

## Supplementary material 1. Full dialogue examples for the 2 neonatal shared decision-making cases

### Case 1. Parent-guided shared decision-making – patent ductus arteriosus treatment in a preterm infant

A female infant was born at 26 weeks and 4 days of gestation, weighing 970 g. At 31 weeks postmenstrual age, she remains on invasive mechanical ventilation due to a hemodynamically significant patent ductus arteriosus (PDA) that continues to affect her respiratory status. Two courses of ibuprofen have failed to close the PDA, though she experienced no side effects. The team now needs to discuss whether to proceed with surgical ligation or attempt another medical therapy.

The neonatologist begins by establishing a human connection and inviting the parents into the conversation.

“Having a baby in the neonatal intensive care unit is really hard. How are you doing right now?”

“Is now a good time to talk about your baby’s heart condition?”

“I know this has been an incredibly difficult journey. We’ve reached a point where we need to think together about the next steps for your baby’s heart condition. Would now be a good time to talk through the options?”

This sets an empathetic tone and signals that a decision is needed without rushing into details.

The physician starts by exploring what the parents already know.

“What have other doctors or nurses told you about your baby’s PDA?”

Then, balanced information is shared in clear language.

“We face some decisions here. Your baby’s PDA has remained open despite 2 courses of ibuprofen, so we now need to decide whether to move ahead with surgery or to try another medication. Surgery is definitive—once the PDA is clipped, it usually stays closed. The operation is brief but does require anesthesia and a small chest incision.”

When the parents express concern, the physician acknowledges their emotions and elaborates: “I understand how worrying this sounds—she’s still so small, and surgery feels like a big step. Let me explain why we consider it. If the PDA stays open, it can continue to strain the heart and lungs, making it harder for her to come off the ventilator and to grow. That’s why we usually discuss closing it after 2 rounds of medication haven’t worked.”

The physician pauses, giving the parents time to process, then adds, “That said, we can talk together about what matters most to you—whether to focus on avoiding surgery for now or to take a more definitive step.”

The mother says, “She’s so small... I’m scared surgery will be too much for her.”

The father adds, “We don’t want to put her through pain unless we have to.”

The physician reflects: “So, what I’m hearing is that avoiding surgery right now feels most important to you—is that right?”

After understanding their priorities, the physician offers an alternative aligned with their values: “Since you would prefer to avoid surgery, there is another option—paracetamol. The success rate is much lower given medications haven’t worked so far, and there’s a theoretical risk of liver toxicity, but major complications haven’t been reported in infants. It could give us another chance with medication while keeping surgery available if needed.”

This exchange illustrates how active listening leads to tailoring medical options around parental values.

After further discussion, the physician summarizes: “We both want her to grow stronger and stay safe. Since avoiding surgery now is most important to you, trying another medication first makes sense. We’ll watch her closely and keep surgery as a backup if things don’t improve.”

This reassurance—“We’ll stay close and re-evaluate together”—alleviates lingering anxiety and preserves trust for future decisions.

The shared plan respects the parents’ values while maintaining clinical safety, demonstrating parent-guided shared decision-making (SDM) in practice.

## Case 2. Physician-guided SDM - tracheostomy in an infant with BPD

A female infant born at 26 weeks and 4 days of gestation, weighing 970 g at birth, is now 5 months corrected age. She has remained on invasive ventilation since birth because of severe bronchopulmonary dysplasia. Despite multiple extubation attempts, she cannot be weaned, and ventilator settings remain high. The team must discuss whether to perform a tracheostomy or continue prolonged endotracheal intubation.

The neonatologist begins: “I know this has been an incredibly difficult journey. We’ve reached a point where we need to think together about the next steps for your daughter’s breathing support. Would now be a good time to talk through the options?”

This empathetic introduction sets a collaborative tone and prepares the parents for shared reflection.

The physician explains the situation gently but clearly.

“At this stage, keeping the breathing tube in place for a long time can cause problems with her airway and make it harder for her to grow and feed. A tracheostomy would provide a more stable and comfortable way for her to breathe.”

The parents’ immediate reactions—fear and sadness—are met with empathy.

“I can see how painful this feels. Can you tell me more about what worries you most?”

The mother says, “She’s been through so much already. Putting a hole in her neck—won’t that hurt her even more? She’s a girl... I don’t want her to live with a scar.”

The father adds, “We’re afraid this means she’ll always be on a ventilator, or that people will see her as disabled.”

The physician reflects back: “So, what I’m hearing is that you’re worried about her future—both her health and how others might see her. Can you tell me more about that?”

This active listening opens space for emotional expression before moving to guidance.

Recognizing the clear medical indication, the physician takes a more directive yet compassionate stance.

“I want to be transparent. Continuing with the endotracheal tube could cause serious harm. Based on what we know, I believe a tracheostomy is the safest and most appropriate step. A tracheostomy is not about giving up—it’s about helping her breathe safely and comfortably. The scar is small, and as she grows, most people won’t notice it. It may even help her spend more time out of bed and learn to feed by mouth.”

“What would you do, doctor?”, the response should reflect the appropriate balance between medical guidance and respect for family values.

In parent-guided situations: “I can share what the options mean medically, but I want to understand what feels right for your family. What matters most to you as you think about this choice?”

In physician-guided situations: “If this were my family member, I would recommend the tracheostomy because it’s the safest way to help her breathe and grow. But I also know this decision is emotionally very hard, and I’ll be here to support you every step of the way.”

The parents’ concerns are acknowledged while restoring hope. They agree to proceed, feeling that their fears were heard and that the recommendation was made with respect and empathy.