



# Neonatal Ethics Teaching Program

## Problem Based Learning in Ethics (PBLE)

### Critically Ill Newborn in the NICU

#### Standardized Patient Guide

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## Case Scenario with the Standardized Patient

**Clothing and positioning for role-playing:** Comfortable, loose clothes (e.g. ‘sweat suit’), you will be sitting in a chair.

**Description for role-playing – SP will know all of this information:**

You, Helen, are a 31 year old mother. Your second child, Leona, was born approximately 24 hours ago at 39 weeks gestational age (term) by emergency caesarean section after there was complete loss of the foetal heart rate during labour. You have just completed your first visit with Leona in the neonatal intensive care unit (NICU) at the Children’s Hospital of Eastern Ontario (CHEO). Leona is critically unwell with a severe brain injury due to a lack of blood flow and oxygen to the brain near the time of delivery. This was your second pregnancy and it was completely normal until the moments prior to delivery. You are healthy and didn’t smoke or take any medication, alcohol or drugs during the pregnancy. You have a healthy 2 ½ year old, Kyle, at home. You were working as a teacher in a primary school prior to staying home full time with Kyle. Your husband, Paul, is a radio technician with the military and is presently in Sierra Leone; he is reachable by satellite phone and was supposed to be back in time for the delivery had it occurred 10 to 14 days later. You recently lost your father to a sudden, unexpected heart attack. You are Catholic. Your family history is otherwise unremarkable (no notable learning problems, developmental delay, or cerebral palsy).

You came to the hospital in labour about 26 hours ago. You were trying to deliver Leona vaginally after requiring a caesarean section for your son’s birth. You were known to be group B streptococcus (GBS) positive but received no antibiotics during the labour. Thirty minutes prior to delivery, your water broke and it was filled with meconium (a greenish substance). About 15 minutes prior to the emergency caesarean section, Leona’s heart rate dropped to less than 60 beats per minute and stayed low for about ten minutes. This persistent low heart rate prompted the doctors to arrange an emergency caesarean section using the epidural; unfortunately, there was complete loss of Leona’s heart rate prior to the actual initiation of the caesarean section (for which they put you to sleep in the end). When they got Leona out, they noted she appeared lifeless and had the umbilical cord wrapped around her neck. The medical team performed complete resuscitation of Leona and got a heart rate back at 13 minutes of life. She was on a machine to breath for her. She did not take any of her own breaths until she was one hour old. Her Apgar scores were 0, 1, 1, 3, and 3. You don’t know her birth weight.

From speaking with the bedside nurse directly and previously on the phone, you also know the following information. Soon after the birth, Leona was transferred from the peripheral hospital in Winchester to the CHEO NICU for continued intensive care, including being ‘cooled’ to try and prevent further injury to her brain. She rapidly developed seizures, acid in the blood, kidney injury, bleeding problems, and liver injury. From the time of her arrival to the CHEO NICU, she did not show any purposeful movements and did not appear responsive to any of her surroundings.

You and your husband understand that Leona is very unwell. You are about to get your first clinical update from the medical team. You are expecting some bad news but remain hopeful that Leona will survive and have a full recovery.

### Information to help role-playing:

1. The doctor/resident will conduct a clinical update on Leona's condition. This should include:
  - Greeting you and expressing sympathies about the current situation.
  - Asking you about your current understanding of Leona's condition (this is outlined in the final paragraph on page 3).
  - Asking you for complementary information (e.g. social/family situation).
  - Sharing with you information about:
    - Present condition, complications and care plan to date.
    - Possible long term outcome (including death or severe neuro-developmental impairment).
    - Present ongoing care and the care plan for the next 18 to 24 hours.
  - Responding to your question: **“Have you done everything you can for my baby? We want everything done.”** (This question should be as persistent as required, and modified if needed, until you are satisfied with the answer and don't feel abandoned.)

*Note:* We may need to stop the simulation for a 3-5 minute discussion if the trainee struggles with their response to this question; you will be asked to wait outside the room.
2. The doctor should ask you if you understood all the information that s/he has shared with you:
  - You may ask more questions if you feel that s/he did not clearly explain any of the following: the outcomes, what may happen to your baby in the next 24 hours or what they are planning to do.
3. At the first meeting, the doctor/resident should mention management options, including palliative care (they may use the somewhat synonymous but perhaps more confronting phrase like “withdrawal of intensive care”). Regardless of the words they use, you need to ask what this exactly means in order to comprehend it. Once you understand the meaning, do not enter into extended conversation about the topic at this time. You may deflect this conversation by emotionally saying something like: “I really can't think about that right now. I have to keep hope that she is going to get better”.
  - That being said, you do clearly acknowledge how terrible the situation seems at present (i.e. you have heard and understand the clinical update and related information).
  - Also, the trainee may, appropriately, bring up that there is the possibility that Leona could die at any moment; this will prompt you to have to consider some of the things you would want done before she possibly died (e.g. pictures taken, baptism performed, getting to hold her, etc ...). You

still do not want to discuss the details of palliative care. If the trainee ask you about whether you want the breathing tube put back in if it falls out, or if you want the medical team to perform chest compressions or give resuscitation medications if Leona needs them, you say: “Just do everything to keep her alive”.

*Note:* We may need to stop the simulation for a 3-5 minute discussion if the trainee struggles with the introduction of palliative care; you will be asked to wait outside the room.

4. When you meet again when Leona is about 48 hours of age, the doctor/resident should explain and offer you options about what can be done if there is no notable change in her clinical condition. Prior to this meeting, you will have spoken with your husband on the satellite phone and discussed the idea of palliative care; you both agree it is something that must be considered and may be in Leona’s best interests, but you are not ready to divulge this to the medical team yet. During this meeting, the doctor/resident should respond to your questions:
  - **“Is this only your opinion or someone else’s too?”** This question should be as persistent as required, and modified if needed, until you are satisfied with the answer.
  - **“If my baby was yours, what would you do?”** This question should be as persistent as required, and modified if needed, until you are satisfied with the answer. By this question, you are actually looking for support and trying to ask: “Are we making the right choice?” and stems from the fact that you are leaning towards palliative care. The trainee needs to explore this initial question with you in order to understand what you are actually looking for and trying to ask. Do not just give them the answer – it must be explored and this should take some time.

*Note:* We may need to stop the simulation for a 3-5 minute discussion if the trainee struggles with their response to one or both of these questions; you will be asked to wait outside the room.
5. The doctor should ask you for your consent with regards to any care plan for your baby:
  - S/he may strongly suggest one course of action (i.e. palliative care) based on Leona’s condition and the near certain poor quality of life for your baby if she survives. They also may not offer the option of palliative care based on personal beliefs, fear or another reason.
  - If s/he does not ask for your consent, you may say that you are the legal surrogate for your baby and you have the right to choose the care of your infant (be it palliative care, continuing intensive care for now, or continuing intensive care for an extended period of time). Your choice of tone on this matter can be altered depending on how the scenario is unfolding.

6. If the doctor/resident does not bring up the option of palliative care, you should, after some time and with emotional difficulty, state that you'd like to explore this option (i.e. **"Should we be doing this to our baby?"**)
7. If the doctor wants you to accept palliative care without presenting and exploring other options with you (e.g. performing further brain imaging, waiting for your husband to return, continuing intensive care indeterminately, etc ...), you do not accept under any circumstances. It is unlikely this scenario will occur.
8. In order to help resolve the above conflict or deal with having to introduce palliative care yourself:
  - The doctor should be open to your position and show some respect for what you are thinking and for what you want for your baby.
  - S/he should try to explain to you that in Leona's specific case, her chance for survival without a severe neuro-developmental impairment (e.g. mental retardation, inability to move alone, etc ...) are likely < 0.5% based on the best medical literature and it may be in **Leona's best interests** to consider palliative care.
  - You will understand the value of best interests and you may want to have more detail about the long-term outcome in this scenario and whether other tests (e.g. EEG, MRI, etc ...) or more time (e.g. status after 'cooling', chance to review more medical literature, etc ...) are needed prior to making a decision.
  - You want to know (as per 4.a) above) if this is only the current doctor's opinion or if other physicians (e.g. other neonatologists or a consultant neurologist) know the case and also recommend palliative care.
  - Based on this information, you may consider agreeing with palliative care. If you remain against palliative care at the present time, the doctor may also decide to respect your wishes for now.
  - You need to speak with your husband first and have him hear the information before giving your consent to a palliative care plan.

*Note: you can introduce the fact that Paul should be arriving in Ottawa in the next 24 hours; still, nothing is certain with the military.*
9. If time allows, the conflict will be resolved after the conversation with your husband; though devastated, you decide upon palliative care at this point as you and your husband "know it is best for our baby". With the help and support of the doctor/resident, you are able to institute the beginnings of a palliative care for Leona. You may need to initiate this talk by stating: "What do we do now?"
  - The process should be clearly explained to you. Ask any questions if something seems unclear (e.g. "Does she have to stay in the NICU?").
  - Autopsy and organ donation may be discussed by the doctor/resident. If so, you are welcome to say "I'll think about it and discuss it with my husband". Otherwise, you could agree or disagree depending on how s/he presents the autopsy request.

*Note:* We may need to stop the simulation for a 3-5 minute discussion if the trainee struggles with discussing the basic details of palliative care; you will be asked to wait outside the room.

## **PBLE Timeline**

### **Introduction (15 min)**

### **Practice with the Standardized Patient (40 min)**

- 1) 25 min to cover the first meeting with the parent.
- 2) 15 min of discussion.

### **Practice with the Standardized Patient (40 min)**

- 1) 30 min to cover the second meeting with the parent.
- 2) 10 min of discussion.

### **Conclusion (20 min)**

## Instructions for the Standardized Patient

1. At the beginning, you will not be introduced to the participants.
2. During the practice session with the trainees, you may be asked to leave and the scenario could be interrupted several times.
3. In the case of interruptions, the supervisor will speak with you again before resuming the session. The supervisor will advise you as to where to restart the interview and if you need to make any modifications to your role-playing.

**Note:**

- Repetition of certain sections is sometimes necessary for the trainees' learning experience.
  - The 'rotating' trainees may want to introduce themselves during the practice session even though they are supposed to be the same person in your eyes. Simply allow them to do so as this step makes them more comfortable.
4. At the end of the scenario, you will be introduced to the trainees and you will have to opportunity to tell them a little bit about your real self (i.e. your occupation and interests in life).
  5. You will listen to the review of the scenario's context, and then you will be asked to provide feedback about the strengths and potential areas for improvement to the trainees.

Thank you! We really appreciate your participation and valuable feedback!