CAN GIVING DEATH BE CONSIDERED AS CARE?

INTERPROFESSIONAL ETHICAL REFLECTIONS

on the prospect of legalizing assisted suicide and euthanasia and their possible impact on caregiving practices.

SIGNATORY

LIST OF SIGNATORY ORGANIZATIONS:

2SPP : Société Française de Soins Palliatifs Pédiatriques

AFSOS : Association Francophone des Soins Oncologiques de Support

ANFIPA : Association Nationale Française des Infirmier.e.s en Pratique Avancée

CLAROMED : Association pour la Clarification du Rôle du Médecin dans le contexte des fins de vie.

CNPG : Conseil National Professionnel de Gériatrie

CNPI : Conseil National Professionnel Infirmier

FNEHAD : Fédération Nationale des Établissements d'Hospitalisation à Domicile

MCOOR : Association Nationale des Médecins Coordonnateurs en EHPAD et du Secteur médico-social

SFAP : Société Française d'Accompagnement et de Soins Palliatifs

SFC : Société Française du Cancer

SFGG : Société Française de Gériatrie et Gérontologie

SNPI : Syndicat National des Professionnels Infirmiers

Groupe de Soins Palliatifs **UNICANCER** (Fédération des centres de lutte contre le cancer)

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SUMMARY

In its Opinion 139, dated September 13, 2022, the Comité Consultatif National d'Éthique (CCNE) acknowledges a major shift in its approach by considering legalizing a form of medically administered death. This recommendation, proposed in the name of the new primacy of the principle of autonomy over the principle of solidarity, fundamentally questions caregiving practice and ethics.

Representing the various sectors of professional practice, the organizations endorsing this ethical opinion have wished to confront their caregiving practice and ethics with the perspectives of such a legislative evolution, by questioning **the actual consequences of implementing a form of medically administered death.**

In the context of the extreme precariousness of our healthcare system and structural questioning of its foundations, the priority should be to provide every citizen with quality care, including end-of-life care.

Considering the implementation of medically administered death as a priority in response to societal demand could further **weaken health care teams confronted daily with complex decisions.**

Beyond this observation, the co-signing healthcare organizations believe that such legalization would inevitably lead the lawmaker to **subvert the notion of care** as it is commonly understood today. This understanding of health care underpins and enlightens complex care interventions, during which requests for death and life are intimately intertwined and motivate health care professional's commitment to the patient.

By breaking down the existing deontological framework, such legalization would inevitably lead to a **major ethical shift**. The implementation of legislative safeguards, which would be manifestly provisional due to the strength of the principle of equality, as reminded by the CCNE[1], would ultimately fail to stem the threats posed by **the injunction of death on the most vulnerable individuals**, as observed today in all countries that have legalized euthanasia. Children, dependent individuals, people with cognitive or psychiatric disorders, people in precarious situations, etc. are currently largely absent from the discussions.
Therefore, in the event of a reform of the legislative framework governing end-of-life care, the cosigning organizations:

- **will continue to unconditionally support all patients.**

- call on the lawmaker to adopt a systemic and long-term approach. In this regard, they **prioritize significantly improving the framework for end-of-life care**, qualitatively and quantitatively, without reducing its complexity to a societal or political dialectic.

- ask the Government and Parliamentarians, if they decide to change the law, to **keep the healthcare sector out of any involvement in a form of medically administered death**.

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[1] *CCNE, Opinion 139, p30: "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."*

INTRODUCTON

THE GENESIS OF THE PROJECT

1/ Perspective for legislative changes opened by the CCNE

On September 13, 2022, the Comité Consultatif National d'Éthique (CCNE) issued Opinion 139, relating to end-of-life situations. This reflection follows a self-referral, per the methodological rules that govern the CCNE.[2]
In this opinion, the CCNE questions the relevance of the current legislative framework, specifically for situations in which

> *"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.*[3]
>
> To respond to this specific problem, 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."*[4]

Concretely, and if it considers the strengthening of palliative care as a necessary condition for any legislative development, the CCNE proposes to the lawmaker a framework allowing the legalization of assisted suicide in the name of the primacy of the principle of autonomy. It also opens the door to an exceptional form of euthanasia in the name of the principle of equality for people who cannot perform assisted suicide.

2/ A change in CCNE's logic

Our caregiving group has taken note of the evolution of the journey of reflection proposed in Opinion 139 of the CCNE. We note the clear break in this opinion with previous reflections on the subject.
In its previous opinion on the question issued in 2013, the CCNE firmly and overwhelmingly recommended the following conclusions:

> *The question of assistance in suicide for certain people who are in the advanced or terminal phase of an illness remains delicate, even if the Committee notes that the changes it recommends are likely to make the requests in this respect even more residual. In other cases, the majority considers that it calls for a clear negative answer: particularly the situations of people not in the advanced or terminal phase of an illness in the sense understood by medicine - people with a disability, possibly mental, a serious progressive illness or severe depression.*
> *Some members of the CCNE consider that assisted suicide and euthanasia should – at least in certain circumstances – be legalized. They believe that respect for individual freedom should extend to this point and allow third parties willing to assist them, to do so without major risk to the bonds of solidarity within society.*
> *However, the committee mostly believes that this legalization is not desirable. Besides the fact that any development in this direction seems very difficult to stabilize, especially considering foreign experiences, it highlights the risks that arise concerning the requirement of solidarity and fraternity, which guarantee coexistence in a society marked by numerous individual and collective vulnerabilities and significant deficiencies in the field of end-of-life policy.*[5]

Today, the conclusions of the CCNE's reflection presented in the majority Opinion 139 consider the legalization of assisted suicide and initiate a process of reflection on the possibility of exception-based euthanasia. It is also worth noting the existence of a minority opinion opposing these two changes. This disagreement illustrates the complexity of the issue and the diversity of opinions currently present within French society, in the context of our distressed healthcare system.

3/ An obligation for health care providers to take a stance

Aware of the legal injunction that may be imposed on them tomorrow, the healthcare organizations from whom this document originates have decided to take up the issue and explore the ethical and practical consequences of such a political decision, explicitly considered by the CCNE.

> *“While the legalization of a form of administered death is primarily a societal issue, its impacts are mainly on caregiving practices.*

Indeed, while the legalization of a form of administered death is primarily a societal issue, its impacts are mainly on caregiving practices.
Currently, no country has legalized a form of administered death without involving a health care provider in the process, whether to carry out the act itself (euthanasia), to prescribe a lethal product (Oregon model of assisted suicide), or to evaluate and validate the request (Swiss model of assisted suicide).[6]

While the nature and degree of these implications may differ, they

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[2] *CCNE, Méthodes et repères, 2020: “The CCNE can be called upon by ministers and major institutions or take up emerging issues on its own initiative based on scientific, medical or societal news.”*

[3] *CCNE, Opinion 139, September 13, 2022, p23.*

[4] *CCNE, Opinion 139, September 13, 2022, p32.*

[5] *CCNE, Avis 121, June 30, 2013, p53.*

[6] *About the different models of legislation: Panorama des législations sur l'aide active à mourir dans le monde, 31 janvier 2022, CNSPFV.*

require the inevitable presence of a minimum of medical guarantee in implementing the lethal act. The CCNE itself emphasized in 2013 the implications of such legislative and societal choices.

> *Granting a person at the end of their life the possibility of taking their own life to respect their wishes remains and will always be an act of extreme gravity. When it entrusts doctors to do so, society assigns them the heaviest task one can imagine. No reform of the laws, whatever it may be, can ever ignore this fact.*[7]

Aware of the demands of some citizens, the risks inherent in the partial application of current legislation, and those related to this potential legislative development, our health care collective wanted to share the constituent elements of its scientific and ethical reflections. These works are based on our interprofessional experiences, reflecting caregiving practices in all centers of life and care.

4/ Our methodology

To carry out this reflection and shed light on the public debate, the signatory learned societies and professional organizations wished to compare current care ethics, the reality of their practice and their social care mandate with the potential implementation of an administered death process as put forward by the CCNE. Based on what is practiced abroad, the medically administered death process selected is as follows:

Each learned society and professional organization has therefore been confronted with this indicative process of euthanasia and assisted suicide to gather the opinions of its members. We were thus able to establish a position on the feasibility or not of each of these acts and to measure the degree of health care involvement. The signatory organizations intend not to pronounce *in abstracto* whether to legalize a form of medically administered death. It is to study the implications of such legalization on daily caregiving practices and inform the lawmaker and public opinion.

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[7] *CCNE, Avis 121, June 30, 2013, p45-46.*

Mapping of the medically administered death process	Assisted suicide	Euthanasia
Reception of the person's initial request	X	X
Verification of the admissibility of the request: patient in full possession of their cognitive faculties, free and informed request	X	X
Verification of the compliance of the request with the criteria of the law	X	X
Creation of the application file	X	X
Overall organization of the implementation	X	X
Fulfillment of the prescription	X	
Obtain the person’s consent	X	X
Preparation of the product	X	X
Setting up the injectable device	X	X
Administration of the lethal substance		X
Patient follow-up until death	X	X
Maintaining contact with loved ones	X	X

I - CARE: A CLEAR AND CONSTANT CORPUS

To study the impact that legalizing a form of medically administered death by health care professionals would have on professional ethics and deontology, it is essential first to recall what health care ethics is and how it contributes to concretizing the definition of care as it is commonly accepted.

1/ Medical deontology and nursing deontology: reference texts

> *The Oath includes the following assertion: "I will do everything in my power to relieve suffering. I will not prolong abusively the agony of the terminally ill. I will never provoke death intentionally."*

At the foundation of medical ethics is a historical text, the Hippocratic Oath or Medical Oath, which has remained constant in its substance for several centuries. In its present version, updated in 2012 by the Conseil National de l'Ordre des Médecins, the Oath[8] includes the following assertion:

> *"I will do everything in my power to relieve suffering. I will not prolong abusively the agony of the terminally ill. I will never provoke death intentionally."*

The content of this reference text, although non-normative, is largely transcribed in section 1 of the *Code de la santé publique*, in subsections R4127-1 and following.

Among these subsections, subsection R4127-38 may be quoted:

> *The physician must accompany the dying person until their final moments, ensure the quality of life as it ends through appropriate care and measures, preserve the patient's dignity, and comfort their loved ones.*
> *They do not have the right to cause death deliberately.*

Nursing practice is also governed by the *Code de déontologie des infirmiers*, transcribed in a regulatory form, in subsections R4312-1 and following of the *Code de la santé publique*.
Among these subsections, and to complement the previously mentioned subsection R4127-38, subsections R4312-20 and R4312-21 can be cited:

> *The nurse has a duty to use all the means at their disposal to ensure a dignified life for everyone until death. They have the duty to help the patient, whose condition requires it, access palliative care and support. In the circumstances mentioned in the preceding paragraphs, they also strive to accompany the patient's loved ones.*
>
> *The nurse must accompany the dying person until their last moments, ensure by appropriate care and measure the quality of a life that is ending, preserve the dignity of the person being cared for, and comfort their loved ones. The nurse must not deliberately cause death.*

2/ The definition of care

The medical and paramedical deontology previously mentioned is consistent with the commonly accepted definition of care. The Académie Nationale de Médecine proposes the following definition: "Care: In medicine, a set of measures and actions aimed at providing a person with the means of diagnosis and treatment allowing them to improve and maintain their physical and mental health."[9]

This definition is in line with that established by the Haute Autorité de Santé in October 2007:

> *Act of care: an act of care is a coherent set of actions and practices implemented to restore or maintain a person's health. An act of care can be broken down into defined and limited tasks, which can be carried out independently. In the same act of care, certain tasks may be carried out by different health care professionals.*[10]

More precisely and in line with the previous definitions, the World Health Organization (WHO) has defined palliative care, which includes the following sentence: "Palliative care provides relief from pain and other distressing symptoms, supports life, and regards dying as a normal process. It neither hastens nor postpones death."[11]

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[8] *Complete text in appendix.*

[9] *Académie Nationale de Médecine, http://dictionnaire.academie-medecine.fr/search/results?titre=soins&fbclid=IwAR0uo34oDNwB0sXg9DB0wsCqMsagkNn1ywQ0g59RhIsICR⊠x81DyZVm8EG8, consulted on March 12, 2023.*

[10] *Haute Autorité de Santé, October 2007, Vocabulaire de base coopération entre professionnels de santé.*

[11] *Complete definition in appendix.*

II - THE RIGHTS OF END-OF-LIFE PATIENTS

As death approaches, healthcare deontology is governed by a dense legislative framework, structured around four main texts: the Law of June 9, 1999, the Kouchner Law of March 4, 2002, the Leonetti Law of April 22, 2005, and the Claeys-Leonetti Law of February 2, 2016. These laws establish three major patient rights, binding health care professionals:

1/ Guaranteeing the patient's will: strengthening the role of advance directives and considering the views of the person's immediate entourage.

The health care team must inform the patient of the therapeutic options and the conditions for implementing their care so that they can participate as much as possible in the health decisions that concern them.
Particular importance is given to the consequences of these decisions on the patient's quality of life in palliative care. The first step is enabling the patient to establish their position regarding treatment, illness, and the life they want. These discussions between patient and health care professionals form the foundation of their care.
To achieve this, nursing ethics also play a central role, as demonstrated by subsection R4312-13-1 of the *Code de la santé publique*:

> *"The nurse implements the right of every person to be informed about their health status, in accordance with their professional skills."*

To ensure respect for the patient's will in the event that they are unconscious or unable to express themselves, the modifications regarding this issue, incorporated into subsection R. 4127-36 and subsections R. 4127-37-1 to 4 of the *Code de la santé publique*, strengthen the role of the designated person of trust and the respect for advance directives. These concepts were introduced as early as 2002 and also include the notion of the therapeutic alliance, as embodied in subsection 1111-4 of the *Code de la santé publique*:

> *"Every person, in conjunction with health care professionals and taking into account the information and recommendations provided, shall make decisions concerning their health."*

2/ The fight against unreasonable obstinacy.

Subsection R. 4127-37 has asserted since 2016 the imperative to "relieve the patient's suffering by appropriate means", while refraining from any unreasonable obstinacy and keeping the possibility of giving up on "undertaking or continuing treatments that appear useless, disproportionate, or have no effect other than the sole artificial prolongation of life."

To contribute to the collective reflection on the necessary implementation of this right, the cosignatory organizations remind us that in the face of a short- or medium-term life-threatening prognosis, health care professionals frequently receive requests from the patient or their entourage that, if immediately considered, would lead to unreasonable obstinacy.

> *"The health care professional's responsibility is to listen, inform, and accompany the patient and their entourage towards sharing and accepting the diagnosis, the therapeutic options, and acquiring a good understanding of the benefits and risks of each of these options.*

In this common occurrence, the health care professional's responsibility is to listen, inform, and accompany the patient and their entourage towards sharing and accepting the diagnosis, the therapeutic options, and acquiring a good understanding of the benefits and risks of each of these options. In this delicate work, health care professionals are guided by the principle of proportionality, which leads them to seek the most appropriate solution for each person receiving care. This work takes on a particular dimension due to the vulnerable situation of the person receiving difficult news.
In this situation, the health care professional's role is also to invite the person receiving care to consider elements of reflection related to their quality of life, not just its duration.[12]
However, the nursing mission does not stop there. Scientific and medical knowledge, creativity, nursing presence, and empathy serve the comfort and well-being of the person cared for. For most teams surveyed, this objective unites the healthcare collective around patients and their loved ones, regardless of the location of care and housing of those receiving care.

3/ The obligation to relieve pain, at any cost

Caregivers focus primarily on prevention and relief to manage pain and end-of-life discomfort.
In recent years, early palliative care has been strengthened in the context of serious incurable diseases that cause multiple suffering and disabilities, for which etiological treatment is maintained to control the disease (reducing its severity or slowing its progression).

Later, if optimal relief according to the threshold defined by the person receiving care cannot be achieved while maintaining the person conscious, it may be proposed to increase the doses of their treatments, considering the risk of making them drowsy or even asleep.

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[12] *Palliative care, by improving quality of life, is also a source of longer life, as confirmed by the following study: J.S. Temel et al. "Early palliative care for patients with metastatic non–small-cell lung cancer." New England Journal of Medicine. 2010; 363(8):733-42.*

It is then the patient who evaluates what seems most appropriate to them.

This possible practice of relief that may lead to sedation is based on the theory of double effect, as recalled in an article by Benoit F. Leheup published in the *Médecine Palliative* journal in 2006[13]:

Everything will be done to relieve pain while avoiding unreasonable obstinacy, and without ever seeking to cause death deliberately.

The application of this principle of double effect, rooted in the notion of intentionality, currently allows medical personnel to take care of patients' suffering and to keep the double promise made in the law: everything will be done to relieve pain while avoiding unreasonable obstinacy, and without ever seeking to cause death deliberately.

> *If four conditions are simultaneously met, an act that produces good and bad effects can be carried out. If the action the subject wishes to perform meets these four criteria, their intention is righteous. The only point verified by these four criteria is that the subject performing the act does not intend the bad effect.*
>
> - ***First criterion:*** *the act must be good or morally indifferent and ordered toward a righteous purpose. Negatively, the action must not be intrinsically bad or prohibited.*
> - ***Second criterion:*** *the bad effect must not be intended and must be only an unintended collateral effect. The action must be undertaken solely to produce the good effect.*
> - ***Third criterion:*** *the bad effect must not be a means to achieve the good effect. The bad effect must remain an effect without becoming a means.*
> - ***Fourth criterion:*** *the bad effect must be risked for a proportionally serious reason. This criterion is one of the right proportion between the good effect, directly intended, and the bad effect that will be caused. This is undoubtedly the most difficult aspect to assess.*

In this section, Benoit F. Leheup develops the link between the principle of double effect (PDE) and sedation practices in palliative care:

> *Intention is for us the cornerstone of the application of PDE to sedation. It is at the basis of the medical decision and will influence how sedation will be conducted. While it is true that it will never be possible to have an exact idea of the physician's intention, the materiality of the facts, recorded in the medical or nursing file, reflects this intention and will therefore allow a third party to form an idea of it. While it is true that the notion of proportionality is fundamental in the application of PDE, the notion of proportionality used alone can no longer claim to be PDE and can become ethically dangerous. Finally, it is important to remember that intention alone is not enough. Three aspects are important to know if sedation is morally permissible: the nature of the act, the final intention of the act, and the value of the final intention. Let us never forget to question the intrinsic nature of the act we want to perform. Some acts will always be intrinsically wrong; performing them with good intentions will not change their value.*

It is important to remember that intention alone is not enough. Three aspects are important to know if sedation is morally permissible: the nature of the act, the final intention of the act, and the value of the final intention. Let us never forget to question the intrinsic nature of the act we want to perform. Some acts will always be intrinsically wrong; performing them with good intentions will not change their value.

Since 2016, to respond to situations where the person being cared for no longer wishes to be conscious due to their refractory symptoms, it is possible to perform deep and continuous sedation until death. As specified in subsection L.1110-5-2 of the *Code de la santé publique*, this provision, regulated by the 2016 law, is applicable under the following conditions:

> *1- When the patient, suffering from a serious and incurable illness leading to a reduced life expectancy, presents refractory suffering to treatments;*
>
> *2- When the decision of the patient, suffering from a serious and incurable illness, to stop a treatment reduces his life expectancy and is likely to cause unbearable suffering.*

It should be reaffirmed that deep and continuous sedation until death is not intended to cause the patient's death, but rather to provide comfort in their final moments of life if they no longer wish to be conscious.

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[13] *Leheup, B. F. "Double effect: ethical considerations concerning sedation for intractable distress in the terminally ill", Médecine palliative, 2006, vol. 5, pp 82-86.*

As some voices are heard denouncing the cessation of artificial feeding and hydration in parallel with this type of sedative practice, the professional signatories of this document recall that:

- *At the end of life, a person does not feel hunger or thirst.*[14] *Prevention of dryness of the mouth, skin and mucous membranes is done through proportionate comfort care.*[15,16]
- *When these procedures are carried out, death occurs due to the illness, and not due to the administration of sedatives or the cessation of artificial feeding and hydration.*
- *Artificial nutrition and hydration are invasive procedures considered by the law as treatments. Therefore, they can be stopped to protect the person receiving care from unnecessary discomfort.*[17]

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[14] Burge, Fl. "Dehydratation symptoms of palliative care cancer patients." J Pain Sympt Manag, 1993; 8(7):454- 464.; Musgrave CF, Bartal N, Opstadt J. "The sensation of thirst in dying patients receiving IV hydratation." J. Palliat Care 1995;11(4):17-21.

[15] McCann RM,Hall WJ, Groth-Juncker A. "Comfort care for terminally ill patients: the appropriate use of nutrition and hydratation". JAMA 1994; 272(16):1263- 1266.

[16] Collège des acteurs en soins infirmiers, « SFAP – l'infirmière et les soins palliatifs, prendre soins : éthique et pratiques », 6th Edition, Elsevier Masson, 270p, January 2021.

[17] Gillick, MR. "Rethinking the role of tube feeding in patients with advanced dementia." N Engl J Med 2000; 342:206- 10.; Casaret D, Kapo MD, Caplan A. "Appropriate use of artificial nutrition and hydration – Fundamental principles and recommandations." N Engl J Med 2005; 354 (12): 2607-12.

III - ADMINISTERED DEATH PROCEDURE CONFRONTED TO ETHICS AND CAREGIVING PRACTICE

1/ Receiving and hearing the patient's request

a/ *The request for individual and collective life*

> *Taken as a whole, they also reflect a growing inability to accept the very fact of death, which no longer finds a place in our collective representations.*

In current caregiving practice, specifically in areas where invasiveness is the strongest - such as in the case of resuscitation - and where some therapeutic benefits remain a potentiality, even if minimal, the request made to health care professionals is primarily for maintaining life, which can sometimes even lead to unreasonable obstinacy if integrally considered. These individual requests for life from patients and/or their loved ones mark the daily healthcare experience, regardless of the professional concerned (doctors, nurses, nursing aides) and place of practice. Taken as a whole, they also reflect a growing inability to accept the very fact of death, which no longer finds a place in our collective representations.

Beyond its individual character, the demand for life is also collective. It has found particular relevance during the COVID-19 crisis when society was reorganized in this logic. Society then sent a strong message to health care professionals by affirming that all citizens collectively consented to give up a wide range of fundamental freedoms (freedom to work, freedom of movement, freedom of assembly) to limit the spread of the virus and to enable them to respond to this demand to save lives in a context of uncertainty.

This collective demand for life is finally exemplified in its most extreme form when caring for people who have attempted suicide. By attempting to end their life, a person clearly expresses their will, materializing it through a serious and clear act. However, in case of failure of the attempt, the mandate given by society to health care professionals is to take care of the person to allow them to regain a state of health, enabling them to stay alive, manifestly *against* their will. This mandate given to health care professionals is also illustrated by a vigorous public policy regarding suicide prevention, presented as a priority within the actions of the Department of Health.[18]

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[18] Instruction No. DGS/SP4/2022/171 of July 6, 2022, updating instruction No. DGS/SP4/2019/190 of September 10, 2019, relating to the national suicide prevention strategy.

Therefore, if a form of administered death was to be legalized, how could health care professionals reconcile:

- on the one hand, the primacy of the collective demand for life over the individual will of the patient in the case of care provided to those who have attempted suicide.
- on the other hand, the primacy of the individual will for death over the collective demand for life in the context of euthanasia or assisted suicide?

This situation is far from insignificant. In France, between 80,000 and 90,000 people are hospitalized every year following a suicide attempt.[19]

b/ *The request for death*

All health care professionals who have signed this opinion are regularly faced with requests for death from their patients. While this phenomenon is not new, it should be studied and considered.

All signatories agree on implementing active and supportive listening to these requests, which is more widely practiced today than some statements suggest.[20] This caring listening often forms the basis for a comprehensive reassessment of the patient's care, allowing for a reciprocal readjustment that precisely eliminates this request for death.

Clinical experience and studies on this issue[21] show that there are several elements behind this request for death: uncontrolled symptoms, persistent moral distress, a request for help, the recognition of suffering, a need to be better cared for, but also the possibility of regaining a sense of capacity for action, transgression, and freedom.

> “*All signatories agree on implementing active and supportive listening to these requests*

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[19] Observatoire national du suicide, Suicide Mesurer l'impact de la crise sanitaire liée au Covid-19, September 2022, pp 164-171.

[20] In October 2004, the Groupe de Travail sur l'Euthanasie Pôle Ethique et Recherche de la Société Française d'Accompagnement et de Soins Palliatifs published a guide Face à une demande d'euthanasie, which proposes a methodology for listening and management of patient requests within the teams.

[21] Leboul D, Bousquet A, Chassagne A, et al. "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 and Social Practice, 2022, 16:1-11. https://doi.org/10.1177/26323524211066925

Health care professionals must hear and decipher these requests with the patient. Resolving a request to "end it all" even constitutes a large part of the process of reflection of health care teams.[22] In this sense, the possibility for the health care provider to grant the request for death would profoundly alter the nature of their mission. Among the most significant impacts envisioned is the renouncing of any individualization of care or the abandonment of a complex redesign of patient care in favor of a simpler alternative.

Most health care professionals, including nurses, coordinating physicians in the Établissements d'Hébergement pour Personnes Âgées Dépendantes (EHPAD)[23], and home care professionals, emphasize the risks such a measure would pose to the individual and collective motivation of health care professionals engaged in end-of-life care, whatever the uncertainties may be.

c/ *Anger regarding care conditions*

The protest expressed by patients towards certain caregiving practices must also be attentively listened to by all healthcare actors and institutional and political decision-makers.

> “*An exclusively technical, hospital-centred approach that neglects the human dimension of the patient is a strong factor of anger and legitimate dissatisfaction among patients in general, particularly those at the end of life.*

An exclusively technical, hospital-centred approach that neglects the human dimension of the patient is a strong factor of anger and legitimate dissatisfaction among patients in general, particularly those at the end of life.

To maintain a high-quality therapeutic alliance, a profound reflection must be initiated on all the most reported "grievances" by patients, which testify to a lack of consideration of their experience during the care process.

These elements legitimately feed the sense of lack of consideration and contribute to reinforcing demands to "end it all" as an expression of revolt and defiance towards the medical framework. In this sense, the palliative approach, which is interdisciplinary

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[22] Schwab, M., Benaroyo,L. "Les divers sens de la notion d'autonomie en médecine et leur pertinence en clinique", Revue Médicale Suisse, October 28, 2009. "In certain clinical situations, it is essential to assess in greater depth and criticize the patient's request and wishes. This reflexive posture attests to a responsible moral attitude, insofar as the illness can affect one or both spheres of autonomy and the ethical aim of care – particularly in situations of uncertainty regarding the expression of will – is first and foremost to restore the patient's wounded autonomy to regain a sense of purpose in their existence."

[23] EHPAD: Residential Care Homes for Dependent Elderly People

by nature, can serve as a source of inspiration and lead to a renewal of caregiving practices by placing greater emphasis on the person receiving care and their entourage. The aforementioned study refers to a patient's testimony illustrating a reality observed by many health care professionals practicing palliative care:

> *"It's changing slightly, you see, when I first got here, in my mind, well, I was thinking different things but the main thought was how to find the way of dying, life had become so unbearable for me... I feel there's more consideration for me here as a human being in my own right." 24*

In this collective's professions, caregivers agree with this testimony: with quality palliative care, the desire for death often fades away.

d/ *Faced with the reiterated request for death: strengthen medical power or accept its limits?*

However, there are exceptional and persistent requests for death, made consciously and autonomously. Despite palliative care, these exceptional and persistent requests impact both the family sphere and the caregiver-patient relationship. In these rare situations, a fully conscious citizen asks another citizen to transgress their deontology and the *Code pénal* to meet their wish.

In addition to legal aspects, these requests demonstrate a confrontation between two freedoms: that of the patient and that of the caregiver, which is now regulated by a clear regulatory and ethical framework. This framework guarantees the proper functioning of the healthcare system, even when professionals must handle complex situations collectively. Different studies and surveys repeatedly show[25]: questioning this normative framework could also threaten the collective dimension of care by breaking down the common ethics, especially if professionals were to invoke a conscience clause to withdraw from the care team in charge of the situation.

The organizations signing this opinion agree that a positive response to this request does not fall within the realm of care, even though it is often directed at healthcare personnel and imposes on caregiving teams the need to put special care and consideration in place.

2/ Assessing the quality of consent: the question of decision-making autonomy

a/ *Faced with suffering and death: the fluctuating nature of will over time*

The signatory organizations of this opinion recall that individual will is changeable, especially when the person is confronted with a prognosis of death in the medium or short-term, particularly if various causes of suffering accompany this prognosis.

> *"The signatory organizations of this opinion recall that individual will is changeable, especially when the person is confronted with a prognosis of death in the medium or short-term, particularly if various causes of suffering accompany this prognosis.*

The challenge for caregivers is to identify these causes and then take care of them, whatever their nature, to allow the person receiving care to continue investing in life under the best possible conditions.

It is common for the same person to express contradictory wishes within a few days, in the same day, or during the same conversation. For example, some patients may request euthanasia but also ask to receive the COVID-19 vaccine.

The signatory organizations of this opinion wish to remind us of the ambivalent and changing nature of the will, particularly as death approaches. This assertion is not a moral judgment towards patients, but a simple observation that health care professionals have learned to approach with kindness.

Conversely, the act of killing is irreversible and ends any process of individual or collective deliberation.

b/ *The difficulty of assessing the suffering justifying a request for death*

Another major difficulty highlighted by all professionals is evaluating a person's suffering. While suffering is inherently multifactorial and arises from physiological considerations (organic, including pain), as well as from psychological and even social considerations, the prospect for a health care professional to accept or refuse a request for death causes profound discomfort and numerous issues:

- What level of suffering would justify the implementation of euthanasia?
- Is a physician authorized to judge a person's suffering and decide on the admissibility of a request?
- If so, will it be necessary to discriminate against patients by categorizing those who would fall within the legal framework of a euthanasia request and those who would not meet the conditions?
- Who will inform the patient requesting euthanasia that their request is not accepted because they do not fall within the framework of the law?

c/ *The quality of the patient-caregiver relationship*

While the caregiver-patient relationship is crucial on a daily basis to collectively define the most appropriate care methods regarding

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24. Leboul D, Bousquet A, Chassagne A, et al. "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 and Social Practice, 2022, 16:1-11. https://doi.org/10.1177/26323524211066925, p5.

25. OpinionWay survey for SFAP, October 2022; Consultation nationale de Valenciennes, SFAP, June 2021.

the patient's autonomy, it should be recognized that dialogue is sometimes deficient, either due to a lack of availability or inadequate training of professionals or due to conflicts in the patient's entourage. It is, therefore, necessary to strengthen the therapeutic alliance[26] by providing the patient, and their entourage with a quality level of attentiveness. A mediation skill could also be implemented to accompany family members in reflecting and formulating their wishes. Finally, specific emphasis must be placed on training health care professionals in end-of-life situations. Without dedicated time and appropriate training, understanding of end-of-life situations and knowledge of the medical and legal devices available to professionals sometimes remains unsatisfactory.

d/ *The issue of the entourage*

In care and housing facilities for dependent elderly people, such as in oncology facilities or for patients receiving home care, the request for death can come from the patient's entourage, rather than the patient themselves.

"She would be better off dead than in her current state", "she's not really living anymore", "it's no longer him": these are all examples of statements frequently addressed to health care professionals who are responsible for caring for people at the end of life in situations of dependence, sometimes aggravated by cognitive impairments. These requests are characteristic of pre-grief, anticipatory grief, or ambiguous loss, as identified by Evelyne Malaquin-Pavan and Marylène Pierrot.[27] More generally, they reveal the complexity of human relationships, especially family relationships, which are influenced by multiple emotions such as love, hate, guilt, protection, etc.

Within healthcare teams, a significant part of the activity involves providing psychological support to relatives, working with them on how to accompany the person receiving care, and dealing with the emotional states of the moment, including anger or fatigue, which can sometimes be expressed violently.

While it is legitimate that these requests are listened to and considered, they nevertheless raise questions about the capacity for pressure that close relatives can exert on a dependent person at the end of life. Home care teams, who are part of the intimate circle of the person and their entourage, are particularly concerned and worried about the risks of abuse if such legislation were adopted.

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[26] « Alliance thérapeutique et « pacte de soins » », as presented by Paul Ricoeur : Paul Ricœur, Revue Esprit, No. 227 (12) (December 1996), pp. 21-33 and Jacquemin, Dominique. "La visée éthique chez P. Ricœur et l'alliance thérapeutique", Dominique Jacquemin éd., Manuel de soins palliatifs, Dunod, 2014, pp. 157-163.

[27] Malaquin-Pavan, Evelyne & Pierrot, Marylène. (2007). « Accompagner une personne atteinte de la maladie d'Alzheimer : aspects spécifiques du deuil des aidants naturels et pistes de soutien.» Recherche en soins infirmiers. 89. pp76-102. 10.3917/rsi.089.0076

e/ *The specific case of heavy dependency*

The issue of free and autonomous consent takes on a particular importance in the context of the EHPADs.

EHPAD residents often suffer from neurodegenerative diseases such as Alzheimer's or related diseases. The extended timeframe in Opinion 139 of the CCNE to a few months would affect more than two-thirds of EHPAD residents already suffering from an incurable disease, for whom life expectancy is measured in months rather than years. These people can no longer give an informed opinion. Applying an advance directive written before the onset of their illness would deprive them of the right to change their mind if this directive were to be applied on the pretext that their life was no longer dignified and that they could no longer express a contrary opinion.

> *"Each caregiver should continue to accompany patients who, while waiting for euthanasia, would send them a message of useless care since they would be applied to people who no longer consider themselves dignified.*

Each caregiver should continue to accompany patients who, while waiting for euthanasia, would send them a message of useless care since they would be applied to people who no longer consider themselves dignified. They would also have to accompany all those who continue to worsen their dependence and may sometimes express a desire for death.

These residents have varying degrees of loss of autonomy, which reaches its maximum in the severe stages of neurodegenerative diseases such as Alzheimer's. Integration into an EHPAD usually occurs when family caregivers can no longer bear the burden of dependence, per the Zarit scale.

Health care professionals working in EHPADs regularly face requests for death from their patients who can still express themselves, often motivated by the refusal to see their physical or mental state deteriorate or their desire not to be detrimental to their loved ones, not to be a burden. The mission of the caregivers working in these establishments lies in the accompaniment of these individuals, in the improvement of their living conditions, and in the recognition of the full dignity that they can provide through their care and their presence.

Nicolas Croître summarizes the particular mission of these caregivers as follows: "What a beautiful job it is to accompany the fragile elderly, what a beautiful job it is to be the guardians of dignity."[28]

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[28] Nicolas Croître, « Les enjeux éthiques du vieillissement. » Éthique publique - Revue internationale d'éthique sociétale et gouvernementale, vol. 10, n° 2, 2008.

> *For these professionals, opposition to the legalization of euthanasia is particularly strong.*

For these professionals, opposition to the legalization of euthanasia is particularly strong. The ethical positioning table mentioned on page 9 of this opinion has generated many reactions of revolt, anger, and rejection. For these professionals dealing with the loss of autonomy, legalizing euthanasia in the name of the primacy of the principle of autonomy as envisaged by the CCNE would send an unbearable message to the elderly residents of EHPADs and to the professionals in charge of taking care of them.

Wouldn't the primary commitment of a caregiver in an EHPAD to preserve the person's dignity until the very end of life be fundamentally called into question by a practice of assisted suicide or euthanasia within their establishment?

3/ Administering a lethal substance: a major ethical transgression

a/ *Intentionality and double effect*

In caregiving practice, what is the difference between current pain management protocols that may hasten death and the implementation of euthanasia?
To answer this question, the signatory organizations recall the fundamental notions of intent and double effect in healthcare ethics and the implementation of validated recommendations and best practices by learned societies and the Haute Autorité de Santé.

The intent of an action or the administration of a substance is always articulated in support of the different components of a specific situation. It requires collaboration and reflection from multiple parties.

Thus, it may be decided to stop treatment to no longer prevent death from occurring, given the overall situation of a patient. This intentionality, shared during collegial procedures, has been reinforced and made more applicable by the Leonetti Law, which requires an analysis of the proportionate benefits and risks of each therapeutic option considering the risk of hastening death. In practice, these mainly include discontinuing treatment allowed by law and sedation to prevent refractory symptoms that could not be otherwise relieved. In this sense, the Leonetti Law was welcomed by health care providers as a real relief.

Adhering to the "intentionality - double effect" framework also ensures the ethical and psychological sustainability of certain complex professional situations, particularly in nursing. In their practice, doctors prescribe, while nurses frequently handle and administer products that can cause death if not prescribed or used properly. These situations require information and contextualization within the teams to understand the purpose and proper transmission among teams. These elements often require a collegial approach based on this ethical framework. Legalizing a form of medically administered death would have "significant psychological and emotional consequences for health care professionals who practice it."[29]

> *Legalizing a form of medically administered death would have "significant psychological and emotional consequences for health care professionals who practice it.*

b/ *Evolution towards a form of medically assisted dying: a change in the definition of care*

In the scenario where every health care provider would be obligated to provide an effective response to the repeated request for death, all the professionals surveyed categorically refuse the euthanasia approach, specifically the acts of preparation, setup, and administration of a lethal substance, as mentioned in the table on page 9 (acts 8, 9, and 10). It should be noted that the prohibition against causing death is reiterated in the Hippocratic Oath and in the *Code de la santé publique* in subsections R4127-38 and R4312-21, as well as in the *Code pénal* in subsection 221-1.

Healthcare workers' opposition is different for "assisted suicide" methods, which exclude the act of administration. However, healthcare workers have a consensus that these methods cannot be considered as care and must be materially separated from caregiving practice.

If necessary, it is up to the lawmaker to propose to the public a precise interpretation of the issues at the heart of this debate. More than integrating a new act into the existing panel of treatments and care, the legalization of a form of medically administered death would fundamentally alter healthcare ethics by changing the meaning of "care."

> *Healthcare workers' opposition is different for "assisted suicide" methods, which exclude the act of administration. However, healthcare workers have a consensus that these methods cannot be considered as care and must be materially separated from caregiving practice.*

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[29] *Position de l'ONI sur la prise en charge de la fin de vie, December 2022, p12.*

CONCLUSION

KEEP SOLIDARITY ALIVE IN A HEALTHCARE SYSTEM FACING STRUCTURAL CRISIS

Opinion 139 of the CCNE, which opens prospects for legislative evolution, comes in a very specific context that seems necessary to recall. The COVID-19 health crisis has revealed to the public the structural difficulties of the French healthcare system.

> *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 healthcare 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.*[30]

The various meetings and feedback from all the concerned healthcare organizations have illustrated this situation of great frailty and reinforced this analysis. At the heart of supporting people at the end of life, palliative care is not spared by these structural difficulties.

In managing end-of-life care in our country, while we must welcome the development of palliative care, which has been enshrined in law since 1999, it is also necessary to recall the numerous failures caused by a lack of financial, but above all, human resources. Underfunding and underutilizing units and teams in charge of home follow-up or health care professionals integrated into nursing homes induce serious deficiencies that parliamentary commissions and the Cour des comptes must quantify.

For the health care profession to address this demographic challenge, the signatory organizations emphasize the importance of the principle of solidarity that guides health care professionals in their daily work and that often remains the last thread in maintaining the commitment of active caregivers.

As the healthcare system in France experiences an uninterrupted series of crises, it appears crucial to fill the glaring gaps in our care model. Conversely, the signatory organizations would not understand how, by legalizing a form of medically assisted dying, the lawmaker could fundamentally transform the definition of care and decide to put an end to collective ethics.

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[30] CCNE, Opinion 139, September 13, 2022, p37.

APPENDIX

1 – The Hippocratic Oath – version updated in 2012 – Order of Physicians

When admitted to practice medicine, I promise and swear to be faithful to the laws of honour and probity.

My first concern will be to restore, preserve, or promote health in all its aspects, physical and mental, individual and social.

I will respect all persons, their autonomy, and their will without discrimination based on their condition or convictions. I will intervene to protect them if they are weakened, vulnerable or threatened in their integrity or dignity. Even under constraint, I will not use my knowledge against the laws of humanity.

I will inform patients of the decisions envisioned, of their reasons and their consequences.

I will never deceive their trust and will not exploit the power inherited from circumstances to manipulate consciences.

I will care for the indigent and whoever asks for it. The thirst for gain or the search for glory will not influence me.

Admitted into the intimacy of persons, I will keep all secret confided in me. I will respect families' secrets and not use my knowledge to corrupt morals.

I will do everything in my power to relieve suffering. I will not prolong abusively the agony of the terminally ill. I will never cause death intentionally.

I will preserve the independence necessary to fulfill my mission. I will undertake nothing beyond my competence. I will maintain and improve my knowledge and skills to the best of my ability to provide the services that will be demanded of me.

I will assist my colleagues and their families in adversity.

May men and my colleagues grant me their esteem if I am faithful to my promises; may I be dishonoured and despised if I fail to keep them."

2 - World Health Organization's (WHO) definition of palliative care

Palliative care aims to improve the quality of life of patients and their families facing the consequences of a potentially life-threatening illness, through the prevention and relief of suffering, early and accurate identification and evaluation of pain and other physical, psychological, and spiritual problems related to it.

Palliative care provides relief from pain and other distressing symptoms, supports life and regards dying as a normal process, does not aim to hasten or postpone death, integrates psychological and spiritual aspects of care for patients, offers a support system to help patients live as actively as possible until death, provides a support system to help the family cope during the patient's illness and their grief, uses a team approach to address the needs of patients and their families, including bereavement support when necessary, can improve the quality of life and possibly also positively influence the course of the illness, is applicable early in the course of illness, in conjunction with other treatments that may prolong life, such as chemotherapy and radiation therapy, and includes investigations that are required to understand better and manage troublesome clinical complications.

NOTES

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