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

March 30, 2020

CCNE - Response to the request from the Ministry of Health and Solidarity on the strengthening of protection measures in EHPADs and USLDs[1]

Dear Minister,

In a request dated March 25, 2020, you sought the CCNE's opinion on **the issue of strengthening protective measures in nursing homes for the elderly (EHPADs), and in extended care units in hospitals (USLDs)**. In the context of a national health emergency, which is accompanied by measures restricting public and individual freedoms, the CCNE is therefore asked for ethical insight into the following question: *"In view of its benefits in terms of public health, but also of the conditions to be implemented to ensure compliance with containment by the residents, including those with cognitive impairments, does a national decision to impose lockdown on all residents appear to be justified? If so, what safeguards should be provided by the government?"*

First, it should be noted that the response to this request, expected in a short turnaround time given the urgency of a decision, is hardly compatible with in-depth ethical reflection, which implies a multidisciplinary review of the question and the possibility of dialogue between potentially opposing points of view. Nevertheless, despite this short time frame, the CCNE quickly set up a working group[2], which met on March 27, 2020 and then prepared a draft letter of response, which was transmitted the same day to all the members of the CCNE, and discussed with them.

This response summarizes these discussions with due modesty under the present circumstances. The CCNE proposes some simple benchmarks: (1) reiterate the most general ethical opinions and principles; (2) examine, with all due modesty, the full extent of the current emergency situation, especially for caregivers; (3) consider some concrete ways to ensure the respect of principles in this particular context.

[1] EHPADs: nursing homes for the elderly / USLDs: extended care units in hospitals
[2] This working group had the following members: François Ansermet, Régis Aubry, Sophie Crozier, Pierre Delmas-Goyon, Pierre-Henri Duée, Karine Lefeuvre, and Frédéric Worms.

The CCNE has been called upon on several occasions to express its views on **ethical issues related to patient care in the case of a pandemic**, in its Opinion 106 published in 2009 on "*Ethical issues raised by a possible influenza pandemic*" and in its recent contribution of March 13, 2020 on "*Ethical Issues in the Face of a Pandemic*". Moreover, in its Opinion 128 *("The Ethical Issues of Aging", 2018)*, the CCNE questioned the **meaning of the "concentration" of elderly people in special homes.**
Finally, during management of the COVID-19 crisis a monitoring study of **people vulnerable** because of their age, disability, or psychiatric condition identified the ethical issues regarding the breakdown of relationships due to lockdown and the banning of family visits to EHPADs[3], the **emotional risk of isolation** and of absolute separation from others, in particular family and important people, **in addition to the epidemic risk.**
In light of this work and in the current context, **the CCNE emphasizes that fundamental ethical principles must be respected.** Health emergencies may justify certain exceptional and temporary[4] binding measures in response to the need to optimize protection of the population against the pandemic. **But this emergency situation cannot be allowed to undermine the fundamental requirements of support and care** in care homes or hospitals. **Respect for human dignity**, which also includes the **right of dependent persons to maintain social bonds**, is a benchmark that must guide any decision made in this context where the health care and administrative teams, as well as care providers, whose exemplary devotion is rightly underlined by all, are increasingly faced with **dramatic situations**. These situations also generate increasing risks to themselves and their loved ones, which **trap caregivers in this dilemma**: their devotion to care comes with a risk to themselves and others that they will be infected as they provide care.

In its Opinion 128, the CCNE had already warned of the difficult situation sometimes experienced by the elderly in residential facilities. **The current health crisis has revealed the lack of pre-existing resources, especially human, in these facilities. The shortage of staff and of essential resources** (protective masks, detection tests), in a context of already established isolation, **exacerbates the pressing difficulties that health professionals must deal with.**

Any binding measure restricting freedoms recognized by our rule of law, including freedom of movement, must necessarily be **limited in time**, **proportionate, and appropriate to individual situations**. It must be explained to residents, families, and caregivers, and monitored.

[3] CCNE Newsletter, March 23, 2020.
[4] Specifying the end date of this period.

Tightened lockdown measures for residents of EHPADs and USLDs, or even restraint orders for those whose cognitive abilities or behavioral responses are too impaired for them to understand and abide by these measures, **cannot be decided in a general and non-contextualized manner**, as the situation differs between institutions.

The CCNE forcefully reiterates that the environment with family or friends that residents can no longer enjoy, is, for many of them, their link with the outside world and their essential reason for living, as unanimously attested by professional caregivers. Depriving them of this too abruptly could cause a serious and irrevocable deterioration in their state of health and even take away some people's desire to live. Awareness of this situation is also likely in the future to cause their loved ones great suffering, which requires special attention.

Before any case-by-case decision is taken, and in order to temper the undeniable rigor of isolation and constraint measures, **all means (human and material resources) have to be identified and mobilized in each institution**: available staff, including in the environment of the institution, controlled use of available premises and outdoor or leisure areas, use of new digital communication technologies, in compliance with the general preventive measures.

There is a need for rapid deployment of the human resources needed to replace professionals on sick leave so that basic care (feeding, washing, moving) is always provided, and of **additional resources** (e.g., to ensure health protection and support), while not omitting to provide for **new human resources and skill sets** to facilitate remote **mediation** between confined residents and their families, and for the presence of **volunteers**, who are often indispensable for effective use of new technologies by residents and family members who do not necessarily have the required skills.

For example, the free space made available to residents, which necessarily varies between and within institutions, could lead to the **organization of separate sectors**, some reserved for people who have tested positive for COVID-19, others for residents who are not infected but for whom regular screening would allow periodic reassessment of their infection status.

The preservation of a physical space, even limited, **for free movement** seems to us imperative, despite the isolation measures, to ensure that lockdown, regardless of its justification in the light of public health imperatives, does not become a coercive measure for those who no longer have the freedom to choose their environment and lifestyle. For residents who test negative[5], visits by relatives who have also tested

[5]If this proves difficult, this measure could be reserved for terminally ill residents who test negative.

negative could be allowed, under strict health and safety conditions. This proposal obviously requires the widespread availability of testing.

For families and caregivers who wish to have the resident join them at least temporarily in their homes, such initiatives should be encouraged, subject of course to the resident's agreement, and tests should be performed to prevent the risk of infection among family members. Appropriate assistance should be provided to these families to enable them to dispense the necessary care. These recommendations can only be implemented if institutions are able to ensure testing of staff and residents for COVID-19. The CCNE therefore reiterates the urgent need in these facilities to facilitate testing and access to protective measures for staff, as well as residents.

Finally, **an organized welcome for families and caregivers**, perfectly adapted to their needs, regulated and secured with the necessary protections, could also be considered, particularly for end-of-life residents.

More particularly, **imposing a lockdown on people with cognitive disorders is extremely complex and may cause other risks**, notably psychological decompensation. How to enforce a measure restricting freedom when it cannot be understood, inter alia because the issues cannot be remembered?
Public health and lockdown measures are based on the principle that everyone understands these dynamics of solidarity. But what about people who are no longer in a position to take personal responsibility and who are still living at home or in an open residential facility (sheltered housing for independent elderly people, EHPADs except for sectioned residents) and whose daily medical care is now disrupted because of lack of caregivers?[6] Should we go so far as to compel these people by applying physical or pharmacological restraint? The answer to this complex question is far from obvious, but **for each situation** this question must be asked and the answer worked out as a function of the specific context. Above all, the answer must be the result of prior, interdisciplinary, and collective discussion, involving exchanges with people from outside the institution, such as professionals from mobile geriatric teams, as well as loved ones, without ever forgetting that one can deny a person's humanity by denying the meaning of his or her wandering.

Any reinforcement of lockdown measures must therefore be decided by the coordinating doctor and the director of the institution, in concert with the authorities and guardians they depend on. It must be **adapted to the capacities of each**

[6] Is the disruption of this routine because of the lack of caregivers not likely to increase anxiety (in an already anxiogenic context) and, by extension, to contribute to the development of behavioral disorders, which themselves will worsen the initial situation and be responsible for hospital admissions that paradoxically expose these already vulnerable populations to COVID-19?

institution, with fully traceable and transparent information on the measures taken provided for health professionals, institutional staff and volunteers, users and their families and caregivers, and citizens.

For the practical implementation of these recommendations, the CCNE reiterates its March 13, 2020 recommendation to set up ethical support units.

We remain at your disposal for any further information you may require within the framework of our advisory mission.

Sincerely yours,

Karine Lefeuvre
Interim President of the CCNE