DISCUSSING COMFORT FOCUSED CARE
WITH PATIENTS AND FAMILIES DURING THE COVID-19 PANDEMIC

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 serious news 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"
4. **Ask Permission** before moving forward giving more information
   - It helps assess readiness, it gives them control and improves information retention

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 that 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 that 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 intend when prescribing medications:
                - "We are very committed to do everything we can for your loved one to be comfortable 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