

COVIPAL Group recommendations on the organisation of palliative care in COVID units - CME AP-HP, 19/03/2020

Project carried out at the request of Prof Rémi Salomon, Chairman of the Medical Board. Group coordinator: Dr Vianney Mourman, vianney.mourman@aphp.fr, tel.: 01 71 20 71 40

The following people participated in the working group: Dr Elisabeth Ballardur (palliative care), Dr Sébastien Beaune (emergency medicine), Dr Guy Benoit (pharmacist), Dr Diane Bouvry (respiratory medicine), Emily Karsenty (psychologist), Prof Bertrand Guidet (intensive care), Dr Sandrine Greffard (geriatric neurologist), Dr Audrey Lebel (oncology and palliative care), Céline Le Bivic (psychologist), Dr Matthieu Le Dorze (anaesthetist), Dr Romain Sicot (psychiatrist), Dr Isabelle Triol (palliative care), Dr Laure Varin (psychiatrist), Prof Marc Verny (care of the older patient), Dr Dominique Vodovar (intensive care), Frédéric Wojeik (nurse)

The COVID-19 epidemic has exposed our hospital system to an unprecedented situation. The high mortality rates described internationally and in certain regions of France have led us to reflect, in a specific sense, on how palliative care is organised in this exceptional situation, which could, in the end, lead to the saturation of our health system.

The purpose of this document is to help the teams who will be required to provide COVID patients with care that goes beyond all curative treatment. It aims to enable patients to reach the end of their lives as comfortably as possible or, at the very least, with the least suffering possible, under these exceptional circumstances. It also hopes to provide support for relatives confronted with the sudden loss of a family member as a result of the highly acute nature of COVID-19. These families and friends will find it all the more difficult due to the self-isolation measures and restricted hospital visits, meaning that they may not have been able to see their loved one as much as they would have liked.

At the patient's bedside, dedicated healthcare professionals will be confronted with often-tragic situations which will continue to occur and for which they are not necessarily prepared. They must be provided with the resources to ensure the best possible working conditions, in order for them to provide the best care, in the most fulfilling and least traumatic way possible for them.

The COVIPAL group, which drew up this document, was set up at the request of the central Medical Board. This document makes some suggestions about operational and organisational aspects to be put in place in the various hospitals of the Greater Paris Public Hospital Authority (AP-HP), so as to improve the palliative care of acute patients hospitalised in COVID units.

The different points covered are:

- The definition of palliative care patient in a COVID unit and the care objectives
- Organisational suggestions according to hospital site
- Approaches to:
 - Receiving patients

- Modes of care
- Supporting the families of patients
- Supporting teams

The proposals made in this document should be rejected, modified or supplemented by the hospital, according to the realities of the field. Their principal purpose is to aid organisation at a local level.

Defining the palliative care patient in a COVID unit

In this document, we will focus on the problems posed by the treatment of patients hospitalised in the COVID unit, namely:

- Those with life-threatening organ failure
- Those for whom a transfer to intensive care is not indicated
- Those for whom all curative treatments have been exhausted

Therefore, it applies to infected, hospitalised patients for whom palliative care is the only option. The purpose of treatment in this case is to improve their quality of life while respecting their dignity. To do this, the resources placed at the disposal of the medical team by the hospital must be directed at relieving any distress the patient might be experiencing. Such distress could be as much physical as mental, social, spiritual or even existential.

This document does not cover the triage of patients presenting with life-threatening organ failure. Recommendations on this subject are currently being published based on the work of a working group, led by intensive care practitioners.

Nor does the document trace the entire care pathway of COVID patients. We will not address, in this document, the care pathway of patients with an asymptomatic form, those presenting with mild symptoms or those hospitalised in critical care departments.

Identifying and recording individual cases

Whether the patient is refused admission to intensive care or whether his/her condition deteriorates while hospitalised in the COVID sector, it is vital that patients for whom palliative care is indicated are identified early on, in order that they may access the care most appropriate to their condition.

To do this, each hospital must define how they will identify patients and how information will be conveyed and recorded.

There is the IT system Orbis, but perhaps other media should also be considered, such as a reference telephone number or paper documents, whereby the patient is identified and information on his/her particular needs is sent to the relevant person, by the hospital responsible for him/her.

Pre-completed documents with tick boxes and colour-coded for quick identification would provide a way of recording the decisions taken and the type of care anticipated. One of the appended documents provided by the College of Palliative Care can be used by teams as a template, which can be adjusted according to their needs or used as is. On one side, the document provides information on taking decisions to withdraw treatment and, on the reverse, recommendations on the envisaged treatment.

Medical administrators can also take responsibility for uploading to Orbis the treatment administered to patients and minutes of conversations with families, as well as compiling the information sent out.

Construct an organisational plan

At central AP-HP level

The COPIVAL working group, set up by the AP-HP Medical Board, intends to launch this dynamic approach to providing individual palliative care in COVID units, within the context of the epidemic. Although imperfect and inevitably incomplete, this document aims to help teams to “come up with” a response to the crisis dealt by the coronavirus epidemic.

The COPIVAL, in partnership with the AP-HP College of Palliative Care Physicians and academic societies, proposes collecting and compiling the various tools and documents likely to facilitate the provision of palliative care in COVID units and to place these at the disposal of these units.

Initiatives, positive or negative experiences and the obstacles encountered in the field may be fed back to the COPIVAL, so that they may be improved and disseminated to all hospital if they can be of help to teams. Feedback from the field will help to find solutions to the difficulties encountered.

The part played by mobile palliative care teams at each hospital

According to the recommendations issued by the French Society of Palliative Care (SFAP): *“If possible, part of the activities of mobiles teams should be redirected to departments receiving COVID patients, as well as emergency and post-acute departments, allocating part of the team to treating COVID patients.”*

According to the working group, mobile palliative care teams, supported, where possible at local level, by care of the older patient and general medicine doctors, should play a leading role at every hospital. These teams should consist of professionals with palliative care experience.

Their objective is to coordinate palliative care in hospitals. Such coordination will take the form of supervising the delivery of palliative care and training and supporting teams in departments confronted by patients infected with COVID-19.

Thus, short training courses should be offered, led by members of the mobile team, in conjunction with a volunteer representative from each team (day and night team).

In parallel with their work in COVID units, palliative care teams should continue to work with patients requiring palliative care in the rest of the hospital.

The teams may also contribute to decision-making processes regarding the withdrawal of pre-intensive care treatment, as an independent party.

According to the SFAP, from an organisational point of view, invariably, *“The availability of mobile teams should be increased, by increasing the length and number of shifts at hospitals.”*

The working group suggests expanding mobile palliative care teams, possibly by redeploying staff from mobile teams virtually unscathed by the COVID-19 crisis (such as those from children’s hospitals, for example). However, care should be taken to leave teams with minimum staffing levels, to ensure they can carry out their usual activities.

Each team is responsible for feeding back their requirements, especially in terms of doctors, nursing staff or support staff (e.g. HCAs).

“The possibility of creating an on-call number for weekends and public holidays, during the daytime and, if possible, at night, depending on the organisation, can be discussed. The possibility of rolling out the on-call role at national level may also be considered.”

(To be discussed in conjunction with the home care teams and palliative care networks?)

Also according to the SFAP, palliative teams could *“Contribute to ‘ethics advisory groups’. In this way, they would contribute to considerations regarding the care of seriously ill patients and to decisions regarding the re-organisation of healthcare departments, in response to the scarcity of resources, thus helping to make the difficult decisions that certain teams may be forced to make.”* The formation of ethics advisory groups is also recommended by the National Ethics Advisory Committee (CCNE). Palliative care teams appear to have a role to play in these proposals, provided that the objectives, scope, leeway and boundaries of the ethics advisory groups are well-defined.

At local COVID unit level

The working group proposes allocating representatives in each COVID unit, who would not be involved in specific palliative care activities, but would support and train their colleagues in these units to deliver palliative care. These representatives would collaborate directly with mobile palliative care teams, so as to receive support and expert help.

Within each unit, each time will appoint a medical representative and a paramedical representative (equivalent to six paramedical representatives per COVID unit).

These representatives must undergo a short training course, covering the following major topics:

- The general framework as regards the withholding of treatment
- Safe prescribing and administration of prescriptions
- Supporting families
- Effectively and accurately differentiating between:
 - o Dyspnoea warranting curative treatment,
 - o Dyspnoea within a palliative situation, with justification for the administration of symptomatic treatment with morphine, and
 - o Hypoxaemic respiratory failure.
- How to use specific symptomatic treatments essential for palliative care, in particular opioids at the minimum dosage effective against dyspnoea and sedation for hypoxaemic respiratory failure.

Healthcare assistants should be involved in the training, since they form an integral part of patients’ care and are those closest to them.

Particular consideration should be given to night teams, who are often more isolated (there is not always a night doctor), less well equipped and witness to many deaths. Perhaps more training and support should be provided for them, along with a regular palliative care team presence or, at the very least, telephone contact for complex situations.

Psychological support should be considered, in collaboration with existing hospital departments, in order to support teams facing the recurrence of unique, complex and distressing situations.

Other interventions for palliative patients

In addition to the usual trio of healthcare assistant, nurse and doctor caring for the patient, it would be pertinent to state that other players must be deployed to care for palliative patients. Psychologists, physiotherapists and other professionals can

improve the patient's wellbeing and their involvement should therefore be considered. At each hospital and in each department, means of intervention should be put in place, based on the needs listed.

Psychologists are already largely in deployment, organised according to the medical-psychology 'white plan' (local plans for increased hospital activity) and psychology white plan representatives at each hospital, and are coordinated with the professional Colleges. Therefore, it would appear pertinent to ask Colleges of hospital and mobile team palliative care psychologists to organise themselves to provide this support. It should be noted that many psychologists who usually carry out consultations (which are no longer taking place) are already supporting these department. Mobile palliative care team (EMASP) psychologists may be supported by their colleagues at many hospitals.

Psychiatrists and psychiatric liaison teams should also be called on and redeployed in this way.

For patients who express or feel the need, it should be possible to involve religious representatives, especially if the patient or his/her relatives would like the minimal rites, in accordance with their traditions (to the extent that this is possible, considering the constraints of the health crisis and, in particular, the need to remove the body immediately). All religious representatives called on must be protected against infection.

Specific COVID palliative care units

The recommendations of the regional health board and the SFAP suggest the *“creation of a dedicated palliative care unit in hospitals receiving infected patients.*

It is necessary to set up such a unit where the capacities of departments receiving COVID patients are at their limit, due to a massive influx of patients, in order to provide curative care.

Their purpose is:

- To receive patients infected with COVID-19. Infection will be identified either at the start of treatment or following initial treatment. The objective of care is purely palliative, with the intention of seeing the patient through until their death.*
- To provide the patient with the best care possible, while adhering to the rules on self-isolation, so as to avoid viral transmission.*

Organisational considerations:

- The unit should be located in a designated “COVID-19” hospital.*
- At best, responsibility for the unit may be entrusted to the doctor leading the hospitals' mobile team or a doctor of older patient care.*
- Professionals from the mobile team will support medical staff working in the unit.*
- Doctors assigned to the unit will be in constant collaboration with other hospital departments caring for infected patients (emergency department-respiratory and infection-intensive care department pathway), in order to facilitate the treatment and determine the route of patients.*
- Visiting will be restricted, as in palliative care units.”*

According to the COVIPAL group, the relevance of setting up such units should be discussed at each hospital on a case-by-case basis.

The group has met and had discussions with medical staff from general medicine units, redeployed to COVID units, who already have experience of providing regular palliative care. It seems that these healthcare professionals would prefer to work in mixed curative-palliative COVID units. This preference can be explained by the idea of not wanting their work to be restricted. In their words, they are scared of being “sent”

exclusively to “the depths” of the palliative care department. They said that they agree to care for palliative patients but that they are also required to care for patients in better health at the same time. They need to see patients improve and recover if they are to properly care for patients at the end of their life.

If such units were to be set up, consideration would need to be given to the possibility of having trained, competent voluntary staff to provide such specific palliative care, within the context of the epidemic. Measures must also be put in place to effectively support these healthcare professionals, whose daily reality could prove to be physically and mentally draining due to the difference with classic palliative care units (death rate, suddenness of deterioration, symptoms, age of patients, etc.).

Considering COVID hospital unit support

There are those who wish to live out the end of life at home. If the patient is no longer benefiting from being in hospital, it would be best to devise a way of allowing him/her to return home quickly, provided this is the patient’s and his/her family’s wish and the patient’s care can technically be administered at home. It is vital to do everything possible to ensure the comfort and safety patient and his/her family once at home.

This arrangement must be reactive to anticipated clinical developments. A return to nursing home could also be arranged, provided the relevant home - which is likely to be reluctant - agrees and is capable to providing the care expected. Support from a specialist team (home care team or palliative care network) is advisable.

The home care team works to help these patients return home quickly. Home care teams have the expertise available to them and are in the process of being strengthened to deal with such clinical scenarios, including sedations. Palliative care support teams and home care networks are working in conjunction with one another to ensure a wide distribution across the region.

The involvement of this body of voluntary professionals and mobile units (non-hospital doctors, nurses in private practice, district nurses) should lead to a steady increase in aftercare, according to the patient’s needs identified on being discharged.

Developing recommendations, protocols and practical tools for teams

The COVIPAL group believes it is necessary to provide medical staff caring for palliative patients with practice, easy-to-use tools and recommendations.

Different teams from the AP-HP, the High Authority of Health (HAS) and the academic societies have already compiled evaluation and treatment tools, which will be collated and distributed.

Such tools could relate to, for example, the place of oxygen, pain relief, the evaluation and palliative treatment of dyspnoea and other symptoms, sedation for respiratory failure, decision-making (Doctor Sebag Lanoe’s questionnaire for older patients), supporting families or communication.

A checklist could be created to aid decision-making, and even palliative treatment protocols and guidelines on which treatments to continue or suspend.

A short, practical training module could be made available to give teams basic training in how to improve the quality of life of palliative patients.

Prioritising access to medicines and essential devices for palliative care

Each hospital should determine the availability and stocks of medicines necessary to

deliver palliative care or induce sedation in the event of possible hypoxaemic respiratory failure.

As a priority, supplies of the following should be determined:

- Paracetamol administered via IV, PO or suppository, used for relief from pain and fever
- Fast-acting morphine PO and morphine (10 mg/1 ml), used for polypnoea and pain
- Midazolam (5 mg/5 ml) used to induce anxiolysis (where PO administration is impossible) or sedation
- Scopolamine (0.50 mg/2 ml - 3-6 vials/24 hours) used for end-of-life airway obstruction
- Largactil (25 mg/5 ml) vials and Haldol (2 mg/ml) PO, used for opioid-induced hallucinations and for nausea and vomiting
- Mouth treatments

Each hospital should be able to define which other medicines may be necessary and to check their local availability.

From an organisational point of view, management, for example, could determine these requirements, assisted by logistical staff and in conjunction with a designated pharmacist. They would work to ensure the availability of sufficient quantities of medicines in departments, 7 hours per day, seven days per week.

A request was sent to the General Agency for Health Equipment and Products (AGEPS) to determine the availability of these medicines, as regards the AP-HP's supplies.

According to the needs and usual practices of the department, the subcutaneous administration of these medicines will take precedence if oral administration is impossible and the patient has not previously received an IV infusion. However, it seems that there will soon be a shortage of syringe pumps. Will manual use of infusion sets be used instead?

Pain relief patches, although seemingly practical to use, will not be considered as a first-line option, due to the long time they take to act and difficulties adjusting dosages, particularly in older patients.

Supporting the patient's relatives

Contact from relatives is highly limited due to isolation measures and restricted visiting in COVID units.

We absolutely understand the hygiene measures in place to slow the spread of the epidemic. However, the COVIPAL group is wondering what adjustments can be made for palliative care patients to ensure that they are surrounded by their loved ones in their final moments.

The debate around the definition of what constitutes the "end of life" is an ongoing one. The opinion of the COVIPAL group is that this period should be determined according to the expertise of the medical staff. Once this time arrives, perhaps the rules can be relaxed and the patient's door re-opened to his or her relatives, in accordance with departments' capacities.

As a result, it seems appropriate that access to the patient's bed should be restricted to those closest to or designated by him or her, setting the limit to a maximum of two people (with a possible rotation and strict compliance with the rules on barrier

measures) and a time limit. It would be interesting to study and possibly roll out the experience of Avicenne hospital, which deployed non-resident medical students to help families dress themselves (which is very time-consuming for medical teams), so as to protect their health.

Would it not be appropriate to create an information sheet for families regarding this type of care, so that they can prepare themselves for it? The sheet would also provide relatives with the contact details for the different points of contact at the hospital.

Keeping families informed of the patient's condition of health is also a vital for the patient's relatives. How this is done is determined by each department; in some departments, it takes the form of regular telephone calls to the patient's family to give them updates. These calls are made by the treating senior doctor or by the junior doctors or nurses in charge of the patient. As well as conveying information, these calls serve to identify those who could be approved to attend the patient's room at the end of his or her life. At certain hospitals, non-resident medical students, trained and supervised by psychologists or transplant coordinators (who have extensive experience of liaising with relatives), could help to communicate with families.

Rolling out the experience of departments which have introduced contact on a tablet, using applications such as Skype or WhatsApp, in order to facilitate communication between patients and their relatives, could be considered, where possible.

However, it is important to ensure, to the extent possible, that the patient agrees to their information being shared and that the boundaries of patient confidentiality are not crossed.

Thought should also be given to how to support relatives with restricted mobility. Intense consideration is being given by colleges of psychology to the psychological support available for the families of COVID patients (e.g. parents and children) and to the aftercare available for grieving families.

Particular thought should be given to children, who particularly require support.

Telephone consultations could be provided, although this raises a number of issues: How to determine who needs them How to facilitate contact with relatives and offer them the help they need What are the limitations of telephone-based support?

Support for relatives at the time of death and immediately afterwards is also crucial. Surely this is a time when psychologists could be present or, at the very least, make regular contact with families? (Whether this be the psychologist who already knows the family or, if not, the psychologist from the mobile palliative care team?)

Given the extent of support required, should the state not be invoked to redeploy psychologists currently confined to their homes due to the departments in which they work being closed? Should a kind of cell centre not be set up (with a freephone number) to provide support for the relatives of hospital patients in a COVID unit where visiting is restricted or prohibited?

Thinking about the unique moments of death and post-death

As mentioned above, because of isolation measures and the visiting ban in COVID units, some families will not see their loved one's condition deteriorate or be present at the time of their death, whereas under normal circumstances they would have. Furthermore, due to hygiene rules, which stipulate that the bodies of the deceased must be quickly sealed in an airtight bag, relatives will not necessarily have access to the body of the deceased to say their final farewells.

It is important for each unit to consider how the death will be communicated; i.e. who will do it and how, particularly during the night?

The question should also be asked, how will not being able to visit and support their loved one at these times impact on their grieving process? Without delving into overly complex psychological theories, one might ask to what extent these events and this reality will haunt them?

Also relevant is being aware of and recording the circumstances surrounding the patient's death, so as to be able to convey these to the family immediately after death but also later on, in case they find this helpful in their mourning.

There is also work to be done with mortuaries - who often play a large role in comforting mourning families - to help them as they receive the families of the deceased and provide care adapted to the deceased, in this unique situation.

It would be beneficial to consider what measures could be put in place to enable families to perform the minimum funeral or even symbolic rites they deem necessary. These rites often have great significance for families, being created by each society or culture to watch over the deceased and to enable mourning to begin. One can imagine their significance at the end of life during the pandemic.

Supporting medical staff

As discussed several times in this document, medical staff (paramedical, medical and trainee healthcare professionals) will be faced with difficult situations during the pandemic. These staff are often highly invested and resolute. Given that these circumstances are likely to last a long time, it is essential that medical staff are offered support.

This involves financial bonuses as well as a recognition of their work and commitment. It also involves measures specific to the different aspirations and prospects of the professionals. Group and individual clinical supervision and other projects proposed by competent staff in the field should be made available. It is important to ensure that staff are aware that these provisions exist.

Moreover, expert help and tailored psychiatric treatment should be available to and easily accessible by colleagues who have reached mental exhaustion in their day-to-day caregiving. Consideration should also be given to how these types of situations are identified. Psychiatry teams in various hospitals are already addressing this issue.