

*Presidenza del Consiglio dei Ministri*



## **MOTION**

### **LONELINESS AMONG SICK PEOPLE IN HEALTHCARE FACILITIES IN TIMES OF PANDEMIC**

**29 January 2021**

The pandemic we are experiencing exacerbates the dramatic situation associated with the isolation of patients during the course of their illness, especially in the final stages of life.

This matter involves sick people, both those affected by Covid-19 and non-Covid diseases, who sometimes remain hospitalized for long periods of time. Similarly, due to the risk of contagion, people are forced into isolation, the elderly and non-elderly, living in nursing homes or in other residential socio-health facilities, such as institutions for people with disabilities (RSD), or those in Hospices. The situation in prisons is also difficult, both due to limited prison visiting and the significant reduction in re-education activities. These prevention problems have in common the fact that the people involved are totally entrusted to the institutions in charge of them. However, there are considerable differences that should be examined each according to its specificity, in order to be able to suggest suitable solutions.

Among the various situations indicated, the Committee currently intends to address the issue of visiting the sick in health facilities, in particular in Covid-19 wards, in intensive care and sub-intensive care units. This motion is therefore in continuity with the document of July 24, 2013 *Intensive care unit "open" to family visits*, in which the Committee recognised the importance of health organization which allows, as far as possible, physical proximity between patients – especially those in conditions of fragility and dependence – and their loved ones, especially during the most serious and critical phases of illness.

The ICB has addressed some aspects of this issue also in two of the four opinions specifically dedicated to Covid-19<sup>1</sup>.

The Committee is aware of the burden of the pandemic on the entire National Health Service, especially on its hospital facilities and hospitalization, as well as the difficulties faced in organizing and guaranteeing to all the best care in strict compliance with contagion containment measures. Also, notable and meritorious is the constant commitment of all the health personnel and of those involved in various capacities in helping the sick to overcome the sense of abandonment, especially in the last moments of life, and in aiding them to liaise with their families.

Nonetheless, the ICB intends to reiterate, also and above all in the dramatic circumstances of the current situation, the relevance of the care relationship<sup>2</sup> within the context of a highly technological environment as the one in which diagnosis and therapy are being developed and where the procedures are often weighted down by excessive bureaucracy. The ICB also draws attention to the centrality of interpersonal relationships and the correlated dimension of interdependence: if on the one hand this increases the risk of contagion, on the

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<sup>1</sup> “The containment measures have resulted in new forms of poverty and states of profound loneliness: let us think of the elderly and people with disabilities, the sick and the many, men and women who lived the final stages of life separated from their loved ones” (in ICB, *Covid-19: public health, individual freedom, social solidarity*, May 28, 2020), and also: “Nor can we forget the terrible ordeal to which the terminally ill are subjected, without the possibility of being able to say goodbye to their loved ones for the last time. In addition to denying the patient accompaniment at the end of life, the epidemic makes it impossible for those who are left behind to be able to share their grief, through the funeral rites. These painful wounds, in addition to many others, will also leave their mark on the lives of people and communities” (In ICB, *Covid 19: clinical decision-making in conditions of resource shortage and the “pandemic emergency triage” criterion*, 8 April 2020).

<sup>2</sup> In the sense of the well-known integration between “cure” and “care” which reconciles the therapeutic dimension with the relational one.

other, by adopting due attention and precautions to protect individuals and the community, it can be a resource to return to normality and to the fullness of existential bonds.

The ICB underlines how the physical proximity to patients of loved ones or trusted people, during the course of illness, is an integral part of taking care of the patient, especially in the terminal phase, and at the same time is of great help in the subsequent grieving process. Patients can benefit from proximity to their loved ones, in particular they can find motivation for personal resilience to the disease, especially during the most critical phases and when they are subjected to invasive and particularly burdensome treatments: the physical presence of family members, or in any case of people freely indicated by the patient, albeit for a limited time, can be a valuable resource for everyone.

The Committee also recalls how the accompaniment of the dying is deeply rooted in human experience. The cultural orientations present in our society on the meaning of the "right to care" and the "dignity in dying" may be radically different, but dying alone, when it is not the consequence of an explicit request, is considered synonymous with suffering not only for those who die but also for those who remain, even more so if they are unable to accompany their loved ones to the very end.

Detailed protocols for health safety in pandemic emergencies have been established within public and private health care facilities, in an attempt to reconcile as far as possible the need for safety with the need for proximity of patients to those who are emotionally close to them; however much still remains to be done<sup>3</sup>. The pandemic has highlighted the need to rethink healthcare organization in order to better respond to the needs of patients without their having to passively adapt to procedures in force in healthcare facilities. It should also be considered that, in light of the excellence of national and international importance, it would be difficult to adapt most of our care facilities to achieve the appropriate organisational flexibility. These shortcomings must be kept in mind in the planning of the future hospital network which must respond to all the issues raised by the Covid-19 experience, starting with the construction of new architectural structures, the introduction of technological innovations and the provision of logistics that leave room for ongoing adaptations. Furthermore, the organisational models of hospitals must be flexible in the light of the emergence of the new needs of their first recipients, the patients themselves, and due importance must be given to the aim of the humanisation and personalisation of care. Attention to this aspect cannot be lacking even in the concrete difficulties, in the short term, of the pandemic emergency.

The ICB therefore recommends that, albeit with the precaution and prudence necessary in order to address the emergency, every possible effort should now be made also within hospital facilities to ensure the presence of at least one family member, or a trusted person, in particular for the most serious situations, in the terminal phases of life and for patients in particularly fragile conditions.

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<sup>3</sup> See the resolution of the Regional Council of Tuscany of 21.12.20, which establishes that in all the Health Authorities in all the Authorities of the Regional Health Service as well as in the socio-health facilities (RSA-RSD), within all assistance and care settings, the right to contact is guaranteed as a priority for people suffering from serious pathology or with a poor prognosis in the short term, through the reshaping of organizational procedures based on specific needs and the severity of the clinical and psychological situation and with palliative care units jointly taking charge.

The duration and quantity of reunions must necessarily take into account the difficulties that the medical team may encounter in reconciling the presence of visitors with care activities. These are also useful measures in order to prevent the fear of going to hospital, which often becomes a refusal of hospitalization, that is needed, due also to the fear of being separated from loved ones. It is also necessary, as already pointed out by the ICB<sup>4</sup>, that health workers are trained and updated in order to be able to respond to the needs of family members also on an organisational level. By means of specific consent, family members, or persons designated by the patient as visitors, must be adequately informed, accompanied and guided regarding the safety and behavioural procedures in the hospital area<sup>5</sup>- which must be fully respected - and on the risks of being infected or infecting: risks that - despite strict compliance with the rules - cannot be completely eliminated. The presence of an operator dedicated to these purposes in the facility is desirable. The Committee also deems it appropriate for visitors to certify their vaccination status, in their own interests, those of patients and healthcare professionals, whenever and wherever possible.

In view of the situation it would be advisable to provide, also in the informed consent, at the time of hospitalization or subsequent to it, the possibility of choosing whether or not to receive visits from family members or loved ones. The patient may decide not to receive visits for fear of infecting others or conversely, for those not affected by Covid-19, for fear of becoming infected. Even more delicate is the case of a dying person who may wish to experience that final journey with a loved one, or alone, away from loved ones, preferring to spare them the persistent image of their suffering.

When requested, the provision of spiritual assistance should be guaranteed. The presence of volunteers to assist the sick should also be encouraged, especially for those without family ties and friends. The patient's decision-making autonomy must in any case be valued<sup>6</sup>.

Where, for reasons of health protection or organisational problems, access to family members is not allowed, or is only exceptionally allowed, the ICB believes that, following the example of experiences already under way<sup>7</sup>, every possible effort should be made to overcome the difficulties. While keeping in mind that virtual communication cannot replace meeting in person, patients must be guaranteed the possibility of contacting their loved ones using available technological devices (tablet, computer, video chat, etc.), providing those who do not use them habitually with all the necessary assistance.

The ICB, while understanding the difficulties that face our National Health Service every day in the context of the current pandemic, recommends persevering in the search for innovative solutions to ensure safety without losing the relational dimension of closeness and proximity.

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<sup>4</sup> ICB, *Intensive care unit "open" to family visits*, July 24, 2013 cit.

<sup>5</sup> E.g. dressing and undressing, hand hygiene; correct use of the mask, carrying out appropriate tests on entry, etc.

<sup>6</sup> In the full application of Law 219/2017 "Provisions for informed consent and advance directives treatment".

<sup>7</sup> E.g. the experience of the Cisanello hospital in Pisa, the Meyer pediatric hospital.

The text was drawn up by Prof. Assunta Morresi. Profs: Stefano Canestrari, Marianna Gensabella, Lorenzo d'Avack, Bruno Dallapiccola, Antonio Da Re, Paola di Giulio, Maurizio Mori, Laura Palazzani, Lucio Romano, Monica Toraldo di Francia, Grazia Zuffa contributed to its drafting.

The discussion was supplemented by hearings which provided a valuable contribution from: Dr. Paolo Malacarne, Director of the Anaesthesia and Resuscitation Unit of the Pisa University Hospital, Pisa Hospital Emergency Department; Prof. Marco Trabucchi, President of the Italian Association of Psychogeriatrics; Dr. Fabrizio Palmieri, Director of the Multispeciality Department Infectious Diseases of the Respiratory System, Scientific Institute for Treatment and Research "L. Spallanzani", Rome; Dr. Emanuele Nicastri, Director of the Multispeciality Department Infectious and Tropical Diseases Scientific Institute for Treatment and Research "L. Spallanzani", Rome.

The motion was approved in the plenary session on January 29, 2021 by Profs: Salvatore Amato, Luisella Battaglia, Stefano Canestrari, Carlo Casonato, Francesco D'Agostino, Antonio Da Re, Lorenzo d'Avack, Mario De Curtis, Riccardo Di Segni, Gian Paolo Donzelli, Mariapia Garavaglia, Marianna Gensabella, Assunta Morresi, Laura Palazzani, Tamar Pitch, Lucio Romano, Massimo Sargiacomo, Luca Savarino, Monica Toraldo di Francia, Grazia Zuffa. Prof. Cinzia Caporale abstained.

Despite their not having the right to vote assent was given by: Dr. Maurizio Benato, the delegate for the President of the National Federation of MDs and Dentists Colleges; Dr. Carla Bernasconi, the delegate for the President of the National Federation of the Orders of Italian Veterinarians; Prof. Carlo Petrini, the delegate for the President of the National Institute of Health.

Profs: Bruno Dallapiccola, Silvio Garattini, Maurizio Mori, Lucetta Scaraffia absent from the session, subsequently assented.