

PRACTICAL PALLIATIVE CARE IN THE NICU

October 16th, 2025
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Neonatology/Palliative Care

FANNP's National Neonatal Nurse Practitioner Symposium: Clinical Update
and Review, 2025 ©



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- No disclosures or conflicts of interest



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Objectives

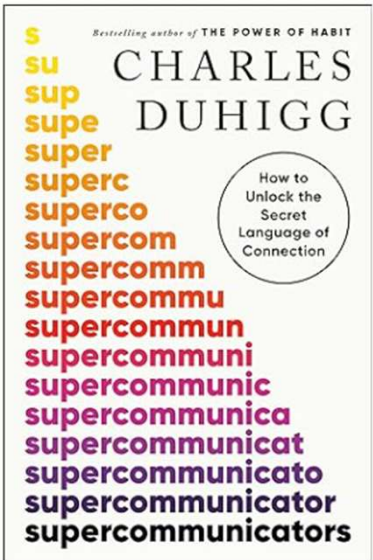
- Learn a communication tool for navigating uncertainty
- Recognize practical communication versus emotional communication
 - Avoiding the Doom Loop
- Learn strategies for responding to emotion
- Recognize common harmful and beneficial things to say
- Learn a framework for navigating moral distress/decision making

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Lessons in Communication
from an 18 month old



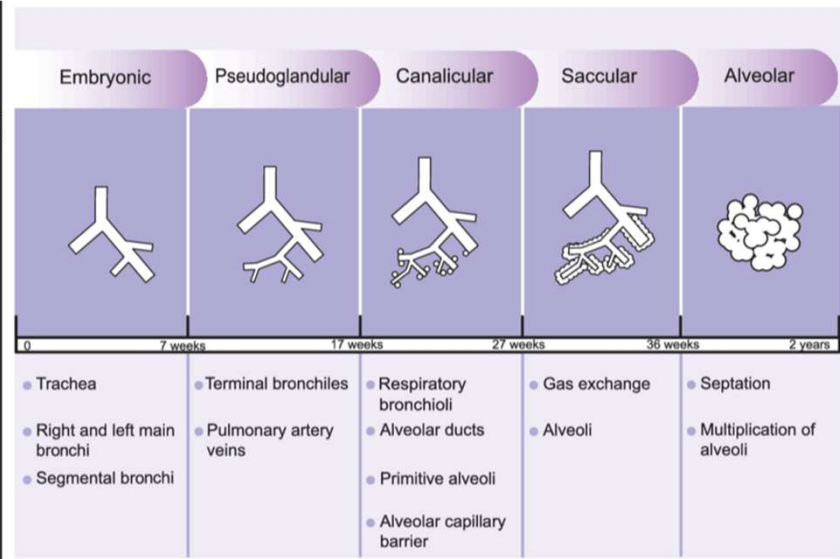
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Example

- Medical jargon
- versus expressing
- empathy



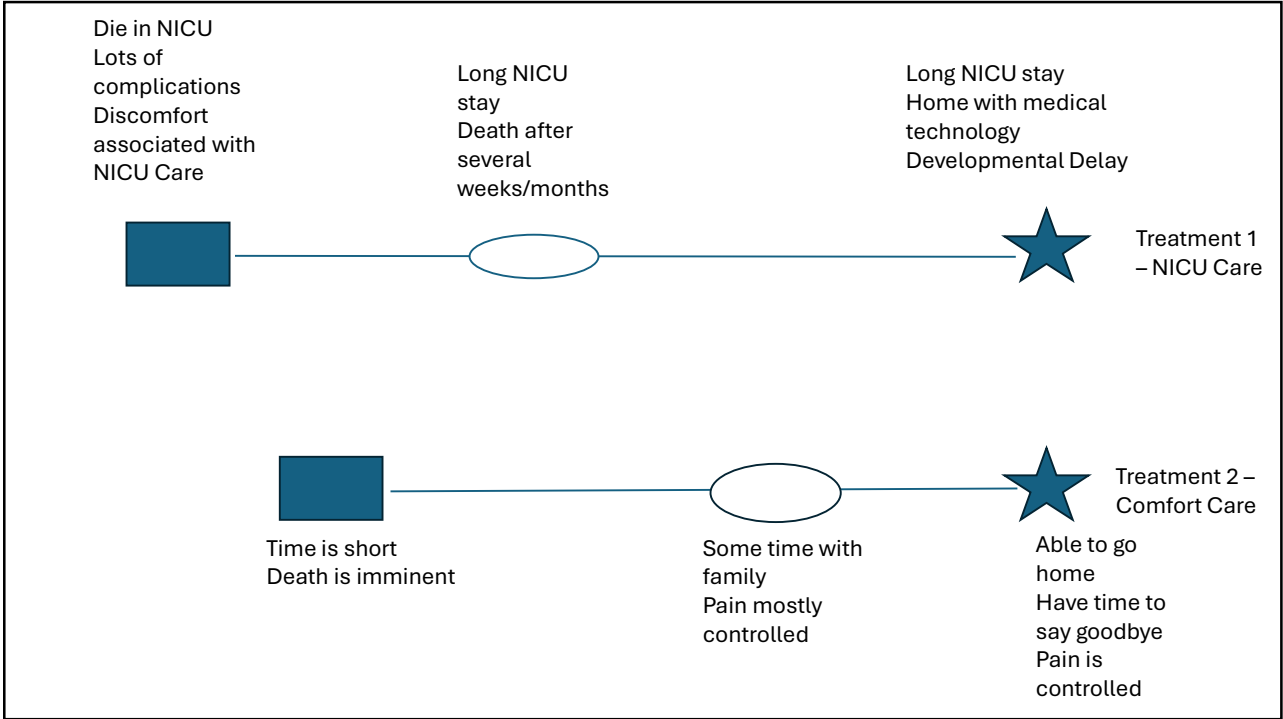
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Avoid the Doom Loop ©

A colorful illustration of a diverse group of healthcare professionals (nurses, doctors, and a respiratory therapist) and a family (mother and father) smiling together. A newborn baby is being held by the mother. A sign in the center reads: "AFTER 155 DAYS IN THE NICU ALIANNA IS GOING HOME". The background shows a hospital room with medical equipment.

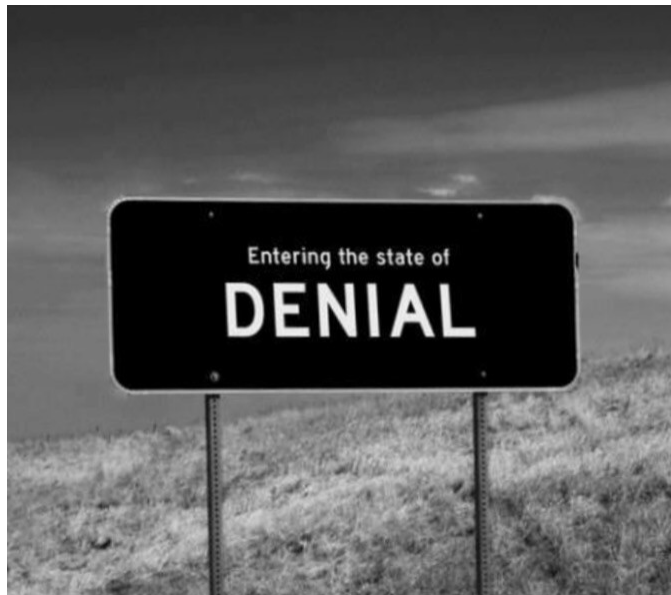
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NURSE tool

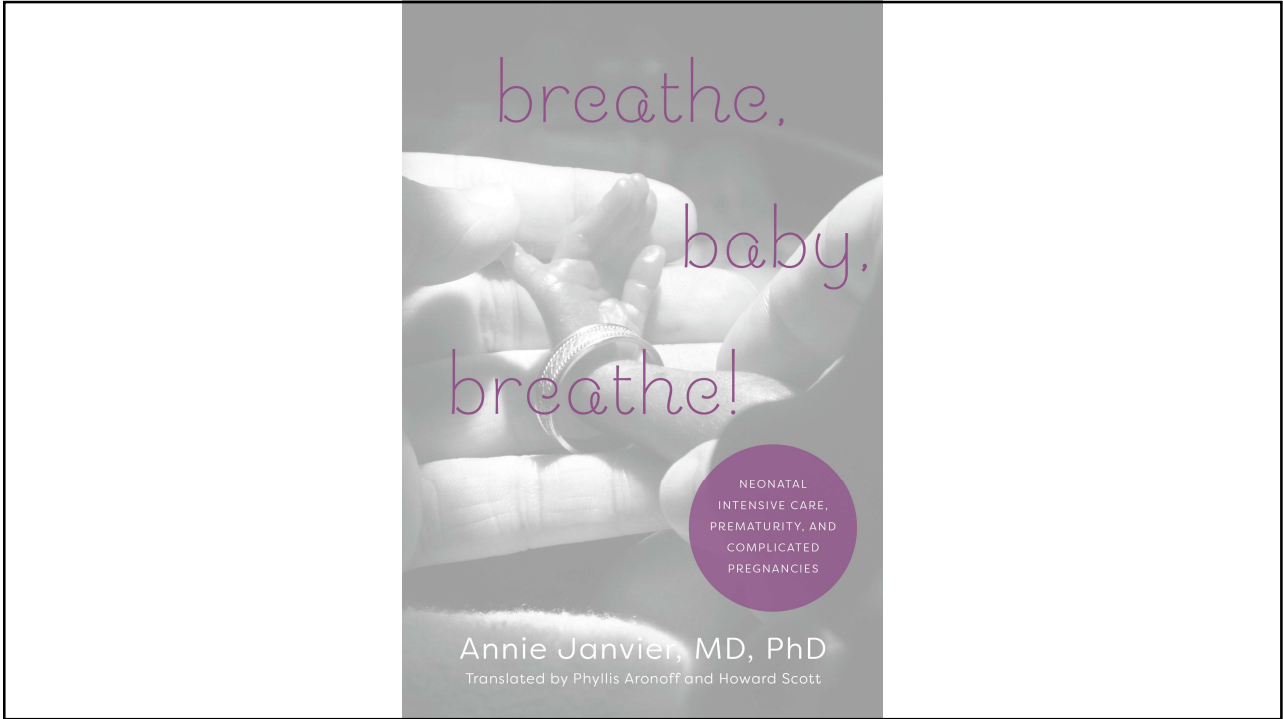
- Naming
 - Ex - "It sounds like you are scared"
- Understanding
 - Ex - "This helps me understand what you are thinking"
- Respecting
 - Ex - "I can see how much you love your son, how hard you have been trying to provide breastmilk for him"
- Supporting
 - Ex - "I will do my best to make sure you have what you need"
- Exploring
 - Ex - "Could you say more about what you mean when you say that..."

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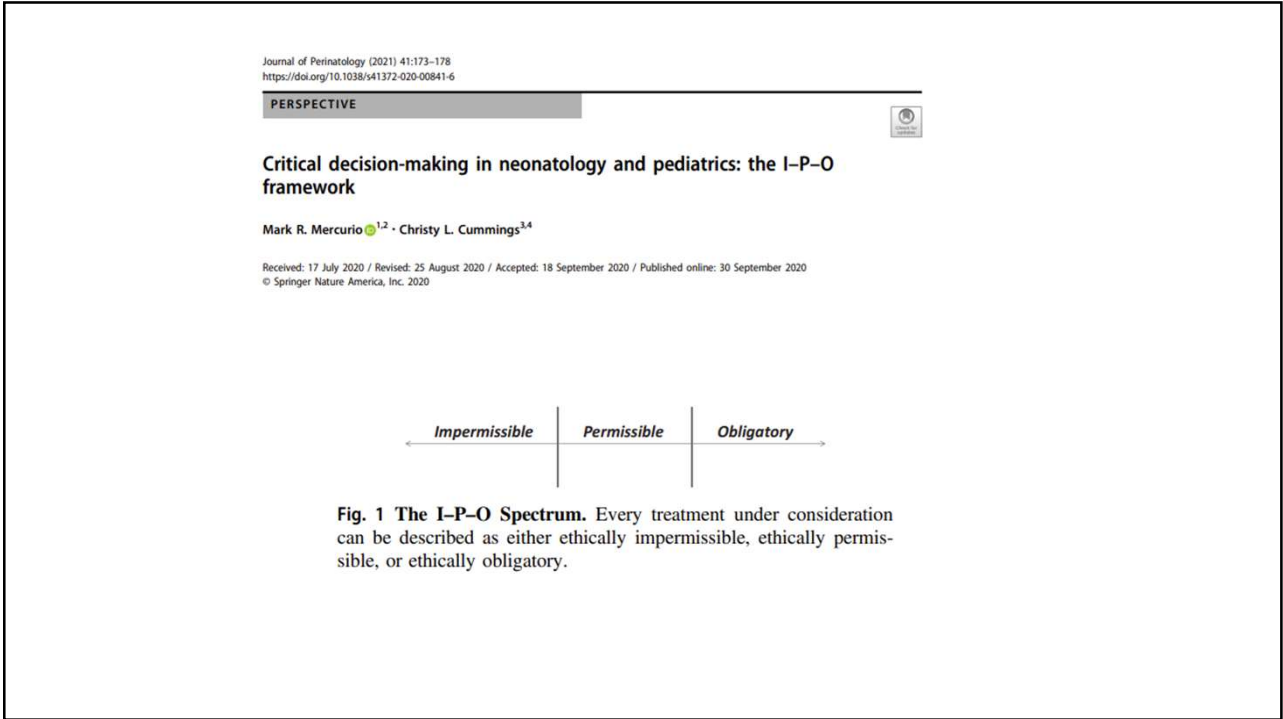
Dealing with Denial



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Special Considerations

Table 3: Special Considerations

| | |
|--|---|
| Difficult withdrawal expected | <ul style="list-style-type: none">• Prioritize the huddle, walk through plan for symptom management prior to withdrawal.• Consider utilization of infusions in addition to IV intermittent dosing.• Terminal wean of ventilator is strongly preferred over abrupt extubation to aid with symptom management.• Consider whether special medications (e.g. pentobarbital) will be required; if so, contact pharmacy in advance to arrange.• Consider Palliative Care consult to aid in medication management. |
| Opioid-habituated patient ¹ | <ul style="list-style-type: none">• Continue current regimen including drips• For loading/PRN opioid dose use 50% of current hourly infusion rate• PRN doses can be q10min and increased by 50% every other dose<ul style="list-style-type: none">◦ Example: dose 1 = 10 mg, dose 2 = 10 mg, dose 3 = 15 mg, dose 4 = 15 mg, dose 5 = 22.5 mg• Consider adjunctive therapies (e.g. benzodiazepines, dexmedetomidine, barbiturates) |
| High risk of bleeding | <ul style="list-style-type: none">• Ex: liver failure, coagulopathy, arterio-venous malformations of airway• Anticipatory guidance is key.• Prepare family and team for what WLST may look like if bleeding is expected.• Use dark towels to help conceal bleeding on linens. |
| High ventilator settings | <ul style="list-style-type: none">• Expect higher symptom burden, especially dyspnea.• Wean ventilator settings prior to extubation, treating symptoms until comfort achieved and prior to removal of artificial airway. |
| Medical Examiner case ² | <ul style="list-style-type: none">• Discuss in huddle and with family.• There is no rule stipulating that DME must remain in place* |
| Patient that does not die right away | <ul style="list-style-type: none">• Provide anticipatory guidance and reassurance to family.• Do not panic, patients will progress at their own pace.• Do not give additional medicines to "hasten" death but continue to treat symptoms purposefully.• Consider hospice referral if patient expected to live longer than few days after WLST. |

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References

- Duhigg, C. (2024). *Supercommunicators: How to Unlock the Secret Language of Connection*. Random House.
- Janvier, A. (2020). *Breathe, Baby, Breathe!: Neonatal Intensive Care, Prematurity, and Complicated Pregnancies* (P. Aronoff & H. Scott, Trans.). University of Toronto Press. (Original work published 2020)
- Critical decision making in Neonatology and Pediatrics. As referenced on slide