DEVELOPED BY THE JOHNS HOPKINS BAYVIEW PALLIATIVE CARE PROGRAM

E. L. Doctorow once said that 'writing a novel is like driving a car at night.
You can see only as far as your headlights, but you can make the whole trip that way.'
You don't have to see where you're going, you don't have to see your destination or everything you will pass along the way. You just have to see two or three feet ahead of you.
This is right up there with the best advice about writing, or life, I have ever heard.
- Anne Lamott, Bird by Bird

Introduction:

Our aim is to provide concise, high-yield palliative tips tailored for point-of-care reference in the extraordinary time of this pandemic. We offer tips and suggestions, based on clinical experience and resources, but we leave it to you as the clinician to decide if/how to apply to any given situation.

We welcome any and all feedback, with the idea that this will be iterative-David S. Wu, MD, FAAHPM <u>dwu38@jh.edu</u> Benjamin Roberts, MSN, RN <u>brober30@jh.edu</u>

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Module 1

MODULE 1: Advance Care Planning

COVID-19 Palliative Care Tips: Outpatient Edition

Guiding Principles:

Engage NOW in Advance Care Planning discussions, especially for patients

at **high risk** for COVID-related mortality:

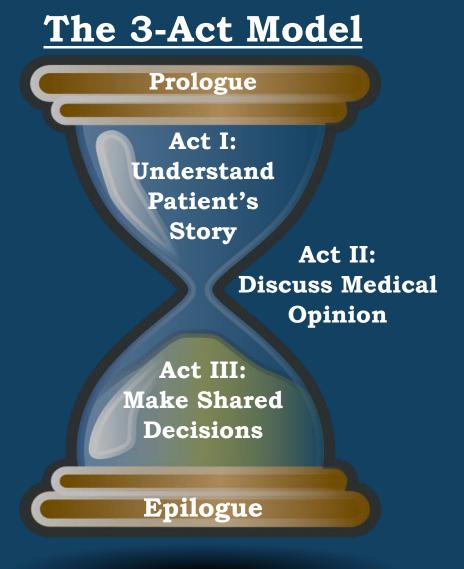
Older adults or those with serious illness, such as:1

- Chronic lung disease
- Heart disease
- Immunocompromised state
- Severe obesity
- Diabetes mellitus
- Chronic kidney disease on dialysis
- Liver disease

Proactive discussions are especially important during the pandemic, due to:

- ☑ Potential for rapidly progressive illness
- ☑ High morbidity/mortality for certain populations
- ☑ Patients may be separated from families in hospital due to visitor restrictions

Consider using the following to guide your approach:2



Prologue

Identify key issues and options to consider

Consider inviting key family members

Telehealth etiquette:

- dress professionally
- arrange for clean background
- set camera at eye level
- patient may benefit from coaching to identify a quiet, private space and adjust the camera for eye contact

Act I: Understand Patient's Story

Introduce

- "I wanted to take some time to talk about **big picture** issues, especially given all that's going on with COVID-19. Is that ok?"
- "What is your understanding of risks surrounding COVID-19 related to your life and health?"

Listen attentively

- Give space
- Be attuned to their story & specific language

Look for deep emotions/values & explore: "I hear you saying..."

- Fears and concerns
- What gives life meaning/joy (acceptable quality of life)
- When might they consider comfort focus
- Family
- Spiritual, cultural, economic concerns

Act II: Discuss Medical Opinion

Brief medical summary

- Simple, clear language
- E.g. "For most people, COVID-19 is mild-moderate. But for some, it can be severe and life-threatening. I am worried about your risk, given [age, comorbidities, etc.]

Act III: Make Shared Decisions

Tailor options to values

- "If you did get severely ill, what would be most important to you?"
 - o "Have you ever thought about what you would or wouldn't want done? Or when you might want to focus solely on comfort?"
- Tailor options to their language/story
 - o Talk through each option
 - o Can give recommendations based on BOTH medical opinion AND their values, and ask if they agree
 - o Consider their acceptable quality of life, as well as longevity
 - o Details flow from values...

Specific issues to consider discussing:

- Hospitalization: visitor restriction policies may be in place for **all** patients
- ICU level care: critical COVID may require weeks on ventilator & extended debility
- Code status: "If your heart or lungs stop working, would you want heroic measures to try to bring you back to life?"
- Comfort care at home: either through hospice or by PCP (see next module)
- Possibility of resource scarcity

Epilogue

Ask for teach back

Summarize discussion

• Hope for the best & prepare for the rest

Concrete action plan

- May need serial conversations
- Stress importance to patient of identifying health care decision-maker and discussing wishes with them
- Advance Directive options: may require planning with clinic staff re workflow
 - o Online: https://mydirectives.com/en/
 - o Maryland state form:
 https://www.marylandattorneygeneral.gov/Health%20Policy%20Docume
 <a href="https://www.marylandattorneygeneral.gov/Health%20Policy%20Docume
 <a href="https://www.marylandattorneygeneral.gov/Health%20Policy%20Docume
- MOLST
- Consider revisiting Advance Care Planning as situation evolves

Module 2

MODULE 2: Comfort Care at End of Life for Patients at Home

COVID-19 Palliative Care Tips: Outpatient Edition

Overview:

If COVID+ patient expresses clear goal to remain at home until end of life with comfort as priority, **home hospice** can give most support. However, during this pandemic, home hospice may have limited availability and some families may decline this service.

- 1. If that happens, PCP's might need to manage comfort care at end of life for their patients without hospice support.
- 2. Respiratory symptoms tend to be prominent and may **progress rapidly**: Use nonpharmacologic approaches and consider opioids for comfort.
- 3. Consider proactive outpatient Palliative Care referral (telehealth visits).

Family Education About End of Life

- Expect progressive decline in mental status due to both disease progression and comfort medicines
 - o Confirm if goal is comfort > alertness
- Anticipate rapid increase in respiratory symptoms
 - o Always use nonpharmacologic approaches (see below) and make sure comfort meds available
- Focus on whether patient *looks and feels* comfortable
 - o Watch for nonverbal signs (e.g. furrow, grimace, moaning, labored breathing)
- Consider living situation, e.g. potential need for 24/7 caregivers, quarantine, and/or PPE for caregivers

Symptom Management

Dyspnea/Pain:

- Nonpharmacologic approaches should always be used, e.g.: fans, cool air, positioning for comfort (proning helpful for some), calming companionship, home oxygen* (consider titrating to comfort)
- Opioids may be helpful as well in the context of comfort care at end of life, according to clinician judgment
 - o Short-acting opioid PRN dosing: While shorter than usual way clinicians order opioids outside of end of life comfort care, 2h interval between PRN doses still allows for peak effect to be seen³
 - o If insignificant response with PRN dose, consider increasing next PRN dose by 50-100% when due,³ according to clinical judgment
 - o Consider scheduling opioids based on 24h opioid usage
 - o Schedule bowel regimen (e.g. senna) for awake patients on opioids

^{*}Anecdotally, need for documented O2 sat might be relaxed during pandemic, but needs confirmation for any given patient/insurance

If Patient Is Opioid-naïve

Common starting rescue doses for end of life comfort care to consider,³⁻⁵ according to clinician discretion:

- Oxycodone 5mg PO q2h PRN, or
- Hydromorphone 2mg PO q2h PRN, or
- Morphine 7.5mg PO q2h PRN (avoid if renal or hepatic dysfunction)

If Patient Is on Scheduled Opioids

Consider using rescue dose at 10% of the total 24h scheduled dose,³ according to clinician discretion

 Example: If patient is taking oxycodone ER 100mg/d, consider adding oxycodone IR 10mg po q2h PRN breakthrough symptoms

If Patient Has Dysphagia:

- Consider crushing short-acting tablets & mixing in applesauce, or
- Consider liquid formulations, which can be administered sublingually, especially if severe dysphagia: oxycodone, morphine, hydromorphone

Anxiety/Agitation

- Nonpharmacologic approaches should always be used and are generally first-line: music, talking, companionship
- May consider medications as well, according to clinician discretion (common starting doses below):
 - Lorazepam 0.5mg PO/SL q4h PRN
 - Haloperidol 0.5mg PO q4h PRN (can also help with nausea)
 - Liquid formulations of both are available
 - Consider scheduling based on 24h PRN usage

Respiratory Secretions

- Main aim: minimize signs of respiratory distress with opioids as above
- Educate family that sound from respiratory secretions thought to be more distressing to observers than to patient
- Medications have significant anticholinergic side effects but can consider if significant distress:
 - o Glycopyrrolate 1-2mg PO/SL q8h PRN secretions
 - Tablet or oral solution can be administered sublingual
 - o Scopolamine patch q72h
 - Consider adding guaifenesin 200mg q4h PRN as expectorant for cough (anecdotally helpful for some patients with COVID)

Logistics

Strongly consider proactive planning in these areas with your multidisciplinary clinic staff:

- Use pharmacy with home delivery option (check re: controlled substances)
- Teach family how to administer crushed/liquid formulations of medicines
- Order medical equipment
 - E.g. hospital bed, bedpan/commode, oxygen, and possibly supplies (e.g. diapers/chux/gloves/PPE)
- Consider post-mortem process: Who does family call when patient dies at home?
- Funeral planning
- Bereavement support

References:

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- 2. Wu DS et al. Narrative Approach to Goals of Care Discussions: A *Novel* Curriculum. JPSM 2019. https://doi.org/10.1016/j.jpainsymman.2019.08.023
- 3. McPherson, Mary Lynn. *Demystifying Opioid Conversion Calculations: A Guide for Effective Dosing, 2nd Edition*. American Society of Health-System Pharmacists, 2018, p.86-95. https://ebookcentral.proquest.com/lib/jhu/reader.action?docID=5553397
- 4. Walsh D, Rivera NL, Davis MP, et al. Strategies for pain management: Cleveland Clinic Foundation guidelines for opioid dosing for cancer pain. Support Cancer Ther. 2004;1(3):157-164.
- 5. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology. Adult Cancer Pain, v.1.2020.

https://www.nccn.org/professionals/physician_gls/pdf/pain.pdf. Accessed May 8, 2020.

Other Helpful Resources:

- a. Center to Advance Palliative Care. https://www.capc.org/toolkits/covid-19-response-resources/
- b. GeriPal blog. https://www.geripal.org/p/covid-progn.html
- c. Evergreen Hospice Care Handbook.

https://www.evergreenhealth.com/documents/Hospice-Care/HOSPICE-hospice-care-handbook.pdf