

# Role of Palliative Care in Chronic Critical Illness Management

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## Meet Jimmy

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- 66 y/o M
- Overweight, High blood pressure
- Admitted for respiratory failure from ARDS
- Intubated for 12 days
- Family is considering a tracheostomy
  - ***What should we tell them to expect?***
  - ***What is the role of palliative care?***

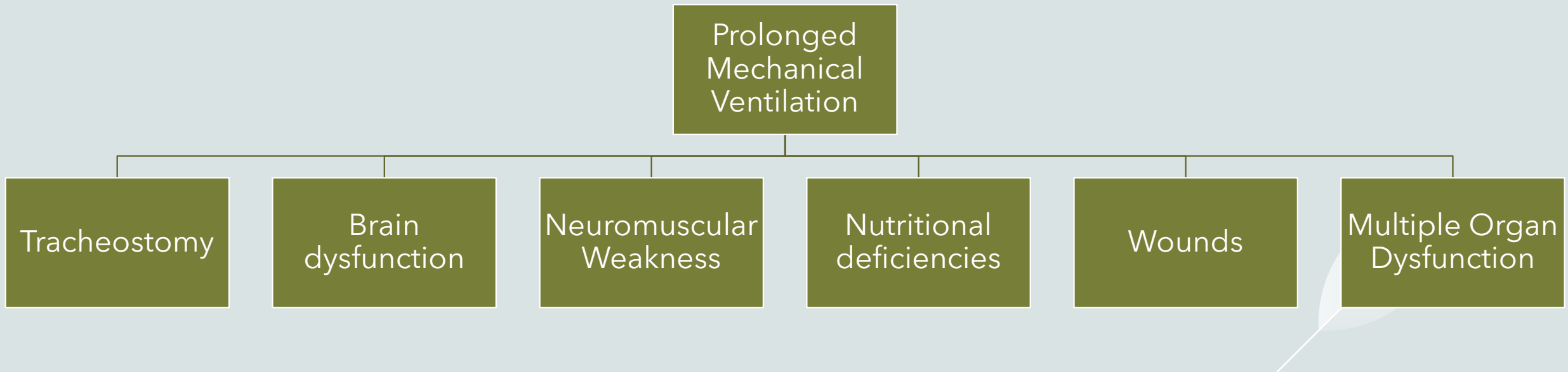
# Outline

- Define Chronic Critical Illness (CCI)
- Epidemiology and Outcomes
- Symptom Management Needs
- Burden of CCI on Families and Caregivers
- Research and Future Directions



Rainbow Falls, Big Island, Hawaii

# Define Chronic Critical Illness (CCI)

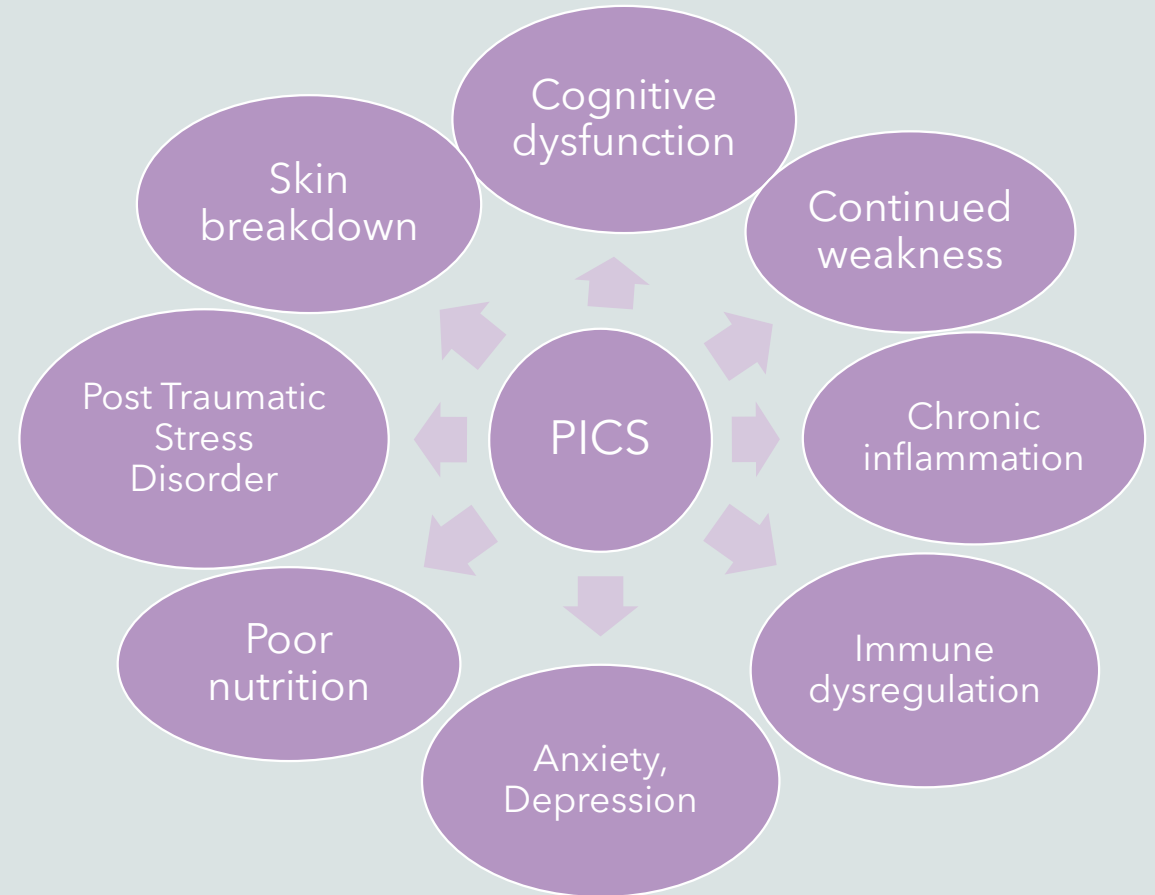


# Patients with CCI often develop Post Intensive Care Syndrome (PICS) if they survive

- **Post Intensive Care Syndrome (PICS)<sup>1</sup>**

- chronic changes in physical, cognitive or mental health arising after a chronic critical illness

- **retained** after the initial acute hospitalization



The slide features decorative white line-art illustrations of leaves and branches in the corners. The top-left and top-right corners show clusters of oval-shaped leaves on stems. The bottom-left and bottom-right corners show larger, more complex leaf shapes with multiple lobes and stems. The background is a solid light blue color.

# What conditions lead to chronic critical illness?

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- ANY CONDITION THAT REQUIRES AN ICU STAY
  - MOST COMMON: **SEPSIS & ARDS**

# Epidemiology: the Positives

- **5-10%**
  - Of patients who are intubated for acute illnesses will develop CCI<sup>1</sup>
- **30-53%**
  - Of those with CCI are weaned from mechanical ventilation<sup>2</sup>
- **16-37 days**
  - Time to wean from mechanical ventilation<sup>1</sup>

1. Nelson JE, et al. *Am J Respir Crit Care Med.* 2010  
2. Engoren M, et al. *Chest.* 2004

# Epidemiology: the Negatives

- **~30%**
  - Mortality during initial hospital stay<sup>1</sup>
- **48-68%**
  - 1 year mortality<sup>1</sup>
- **10%**
  - Return to functional independence<sup>2</sup>

1. Marchioni A, et al. *Eur J Clin Invest*. 2015

2. Kahn JM, et al. *Crit Care Med*. 2015



Who is unlikely to wean from mechanical ventilation?

A. Irreversible lung disease

B. Severe neurologic injuries

C. Those who require hemodialysis

D. Mechanical ventilation longer than 60 days

E. All of the above

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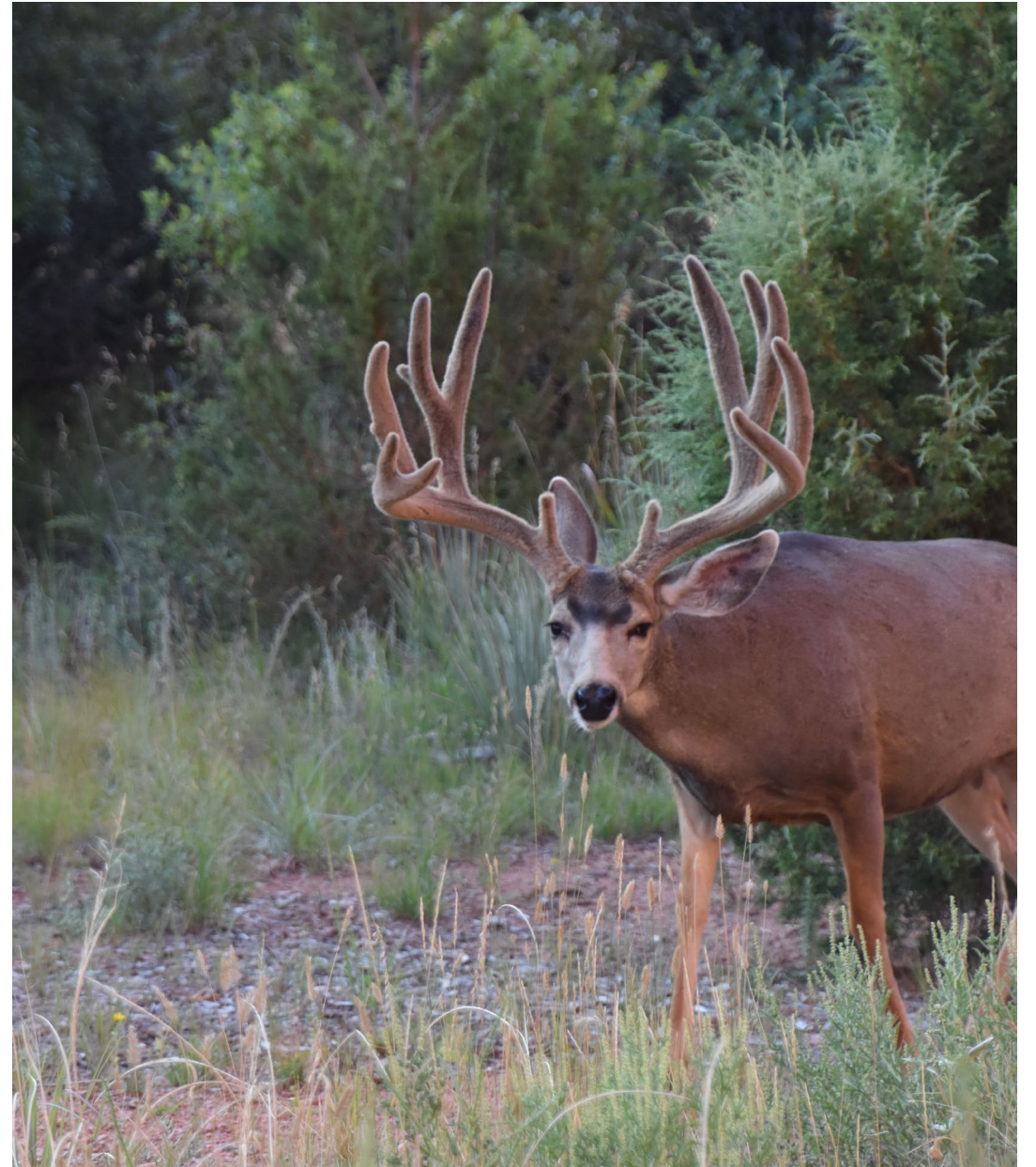
## Back to Jimmy...

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- Family elects for a tracheostomy
- Jimmy is discharged to a long-term acute care hospital (LTAC)
- His cognitive function continues to improve, and he is now asking for water
- ***What symptom management needs would we expect for Jimmy?***



# Symptom Management Needs in CCI



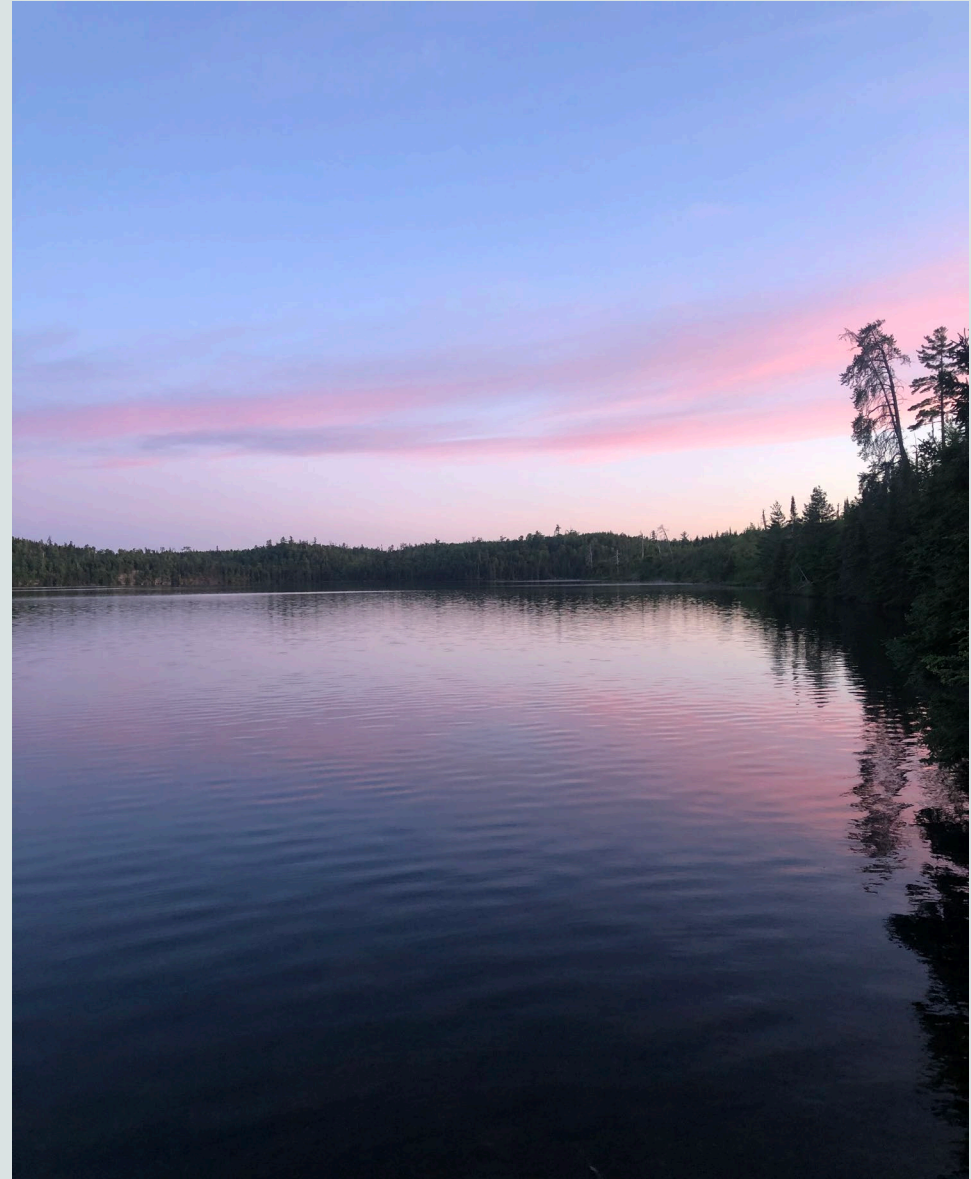
Garden of the Gods, Colorado

# Pain

- 40% of CCI patients report severe pain<sup>1</sup>
- Tylenol for mild pain
- Opioids preferred for severe pain
  - Use dilaudid or fentanyl if renal dysfunction
- Consider giving doses prior to turns or dressing changes

# Dyspnea

- Sensation of “breathlessness”
- 60% of patients report dyspnea<sup>1</sup>
- Treatment options
  - Fan
  - Meditation
  - Pursed lip breathing
  - Low dose opioids



Lake Near Grand Marais, Minnesota

# Depression

- 60% of patients with CCI report psychological symptoms (sadness, worry, fear)<sup>1</sup>
- 40% experience depression<sup>2</sup>
  - **3x** more likely to remain vent dependent<sup>2</sup>
  - **2x** more likely to die<sup>2</sup>
- Treatments
  - SSRIs
  - Stimulants (Methylphenidate)

1. Nelson JE, et al. *Crit Care Med.* 2004.

2. Jubran A, et al. *Intensive Care Med.* 2010

# PTSD in Chronic Critical Illness

- **10-30%** of ICU survivors experience PTSD<sup>1</sup>
- **Common symptoms<sup>2</sup>**
  - Fear of death
  - Helplessness
  - Memories of frightening ICU experiences
  - Hypervigilance, Nightmares
- **Risk factors<sup>1,2</sup>**
  - Delirium
    - Benzodiazepines, Restraints
  - Prior mental health conditions

1. Marra A, et al. *Surg Clin North Am.* 2017.
2. Jackson JC, et al. *Rehabilitation Psychology.* 2016



# Interventions to help improve PTSD in the ICU<sup>1</sup>

- Prevent delirium
- Clinical Psychologist<sup>2</sup>
- ICU diary<sup>3</sup>
- Early psychological intervention
- SSRIs



Door County, Wisconsin

1. Jackson JC, et al. *Rehabilitation Psychology*. 2016
2. Peris A, et al. *Crit Care*. 2011
3. Jones C, et al. *Crit Care*. 2010.

# Unsatisfied Thirst

- One of the most intense symptoms reported
- Treatment
  - Good daily oral care
  - Mouth swabs
  - Biotene mouthwash
  - Saliva substitute
  - Ice chips



Godafoss, Iceland

# Communication with CCI Tracheostomy Patients

- 90% of CCI patients report distress due to difficulty communicating<sup>1</sup>
- Speaking valve
- Communication board
- Touch screens or specialized keyboards

The image shows a 'Critical Care Communication Chart' from Widgit. It features a grid of icons for various needs and symptoms, a pain scale, and a 'no' indicator. The chart is titled 'Critical Care Communication Chart' and includes a 'Turn over' button. The icons are arranged in a grid and include:

- A green checkmark icon labeled 'yes'.
- A toilet icon labeled 'toilet'.
- A lightbulb icon labeled 'light on / off'.
- An icon of a bed being adjusted labeled 'adjust bed'.
- A red 'X' icon labeled 'no'.
- A grid of 24 icons representing various symptoms and needs: sip water, clean mouth, lip salve, dry mouth, short of breath, can't breathe, medication, sore throat, allergic, suction mouth, cough, feel hot, feel cold, suction tracheostomy, headache, feel sick, uncomfortable, and oxygen.
- A pain scale with faces from 0 to 10, with a 'very tired' icon at the end.
- A 'don't know' icon.

1. Nelson JE, et al. *Crit Care Med.* 2004.



## June & Jimmy

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- It has been 1 month in the LTAC and 2 months since being hospitalized
- Jimmy remains on mechanical ventilation
- Jimmy's wife June is having trouble making ends meet due to medical bills
- June is second guessing her decision to pursue tracheostomy for Jimmy
- ***What is the burden on the families of those with CCI?***
- ***How can we better communicate with families?***

# Burden of CCI on Families and Loved Ones

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- Average hospital length of stay for CCI
  - **2 months**<sup>1</sup>
- Most patients will remain institutionalized or with paid caregiver support
- High rates of **depression** and **financial hardship**<sup>2,3</sup>
- Rates of caregiver stress worse than caregivers of patients with Alzheimer's disease<sup>3</sup>
- Rates of caregiver stress high even if the patient is institutionalized<sup>1</sup>

1. Nelson JE, et al. *Respir Care*. 2012.

2. Im K, et al. *Chest*. 2004.

3. Douglas SL, et al. *Chest*. 2003.





How can we better  
communicate with  
families and loved  
ones in these  
situations?



Boundary Waters Wilderness, Minnesota

# Be clear about what to expect

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- Most families report hearing **no** information about prognosis
- **90%** of families think that their loved one will survive at 1 year<sup>1</sup>
  - Compared to 44% of providers
- **70%** of families believe their loved one will fully regain their physical functioning<sup>1</sup>
  - Compared to 6% of providers

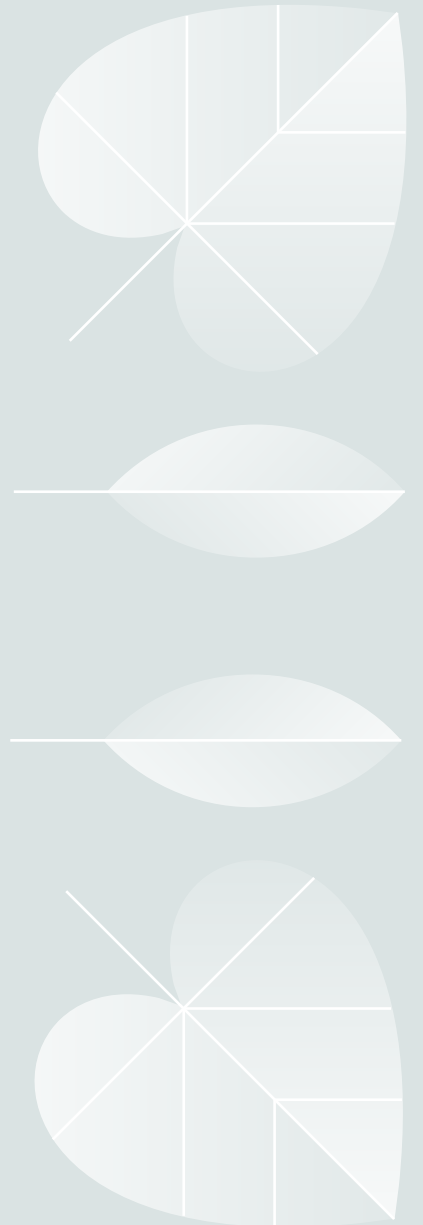


# Factors that Worsen Survival

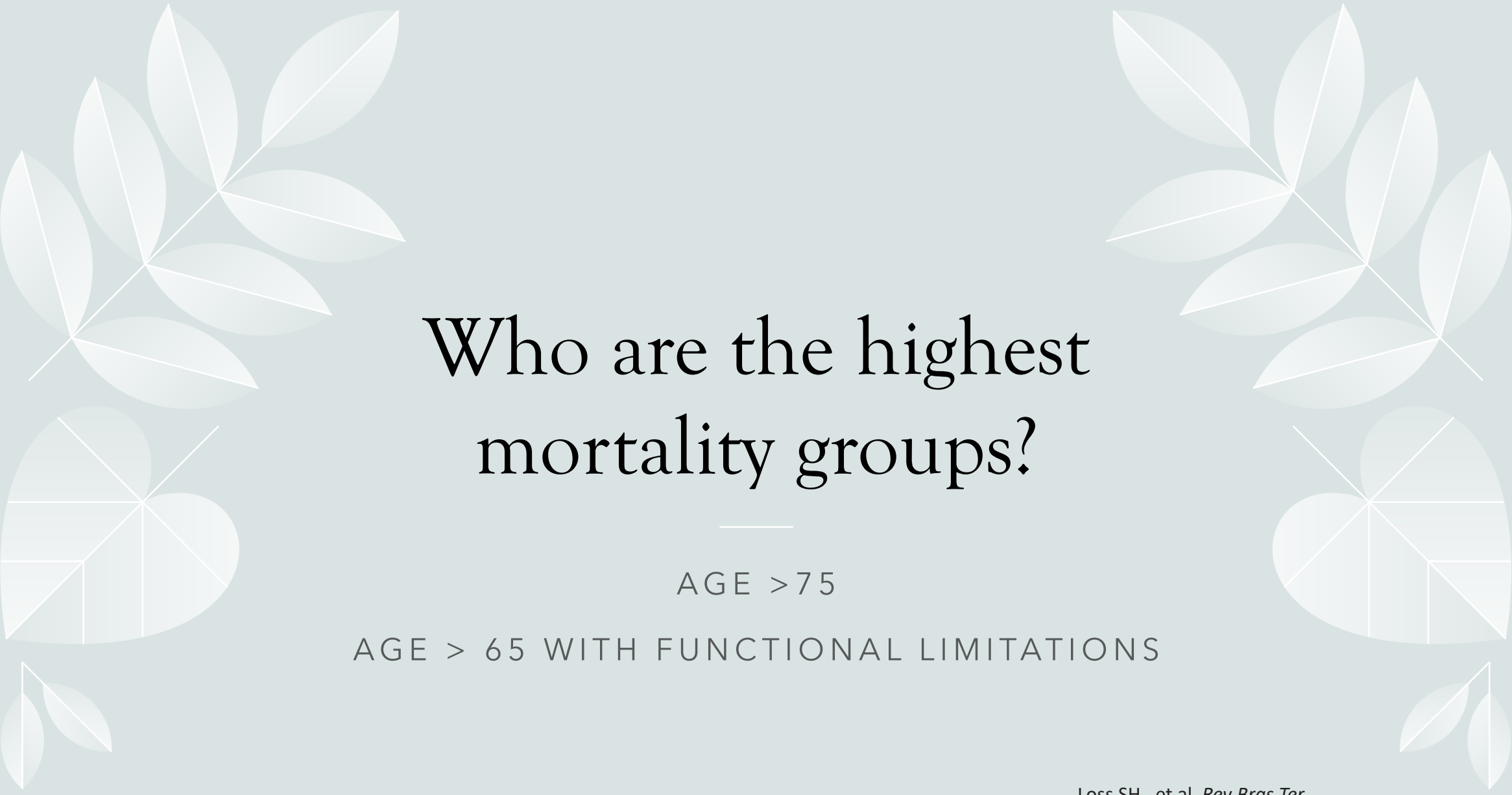
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- Advanced age<sup>1,2</sup>
- Residual organ failures
- Poor prehospital functional status
- **Good prognosis:** young patients admitted after a trauma<sup>3</sup>

1. Nelson JE, et al. *Respir Care*. 2012.
2. Loss SH, et al. *Rev Bras Ter Intensiva*. 2017.
3. Engoren M, et al. *Am Surg*. 2005.







# Who are the highest mortality groups?

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AGE > 75

AGE > 65 WITH FUNCTIONAL LIMITATIONS

# Assess understanding before proceeding

- Listen more than you speak
- Ask, tell, ask
- Involve bedside nurse and other team members in the discussion
- Use consistent language among team members



Jökulsárlón Glacier Lagoon, Iceland

# Attend to emotions

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- Providers often miss opportunities to attend to emotions
- Use the “NURSE” mnemonic

	Example
<b>Naming</b>	“It sounds like you are frustrated”
<b>Understanding</b>	“This helps me understand what you are thinking”
<b>Respecting</b>	“I can see you have really been trying to follow our instructions”
<b>Supporting</b>	“I will do my best to make sure you have what you need”
<b>Exploring</b>	“Could you say more about what you mean when you say that...”

# In discussions of withdrawal of life support

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- Don't use the word "withdrawal" use "focus on comfort" instead
  - But explain that "death is the expected outcome"
- Reassure
  - *You won't abandon the patient prior to death*
  - *You won't let the patient suffer*
- Support their decision even if you disagree with it






## Update on Jimmy...

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- It is now 7 months since Jimmy was admitted to the LTAC
- Unfortunately, he has not weaned from mechanical ventilation
- He is now readmitted to the hospital for the second time with an antibiotic resistant ventilator associated pneumonia and is requiring vasopressors for blood pressure support
- June is very concerned and is asks the provider **"why isn't Jimmy getting better?"**
- **The provider is worried about Jimmy and feels that a goals of care discussion is needed**



Think about a time you  
had to have a serious  
conversation with a family  
member like June.

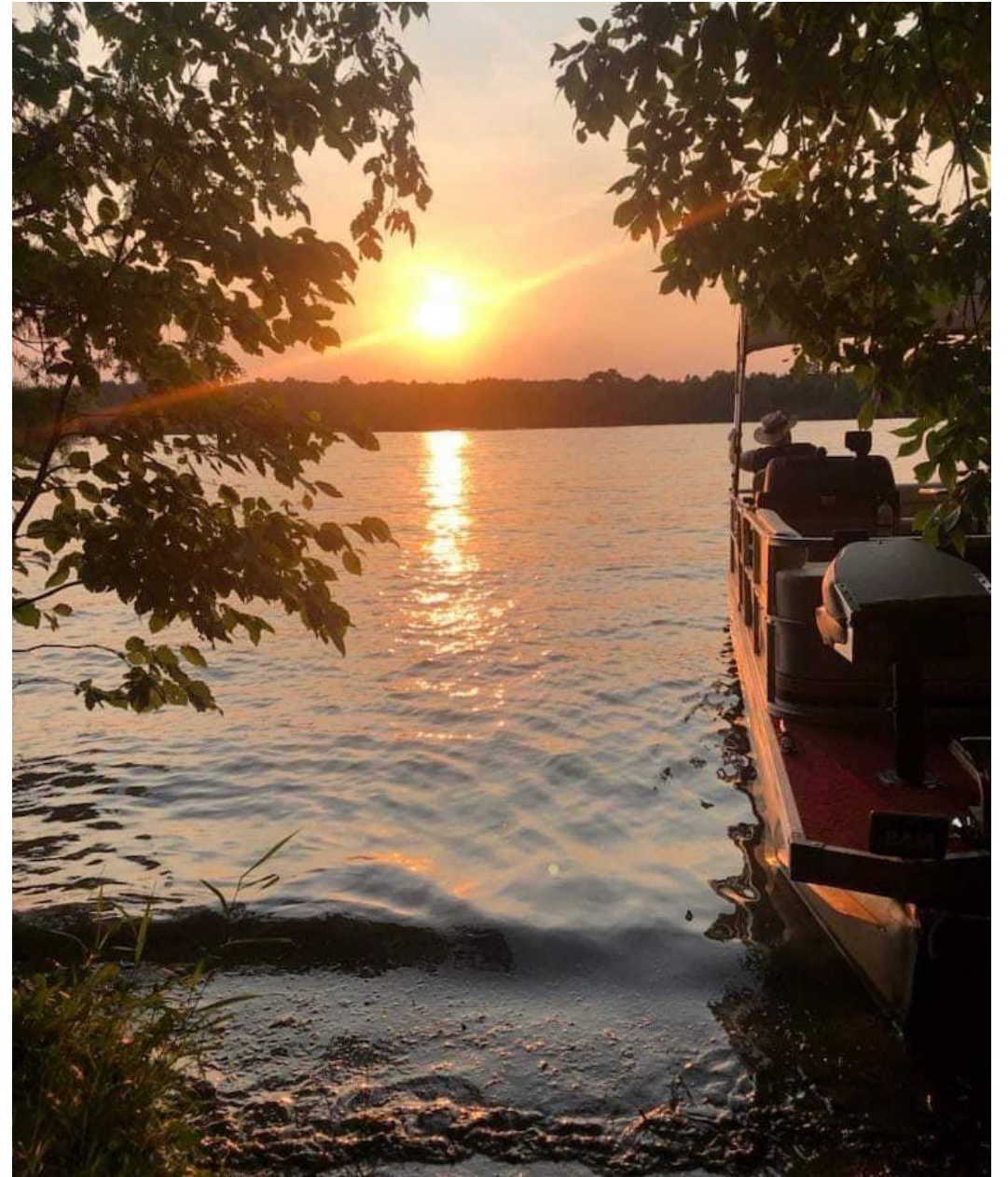
• **IT'S HARD**

• **IT'S NORMAL TO FEEL  
INADEQUATELY  
PREPARED**

• **MANY OTHER PROVIDERS  
HAVE SPOKEN WITH  
THEM IN THE PAST, WHAT  
AM I GOING TO STAY  
THAT'S ANY DIFFERENT?**



Goals of care  
discussions around  
chronic critical  
illness



Bear Lake, Manawa, Wisconsin

# The Reality of Medical Decision Making in CCI

- Most CCI patients will not be able to fully communicate
  - **Surrogate decision maker**
- Stepwise approach to decision making
  - **Advanced directive**
  - **Substituted judgement**
    - What would the patient want in these circumstances?
  - **Standard of best interests**
    - Standards for care based on community norm



# Unique Considerations for Goals of Care Discussions in CCI

- Most patients with CCI don't have life sustaining treatments withheld even when near death<sup>1</sup>
- 1/3 of families denied a role in the decision for a tracheostomy<sup>1</sup>
  - *The doctor made the decision*



Lanikai Beach, Oahu Hawaii

Most families report they haven't heard the prognosis

- **What might be some reasons for this?**

- Providers haven't shared it with families
- Health optimism, reliance on intuition
- Distrust in medical providers
- Religious beliefs, belief in miracles
- Emotions: anger, grief, fear

# Tips for Goals of Care Discussions

- Explain the role of a **surrogate decision maker**
  - *You will be making the decision on behalf of Jimmy*
  - *If Jimmy were in the room listening to us, what would he say?*
- Assess the patient's values
  - *Would this quality of life be acceptable to Jimmy?*
- Make a recommendation




Pololū Beach, Big Island Hawaii

# Make a recommendation

- Create a mutually agreed upon plan of care
- Suggest a time limited trial if that makes sense
- If consensus cannot be achieved
  - Provider can exercise professional judgement
    - *Decide if risks or burden outweigh the benefits*
  - Clearly explain your reasoning



Pigeon River Falls, Minnesota/Canada Border

The slide features a light blue background with several decorative leaf graphics in a lighter shade of blue. There are two clusters of leaves in the upper corners, two large heart-shaped leaves with internal vein patterns in the lower corners, and a small cluster of leaves at the bottom center.

# Remember that we are an interdisciplinary team

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- DON'T FORGET YOUR TEAM MEMBERS TO HELP WITH SPIRITUAL, SOCIAL, AND EMOTIONAL NEEDS OF OUR PATIENTS AND FAMILIES



## Back to Jimmy...

- The provider expresses worry to June that Jimmy is dying and recommends transitioning to a comfort focused plan of care
- June talks it over with their three sons and agrees to withdraw care
- Jimmy is religious, the chaplain provides spiritual support to June and Jimmy
- The social worker assists June with the funeral arrangements
- Jimmy is removed from mechanical ventilation with aggressive symptom management and dies peacefully surrounded by his family



# Research and Future Directions

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- How can we prevent development of chronic critical illness?
- How can we treat the immune dysregulation or chronic inflammation?
- How can we wean from mechanical ventilation?
- What is the best nutritional plan?
- How can we better communicate with families?
- When should we involve palliative care?

Punalu'u Beach, Big Island Hawaii



## Final tips & takeaways

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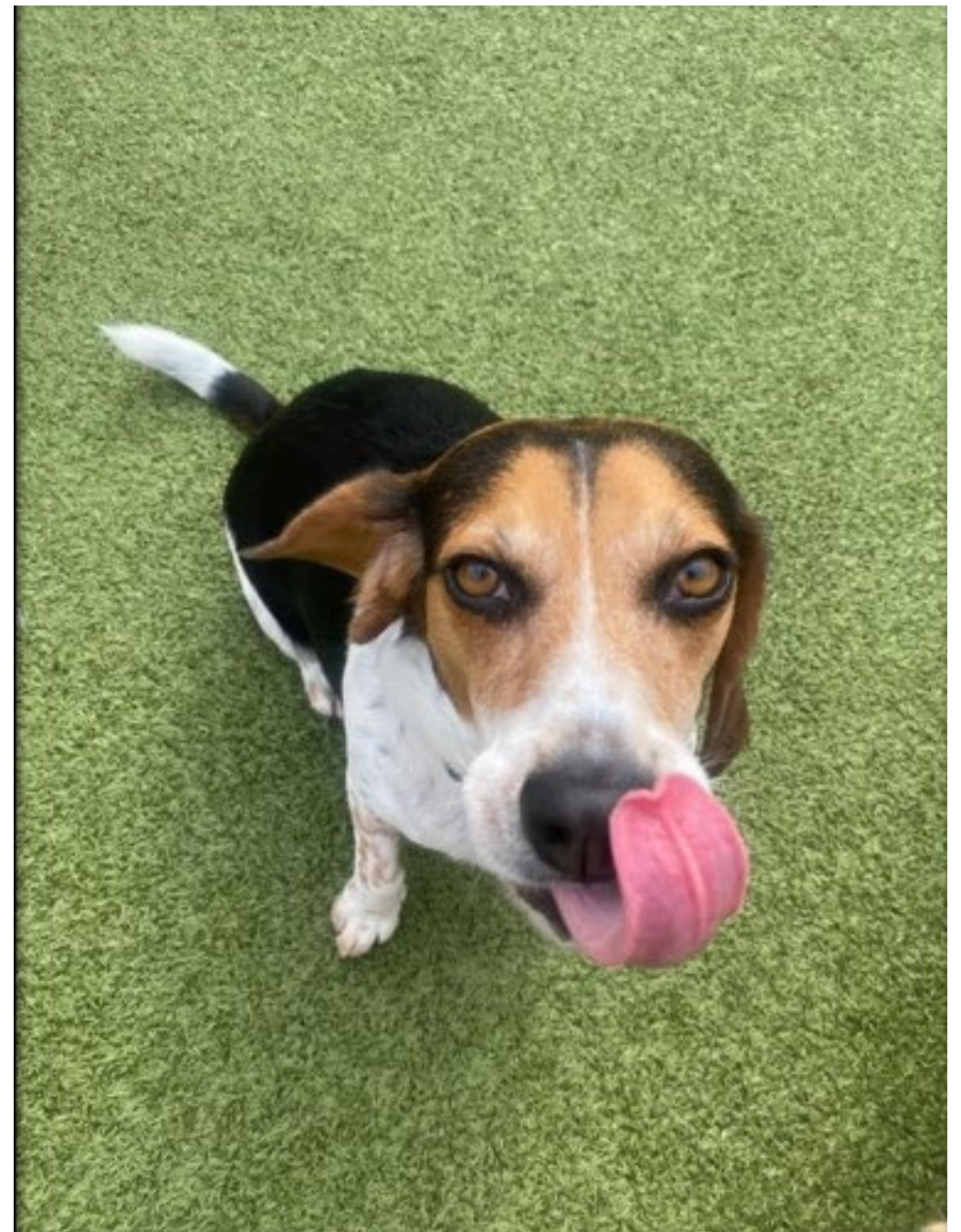
- **Chronic critical illness** is a multifaceted disorder characterized by prolonged mechanical ventilation
  - *But affecting multiple different organ systems*
- Mortality rates are high for those of older age or with physical debility
- Families aren't well informed of the outcomes
- There are opportunities to manage symptoms, but we must be careful about using medications that cause delirium
- Consider early frequent communication and use the tried-and-true techniques
- Rely on the interdisciplinary team to support patients and families.  
**Know that your role matters.**





# Thank you

- Megan Christenson  
*mchrist27@gmail.com*



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