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A Resource Center for Today's Case Manager

## Impasses and Ethical Challenges at the End of Life: From the NICU to the SICU

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## Agenda

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- Welcome and Introductions
- Learning Outcomes
- Presentation:
  - **Michelle Baker, BS, RN, CRRN, CCM**  
Chair-Elect, Commission for Case Manager Certification
  - **Laura Guidry-Grimes, Ph.D.**  
Assistant Professor Of Medical Humanities and Bioethics; Clinical Ethicist, University of Arkansas for Medical Sciences, Arkansas Children's Hospital
- Question and Answer Session

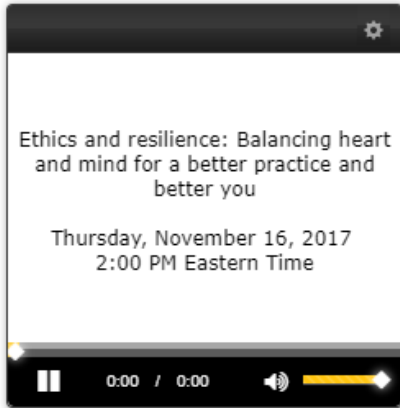


A Resource Center for Today's Case Manager

## Audience Notes

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- There is no call-in number for today's event. Audio is by streaming only. Please use your computer speakers, or you may prefer to use headphones. There is a troubleshooting guide in the tab to the left of your screen. Please refresh your screen if slides don't appear to advance.



### How to submit a question

To submit a question, click on Ask Question to display the Ask Question box. Type your question in the Ask Question box and submit. We will answer as many questions as time permits.

*Click here*

Ask Question

Submit





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## Audience Notes

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- A recording of today's session will be posted within one week to the Commission's website, [www.ccmcertification.org](http://www.ccmcertification.org)
- One ethics CCM continuing education credit for board-certified case managers (CCM) and one ANCC nursing contact hour continuing education credit is available for today's webinar only to those who registered in advance and are participating today.



## Learning Outcomes Overview

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*After the webinar, participants will be able to:*

1. Identify common ethical challenges that arise at the end of life for pediatric and adult patients.
2. Explain an ethically-reasoned procedure for handling impasses and conflicts that arise among family members and healthcare teams when advocating for the interests of the dying patient.
3. Employ the procedure previously explained to help patients/families handle end-of-life conflicts and challenges, while maintaining your own ethical principles and resilience.

## Impasses and Ethical Challenges at the End of Life: From the NICU to the SICU

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**Michelle Baker, BS, RN, CRRN, CCM**  
Chair-Elect  
Commission for Case Manager Certification

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## PACE<sup>™</sup>



*CareManagement*







**Code of Professional Conduct for Case Managers:**  
[https://ccmcertification.org/sites/default/files/code\\_of\\_professional\\_conduct\\_2.pdf](https://ccmcertification.org/sites/default/files/code_of_professional_conduct_2.pdf)

# Code of Professional Conduct for Case Managers

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**Principle 1:** Board-Certified Case Managers (CCMs) will place the **public interest above their own** at all times.

**Principle 2:** Board-Certified Case Managers (CCMs) will **respect the rights and inherent dignity** of all of their clients.

**Principle 3:** Board-Certified Case Managers (CCMs) will always **maintain objectivity in their relationships with clients.**

**Principle 4:** Board-Certified Case Managers (CCMs) will **act with integrity and fidelity with clients and others.**

## Introduction

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### **Laura Guidry-Grimes, Ph.D.**

Assistant Professor of Medical Humanities and Bioethics; Clinical Ethicist, University of Arkansas for Medical Sciences, Arkansas Children's Hospital



# IMPASSES AND ETHICAL CHALLENGES AT THE END OF LIFE: FROM THE NICU TO THE SICU

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**CLINICAL ETHICIST**

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# Disclosures

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- ◇ *I have no relevant disclosures or conflicts of interest.*
- ◇ *The cases, though inspired by actual experiences, have been modified and deidentified. Photos are licensed for public use.*

# What Makes a Case an End-of-Life Case?

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## Medical condition

comorbidities, psychiatric overlay

## Resource limitations

inadequate insurance,  
discharge options, shortages

## Social situation

insufficient support

## Decision making

preferred plan of care



# Possible Impasses and Conflicts

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## ◇ Medical condition

- ◇ Disagreements about diagnosis, prognosis → delays, lingering
- ◇ Psychiatric episodes leading to fasting, physically resisting care, self-harming or self-neglectful behavior

# Possible Impasses and Conflicts

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## ◇ Resource limitations

- ◇ Challenges in determining a *safe* discharge plan
- ◇ Treatments, skilled care, or facilities that would give the patient a better chance at survival are unavailable (e.g., due to geography or insurance)
- ◇ Pts/families wanting costly treatment options, scarce resources that the hospital is unwilling to provide in this case



# Possible Impasses and Conflicts

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## ◇ Social situation

- ◇ Unwilling or unavailable surrogate decision-makers → unrepresented patient
- ◇ Patient living without any supports – homeless, living alone
- ◇ Complex family dynamics that lead to arguments about goals of care → avoidance, delays, miscommunication, broken therapeutic trust
- ◇ Obstacles for patient accessing necessary health information, appointments, Rx, home equipment

# Possible Impasses and Conflicts

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## ◇ Decision making

- ◇ Advance directive seemingly indicates patient would not want “aggressive” treatments, but difficulties interpreting document
- ◇ Patient/surrogate choosing to prioritize comfort or time with loved ones, even though the healthcare team believes more can be done
- ◇ Patient refusing recommended treatments or tests, leaving AMA

# Dissecting the Ethical Issues

## Identify:

### **Stakes**

*For example:* Patient preferences? Family interests? Pain/suffering? Resource allocation? Professional integrity? Protecting vulnerable persons?

### **Constraints**

*For example:* Laws? Institutional policies? Insurance limits? No more medicine can accomplish?

### **Obligations**

*For example:* Professional role-based duties? Parental/familial? Patient? Societal?

### **Resolution – *principled advocacy***

*For example:* What are ethically supportable options? What steps are fair and respectful of the different perspectives and interests of involved parties? Any lingering moral concerns?



# From the NICU: To Trach or Not to Trach

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- ◇ Jesse has been vent-dependent since he was born prematurely 4 months ago. The NICU physicians diagnosed him with bronchopulmonary dysplasia (BPD), and they believe tracheostomy will give him the best chance at long-term survival.



## From the NICU: To Trach or Not to Trach

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- ◇ If he receives the trach, he will need to stay in the hospital for another 6-12 months before being discharged home. Both parents would need to be trained on trach care. At home, he would need 24-hour “awake care” to make sure he does not have any plugs that could quickly become fatal. The parents’ insurance would cover only about 18 hours per week of home healthcare aide assistance. He would likely need to stay on the trach for 3-6 years.



## From the NICU: To Trach or Not to Trach

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- ◇ The parents, Mariel and Fernando, consistently tell the healthcare team that they want “everything” to keep Jesse alive. At the same time, they do not want Jesse to receive a trach because they believe that he will “grow out of” the BPD. Fernando also mentions to the case manager that “God will make sure he heals,” and Fernando does not want healthcare aides intruding on their privacy.

# Dissecting the Ethical Issues

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**S**takes

**C**onstraints

**O**bligations

**R**esolution –  
principled  
advocacy



# From the SICU: When No One Can Agree

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- ◇ Ms. Jones was admitted for GI bleeding and signs of sepsis with an unknown source. She alternates between AMS and unconsciousness. Her niece, Sylvia, is bedside the most often. Sylvia claims she is a nurse and that she is the decision maker. Sylvia wants Ms. Jones to be full code with all aggressive measures pursued, except for an exploratory surgery recommended by the physicians.





# From the SICU: When No One Can Agree

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- ◇ One day when Sylvia is at work, the patient's nephew, Roger, arrives and requests the exploratory surgery, which the team then performs. They find necrotizing bowel, which is not treatable due to how advanced it is. When Sylvia returns, she is furious with the healthcare team and her brother.



# From the SICU: When No One Can Agree

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- ◇ The next day, Roger gives the team a copy of an advance directive (AD) from 5 years ago, back when Ms. Jones had cancer, stating that she would not want aggressive measures if terminal. When a case manager mentions to Sylvia that Ms. Jones's AD is now on file, Sylvia insists that the AD is old and does not represent her aunt's most recent preferences.

# Dissecting the Ethical Issues

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**S**takes

**C**onstraints

**O**bligations

**R**esolution -  
principled  
advocacy

# Stresses of Decision-Making for Another Person

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- ◇ After making decisions, mostly at EOL, at least 33% of surrogates had negative emotional burden that lasted years – guilt, trauma, “extraordinarily high” stress
- ◇ When making decisions for pts in the ICU, 33% of surrogates were at moderate to major risk of PTSD
  - ◇ Higher rates when they believed they had received incomplete information (48.4%), whose relative died in the ICU (50%), whose relative died after EOL decisions (60%), and who shared in EOL decision (81.8%)

## Question and Answer Session

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### **Laura Guidry-Grimes, Ph.D.**

Assistant Professor of Medical Humanities and Bioethics; Clinical Ethicist, University of Arkansas for Medical Sciences, Arkansas Children's Hospital



# Thank you!

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- Please fill out the survey after today's session
- Those who signed up for continuing education will receive an evaluation from the Commission.
- A recording of today's webinar and slides will be available in one week at <http://ccmcertification.org>

## Commission for Case Manager Certification

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