SINCE 2000

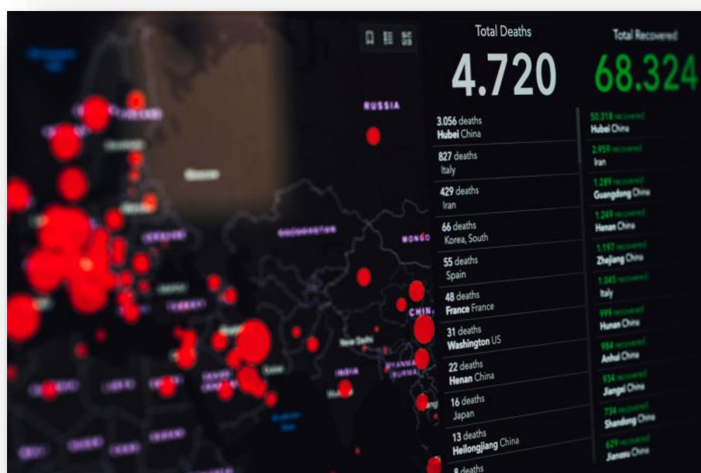
ELNEC

END-OF-LIFE NURSING EDUCATION CONSORTIUM

Advancing Palliative Care

Final Hours

Adapted for COVID-19 Crisis



Care of the Dying During the Coronavirus

- Nurses at the bedside are now being asked to "do it all" (despite limited staffing, resources and medications), to provide physical, psychosocial and spiritual care to patients who are dying alone.
- Nurses are called to provide end-of-life (EOL) care differently than we are used to, as patients and families are being separated during the dying process due to visitation restrictions.
- The nurses are the ones who ensure that patients are not abandoned, especially those not expected to survive, and nurses are assuring families that their loved ones are being cared for.

NCP Guidelines

- *Domain 7: Care of the Patient Nearing the End of Life*
  - Care provided to patients and their families near the end of life, with emphasis on the days leading up to and just after the death of the patient
  - Comprehensive assessment & management of pain and other physical symptoms
  - Assessment & management of social, spiritual, psychological, and cultural aspects of care as the patient nears death
  - The COVID-19 pandemic has limited or eliminated access to interdisciplinary team members, leaving the bedside nurses to manage all aspects of care

NCP, 2018

Limited Access to Interdisciplinary Team Support

- Ideally, interdisciplinary care is essential in serious illness care and at end-of-life. The reality is, in a crisis, that the bedside nurse may be the only one to deliver physical, psychological, social and spiritual support
- Remember the medical record may indicate conversations interdisciplinary team members may have had with the patient or family/surrogate that may help the nurse provide psychosocial and spiritual care.

Nursing Conversations about Goals of Care

- Initiate advance directives discussion on admission, if not yet done. Patients often get critically ill rapidly and cannot participate in decision making.
  - It is critical to identify and support:
    - Surrogate decision-maker/family member as soon as the patient is admitted
    - Goals of care (if patient wants ICU, intubation, etc.)

Ventilator Support

- Some patients may be triaged to comfort care without ventilator support because of the limited availability of equipment and ICU beds. These patients need compassionate EOL care.
- Patients, or family member/surrogate, who have the option of ICU care and ventilator support, if needed, should be asked about goals of care.
  - Some patients may have expressed previous wishes not to be intubated or even hospitalized if seriously ill, but to go home to die with their family.

Preparing for Death

- Many nurses who do not work in areas where death is frequent, are witnessing numerous deaths for the first time.
  - Seek support from fellow nursing colleagues to deal with this cumulative loss.
  - Be familiar with the signs and symptoms of active dying so you can be proactive in anticipating and addressing changes in patient status.
  - Communicate this information to the family, so they can be as prepared as possible to say last goodbyes via video.

Communicating to Share Last Words

- Assist family via video chat or call
  - Some family members may not know what to say. Remind them if their loved one is unresponsive that hearing is the last sense to leave the body.
  - Give them suggestions to get started: "Here are 5 things some people have wanted to say:"
    - I forgive you
    - Please forgive me
    - Thank you
    - I love you
    - Goodbye

  - Stay on the line after the call to ask the family member if there is anything else you can help them with and to see how they are doing before hanging up.

CAPC, 2020

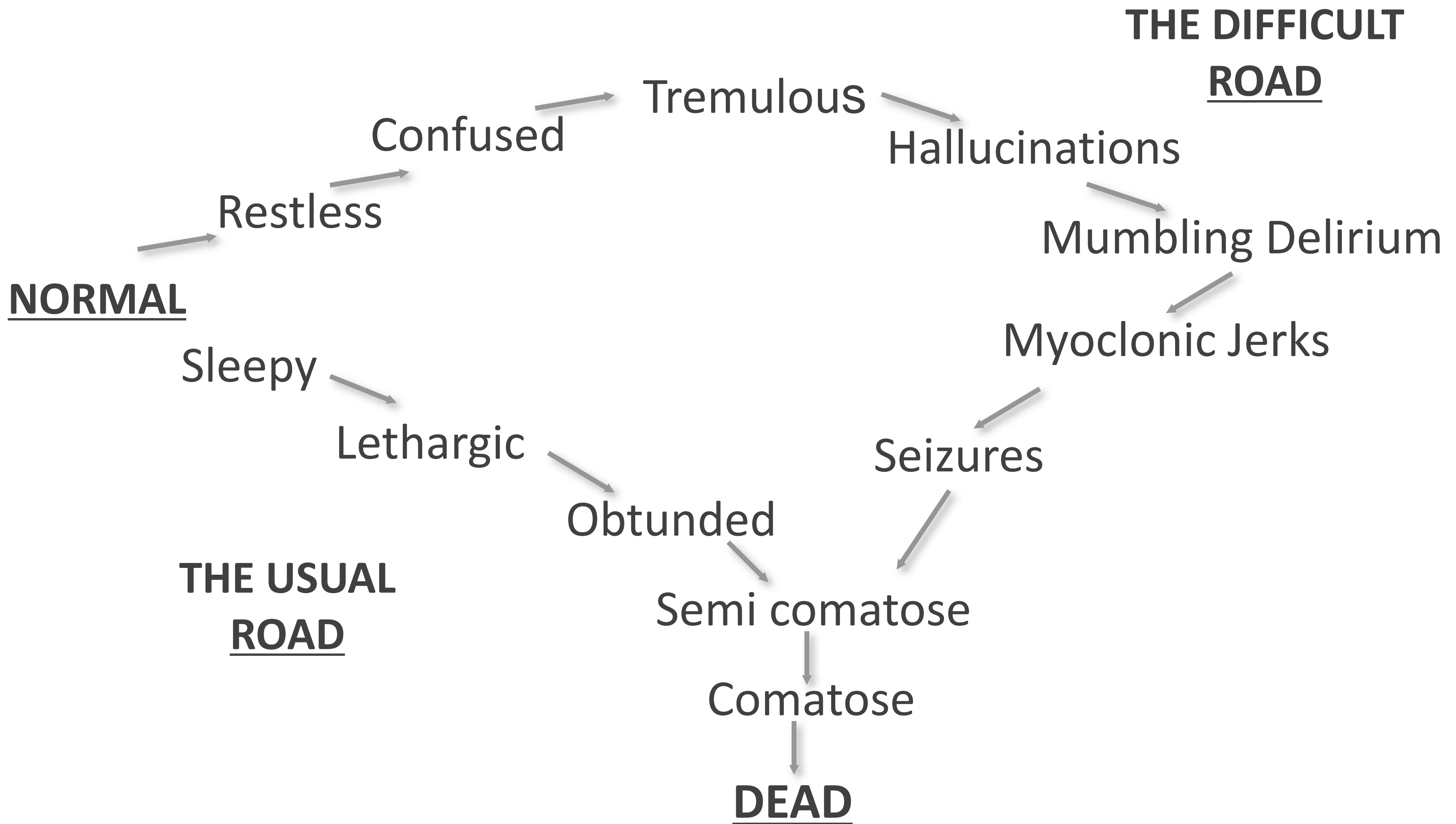
Spiritual Considerations When Death is Imminent

- With limited or no chaplaincy available during COVID-19, the nurse should assess spiritual needs and when possible, provide spiritual interventions.
  - Ask questions such as:

- "Do you (or your loved ones) have a faith belief?". If yes, find out about what aspects of that belief give support; if prayer, offer to pray with them (even if you don't know the prayer, let them lead you)
- "What gives your life meaning?" A person doesn't have to be religious to be spiritual. If nature gives meaning, can you find a picture for the room? If music, can you bring a video or music into the room? If family, can you bring them in "virtually"?

Puchalski, 2014

Two Roads to Death



Most Common Symptoms Experienced by Patients with COVID-19 in Final Days/Hours

- Cough
  - Manage with opioids
- Dyspnea
  - A subjective symptom not based on oxygen saturation
  - Opioids are the mainstay for management
  - Consider positioning for comfort
- Noisy breathing/respiratory congestion
  - Reposition on side with head of bed upright
  - Advocate for use of anticholinergic agent (i.e. scopolamine)
  - Suctioning is not helpful and can cause discomfort

Berry & Griffie, 2019

Symptoms in Final Days (cont.)

- Fever
  - May be managed on a scheduled basis for symptom relief with acetaminophen, which can be administered orally, rectally or parenterally
  - Avoid NSAIDs as their use with COVIC-19 is controversial

Day, 2020

- Pain
  - If patient has co-morbid conditions that are painful, make sure pain assessment & interventions continue
  - Be mindful of potential for skin breakdown, with limited staff and patient interaction, this can be an unexpected source of pain

Use of Opioids in the Final Days/Hours

- Dosing of opioids for pain control during last hours based on appropriate assessment and reassessment.
  - May need to be increased or decreased (as kidney function declines)
- All opioids will manage dyspnea
  - It does not have to be morphine, use what is available
- Oral route can be used even in last hours of life if concentrated form of opioid is administered

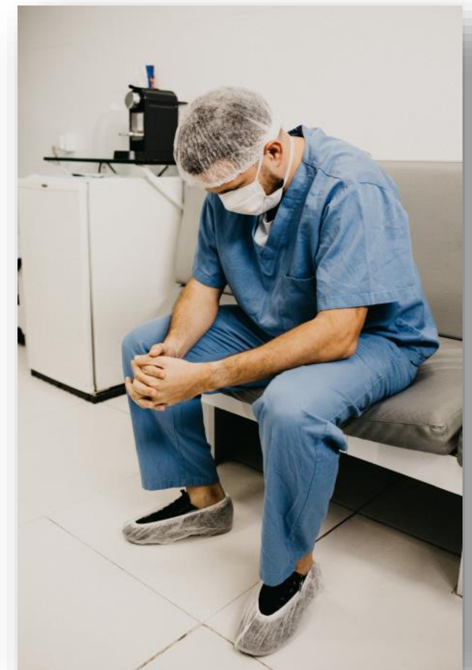
Symptoms of Imminent Death

- Profound weakness
- Drowsiness (reduced awareness) and disorientation
- Lack of interest in food/fluids
- Decreased urine output
- Cold and mottled extremities as seen in dependent areas (back of legs, sacrum)
- Vital signs and breathing changes (“central fever”, cool to touch but increased temperature)
    - Decreased blood pressure
    - Cheyne-Stokes breathing
    - Remember, if the plan of care no longer includes intervening in vital signs changes, measurements are no longer needed

(Berry & Griffie, 2019)

Care Following Death

- Communication with the family
  - It will be hard as they probably cannot see their loved one. Let them express their emotions and help validate their feelings by saying, “I cannot imagine how hard this must be for you” or “I wish things were different and you could’ve been with your loved one.”
- Prepare family for next steps
  - What will happen to the body
  - The importance of them getting follow-up grief counseling
    - Most local hospices offer grief counseling to everyone, even if family was not in hospice care



Care and Respect of the Body

- Reflects importance and value of the patient
- Respect family rituals
  - If family cannot be with the patient, make sure essential cultural and spiritual rituals are honored; it may be possible to have the family participate in these rituals "virtually".
- Consider legacy
  - Think out of the box!
  - Families may wish to have a handprint or a picture. Items such as a handprint must be secured so as not to spread the virus.

Post-Mortem Concerns

- In cities severely hit with COVID-19, there is a lack of morgue and funeral home space for the deceased. Families are required to "find their own funeral homes", but many are already filled.
- Nurses should help families/surrogate hope for the best and prepare for the worst by telling them: "We hope you don't need a funeral home, but in the worst case scenraio, you will have difficulty during the pandemic to secure one (even if you already have pre-arrangements). It is important to start working on this now."

Post-Mortem Concerns (cont.)

- If the patient has died at home and the family is unable to secure a funeral home, the family can call 911 and a policeman and medical examiner will come to the home.
- The body will be taken to the city morgue, but can only stay there 6 days. Families must continue to try to secure a funeral home.
- This burden on the family can cause needless suffering- the nurse must be proactive and encourage family/surrogate of patients not expected to survive, to try to find a funeral home before it is needed.

Honor the Deceased and Grieve the Loss

- Nurses are in the midst of witnessing cumulative loss like never before.
- Think of ways to honor the individual who has died, grieve the loss, and give thanks to the team who did everything they could to save this person.

- Watch the video on the next slide, as it is a powerful example of one nurse's idea on how to honor the person who has died, and to address her own grief.
- Consider adopting this practice in your own clinical setting.

The Pause

A *Pause* is a brief acknowledgment of the patient's humanity just after death has been declared

https://www.youtube.com/watch?v=_HVXM2YhZ2A

2:16 minutes

Conclusion

Family members will always remember the last days, hours, and minutes of their loved one's life. **Yet, amidst this crisis, many may not be able to physically share this time with their loved ones.**

Nurses have a sacred opportunity to be at the bedside with patients who are dying and to support their grieving families at one of the most challenging times in our healthcare system's history.

Thank You for the Great Work You Are Doing, You are the Real Heroes

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