

# Ethical Framework for Decision Making in HPC During the COVID-19 Pandemic

Version, March 27, 2020

*"In times of financial hardship or personal distress, we should fall back on that which we value most deeply to remind us of who we are and who we want to be."*

- NHPCO Guide to Organizational Ethics in Hospice Care, 2016, p. 3

Hospice and palliative care programs await regulatory guidance related to changes in practices in the time of COVID-19. CMS has encouraged programs to make decisions on a case by case basis with ample documentation to demonstrate how goals of care for each patient are being met in a safe and appropriate manner.

This Ethical Framework, drafted by members of NHPCO's Ethics Advisory Council, is offered not in place of regulatory guidance from CMS, but as a tool to assist programs and professionals in having these critical conversations. Even when regulations are provided, all decision-making is best served when grounded in and structured by the ethics and values we are bound to uphold.

This document is not intended to be the final word on the matter but is offered as a starting point for an on-going and evolving dialogue. We welcome feedback and suggestions for resources to add to those offered at the end of this document.

When faced with decisions in hospice and palliative care, rarely is there a one-size fits all solution. Differences in practice settings, patient and family characteristics, agency type, availability of resources, etc. all come into play.

The following questions may be used in any situation to guide the conversation as we consider what the core ethical principles of healthcare require of us through each decision.

## **Autonomy**

- Are we honoring patient and family dignity, rights, values, preferences, and providing them with all the information they need to make a reasoned choice?
- How are we communicating with the patient/circle of care to provide adequate information about their options and following their lead?

## **Participation**

- How are stakeholders being involved in developing and implementing criteria, processes, and policies?
- Whose voices are not present at the table that should be included?

## **Beneficence**

- How can we provide the most benefit to this patient and family, acting in their best interest, given resources available?

## **Utility**

- How may we serve the greatest good for the greatest number?

## **Nonmaleficence**

- What is the least harm possible as we seek a beneficial outcome?
- What unintended consequences may impact this person/family in the short- and long-term based upon this decision?

## **Liberty**

- What is the least restriction we can place on the patient and family's self-determination to achieve a legitimate goal?

## **Efficiency**

- How are we minimizing the resources needed to maximize results?

## **Duty to Care**

- What is a reasonable expectation of healthcare professionals to place their own health at risk in order to not abandon a patient and family?

## **Organizational Responsibility**

- How are we supporting our staff to perform their duties in both the short- and long-term?
- How are we tending to the physical, emotional, and spiritual safety of our staff and volunteers from harm, trauma, moral injury?
- How are we providing proper equipment and access to basic needs?
- What advocacy may we engage in to request adequate support from legislative and regulatory agencies to ensure access to care for all and the protection of staff?

## **Conscientious Objection**

- Under what circumstances and by what means may professionals decline to provide care and what is their responsibility to ensure continuity of care through adequate referrals?

## **Justice and Fairness**

- Are we applying criteria equally and consistently?
- Once precedent is established, will we be able to continue applying the same treatment to others?
- Are we supporting equal access to care or contributing to health disparities?

## **Transparency**

- Are we open and clear with patients, families, staff, and the public about the criteria (the why) and processes (the how) we are following in our decision-making?

## **Review and Revisability**

- How are stakeholders given opportunity to review and appeal adopted policies?
- What process is in place to regularly revise policies as situations change and/or new information is available?
- Where ethical principles appear to conflict, what process will be employed to resolve them?

Multiple principles will likely apply to each situation and may even appear to be in conflict. For instance, when issues of autonomy of the individual and obligations to utility and justice for the many appear to conflict, we must turn to the other principles to guide us. In this way we can work to produce the least harm, with utmost compassion and transparency, given the limits of what is possible in a given situation, and with stakeholders involved in those negotiations.

## Other Questions Specific to Times of Pandemic:

- Has the organization made a decision about its capacity (including specific purpose fundraising) and criteria for holding billing or writing off costs for patients who are only being supported telephonically?
- When staff shortages arise, what changes to guidelines for admission should we make to maintain the ability to provide competent care and protect staff?
- In lieu of accepting patients whom we are currently unable to serve, what education can we provide to facilities and families about the provision of holistic EOL care?
- Who should get priority access to healthcare resources as shortages occur?
- Do the agency and the patient and family feel confident the patient and family can be safely and effectively cared for with only telephonic and video support?
- Should billing be held until further clarification is provided?
- Can anything be done within reason to resolve barriers to the effective provision of care?
- If not, then is discharge or transfer to another provider appropriate?
- How well are psychosocial-spiritual supports being provided to the patient and family through telephonic and video means?
- What considerations need to be given to providing screening, assessment, education, interventions, changing of treatments, provision of counseling, offering of prayers and rituals, etc. via telephone and video?
- Are we sufficiently documenting the reasons for the provision of telehealth?
- Is an in-person RN visit every 14 days essential for the well-being of the patient/family?
- Have all options been accounted for in the emergency plan?
- Have we considered guidance from our state hospice organization?
- What other questions should we be asking?
- If an agency or professional decides they are not able to provide adequate care given their limitations of resources (staff, equipment, expertise, etc.) what is the responsibility to provide an adequate referral and assist with the transition to another agency or professional that can provide care?
- If no other such equipped agency is available in the area, can the case be made that the presence of nurses, social workers, spiritual care counselors, etc. via telehealth to offer guidance, presence, and support would be more ethical than abandonment?
- How much of our decision is being driven by fear and finances—such as regulatory and reimbursement uncertainty, our relative lack of and conflictual knowledge about COVID-19—rather than the foundational philosophies we proclaim?
- Is the greater good served by keeping our doors open to serve patients in the future or by showing up in this world crisis, regardless of reimbursement?
- Where fears, uncertainty, and other barriers are in the way to our providing competent care
- What can we do to remove those barriers to access to care?

- What partners can we bring in/join with to find creative solutions?
- Is there an opportunity to join forces with another agency, even a competitor, so that our combined resources give us enough staff, expertise, supplies, etc. to care for patients during this crisis and we can figure out creatively who will bill for whom?
- Are we selling ourselves and our supportive care teams short by minimizing the value of presence, even if virtual?

**References and Resources:**

"Ethical Issues in Pandemic Planning and Response", NCBI Bookshelf article

<https://www.ncbi.nlm.nih.gov/books/NBK54169/>

NHPCO Guide to Organizational Ethics in Hospice Care

[https://www.nhpc.org/wp-content/uploads/2019/04/Ethics\\_Guidelines.pdf](https://www.nhpc.org/wp-content/uploads/2019/04/Ethics_Guidelines.pdf)

NHPCO Hospice and Palliative Care Code of Ethics

[https://www.nhpc.org/wp-content/uploads/2019/04/Code\\_Ethics\\_Statement.pdf](https://www.nhpc.org/wp-content/uploads/2019/04/Code_Ethics_Statement.pdf)

VA Ethical Issues in Pandemic Influenza Preparedness and Response

[https://www.ethics.va.gov/activities/pandemic\\_influenza\\_preparedness.asp](https://www.ethics.va.gov/activities/pandemic_influenza_preparedness.asp)

# Appendix

See additional Resources

"The greatest moral challenge posed by a pandemic is how to respect commitments to social justice in the face of the overwhelming and entrenched inequalities in health, well being, and resources that will constitute the backdrop for, and the harsh realities of, any global outbreak of devastating disease." Ruth Faden: Johns Hopkins University.

Paraphrase: Ethics must lie at the heart of preparedness efforts because it helps us see what the right thing is to do under the circumstances of pandemic. It must examine both substance and consequences of alternative policies, practices and processes by which they are developed and selected.---Alexander Morgan Capron: USC

World Health Organization identified the following as ethical considerations in pandemic:

- priority of access to healthcare resources with increased demand and possible shortages;
- obligations of healthcare workers in light of risks to their own health;and
- the fine balance between reducing disease spread through isolation and travel measures whilst protecting the right of individuals to freedom of movement.

Ethical Principles to consider in pandemic:

Beneficence--produce benefit, to do good, to always act in the best interests of the patient

Non-maleficence--inflict the least harm possible to reach a beneficial outcome

Respect for persons--all persons deserve the right to fully exercise their autonomy

Justice--fair treatment of individuals, equitable allocation of healthcare dollars and resources, fairness, equality, and equitable treatment.

Some of the ethical approaches for consideration:

Consequentialism--a person should act in the way that produces the best outcome

Deontology--people should act as to fulfill their duties to others

Utilitarianism--the right action is that which maximizes human welfare or well-being/produces the greatest good

---Alexander Morgan Capron: USC

Capron identified four areas of ethical concern:

- 1) Equitable access to health care in pandemic--how health care resources in general should be allocated, both before and during the pandemic.
- 2) Ethics of public health actions taken in response to a pandemic--surveillance of outbreaks, dissemination of outbreak information, separation measures and border control

## The following are excerpts from "Ethical Issues in Pandemic Planning and Response"

- 3) Obligations of healthcare workers during a pandemic and the obligations of society to them in return--danger to and mortality of healthcare professionals, personal vs professional obligations
- 4) Obligations among countries and the obligations of intergovernmental organizations--vaccine allocation strategies, release or hoard of scarce supplies

Relevant Ethical Principles in pandemic that should underlie planning and response:

- 1.) Utility--acting so as to produce the greatest good.
- 2.) Efficiency--minimizing the resources needed to produce a particular result or maximizing the result that can be produced from a particular set of resources.
- 3.) Fairness--treating like cases alike (the risk of unfair discrimination).
- 4.) Liberty--one should impose the least burden on a person's self-determination that is necessary to achieve a legitimate goal. (Don't trade all freedom for security.)

Relevant Principles concerned with the procedures by which decisions are made:

- 1.) Transparency--information about the processes and bases of decisions should be made available to the affected population.
- 2.) Participation--the stakeholders should be involved in the processes of formulating the objectives and adopting the policies.
- 3.) Review and Revisability--stakeholders should have a way to appeal policies after they have been adopted, and processes should be in place that allow policies and plans to be reviewed and revised in light of experience.
- 4.) Effectiveness--there must be ways to translate the other principles into practice.

These eight principles, in some sense, summarize people's general expectations of how the government should respond in a pandemic. --Alexander Morgan Capron: USC

Issues at hand:

- 1.) Access to healthcare services--problem--how to fairly distribute healthcare resources that are not going to be adequate to provide for everyone in need.
  - What counts as a fair distribution?
  - What sort of justice is being sought?
    - Compensatory justice states it is important to make up for any special burdens that a person has suffered.
    - Distributive justice states we must attend first to the needs of those who are worst off in society (health, income, etc)
    - Procedural justice is the idea of fairness in the processes that resolve disputes and allocate resources.

- Regarding justice, what is the basis of comparison?
  - Maximization of well being?
  - The effects on well being among different members of society?
  - Are we concerned only with lives saved?
  - Justice in terms of economic and social cost?

The fairness of the process will be crucial in producing allocation decisions that are defensible.

Information, participation, transparency and revisability will be key to the decision making process.

2.) Public Health Interventions--quarantine, social distancing, isolation of infected people, etc.

- Do we know how to measure the benefits that will come from any of these interventions?
- Important in the discussion of personal freedom vs. achieving public goal that can only be realized by these means.
- If we cannot show data that proves the measures are working, we cannot impose on people's rights of self-determination.

"If providing care increases risk for healthcare workers, there is a legitimate reason to provide them with preferential access to prophylaxis and treatment on the grounds that are narrower than simply rewarding general social utility. That is, using scarce medical resources on healthcare workers would be directly associated with the continued ability of the healthcare system to provide these interventions to everybody else." Alexander Morgan Capron: USC

Two ways to view this:

- 1.) If there is added risk, the choice to take it on should be, at first, a voluntary choice.
- 2.) It may be necessary for healthcare workers to be obligated to act because their conduct is mandated by the profession or by the state.

The Three Moral Tasks of Social Justice: Ruth Faden: John Hopkins University

- 1.) Identify which of the likely inequalities in burden are the most morally egregious. Suffering is relative; determine which is most unjust.
- 2.) Determine, among the more egregious inequalities, which are the most easily prevented or at least mitigated. This will help blunt or narrow some of the worst injustices.
- 3.) Implement whatever changes in policy and practice are necessary to reduce those inequalities that are amenable to prevention or mitigation.



# Coronavirus Disease 2019 (COVID-19) Shared Decision-Making Tool

March 19, 2020

## 1. What is my, or my loved ones, likelihood of surviving COVID-19?

The most important predictors of survival are age and pre-existing conditions.

### AGE<sup>1</sup>

AGE	DEATH RATE <i>Confirmed Cases</i>	DEATH RATE <i>All Cases</i>
80+ years old	21.9%	14.8%
70-79 years old		8.0%
60-69 years old		3.6%

### PRE-EXISTING CONDITIONS<sup>2</sup>

PRE-EXISTING CONDITION	DEATH RATE <i>Confirmed Cases</i>	DEATH RATE <i>All Cases</i>
Heart disease	13.2%	10.5%
Diabetes	9.2%	7.3%
Chronic lung disease	8.0%	6.3%
High Blood Pressure	8.4%	6.0%
Cancer	7.6%	5.6%
no pre-existing conditions		0.9%

### Determine your risk level:

- Highest:** > age 80 AND 1 or more chronic conditions
- High:** age 70 – 79 AND 1 or more chronic conditions
- Moderately high:** age > 60 AND/OR 1 or more chronic conditions

<sup>1</sup> <https://www.worldometers.info/coronavirus/coronavirus-age-sex-demographics/>

<sup>2</sup> <https://www.worldometers.info/coronavirus/coronavirus-age-sex-demographics/>

## 2. What are the symptoms?

Symptoms progress from onset of mild to difficulty breathing within an average of 5 days and Acute Respiratory Distress Syndrome (ARDS) in 8 days.

### Early symptoms may include:

- Fever
- Cough
- Shortness of breath

### Serious symptoms:

- Difficulty breathing or shortness of breath
- Persistent pain or pressure in the chest
- New confusion or inability to arouse
- Bluish lips or face

Call your physician to determine whether you should get tested

## 3. What is my likelihood to survive?

Most COVID-19 hospitalizations are due to problem breathing

- Up to 32% end up in the intensive care unit (ICU) and up to 15% die<sup>3</sup>

In general, even in the absence of COVID-19, of people older than 66 years who stay in the ICU over 14 days on mechanical ventilation, only 19% were discharged home directly from the hospital

- 40% died within 12 months of discharge from the ICU
- The surviving patients had severe and persistent functional dysfunction and cognitive impairment, including inability to problem solve and memory loss<sup>4</sup>

### DECISION POINT

#### Based on my risk level I want to be treated at:

\_\_\_\_\_ Home with palliative care or hospice for symptom management to maintain comfort

##### Advance Directives completed?

- Yes / type:
- No

##### POLST/MOLST completed?

- Yes / type:
- No

\_\_\_\_\_ Hospital for symptom management to maintain comfort if available

##### Advance Directives completed?

- Yes / type:
- No

##### POLST/MOLST completed?

- Yes / type:
- No

\_\_\_\_\_ Hospital for full life saving measures if available

[CLICK HERE](#) to access your free State's Advance Directive

[CLICK HERE](#) to access Five Wishes

<sup>3</sup> <https://www.worldometers.info/coronavirus/coronavirus-death-rate/#hfr>

<sup>4</sup> Parotto, M & Herridge, M. (2017). Outcomes after 1 week of mechanical ventilation for patients and families. ICU Management & Practices. 17(3):174-176.

## It is essential to manage expectations

Created by CHI Franciscan Hospice and Palliative Care & Spiritual Care Departments

The most important part of a successful conversation about transition to comfort focused care is **managing expectations** from the time of admission. This means communicating clearly the fact that there is **no effective treatment available** against COVID-19 and therefore the best care possible is a combination of:

1. A **time trial of supportive measures** with the hope that the patient has enough physiological reserve to survive and recover from the infection.
2. A **daily assessment** followed by a conversation with the family about **how the treatment trial is going** and how this impacts **available treatment options** and **recommendations**

**The following recommendations are anchored in 4 important assumptions:**

1. Replace the term “comfort care” with **“skillful symptom management focused on comfort.”**  
The change in terminology may eliminate any confusion by the family as to what comfort care means.
2. Rather than asking “what do you want us to do?”, patients and families trust that as a health care provider, you will be making **medical recommendations** that represents: the patient’s goals, medical facts **and available resources (if scarcity is an issue)** in high consequence situations.
3. If the recommendation is to limit or discontinue interventions **ALWAYS replace it with something else**, in this case with skillful symptom management focused on comfort.
4. In the face of a situation where scarcity of resources limit available options, the language we use must represent the fact that we don’t have a choice (**see SCENARIO 4**)
5. Death is not the failure, **suffering is the real failure**

### **AT THE TIME OF ADMISSION AND AT LEAST DAILY:**

Have a **same page conversation** with the medical/ED/ICU team/Mission-Ethics team (when appropriate, especially if scarcity of resources is limiting options), regarding where the patient is in the disease trajectory at present and what psycho-social and spiritual needs may need attending to:

- After consideration of all available information (age/comorbidities/prognosis for recovery/**available resources**) determine which scenario applies AND **share information** with family as follows:
  1. Give serious news in **in the form of a headline:**  
**“Despite giving your loved one the best care possible, her condition is worse today.”**
  2. After giving the information, you **follow it by silence** and **allow them to break the silence**
    - This is essential for them to process information, it will improve information retention and your encounter will likely take less time
  3. Be ready to **respond to emotions:**
    - “I wish things were different”,
    - “I can’t imagine how difficult this is for you”
    - “I can see that this is very hard”

The following are common scenarios with suggested language: (The headline for each scenario is in bold letters)

**SCENARIO 1:** Patient would benefit from a time trial of escalation of care including ventilators if available:

- “Your loved one is still seriously ill and **if she worsens, it will be appropriate to consider placing her on a ventilator since recovery is still possible, do you think this would be ok with her?**”

**SCENARIO 2:** Patient would benefit from a time trial of escalation of care without ventilators since need for a ventilator will mean that patient will not be able to come off ventilator

- “We recommend that we continue all our current efforts hoping she improves, we also recommend that, if despite giving your loved one the best care possible she gets worse, that instead of placing her **on a ventilator that we redirect our efforts towards keeping her comfortable and allow the natural dying process to take place.** I will also not recommend CPR because it will not benefit your love one”

**SCENARIO 3:** Patient would NOT benefit from continuation or escalation of care because of clinical deterioration despite all medical efforts (patient may or may not already be on a ventilator)

- “Despite giving your loved one the best care possible, she continues to get worse and **continuing current treatments will at best prolong her dying process and suffering.** For this reason we recommend that we redirect all our efforts towards keeping her comfortable and allow the natural dying process to take place without machines. I will also not recommend CPR because it will not benefit your love one”

**SCENARIO 4:** Patient will NOT receive additional escalation of care because of limited resources

- “We are facing a very difficult situation where, **given the limited availability of ventilators/resources, if your loved one continues to get worse, the best care possible at that time will be to redirect all our efforts towards keeping her comfortable and allow the natural dying process to take place.** We will also not perform CPR because it will not benefit your love one at this time”

- **Before discussing the details about Comfort Care:**

1. Consider inviting a chaplain and/or Palliative Medicine to join you in the family meeting. They can provide emotional support to families, and moral support to you.
2. Have clarity about resources available for symptom management by collaborating with clinical pharmacist. Also remember that medications for comfort **can be administered through various routes:**
  - **IV meds:** Morphine, Fentanyl, Hydromorphone, Midazolam, Lorazepam, Haloperidol, Ondansetron, Glycopyrrolate, Methadone
  - **PO meds:** Morphine, Hydromorphone, Hydrocodone, Oxycodone, Lorazepam, Clonazepam, Alprazolam, Haloperidol, Ondansetron, Glycopyrrolate, Hyoscyamine
  - **SC Medications:** Fentanyl, Morphine, Hydromorphone, Versed
  - **Intranasal:** Fentanyl, Versed
  - **Rectal:** Morphine, oxycodone, hydromorphone, methadone

3. Have clarity about whether the patient will need sedation for effective symptom management once the patient is transitioned to comfort care:
    - Breathlessness is likely to be the main symptom to treat in patients with COVID 19 whose main goal/options is comfort care.
    - Opiates alone may not provide adequate relief from breathlessness and sedation may be necessary
      - If you believe sedation will be necessary to control symptoms, disclose it during the conversation
        - “Given how uncomfortable your loved one is with her breathing/symptoms, I expect she will require sedation to ease her suffering”
      - Also be very explicit about your intent when prescribing medications:
        - “We are very committed to doing everything we can for the comfort of your loved one by minimizing her suffering as we allow her to die naturally”
        - “Our intention is to make sure your loved is comfortable and doesn’t suffer, not to shorten her life”
- **After discussing the details about Comfort Care (particularly if facing scarcity of resources):**
    1. Pause and check in with yourself and your team
    2. Pay attention to levels of stress and how that might be impacting you and others
    3. Return to any practice that helps to calm and/or center you
    4. Consider arranging debriefing if you feel you or the team could benefit
    5. Consider consulting with a Chaplain to round on staff involved. Chaplains are trained professionals who care for all people with sensitivity and compassion regardless of religious/spiritual affiliation

## Created by Franciscan Hospice and Palliative Care & Spiritual Care Departments

When a resident develops symptoms concerning for COVID-19, **it is essential to manage expectations.** Following are some recommendations for how to talk with residents and families about what to expect.

### These recommendations are anchored in the following general precepts.

1. Facility residents are fragile and at high risk for developing a COVID-19 infection. The reality is that **there is no effective treatment available against COVID-19.** Some residents have a limited life expectancy, and some have made decisions about care during a serious illness or at the end of life. We must be very careful to support their decisions and be very clear and honest with the medical disclosure.
2. In this extraordinary situation where scarcity of resources may limit options, our communications must compassionately and truthfully reflect the facts.
3. In making a medical recommendation, focus on what you **can** do—such as skillful symptom management—rather than what you cannot do.
4. Make medical recommendations that honestly represent care that is available at this time. Avoid asking “what do you want us to do?” Ask instead if they agree with your recommendation, **“what do you think about that?”** or **“what would mom think about that?”**
5. Use the phrase **“skillful symptom management focused on comfort.”** Avoid the term “comfort care” as this can be confusing to residents and families.

### FOR ALL RESIDENTS / FAMILIES

- Be ready to acknowledge strong emotion and the difficulty of having this conversation.
- Ask if there is anyone else you should talk to.
- Encourage them to reach out with any questions.

### AT THE TIME THE RESIDENT DEVELOPS SYMPTOMS

- Acknowledge the symptoms and their severity. Ask the resident/family **what they have heard** about COVID-19 to assess their knowledge and emotional state. Determine any needs.
- Respond to emotion: **“This must be very scary”** or **“I am sensing you are very concerned.”**

## AT THE TIME THE RESIDENT DEVELOPS SYMPTOMS (continued)

- Ensure that medications for symptom management are available and ordered for **this resident** (see attached COVID-19 Clinical Resource from CAPC for guidance).  
“Symptom Medications” [www.capc.org/toolkits/covid-19-response-resources/](http://www.capc.org/toolkits/covid-19-response-resources/)
- If symptoms are mild: provide support and reassurance to the resident: **“We will be monitoring you every day. Please make sure to report any changes.”**
- If symptoms are moderate: talk about what you will do if symptoms worsen.
  - **Ask permission** to have that discussion.
  - Recommend skillful symptom management with focus on comfort **while staying in their familiar setting**.
  - Assure the resident that you will be ordering medications to help their symptoms.
  - Acknowledge that the resident is at risk for developing more serious symptoms and may be at risk for dying.
  - **Use silence** while the resident thinks about what you said.
  - Continue to be aware of and **respond to emotions**.

## RESIDENT DEVELOPS WORSENING SYMPTOMS

- Acknowledge symptoms and that they are worsening.
- Continue to be aware of and respond to emotions.
- Make your recommendation for the best care possible:
  - **“I’m worried that going to the hospital would actually be dangerous and uncomfortable for him. I recommend that we provide skillful symptom management focused on comfort here in his familiar setting.”**
- Continue to talk about what you **will** do:
  - **“We will continue to adjust his medications to keep him comfortable.”**

## SYMPTOMS CONTINUE TO WORSEN

- Continue aggressively managing symptoms.
- Continue to support the resident/family while acknowledging the reality of the situation:
  - **“I am worried that her condition is changing and that her time may be short.”**
- Respond to emotion:
  - **“I can’t imagine how difficult this must be.”**
  - **“I wish this were different.”**

### **SYMPTOMS CONTINUE TO WORSEN, RESIDENT AT HIGH RISK FOR DYING**

- Continue aggressively managing symptoms.
- Be very explicit about your intent when discussing medications:
  - **“We are very committed to doing everything we can to keep your loved one comfortable and minimize her suffering while we allow her to die naturally.”**
  - **“Our intention is to make sure your loved one is comfortable and doesn’t suffer, not to shorten her life.”**

### **REMEMBER ALWAYS**

- Pause and check in with yourself and your team.
- Pay attention to levels of stress and how that might be impacting you and others.
- Return to any practice that helps to calm and/or center you.
- Consider arranging debriefing if you feel you or the team could benefit.
- Consider consulting with a chaplain to round on staff involved. Chaplains are trained professionals who care for all people with sensitivity and compassion regardless of religious/spiritual affiliation.

**Death is not the failure, suffering is the real failure.**



## Rescue Medications for Symptom Distress

Rescue medications are for symptoms that are unrelieved by regularly administered medications. Once acute symptoms are controlled, switch to standing (around the clock) regimen of the effective dosage, every 4 hours for morphine, every 6 hours for haloperidol, lorazepam, and metoclopramide. For more opioid prescribing guidance, see [pain card](#).

### Pain or Shortness of Breath or Cough:

#### ORAL or SUBLINGUAL:

Morphine liquid: 10 mg per 5 ml, take 2.5 ml every 30 minutes until relief. Increase to 5 ml if no relief from starting dosage.

Morphine tablets 15mg: ½ tablet PO every 30 minutes until relief. Increase to 1 tablet if no relief from starting dosage.

#### IV or SQ:

Morphine 5mg IV or SQ every 30 minutes until relief. Increase to 10 mg if no relief from starting dosage.

### Nausea, Restlessness, Anxiety, Agitation, or Confusion:

#### ORAL or SUBLINGUAL:

Haloperidol liquid (Haldol): 2 mg per ml, Give ¼ ml to ½ ml by mouth or under tongue every hour until relief or calm.

Haloperidol tablets: 1 mg tablet, give half tablet every 1 hour until calm, increase to full tablet if no relief from starting dosage.

#### IV or SQ:

Haloperidol 2 mg/ml ¼ ml every hour until relief, increase to ½ ml if no relief from starting dosage.

### Anxiety, Restlessness, or Agitation (not relieved by haloperidol):

#### ORAL or SUBLINGUAL:

Lorazepam liquid (Ativan): 2 mg per ml, Give ¼ to ½ ml by mouth or under tongue every hour until relaxed/calm, increase to 1ml if no relief from starting dosage.

Lorazepam tablets: 1 mg tablet, give ½ tablet every hour until calm, increase to 1 tablet if no relief.

#### IV or SQ:

Lorazepam 1 mg/ml, give ½ ml every hour until relief, increase to 1 ml if no relief from starting dose.

## Symptom Control

### Pain, dyspnea, cough:

#### ORAL or SL:

Morphine Sulfate: 15 mg ½-1 tablet every 4 hours AROUND THE CLOCK. (once we know what the average daily total requirement is to keep pain or dyspnea below a 5 out of 10, switch to a long acting pain medicine, see [pain card](#)).

#### IV or SQ:

Morphine 5 mg IV or SQ every 3 hours around the clock. Increase by 50% for pain unrelieved by starting dose.

### Nausea:

#### ORAL or SUBLINGUAL:

Metoclopramide: 10 mg every 6 hours around the clock.

OR

Ondansetron: 4 mg every 8 hours, increase to 8 mg if no relief from starting dosage.

#### IV or SQ:

Metoclopramide 5 mg/ml, give 1 ml every 6 hours around the clock.

OR

Ondansetron: 0.15 mg/kg IV every 8 hours

**\*\*If using antiemetics for opioid-induced nausea give 30 minutes before morphine to prevent nausea - this should only be necessary for 3-4 days as nausea wears off with time.**

### Preventing Constipation:

Miralax powder: 1-2 capfuls in water or juice or any liquid you like *every day*. If no daily bowel movement increase to 3 capfuls. Over the counter.

+

Dulcolax suppository: 1 or 2 per rectum *every morning* after breakfast. Over the counter.

# Scripting for Hospice patients who are symptomatic and being monitored

3/26/20

Please refer to CHI Franciscan document “DISCUSSING COMFORT FOCUSED CARE WITH PATIENTS AND FAMILIES DURING COVID-19 PANDEMIC” for the fundamentals.

When one of our patients becomes symptomatic we need to **MANAGE EXPECTATIONS**.

The reality is there is no effective treatment available against COVID-19, our patients already have a limited life expectancy, and most have made decisions about care at the end of life. We must be very careful to support their decision and be very clear and honest with the medical disclosure.

Day 1. Patient/Family call to report symptoms.

- Acknowledge the symptoms. Ask what they **have heard** about the COVID-19 virus to assess their understanding. Assess their risk with the information you have regarding their diagnosis and severity of symptoms. Determine any needs.
- Consider ordering a comfort kit if one is not in place.
- Respond to the emotion, e.g. ‘This must be very scary’.
- If symptoms are mild tell patient we will be monitoring every day and to report any changes.
- If symptoms are moderate suggest you talk about what to do if symptoms worsen. Ask permission to have that discussion. In most cases our recommendation would be for skillful management of symptoms and focus on comfort. Consider Hospice House if this cannot be done at home. Acknowledge patient is at risk for dying sooner than expected and it is important they know that.
- Be ready to acknowledge the emotion and the difficulty of having this conversation on the phone.
- Ask if there is anyone else you should talk to.
- Encourage them to reach out with any questions.

Day 2. Patient/Family call to report symptoms worsening.

- Acknowledge symptoms and that they are worsening.
- Acknowledge emotions you are sensing.
- Ask to schedule a visit if patient gives permission.
- Give your recommendation for ongoing care—most likely skillful symptom management.
- Respond to emotion.
- If symptoms are improving acknowledge same and discuss ongoing monitoring until resolved or no need for special precautions.

Day 3 and Beyond.

- Continue to support family in their decisions and the reality of the situation.
- Manage symptoms.
- Respond to emotion, e.g. “I wish this were different”.