation Jusqu'à la mort accompagner la vie (JAMALV)
Philippe Petit, member of the National Union of Associations of Families of Head Injured and Cerebral Palsy Patients (UNAFTC)

Catherine Deroche, President of the Senate Social Affairs Committee
Fadila Khattabi, President of the Social Affairs Committee of the National Assembly
Jean Leonetti, cardiologist, honorary deputy, author of two laws on the end of life (2005, 2016),
Jean-Louis Touraine, Professor of Medicine, Member of Parliament, author of a bill "on the end of life with dignity”

Pascale Fombeur, State Councillor, President of a chamber of the Council of State's litigation section
François Stasse, Honorary State Councillor, former Director General of the Assistance publique-Hôpitaux de Paris
Gilles Raoul-Cormeil, Professor of private law and criminal sciences, University of Western Brittany

Women's Grand Lodge of France
Grand Lodge of France
Grand Orient de France

Appendix 3 Voluntary assisted Dying - Foreign Legislation

The purpose of this document is to present foreign legislation on voluntary assisted dying and has been drawn up mainly on the basis of the legislative texts of the countries concerned. Given the evolving nature of the subject and the difficulties in translating certain texts that are only available in foreign languages, it does not necessarily cover all existing regulations.

Comparative table of authorised practices

Euthanasia	**Assisted suicide**	**Euthanasia and assisted suicide**
Belgium	Switzerland	Netherlands
	United States (ten states)	Luxembourg
	Austria	Spain
		Canada
		Australia (five states)
		New Zealand

1. Belgian legislation on euthanasia

Euthanasia was legalised in Belgium by a law of the 28th of May 2002, in force since the 22nd of September 2002.[75] The patient who wishes to be euthanised must be in a hopeless medical situation and be suffering constant and unbearable physical or psychological pain which cannot be alleviated and which is the result of a serious and incurable accidental or pathological condition. The law does not impose any condition of nationality or residence.

Euthanasia is open to minors with the capacity of discernment, under more restrictive conditions: the suffering reported by the minor must be physical and death must be foreseen in the near future.

The patient is examined twice by separate doctors. If death is not expected soon, a third doctor is consulted and euthanasia cannot, in principle, take place less than one month after the request. Several interviews, spaced out over a reasonable period of time in relation to the patient's condition, make it possible to ascertain the persistence of the patient's suffering and their reiterated wishes. Interveners benefit from a conscience clause. A Federal Commission for Control and Evaluation is responsible for the a posteriori control of the procedure.

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[75] Law of the 28th of May 2002 on euthanasia, available for download in PDF format on the website of the European Bioethics Institute: https://www.ieb-eib.org/docs/pdf/2019-04/doc-1554801153-49.pdf

An unconscious person whose condition is irreversible may be granted euthanasia on the basis of an advance declaration drawn up in the presence of two witnesses, which may include the appointment of a “trusted person”. Their condition must be confirmed by two doctors before the euthanasia. People who are in an advanced state of dementia but are still conscious cannot be euthanised.

22,081 people were officially euthanised between 2002 and 2019, and 2,656 people were euthanised in 2019.[76]

2. Legislation allowing only assisted suicide

a. Switzerland

Assisted suicide is only criminally punishable when motivated by a "selfish" motive.[77] If it is not motivated by a "selfish" motive, it is therefore indirectly authorised by federal legislation, without any further conditions. In view of this situation, assistance is usually provided privately by associations[78] which themselves define their own conditions of eligibility.[79]

Where assistance is provided in hospitals or medical-social institutions, the regulation is a matter of cantonal health policy. Three cantons currently require these institutions to allow assisted suicide for patients with serious and incurable diseases: the canton of Vaud (since 2012), the canton of Neuchâtel (since 2014) and the canton of Geneva (since 2018).

In 2018, 1,176 assisted suicides were recorded in Switzerland, i.e. 1.8% of the year's deaths. The number has thus tripled since 2010.[80]

b. The United States

Euthanasia is illegal in all states. In 1997, Oregon passed a law legalising assisted suicide.[81] Subsequently, the states of Washington, Vermont, California, Colorado, the Dis-

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[76] Report of the Federal Commission for the Control and Evaluation of Euthanasia for the years 2018 and 2019, available on the website of the Federal Public Health Service: https://organesdeconcertation.sante.belgique.be/fr/documents/cfcee-rapport-euthanasie-2020

[77] Swiss Criminal Code, Art. 115. The Penal Code is available at: https://www.fedlex.admin.ch/eli/cc/54/757_781_799/fr

[78] Exit Suisse Romande, Exit Deutsche Schweiz, Dignitas, Lifecircle, Pegasos et Ex International.

[79] For an example of the conditions set by the associations: the website of Exit-ADMD Suisse ro-mande.

[80] The figures are provided by the Swiss Federal Statistical Office, in a press release available at: https://www.bfs.admin.ch/bfs/fr/home/actualites/communiques-presse.assetdetail.15084043.html

[81] "Death with Dignity Act 1997, available for download from the Oregon government website: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ors.aspx

trict of Columbia, Hawaii, New Jersey, and Maine have passed similar legislation. In 2009,[82] the Montana Supreme Court also made it possible for medically competent adults with a terminal illness to receive assisted suicide.

The Oregon law, which has served as a model for other states, allows assisted suicide for Oregon residents with an incurable and irreversible disease that will result in death within six months. A patient who suffers from a psychic or psychological disorder or depression resulting in impaired judgment is ineligible for assisted suicide. The patient must make an oral request, which they confirm in writing in the presence of two witnesses and then reiterate orally. These steps are spaced out in time. The patient is examined twice by separate doctors, and a psychiatric examination if there is any doubt about their mental state.

In 2020, 370 people in Oregon received a prescription for a lethal substance, and 60% of these people died from ingesting it.[83] Since 1997, 1,905 people have died from assisted suicide in Oregon.

c. Austria

Assisted suicide was legalised by a law of the 16th of December 2021, which came into force on the 1st of January 2022.[84] In order to benefit from it, the applicant must be in a state of unavoidable suffering due to either an incurable terminal illness or a serious and lasting illness with persistent symptoms, the consequences of which have a lasting effect on the person's entire way of life. In addition, the applicant must be an Austrian citizen or have their usual residence in Austria.

The applicant is examined twice by separate doctors, with an additional examination if there are doubts about their mental state. If the applicant is deemed capable of making a decision, they may then draw up an end-of-life arrangement,[85] a document that allows them to record their wish to be assisted in suicide. The end-of-life arrangements are drawn up in writing with the help of a legally qualified person. The lethal substance is delivered to the person or their representative, in a pharmacy, upon presentation of the end-of-life arrangements. Suicide takes place in a private setting with the assistance of a third party, within one year of the delivery of the substance.

3. Legalisation of euthanasia and assisted suicide

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[82] Montana Supreme Court, Robert Baxter v. State of Montana, 2009

[83] Report of the 6th of February 2021 published by the Oregon Department of Health, available in PDF at: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf

[84] Law on end-of-life provisions ("Sterbeverfügungsgesetz"), adopted following a decision of the Austrian Constitutional Court and available for download on the website of the Austrian Parliament: https://www.parlament.gv.at/PAKT/VHG/XXVII/I/I_01177/index.shtml#tab-Uebersicht

[85] « Sterbeverfügung »

a. The Netherlands

Euthanasia and assisted suicide were legalised by a law of the 12th of April 2001 which came into force on the 1st of April 2002.[86] It imposes six requirements[87] on the doctor, which include ensuring that the patient's request is voluntary and well-considered, that their suffering is enduring and unbearable, and that no other reasonable solution can be found. The patient is examined twice by separate doctors. Subject to parental consent, minors are eligible for assisted dying from the age of 12. The law does not impose any condition of nationality or residence.

A patient who is unable to express their will may be euthanised by virtue of a written declaration drawn up earlier. Such a declaration may benefit people with advanced dementia.

An a-posteriori control is carried out by regional control commissions for the end of life. In 2019, 6,361 reports of assisted dying were registered, representing 4.2% of the total number of deaths in the country (151,793).[88]

b. Luxembourg

Euthanasia and assisted suicide were legalised by a law of the 16th of March 2009, in force since the 17th of March 2009.[89] The patient who wishes to benefit from it must be in a medical situation with no way out and be suffering constant and unbearable physical or psychological pain with no prospect of improvement, resulting from an accidental or pathological condition. The law does not impose any condition of nationality or residence.

The patient undergoes two examinations by separate doctors, and several interviews spaced out over a reasonable period of time to ensure that the patient's suffering persists and that the request is maintained. The interveners benefit from a conscience clause.

An unconscious person whose condition is irreversible may be euthanised on the basis of end-of-life provisions drawn up in the presence of two witnesses (which may include

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[86] The law of the 12th of April 2001, entitled " Termination of Life on Request and Assisted suicide Act ", is available on the World Federation of Right to Die Societies (WFRTDS) website : https://wfrtds.org/dutch-law-on-termination-of-life-on-request-and-assisted-suicide-complete-text/.

[87] “requirements of due care”

[88] Report of the regional control commissions for the end of life for the year 2019, available in PDF format at the following address: https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports

[89] The law of the 16th of March 2009 on euthanasia and assisted suicide is available on the Luxembourg government website: https://legilux.public.lu/eli/etat/leg/loi/2009/03/16/n2/jo

the designation of a “trusted person”). The condition must be confirmed by two doctors. A person in an advanced state of dementia but still conscious cannot, in principle, benefit from assisted dying.

A National Control and Evaluation Commission is responsible for the a-posteriori control of the procedure. Since 2009, 112 declarations have been registered. While the number of annual declarations averaged between 8 and 10 until 2018, it will rise to 16 in 2019 and 25 in 2020.[90]

c. Canada

Euthanasia and assisted suicide were legalised by a law of the 17th of June 2016,[91] amended in 2021.[92] In order to benefit from it, the person must be affected by serious and irremediable health problems: a serious and incurable disease, disorder or disability resulting in an advanced or irreversible decline in their capacities and causing them persistent, intolerable physical or psychological suffering that cannot be alleviated under conditions that the person considers acceptable. They must also be eligible for Canadian-funded health care. People with a mental illness are not eligible for assisted dying.

The request must be made in writing and witnessed by two people. The person is examined twice by separate doctors or nurses. There are minimum time limits between the different stages of the procedure. When a doctor or nurse provides assistance in dying, the person must in principle renew their consent to the procedure.[93] Those involved have a conscience clause.

In 2020, 7,595 cases of medical assistance in dying were reported, representing 2.5% of all deaths in the country.[94] Between 2016 and 2020, 21,589 deaths attributable to medical assistance in dying were reported in Canada.

d. Australia

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[90] Report of the National Control and Evaluation Commission for the years 2019 and 2020, available in PDF version at the following link

https://sante.public.lu/fr/actualites/2021/03/euthanasie/euthanasie-rapport-2019-2020.pdf

[91] The Criminal Code Amendment and Related Amendments (Medical Assistance in Dying) Act of the 17th of June 2016, available on the Government of Canada website: https://laws-lois.justice.gc.ca/fra/loisAnnuelles/2016_3/page-1.html

[92] Act C7 of the 17th of March 2021, available on the Parliament of Canada website: https://www.parl.ca/DocumentViewer/fr/43-2/projet-loi/C-7/sanction-royal

[93] The 2021 reform, however, allows the assistance to be administered without the final consent of the person who has lost the capacity to consent after making the first request and had made an agreement with the doctor or nurse to anticipate this situation.

[94] Second Annual Report on Medical Assistance in Dying, available on the Canadian government website: https://www.canada.ca/fr/sante-canada/services/aide-medicale-mourir/rapport-annuel-2020.html

Several Australian states have passed laws legalising euthanasia and assisted suicide, with similar conditions: Victoria,[95] Western Australia,[96] Tasmania,[97] South Australia[98] and Queensland.[99]

In general, the applicant must have an incurable, progressive and advanced disease that is likely to result in death within six months (twelve months in the case of neurodegenerative disease) and that causes suffering that cannot be relieved in a manner that the applicant considers tolerable.[100] The patient must be capable of making a decision, which may exclude certain mental disorders.[101] The laws impose citizenship and residency requirements.

The procedure is similar in all these states: the patient must make three requests, one of which must be in writing and witnessed by two witnesses. They undergo two reviews by separate practitioners. The different stages are spaced out in time. Practitioners have the right to conscientious objection. Euthanasia can only take place if self-administration is deemed inappropriate (but mere reluctance on the part of the patient is actually sufficient to establish this).[102] The laws establish bodies to ensure compliance with legal requirements.

e. New Zealand

Euthanasia and assisted suicide were legalised by an Act of the 16th of November 2019, which came into force on the 7th of November 2021.[103] To be eligible, the person must

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[95] Voluntary Assisted Dying Act of 29 November 2017, in force from 19 June 2019, available for download from the Victorian legislation website: https://www.legislation.vic.gov.au/in-force/acts/voluntary-assisted-dying-act-2017/005

[96] Voluntary Assisted Dying Act of the 17th of December 2019, in force from the 1st of July 2021, available for download from the Western Australia legislation website: https://www.legislation.wa.gov.au/legislation/statutes.nsf/law_a147242.html

[97] End-of-Life Choices Act of 12 April 2021, due to come into force on 23 October 2022, available on the Tasmanian legislations website:
https://www.legislation.tas.gov.au/view/whole/html/asmade/act-2021-001

[98] Voluntary Assisted Dying Act of the 24th of August 2021, with an undetermined commencement date, available for download from the South Australian Government website:
https://www.legislation.sa.gov.au/lz?path=%2FC%2FA%2FVOLUNTARY%20ASSISTED%20DYING%20ACT%202021

[99] Voluntary Assisted Dying Act of the 16th of December 2021, due to come into force on 1 January 2023, available on the Queensland legislations website:
https://www.legislation.qld.gov.au/view/pdf/asmade/act-2021-017

[100] In Western Australia and Tasmania, incurability is not required. In Queensland, death must be expected within 12 months.

[101] The laws of the various States contain very detailed provisions to assess this capacity to consent and not to exclude de facto persons with mental or communication disorders.

[102] With the exception of South Australia, where euthanasia is only possible if the applicant is physically unable to administer the drug or ingest it.

[103] The End of Life Choice Act of the 16th of November 2019 is available on the New Zealand legislations website: https://www.legislation.govt.nz/act/public/2019/0067/latest/whole.html#DLM7285958

be terminally ill (expected to die within six months), in an advanced and irreversible state of physical decline, and have unbearable suffering that cannot be relieved by any means the person considers tolerable. The patient must be capable of making an informed decision regarding assistance in dying. The patient must be a New Zealand citizen or have permanent residence in New Zealand.

The patient must make an oral request and then a written request. The patient has several interviews with the responsible doctor. They are examined twice by separate doctors. Finally, they complete a form to choose when, where and how they will be assisted (by a doctor or nurse). The person must reaffirm their choice at the time of administration. Workers have the right to conscientious objection. A review committee ensures afterwards that the legal requirements are met.

f. Spain

Euthanasia and assisted suicide were legalised by a law of the 18th of March 2021.[104] In order to benefit from it, the patient must suffer from a serious and incurable disease[105] or a serious, chronic and incapacitating condition.[106] They must be a Spanish citizen or a legal resident in Spain.

The patient must make two written requests at intervals and then confirm these orally. The patient is examined twice by separate doctors. A patient who is not in full possession of their faculties may receive assistance in dying, subject to a document drawn up beforehand for this purpose, which may include the designation of a "trusted person". Those involved have a conscientious objection. A guarantee and evaluation commission shall carry out a pre-dying check and a post-dying check.

4. Court rulings and reform proposals on voluntary assisted dying

Some countries have had important court decisions or are in the process of legalising some forms of voluntary assisted dying. Without being exhaustive, the cases of Colombia, Italy, Germany, Portugal and the United Kingdom can be highlighted.

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[104] Euthanasia Regulation Act of the 18th of March 2021 ("ley de regulacion de la eutanasia"), available on the website of the Spanish Official Bulletin: https://www.boe.es/diario_boe/txt.php?id=BOE-A-2021-4628

[105] Defined as the disease causing constant and unbearable physical or psychological suffering with a limited vital prognosis, in a context of progressive fragility

[106] Such a condition involves a limitation in autonomy associated with constant and intolerable physical or psychological suffering for the sufferer, with the certainty or strong likelihood that these limitations will persist over time with no possibility of recovery or significant improvement.

For example, in several decisions, the Colombian Constitutional Court has ruled that a doctor who performs euthanasia on a patient who appears to be terminally ill is not criminally responsible, subject to certain restrictive conditions.[107]

In Italy, following a decision of the Italian Constitutional Court, the Parliament is examining a bill providing for the decriminalisation of assisted suicide for adult patients suffering from an irreversible and fatal pathology, the source of physical and psychological suffering deemed intolerable, and maintained alive by treatment.[108]

In Germany, three bills to regulate assisted suicide were tabled in Parliament in April 2021,[109] following a decision by the Federal Constitutional Court in Karlsruhe on the 26th of February 2020.[110]

In Portugal, a law decriminalising euthanasia, adopted on the 29th of January 2021, was invalidated by the Constitutional Court on 15 March 2021.[111] It was rewritten but the Portuguese President vetoed the new version.[112]

Finally, in England and Wales, a bill providing for the legalisation of assisted suicide for people with a terminal illness (death must be expected to happen within 6 months) has been introduced in the British Parliament.[113]

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[107] Colombian Constitutional Court, 1997, decision C239/97, reiterated in 2014 by decision T-970/14

[108] « Suicide assisté, l'Italie relance le débat », La Croix, 13/12/2021.

[109] « Allemagne : deux propositions de loi pour dépénaliser le suicide assisté », Institut Européen de Bioéthique, 12 mai 2021. / « En Allemagne, le débat sur le suicide assisté franchit une nouvelle étape », La Croix, 24/06/2022. Voir : https://www.la-croix.com/Monde/En-Allemagne-debat-suicide-assiste-franchit-nouvelle-etape-2022-06-24-1201221704

[110] « Allemagne : l'interdiction du « suicide organisé » jugée inconstitutionnelle », Le Monde, 26/02/2020

[111] « Au Portugal, la Cour constitutionnelle annule la loi autorisant l'euthanasie », Le Monde, 18/03/2021

[112] « Portugal's president vetoes law legalising euthanasia », euronews, 30/11/2021

[113] Assisted Dying Bill, UK Parliament website

Appendix 4 Statistics on the Application of the Main Foreign Laws

The Netherlands

In their 2019 report,[114] the regional supervisory commissions for the end of life in the Netherlands make the following finding.

In 2019, the regional commissions registered **6,361 reports of assistance in dying**, representing **4.2% of the total number of deaths** in the country (151,793). By way of comparison, in 2012 there were 4,188 cases of euthanasia and assisted suicide and 1,815 in 2003.

These figures mark an increase of 3.8% compared to 2018 (6,126 reports) but are down compared to 2017 (6,585 reports, 4.4% of total deaths).

6,092 reports (95.8%) concern cases of euthanasia, 245 (3.9%) cases of assisted suicide and 24 (0.4%) a combination of both (situation in which the person consumes the substance but does not die within the expected timeframe).

In 91.1% of the cases (5,792), the patients were suffering from:
- incurable cancer (4,100) ;
- Nervous system diseases (408) such as Parkinson's disease, multiple sclerosis or Charcot disease;
- cardiovascular diseases (251);
- pulmonary diseases (187);
- polypathologies (846).

160 reports concerned people whose suffering was caused by the onset of a dementia process, but who were considered capable of expressing their wishes because they were still able to consider the consequences of assistance in dying. 68 reports concerned people whose suffering was caused by one or more psychiatric disorders.

172 reports concerned people suffering from various geriatric pathologies (vision and hearing problems, osteoarthritis, osteoporosis, balance problems, cognitive impairment) which caused them suffering deemed unbearable and with no prospect of improvement.

Two reports concerned people who were no longer able to express their wishes and whose euthanasia was carried out on the basis of end-of-life provisions.

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[114] The report is available in French, in PDF format, on the website of the regional control commissions for the end of life: https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports

As regards the concerned age groups, the majority of reports concerned people in their 70s (32.7% of cases), 80s (25.6% of cases) and 60s (21.4% of cases). No minors were reported in 2019. 60 reports concerned the 18-40 age group.

In 80.1% of the cases, the euthanasia took place in the patient's h1ome. The other cases concerned palliative care facilities (7.6%), long-stay facilities (4.3%), nursing homes (3.6%), hospitals (2.8%), or other places (1.6%, e.g. home of a relative).

34 reports concerned simultaneous euthanasia of partners.

In 0.1% of cases (4 reports), the commissions considered that the criteria set out in the law had not been properly respected.

Belgium

The latest report of the Federal Commission for the Control and Evaluation of Euthanasia concerns the years 2018 and 2019.[115] The Commission notes the following.

Between 2002 and 2019, 22,081 people were officially euthanised. The Control Commission counted 2,359 euthanasias in 2018 and 2,656 euthanasias in 2019, thus noting an increase of 12.6% in euthanasia cases. Since 2010, euthanasia cases have almost tripled (953 cases in 2010) and have increased by a factor of about 11 between 2003 and 2019.

In terms of age groups, 58% of euthanasias were carried out on patients aged between 40 and 79 years, and 40% on patients aged over 79 years. It is mainly patients in the 60, 70 and 80 age groups who ask to be euthanised.

For the 2018-2019 period, **49 people were euthanised on the basis of an advance declaration**, which corresponds to 1% of the total number of official euthanasias over this period (a percentage that has been falling for several years).

For the period 2018-2019, 45**% of euthanasias took place at home** (an increase), **37% in a hospital** (a decrease) and 16% in rest and care homes (three times more than in the period 2002-2003).

As regards the main diseases concerned, **the majority of euthanasias concerned people with cancer** (3,107 people, or 62% of euthanasias). Among the other reasons for requesting euthanasia, the control commission noted polypathologies (18% or 898 peo-

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[115] The report is available on the website of the Federal Public Health Service: https://organesdeconcertation.sante.belgique.be/fr/documents/cfcee-rapport-euthanasie-2020

ple), diseases of the nervous system (9%), diseases of the circulatory system (4%), diseases of the respiratory system (3%), psychiatric conditions (1% or 57 people) and cognitive disorders (dementia syndromes) for 48 people.

In the period 2018-2019, **105 people with mental disorders were euthanised** (an increasing figure). The number of euthanasias for cognitive disorders (dementia) doubled between the period 2016-2017 and 2018-2019, from 24 people to 48 people. For 43 of these 48 patients, death was not expected in the near future.

As regards people with mental disorders, they were affected by the following pathologies: 17 people suffering from mood disorders (depression, bipolarity,...), 48 people suffering from organic mental disorders (dementia, Alzheimer's,...), 26 people with personality and behavioural disorders (compared to 13 in the previous period), 4 people with neurotic disorders, stress-related disorders and somatoform disorders, 7 people with schizophrenia, schizothypic disorders and delusional disorders, and 3 people with organic mental disorders such as autism.

Between 2018 and 2019, 794 euthanasias were carried out on patients whose death was not expected in the near future, i.e. in the coming days, weeks or months (16% of cases, compared with around 8% of cases in 2010).

In 81% of the cases, patients reported physical and psychological suffering. In 15% of cases, only physical suffering. In 4% of cases, only psychological suffering.

At least 45 patients residing abroad were reportedly euthanised in Belgium between 2018 and 2019 (this figure is difficult to assess because in principle only the place of birth of the persons is mentioned, not the place of residence).

Luxembourg

The latest report of the National Control and Evaluation Commission concerns the declarations of euthanasia and assisted suicide received between 1 January 2019 and 30 December 2020.[116]

Since 2009, 112 declarations have been recorded. While the number of declarations per year averaged between 8 and 10 until 2018, **it rose to 16 in 2019 and 25 in 2020.** 4 requests concerned suicide assistance and 1 was based on end-of-life provisions.

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[116] The report is available, in PDF: https://sante.public.lu/fr/actualites/2021/03/euthanasie/euthanasie-rapport-2019-2020.pdf

The declarations mainly concerned the 60-79 age group (64 requests since 2009) and people aged 80 or over (36 requests). The remaining 11 declarations were in the 40-59 age group.

36 euthanasias took place at home, 55 in hospital and 17 in an integrated centre or nursing home.

The majority of declarations concerned cancers (88 declarations) and neurodegenerative diseases (17 declarations).

The commission has registered 3,981 end-of-life dispositions since 2009, of which 408 in 2020 (a declining number compared to previous years).

Switzerland

According to a study by the Swiss Federal Statistical Office for the year 2018,[117] 1,176 assisted suicides were recorded in Switzerland in 2018. The number of assisted suicides has thus tripled since 2010 and is 17% higher than in 2017. Assisted suicide accounted for 1.8% of deaths in Switzerland in 2018.

According to the Office, assisted suicides were more frequent among people aged 65 or over (431 men and 598 women) than among people under 65 (68 men and 79 women). Assisted suicide was most often related to the following diseases: cancer (40.7%), nervous system diseases (11.5%), cardiovascular diseases (12.8%) and others, such as chronic pain, dementia, depression and multiple morbidity (35.0%).

In 2020, 1,282 people were reported to have used assisted suicide through association Exit, 68 more than in 2019.[118]

In 2020, people with cancer accounted for 66% of assisted suicide deaths. 11% of the other cases concerned people with cardiovascular diseases and 8% with neurological diseases.

According to Le Figaro, between 2008 and 2012, 66 French people were reported to have benefited from assisted suicide in Switzerland, compared to 268 Germans and 126 Britons.[119]

Oregon

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[117] The press release is available on the website of the Federal Statistical Office: https://www.bfs.admin.ch/bfs/fr/home/actualites/communiques-presse.assetdetail.15084043.html

[118] « L'an dernier, plus de 1280 personnes ont fait appel à Exit pour mourir en Suisse », Le Temps, 22/02/2021.

[119] « les français plus nombreux à choisir de mourir en Suisse », le Figaro, 22/08/2014

According to a report of the 6th of February 2021 published by the Oregon Department of Health,[120] the data for 2020 is as follows.

370 people received a prescription for a lethal substance in 2020, a 25% increase over 2019. 60% of these people died from ingesting the prescribed substance.

245 people died from ingestion of a lethal substance in 2020 compared to 191 in 2019.

Since 1997, 2,895 people have received such prescriptions and 1,905 people (66%) have died from ingesting the substance.

Canada

The Canadian government's second annual report on physician assisted dying[121] highlights the following.

In 2020, 7,595 cases of medically assisted dying were reported in Canada, which represents 2.5% of all deaths in the country. The number of medically assisted dying cases in 2020 represents a 34.2% growth rate over 2019.

The total number of medically assisted dying deaths reported in Canada since 2016 would be 21,589.

In 2020, men accounted for 51.9% of medically assisted dying cases and women for 48.1%. The average age of the individuals was 75.3 years.

In the majority of cases, the applicants were suffering from cancer (69.1%). The other main conditions were cardiovascular disorders (13.8%), chronic respiratory diseases (11.3%) and neurological disorders (10.2%). These trends are similar to those observed in 2019.

In 2020, the main locations for the provision of medical assistance in dying were private homes (47.6%) and hospitals (28.0%). Other locations were hospices (17.2%) and residential care facilities such as long-term care facilities (5.7%). In 2019, the rates of administration in hospitals (36.4%) and in private homes (35.1%) were almost equal.

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[120] The report is available in PDF : https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf

[121] The report is available on the Canadian government's website : https://www.canada.ca/fr/sante-canada/services/aide-medicale-mourir/rapport-annuel-2020.html

The most common intolerable physical or psychological suffering cited by patients was loss of ability to participate in meaningful activities (84.9%), followed closely by loss of ability to perform activities of daily living (81.7%).

Only 78.8% of written requests for medical assistance in dying resulted in the provision of assistance in 2020. The remaining requests were not granted because the patient had died beforehand (12.7%), was ineligible (6%) or the request was withdrawn (2.5%).

Appendix 5: Clandestine Euthanasia and Assisted Suicide

Euthanasia and assisted suicide carried out clandestinely are, by their very nature, particularly difficult to quantify, and there are no precise official statistics on this subject. The figures generally quoted come mainly from hearings of foreign health professionals and from studies often relayed by associations.
This difficulty of evaluation is underlined by the official report of the Belgian Control Commission for 2018-2019: "as already pointed out in previous reports, the Commission does not have the possibility to evaluate the proportion of the number of declared euthanasias compared to the number of euthanasias actually performed".[122]

Some hearings of foreign health professionals carried out in the context of the Sicard report in 2012[123] thus highlighted the existence of assistance in dying provided outside legal procedures in Belgium (hearing of Claire Marie le Huu, p.71). In the Netherlands, according to Professor Van Delden, only 77% of cases were reported to the supervisory commissions. The doctor linked the unreported cases to the increase in the practice of terminal or deep sedation (p.74). Finally, in Oregon, the report noted a study conducted between 2004 and 2006, according to which ineligible patients were prescribed lethal medication (p.78).

In a publication on its website, the SFAP notes a survey carried out in the Netherlands in 2012 according to which 23% of assisted suicides performed in the Netherlands were not recorded,[124] which is in line with the figures mentioned by Professor Van Delden in the Sicard report.

A report by the National Assembly, based on a survey of a panel of doctors, highlighted the following figures for the Netherlands in 2005: "The reporting rate for euthanasia is increasing, reaching 80% in 2005, compared to 60% in 2003 and 54% in 2001. At the same time, this means that the rate of clandestine euthanasia was 20% in 2005, which undermines the virtues of transparency attributed to this legislation by its promoters”.[125]

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[122] The report is available on the website of the Belgian Federal Public Health Service: https://organesdeconcertation.sante.belgique.be/fr/documents/cfcee-rapport-euthanasie-2020

[123] Report of the Commission of reflection on the end of life in France, 18/12/2012, available in pdf format: https://solidarites-sante.gouv.fr/IMG/pdf/Rapport-de-la-commission-de-reflexion-sur-la-fin-de-vie-en-France.pdf

[124] https://sfap.org/actualite/4-000-euthanasies-clandestines-par-en-france-c-est-faux

[125] Information report drawn up on behalf of the mission to evaluate law no. 2005-370 of 22 April 2005 on patients' rights and the end of life.

Appendix 6 The Semantics of Suicide

There is a wide variety today of terminologies to designate what is traditionally called "medically assisted suicide" or "assisted suicide". Death with dignity, assisted dying, physician aid in dying, medically assisted dying, etc., are all terms used to refer to the same act: that by which a person intentionally takes their own life, usually by means of a lethal substance supplied by a third party. Of course, the use of these alternative terminologies to refer to the same phenomenon is not without reason. The associations, organisations and supporters or not of the legalisation of physician-assisted suicide (PAS, hereafter), give very specific reasons for this. The negative emotional charge attached to the word suicide is denounced. Insofar as a word is never limited to a pure and simple meaning, but always implies and carries with it, to varying degrees, a set of representations, values and preconceptions, the word suicide, by virtue of the negative moral and emotional charge it carries, takes the debate in a certain direction, prefiguring certain conceptions of the question and potential responses, and this is why a more neutral terminology is often called for. The use of the term suicide also opens the way to the often denounced contradiction between *preventing* suicide and *legalising* PAS. Thus, some associations argue that "the practice of medical aid in dying is distinct from the act that is traditionally and ordinarily called 'suicide', the tragic event that our organisation works so hard to prevent".[126] The question, therefore, is whether or not a separate, more neutral and appropriate terminology should be used than the terms "assisted suicide" or "physician-assisted suicide".

Conceptually, there does not appear to be sufficient reason to assert that assisted suicide is not suicide. Suicide is, in its most commonly accepted sense, understood as the action by which the agent causes their own death, foreseeing, at least approximately, how this act will cause their death, and intending to bring it about.[127] There is no doubt that the first two points are present in PAS: the person causes their own death since it is they, and not a third person, who take their own life (generally by ingesting a lethal substance) and they do so, certainly, with full knowledge of the facts (given all the legal precautions that exist in the countries that have legalised PAS, it does not seem possible to argue the contrary). Less obvious is the question of intent, as it has been argued that in assisted suicide the person would not really intend to kill themselves. However, for many reasons,[128] it seems difficult to support this position to the end, if only to the extent that the agent decides to ingest a lethal drug *in order to* kill themselves. So much so that death is indeed considered here as an end, albeit a conditioned one, of which the lethal substance is the means. That assisted suicide is indeed suicide,

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[126] American Association of Suicidology, “Statement of the American Association of Suicidology: ‘Suicide’ Is Not the Same as ‘Physician Aid in Dying,’” 2017, https://ohiooptions.org/wp-content/ uploads/2016/02/AAS-PAD-Statement- Approved-10.30.17-ed-10-30-17.pdf.

[127] Reed, P. Is “aid in dying” suicide? *Theoretical Medecine and Bioethics,* 40, 123–139 (2019). https://doi.org/10.1007/s11017-019-09485-w.

[128] *Ibidem*.

however, does not mean that it *should necessarily* be qualified as such. There may be other reasons for it that do not relate to an ontological difference. For, even if PAS is suicide, it may be that it is so particular that a differentiation, both terminologically and practically, is necessary.

The work[129] that has been done on the issue suggests, however, that "it is far from clear that individuals who choose PAS are in a fundamentally different position from those who decide to commit suicide".[130] The various arguments put forward to establish a difference between ADM and other forms of suicide - such as the ability to make an informed choice, the existence of family support, differences in suffering or reasons for wanting to kill oneself, or in hope - do not lead to a clear and precise conclusion that there is a fundamental difference between the two and therefore a need to separate them, at least in terminological terms. For even if there is a case for differentiating them in practical terms (i.e. in terms of how they should be treated and dealt with in terms of supervision, prevention, etc.), this does not imply that they should be differentiated terminologically. "It does not seem obvious that there is anything impertinent in arguing that we are working to prevent suicide in general while allowing physician-assisted suicide as an exception."[131]

If, therefore, there is no ontological or even specific difference between PAS and other forms of suicide, there may be other reasons for calling them different. One reason in particular needs to be highlighted: the emotional and moral charge that the word suicide carries. The idea is that there would be less stigma attached to PAS if it were linguistically differentiated from suicide. Several studies[132] have highlighted the lack of neutrality of the word suicide in the debates on the legalisation of PAS and the effects it can have on both the perception of the issues and the possible answers, due to the framing effects[133] it implies. Opting for a more neutral terminology, less loaded in terms of value and judgement, would be a way to have a debate less about the feelings and representations linked to the words, and more about the arguments that focus on the concept. As relevant as this argument may seem, it is nonetheless problematic in several respects. To do so is, first and foremost, to accentuate and reinforce the stigma

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[129] Friesen, P., 2020, "Medically Assisted Dying and Suicide: How Are They Different, and How Are They Similar?", *Hastings Center Report*, 50: 32–43 ; Reed, P., 2020, "Against Recategorizing Physician-Assisted Suicide", *Public Affairs Quarterly*, 34: 50–71/.

[130] Friesen, *ibidem*.

[131] Reed, *ibidem*.

[132] Magelssen, M., Supphellen, M., Nortvedt, P. *et al.* Attitudes towards assisted dying are influenced by question wording and order: a survey experiment. *BMC Med Ethics* 17, 24 (2016). https://doi.org/10.1186/s12910-016-0107-3 ; L. Saad, "U.S. Support for Euthanasia Hinges on How It's Described," http:// news.gallup.com/poll/162815/support- euthanasia-hinges-described.aspx, accessed February 15, 2018 ; Cholbi, Michael, 2011, *Suicide: The Philosophical Dimensions*, Peterborough, Ontario: Broadview. ; « On clarifying terms in applied ethics discourse: Suicide, Assisted Suicide and Euthanasia", *International Philosophical Quarterly*, vol 43, No. 3, Issue 171, September 2003, Craig Paterson.

[133] Framing effects "occur when (often small) changes in the presentation of an issue or the production of an event produce (larger) changes in opinion" and the main idea "of framing theory is that an issue can be viewed from a plurality of perspectives and constructed in such a way that it would have a diversity of implications with respect to certain values and considerations. Framing refers to the process by which people develop a certain conception of an issue or change their way of thinking about a problem". cf. Chong D, Druckman JN. Framing theory. Ann Rev Polit Sci. 2007;10(1):103-26.

surrounding suicide itself. "Many attempts to distance the two acts harshly describe suicide, contributing to a conception of suicide as selfish and immoral",[134] as reflected in the "discriminatory" tone present in the discussions on the distinction between suicide and PAS.[135] Furthermore, it should be pointed out that if the lack of neutrality of the term suicide has an effect on the debate on legalisation, it is mainly due to the lack of information, investigation and ethical questioning of the population in the debate. The problem is not so much the emotional charge and values that the word suicide carries, but the lack of ethical education on the issue. Then, we must also realise that choosing another terminology is only a way of disguising a bias in favour of the legalisation of PAS, in exactly the same way that those who oppose it prefer to keep the expression "assisted suicide" in order to benefit from the prejudices attached to the word suicide.

In the end, and in the absence of sufficient evidence for a change in terminology as well as of suitable candidates to replace the expressions "assisted suicide" or "physician-assisted suicide", it therefore seems advisable to retain them in discussions of the phenomenon they desire. All the more so because, although these expressions are not free of difficulties, they are nonetheless conceptually appropriate to designate the phenomenon in question. The neutrality of the term suicide, which is undoubtedly its most problematic aspect, should become established as we focus more on the real points of debate, on what it refers to, and less on the prejudices that are sometimes assigned to it without even realising it.

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[134] Friesen, *ibidem*.

[135] B. D. Kelly and D. M. McLoughlin.“Euthanasia, Assisted Suicide and Psychiatry: A Pandora’s Box,” *British Journal of Psychiatry*.

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