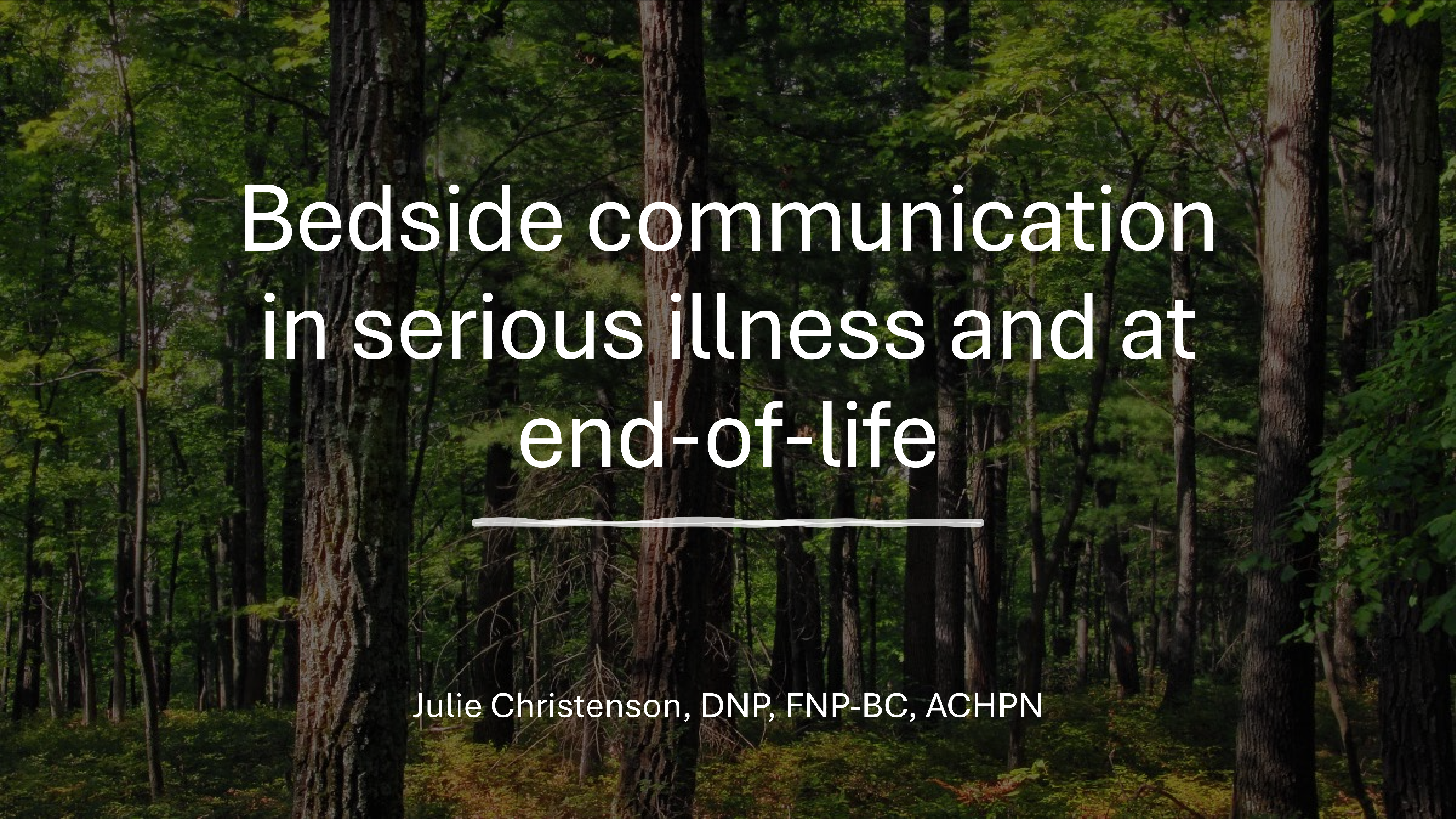

Bedside communication in serious illness and at end-of-life

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Introduction

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What you say matters!

- Family will look to you to help them to understand what to expect when a patient is dying.
- The most important thing you can do is help to normalize the dying experience for the family.
- Let them know what to *expect* and what is *normal*.
- This helps to reduce fear in those at the bedside.

EOL Prognostication

- "I know you don't have a crystal ball, BUT……"
- There will almost always be questions about time, so be ready to discuss.
- Be ready to talk about time with families of patients who are actively dying and/or on comfort care only
- Do not give specific parameters, but don't say "I don't know."
  - "Time is getting shorter."
  - "Hours" ("that could mean….")
  - "Anytime to a day, maybe 2"
- Most families want an update as to "where things are." They do not expect you to give an exact prognosis.
- Most often, when you share a potential for limited prognosis families aren't surprised. Often once decision for CCO is made, families are relieved when time is short.
- Families often ask for your opinion on "how long" so they can make plans.
  - "Death watch"
  - Stay or go home, call out of town family
  - "No one regrets coming too soon…"

Collaboration

- Make time to touch base with the patient's other team members
- Talk to the nurse to get their input on
  - Symptom management
  - Needs for med adjustments
  - Family coping - ”heads up, that son in there…”
  - Overall sense of prognosis
    - Consensus prognosis tends to be more accurate that individual
    - Study – hospice nurses were more accurate than hospice MDs at time

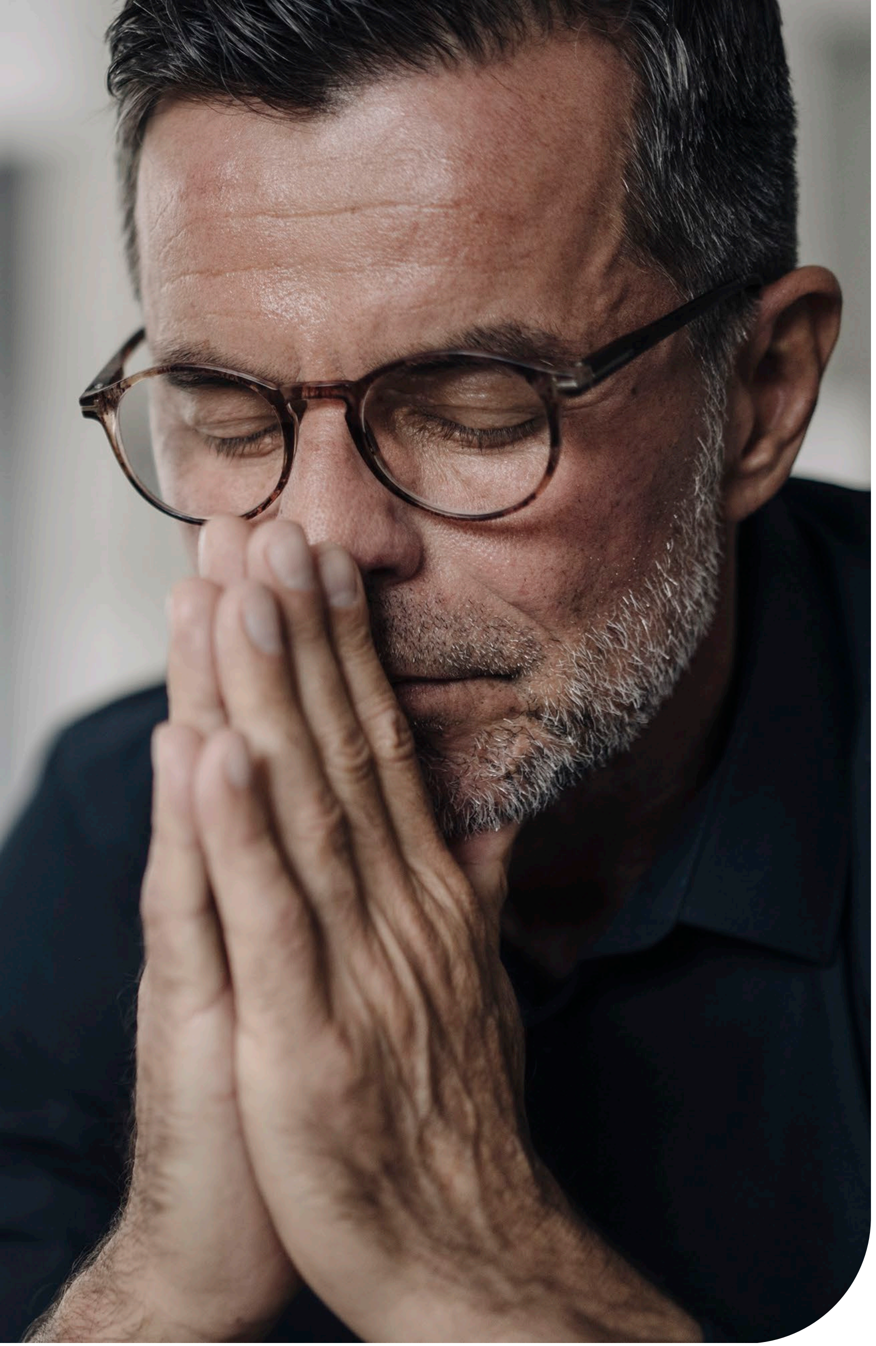
White, N., Reid, F., Vickerstaff, V., Harries, P., & Stone, P. (2020). Specialist palliative medicine physicians and nurses accuracy at predicting imminent death (within 72 hours): a short report. *BMJ Supportive & Palliative Care*, *10*(2), 209-212.

Medications for Symptom Management

- Patient & Family Concerns:
  - Families don’t want their loved one “too sedated” during their final days
    - Often want patient to “wake up one more time” or have another conversation
  - Morphine and other “strong medications” will hasten death
    - Many don’t want to “start the morphine” until the very end; they associate it with being given just prior to death
  - Members of family feel differently about how/when to use medications
  - Patient concerns about addiction
  - If we start “strong” meds too soon, there won’t be anything left for the very end
  - If medications used make patient too sleepy, patient will not be able to eat and drink
  - Staff is using medications to sedate patient due to no longer trying for cure, staff having little time, etc.

Medications used in Comfort Care & Hospice

- Treat symptoms not numbers
- Nothing HAS to be stopped except disease-targeted/active treatment
  - Many medications can continue; always weighing risk vs benefit
    - E.g. seizure medications, anticoagulant, etc.
- A NOTE:
  - At home – hospice nurses help loved ones learn to administer meds to the patient. Modern hospice started as way to <u>support</u> loved ones at home taking care of the dying, not to be present 24/7.
  - Now - more acuity can mean difficulty managing meds



Real Quotes:

- “If the medication makes him not want to eat or makes him sleep too much he will die of starvation, right?”
- “If you keep giving all those drugs, then she’s too sleepy to drink water. She either needs to drink water or get an IV, right?”
- “We agreed to hospice & comfort care only, we didn’t think you would just drug her until she was unconscious.”
- “I want you to hold off on giving any more medications until… maybe Sunday? Her family will be here tomorrow.”
- “I don’t want to feel like I am “putting him to sleep” like a dog.”
- Regarding actively dying patient: “I just don’t want him to get such strong medicine. He could get addicted.”
- “I just don’t want you to start it yet. I’m not ready.”

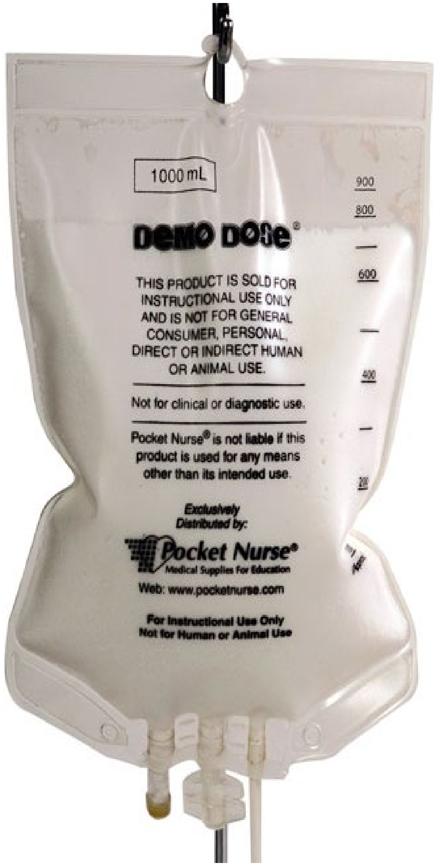
How to address these concerns…

- We will *always* have options for management of his/her discomfort. There is no limit to what we can use or try to make him/her comfortable during this time.
- I know it can be a scary word, but morphine (Dilaudid, Lorazepam, etc.) is often used by patients throughout the course of their illness, not only at the end.
- We are always weighing the benefits and burdens of this type of medication. Sometimes it can be a challenge to balance the symptom management with the side effects.

How to address these concerns…

- Our number one priority is his/her comfort during this time. He/she has been through so much that he/she deserves to be comfortable in the final days. It is *never* our intention to give more medicine than is needed for comfort.
- It can become difficult in the final days to know whether sedation/sleeping is caused by the medicine or the natural course of the disease. No matter what kind/amount of medicine they are getting, people most often have increased sleeping and less awake time (until they are sleeping almost all the time) during their final days.
- There is a difference between dependence/tolerance and addiction.
- Many patients remain clearheaded while taking pain medications. Others may experience some drowsiness. This often decreases after several days of taking the medication.

Food & Fluids/Artificial Nutrition & Hydration



- *This is one of the hardest things that families struggle with. These are some of the hardest questions to answer.*
- It is very, *very* rare for a patient to want or be able to eat in the final days & weeks of life.
- Patient & Family Concerns:
  - The patient is dying because they are not eating & drinking.
  - The patient *needs* ANH and that it is standard when someone is no longer eating or drinking.
  - If the patient would eat, they would live longer/get stronger.
  - It is very uncomfortable to not eat & drink for days/weeks.
  - The patient is suffering. “I know starving is a terrible way to die.”
  - They are doing something wrong if they don’t push food/fluids/ANH.
  - Mistrust - that F&F/ANH would not be withheld if he/she were…. (older/younger/different race/richer/etc.)

Real Quotes:

- “Are the IVs helping her stay hydrated since she won’t drink?” (regarding a patient only on IV pain medication; no IVF)
- “I know how I get when I don’t eat for awhile. It feels awful. She must be miserable.”
- “I didn’t know people were forced to starve just because they chose hospice.”
- “Can’t we make him eat something?”
- Regarding an actively dying patient who had been unresponsive for 3 days: “Did he eat anything this morning?”
- “Will her cause of death actually be starvation, then?”
- “You’re pumping him full of all these drugs on an empty stomach. He always waited to take his medicine until he ate.” (regarding a patient only receiving IV/SC medications)

Treatment for Nutrition – Non-Drug

- Reduce pressure on self/patient (try not to make it the focus)
- Prioritize protein
- Eat small amounts throughout the day
- Eat what you like or what tastes good
- (Usually) no perfect or prescribed diet
- Supplement – Ensure, Boost, etc. (clear/breeze!)

How to address these concerns…

- *It is okay not to eat. It is okay not to drink.*
- Food is the way we energize our body, to keep it going. We eat to live. As the body prepares to die, it is natural for eating to stop.
- Most often patients don't feel like eating. Nothing tastes right and they often feel badly when they push it.
- From studies that have been done, we have found that people generally do not feel hunger and thirst during this time. They do not feel like we would if we didn't eat or drink.
- He/she is dying because of [the terminal disease], not because he/she is not eating.

How to address these concerns…

- During this time, eating is for pleasure.
- "The body is really smart." It knows that it is no longer able to properly use nutrition or hydration, so it stops craving them. Introducing them artificially can cause an increase in uncomfortable symptoms (swelling/edema, lung congestion, nausea).
- Feeding tubes and ANH are used as a medical treatment, often short-term, for people expected to recover from their illness.
- It is not expected that he/she gets ANH. It is recognized that not eating/drinking/no ANH is part of the natural process of the body shutting down.
- Just like in treating his/her pain, we are listening to his/her body to guide us now. *We wouldn't treat pain with no indication that patient uncomfortable*.

A Framework for discussing & treating symptoms at EOL **[WWMA]**

- **W**hat is happening? (What is the symptom?)
- **W**hy is it happening?
- **M**eaning of the symptom
- **A**ction you will take

Explain WHAT is Happening

- What are we *seeing*?
  - (e.g. mottling, respiratory rate changes, restlessness, pain behaviors)
- What are we *hearing*?
  - (e.g. terminal congestion, respirations changing, groans, sighs, coughing)
- SHOW family what you're assessing for & talking about
  - Show breathing pattern while pt is actually doing it
  - Have family *feel* changes in skin temp (cool hands)
- Demonstrate if needed
  - Cheyne-Stokes/Agonal Breathing
  - Pain behaviors

Explain WHY it is happening

- Simplify what YOU know about why it’s happening
  - “During this time there is a reduced ability for the body to regulate temperature.”
  - “Because he/she isn’t swallowing and the muscles are so weak, secretions can gather in the throat.”
- It is okay to:
  - use common medical terms
  - use the words “die,” “dying,” & “death”
  - say “We aren’t sure why this happens…”
- Normalize what it is happening
  - “This is so common that there is a name for it…”
- Remind family that patient is not “suffering”

Describe what it MEANS in the dying process

- In most cases, this means giving some sense of time to the process (“Where are we at?”)
  - “This usually means we are getting closer to the end.”
  - “Anytime to 1-2 days”
  - “It means he continues to decline” (I used to say “progress” – NO)
  - “Most importantly he appears comfortable, but these are signs that the time is coming closer.”
- If possible, tell them what they might be able to expect to happen next.
- Often this is an important topic for decision-making
  - Should they go home for the night or stay?
  - Should they call the priest?
  - Should family who want to be at the bedside at TOD come now?

Describe what ACTION(s) you will take to address the symptom

- What are you going to DO about the symptom?
  - **Medications**
  - Repositioning
  - Warmth or removing blankets
  - Comforting touch, hand holding
  - Music, quieting room
  - Suction mouth
  - Nothing at this time
    - It is okay to say “We don’t need to do anything about this unless he seems like he’s uncomfortable.” (Remind the family that you are assessing frequently for discomfort).
    - “We are looking to her body now to tell us how she is feeling.”
    - “People generally find a way to let us know when they are uncomfortable.”

Remember

- Actually touching and showing on the patient can illustrate what you're talking about
- Speak respectfully, quietly, and unhurried
- Sometimes nice to show them what you're talking about on the patient and then step out to explain what it means in dying process
- Our most important role for those waiting at the bedside is to explain what we are seeing and what to expect.
  - Knowing what to expect reduces fear of the unknown and fear that the loved one is suffering
- And maybe most importantly…

SIT!

Symptoms Commonly Treated in Hospice/EOL

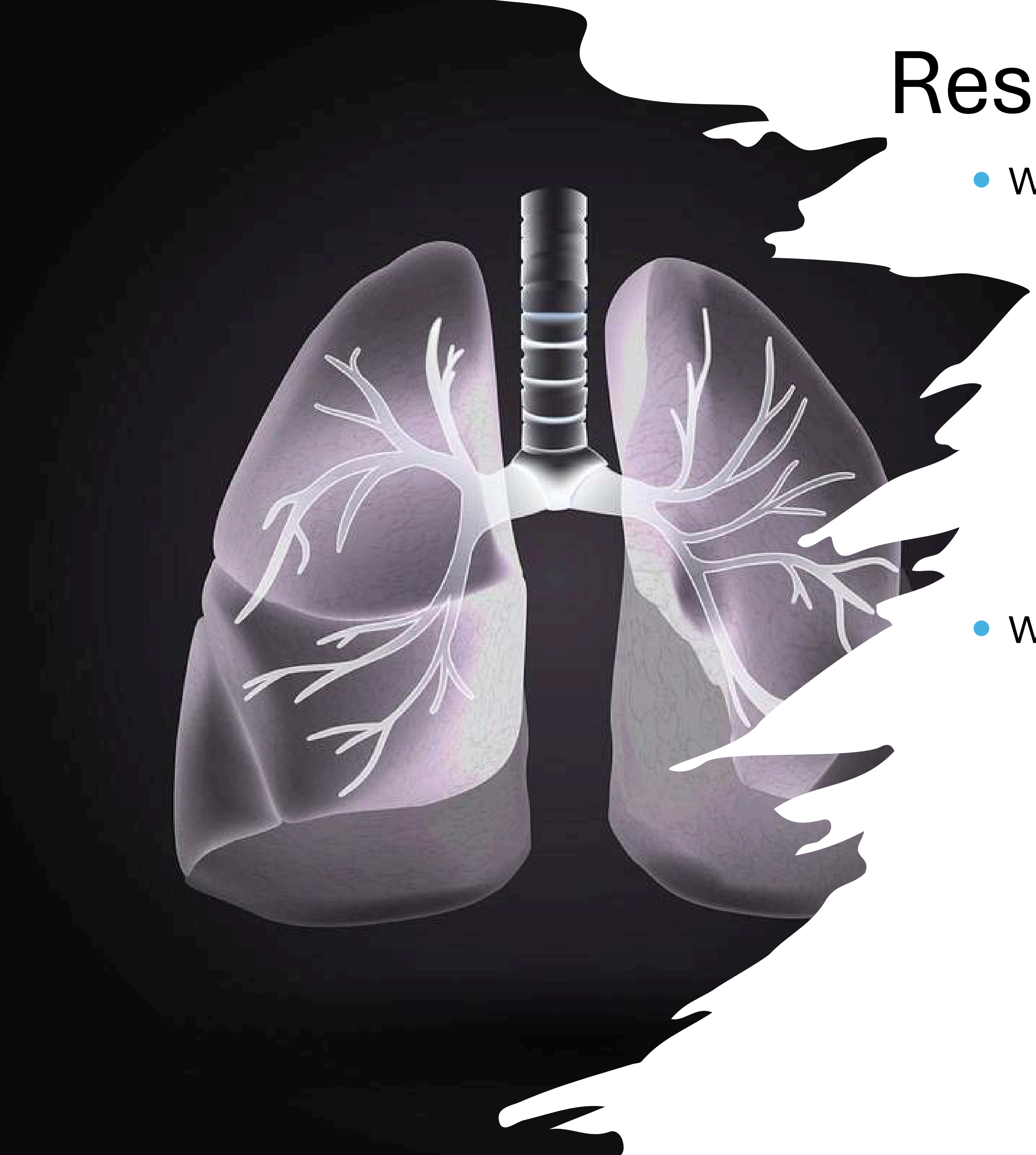
- Pain
- Dyspnea
- Terminal agitation/delirium/anxiety
- Nausea/Vomiting
- Constipation
- Circulatory changes

Pain & Analgesia

- What
    - Sometimes, *but not always*, there is increased pain in final hours and days
    - Sometimes the pain is the same as the pain he/she has been having during the course of the illness, but sometimes it is new
    - Sometimes someone who never had pain can begin having it and vice versa
    - Pain can be shown in many ways; we will use our best judgment to assess behaviors for pain
- Why
    - Changes in body systems & systems shutting down can cause some level of discomfort
    - Increased pain can can be caused by disease progression (e.g. tumor growth, obstruction caused by tumor, fluid retention)
    - Becoming bedbound

Pain & Analgesia

- Meaning
  - While pain can occur at any stage of the disease process, there are times when pain becomes acutely severe at the end of life
  - Acute increase in pain can signal disease progression, tumor growth, organ failure, obstruction, etc…
- Action
  - A thorough assessment to narrow down possible causes of pain (e.g. positioning, skin breakdown, visceral/CA pain)
  - Explain that we will continue to adjust and work with medications until we find the right plan (‘the right dose is the one that works’).
  - We will always have more options for pain management.
  - We will continue to reposition him to ensure it isn’t positioning causing discomfort.



Respiratory Changes at EOL

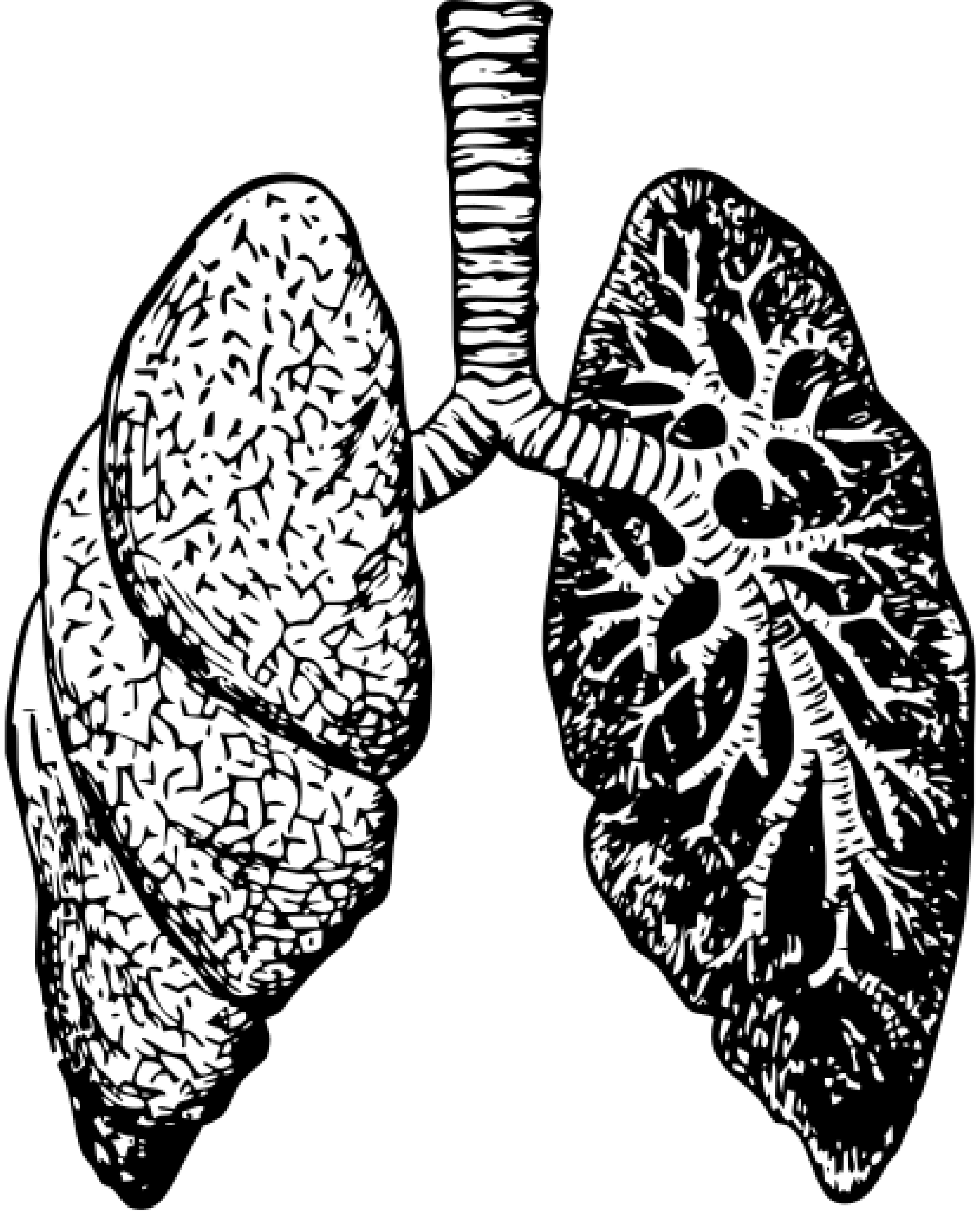
- What
    - Breathing can become very rapid or very slow
    - You may notice the shoulders or jaw are moving a lot with breathing. This is called using accessory muscles to breathe.
    - There is commonly a breathing pattern where people stop breathing, or have apnea, alternating with rapid/shallow & slow/deep breathing. This is so common there is a name for it.
- Why
    - The body is working really hard to continue breathing
    - He/she is using all of their muscles to continue exchanging air
    - There has been some loss in regulation in breathing making it look much more irregular
    - Lung disease or cancer can make breathing more challenging, but there are many things we can do to make it more comfortable.

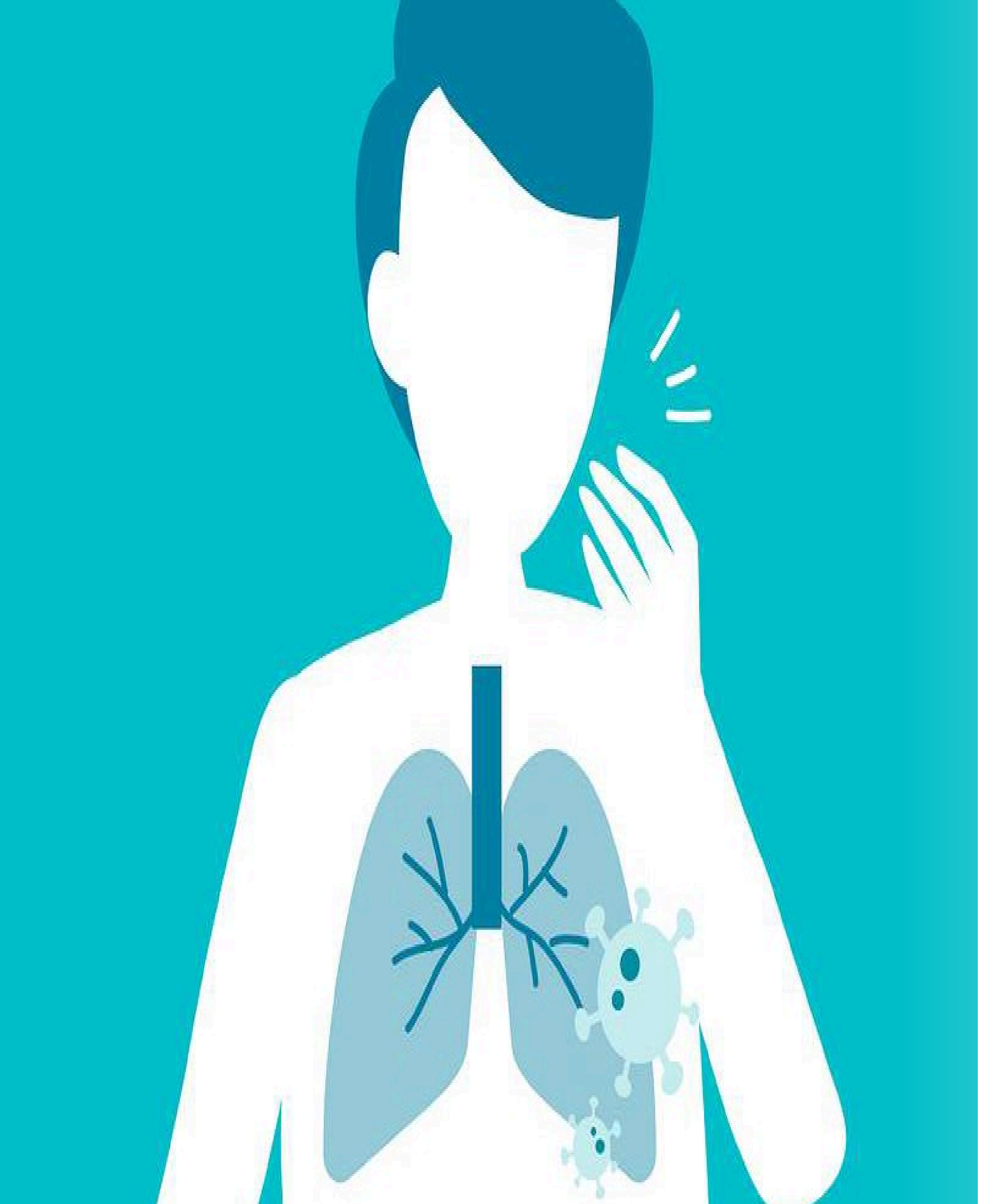
Respiratory Changes at EOL

- Meaning
  - Cheyne-Stokes breathing (or “this type of breathing”) generally indicates that he/she is within the final days.
  - Agonal breathing can be a sign that he/she is within hours of death
  - When you see him/her using their accessory muscles like this, it means that he/she is using everything they have to breathe.
- Action
  - These changes are normal as he/she continue declining toward dying.
  - There are medications we can use if it seems like he/she is struggling in any way.
  - We can elevate the HOB or try different positions to help his/her breathing remain comfortable.
  - Oxygen most often does not provide additional comfort at this stage and can prolong dying.

Dyspnea

- Air hunger
- Subjective sensation of difficulty in breathing
- An abnormally uncomfortable awareness of breathing
- Experienced when there is an imbalance between the perceived need to breathe and the perceived ability to breathe
- Not the same as expected EOL respiratory changes



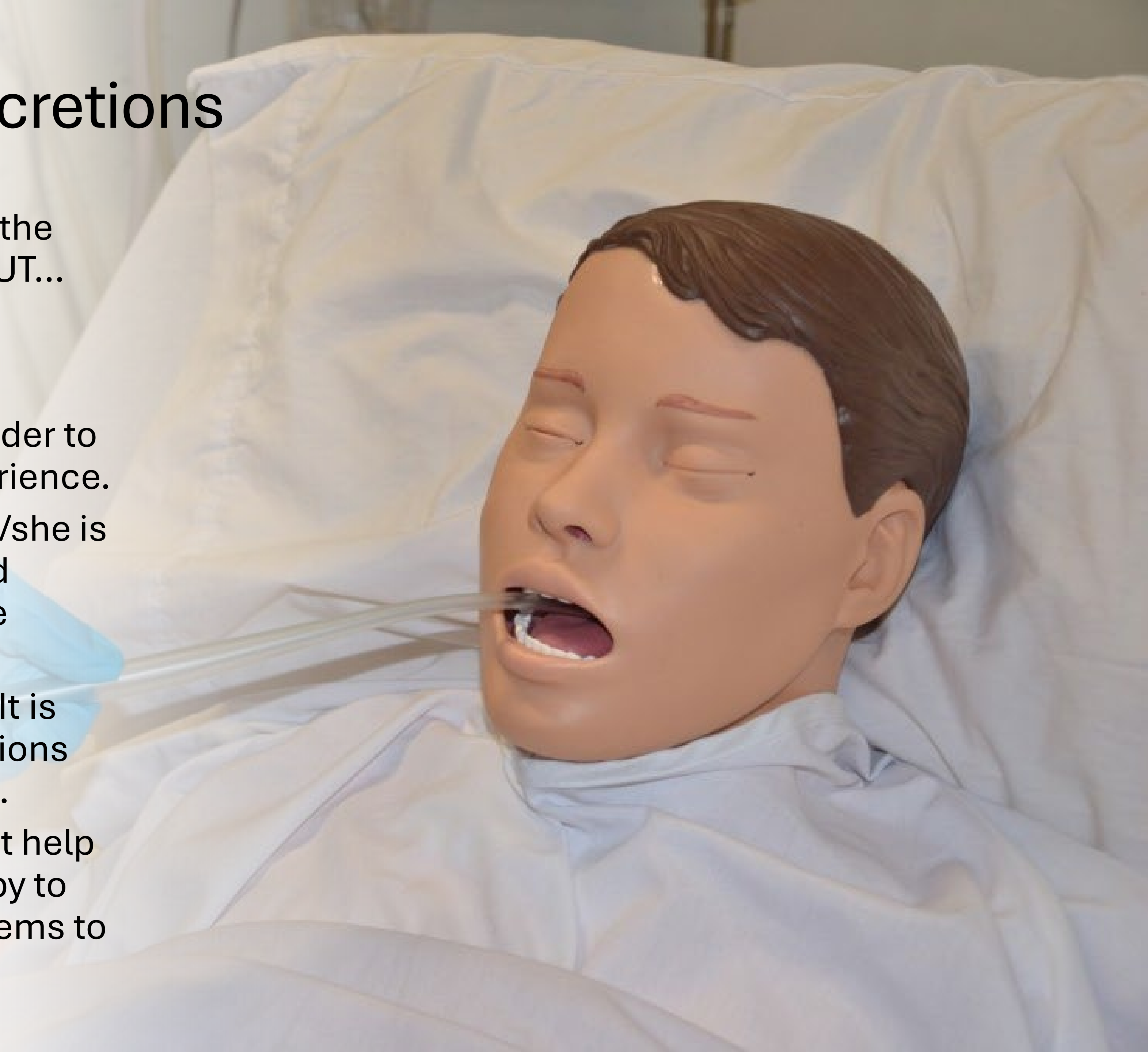


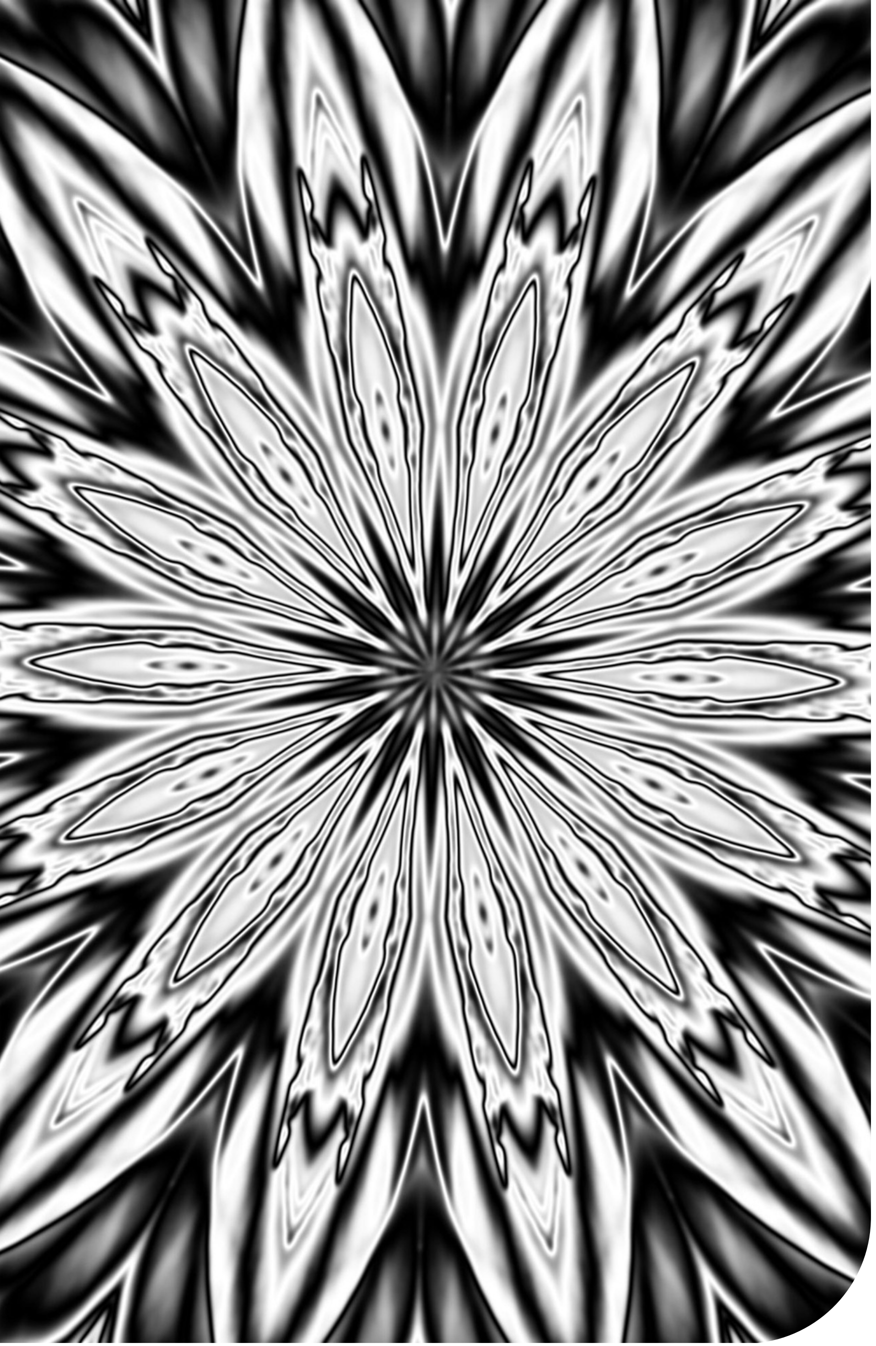
Terminal congestion/secretions

- What
  - Rattling sound in the upper airway
  - Wet-sounding breathing
  - It can sound like he/she needs to cough but can’t ‘get the phlegm up.’
- Why
  - Secretions gather in the throat with no way to clear them
  - He/she is too weak to drink, swallow, or cough
  - Air moves through this mucus and causes that sound

Terminal congestion/secretions

- Meaning
  - This EOL sign generally occurs in the final 24-48 hours before death, BUT…
- Action
  - Family education!
  - The congestion is often much harder to hear than it is for him/her to experience.
  - Air continues to exchange and he/she is breathing well. It just sounds loud because air is moving through the mucus. (listen to lungs)
  - There is a medication we can try. It is often not effective and the secretions can be tenacious, but it may help.
  - Deep suctioning generally doesn't help this kind of congestion. I am happy to suction his/her mouth when it seems to be needed.

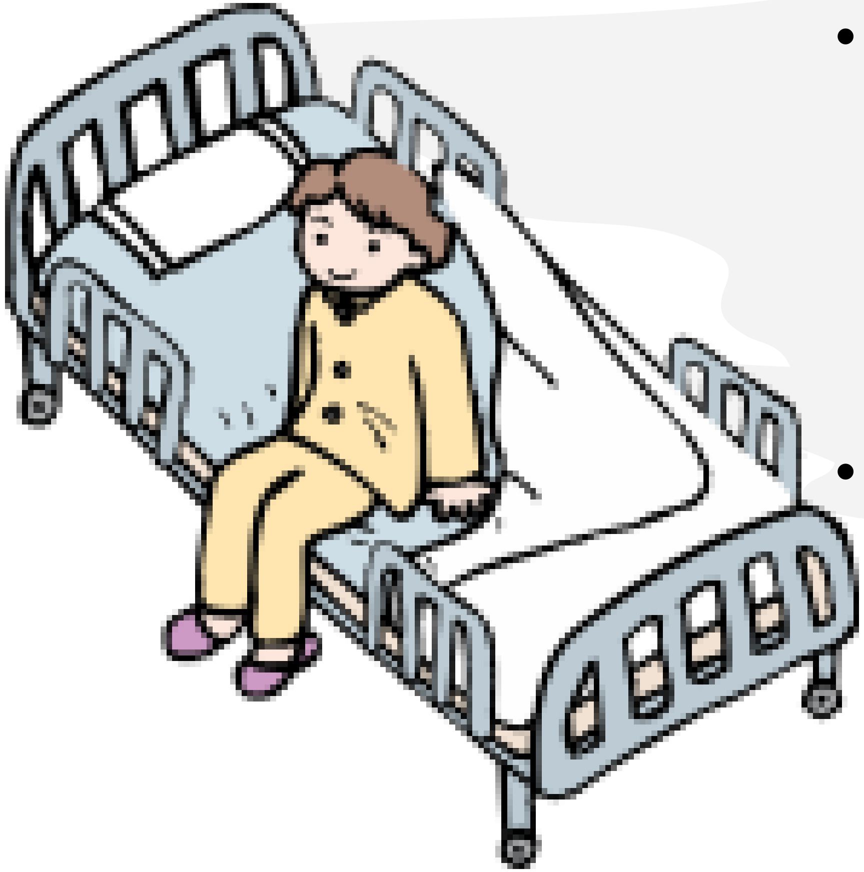




Terminal agitation/delirium

- Altered level of consciousness (i.e. AMS) with associated features of: reduced attention and memory, perceptual disturbances (hallucinations and/or delusions), incoherent speech, and altered sleep/wake cycle.
- Occurs to some degree in virtually all patients before death
- The cause is often multifactorial; exact etiology cannot be established in 40% or more of patients
- Presents as either a: agitated/hyperactive delirium: climbing out of bed, pulling out IVs, picking at air, mumbling speech; or a hypoactive/hypoalert delirium: quiet, very sleepy, mumbling speech

Terminal agitation



- What
  - You may notice that he/she is restless during this time. This is very common.
  - It can be difficult to control.
  - It may look like he/she is pulling at clothing/linens or trying to get out of bed.
- Why
  - We think this restlessness is caused by changes in the body. This can include metabolic changes or lack of oxygen in the blood.
  - It is possible that these changes are caused by his/her limited ability to interact with the outside environment.
  - *We don’t always know why this happens*.

Terminal agitation

- Meaning
  - While restlessness or agitation can occur at any stage, we often see this during the final days.
  - Some movements and gestures can be normal; we are using our best judgment to assess for discomfort.
- Action
  - There are medications we can try to make him/her more comfortable.
  - We generally understand that this is likely an uncomfortable way to feel and behave and that he/she would like to be able to rest more easily.
  - We can help maintain a calm environment by limiting the noise in the room, family presence, playing soft music, hand holding, etc.

Circulatory Changes

- What
  - Increased heart rate, irregular heart rate, fever/sweating, cool/cold hands and feet, dusky nails, blotchy skin, etc…
  - Edema
- Why
  - There are changes to his/her circulation during this time.
  - The circulation pulls in to the core so the hands and feel can feel cool.
  - The body is working very hard to move blood, but it is becoming weaker.

Circulatory Changes

- Meaning
  - All of these things are signs that things continue to change/decline.
  - Pedal pulses can stop during the final days
  - When the radial pulses cease, it generally means we are in the final hours.
  - Mottling of the skin can come and go but usually occurs in the final days.
- Action
  - There isn’t much we need to do for these symptoms aside from adjusting the environment to help with comfort
    - Minimal blankets if patient has fever
    - Cool washcloth to forehead

Questions?

Thank you!