



# Neonatal Ethics Teaching Program

## Problem Based Learning in Ethics (PBLE)

### Antenatal Consultation at the Limit of Viability

#### Trainee Guide

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## Description of PBLE

A PBLE teaches some of the competencies of the Neonatal Ethics Teaching Program that the NICU fellows are expected to acquire before completing their Neonatal-Perinatal Medicine training at the University of Ottawa. Furthermore, a PBLE provides trainees the opportunity to practice and learn how they would interact with a true patient in a given clinical scenario. This helps trainees improve their communication skills and application of ethical principles when they have to interact with parents in delicate, difficult, and ethically charged situations regarding either their unborn or born child. Trainees are encouraged to refer to a procedural form that outlines the steps they should follow during a one-on-one medical encounter and use the Standardized Patient (SP) as a teaching tool.

## Objectives

1. To identify areas of potential conflict at the limit of viability.
2. To explain the major ways to resolve conflict at the limit of viability.

## Required Reading

- 1) Halamek LP. Prenatal consultation at the limit of viability. *Neo Reviews* 2003;4:e153-e166.
- 2) CPS Position Statement:  
<http://www.cps.ca/en/documents/position/management-anticipated-extremely-preterm-birth>

## Additional References

- 1) Yee WH. What information do parents want from the antenatal consultation? *Paediatr Child Health* 2007;12:191-196.
- 2) Boss RD, Hutton N, Sulpar LJ, Wes AM, Donohue PK. Values parents apply to decision making regarding delivery room resuscitation for high-risk newborns. *Pediatrics*;2008;122:583-589.
- 3) Lavoie ML, Keidar YK, Albersheim D. Attitudes of Canadian neonatologists in delivery room resuscitation of newborns at threshold of viability. *JOCG*;2007;29:719-725.
- 4) Kavanaugh K, Savage T, Kilpatrick S, Kimura R, Hershberger P. Life support decision for extremely premature infants: report of a pilot study. *Journal of Pediatric Nursing* 2005;20:347-359.
- 5) Young E, Tsai E, O’Riordan A. A qualitative study of predelivery counselling for extreme prematurity. *Paediatrics & Child Health* 2012;17:432-6.

## How to prepare for this PBLE

- 1) Read the required readings.
- 2) Review, in detail, the case scenario with the SP (see Appendix A).
- 3) Review, in detail, the “Procedural Form: Antenatal Consultation” (see Appendix B).

## **PBLE Timeline**

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

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

- 1) 25 min to cover the initial steps of the medical encounter.
- 2) 15 min of discussion.

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

- 3) 25 min to proceed accordingly through the medical encounter.
- 4) 5 min to cover the closure of the medical encounter.
- 5) 10 min of discussion.

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

Appendix A  
**Case Scenario with the Standardized Patient**

<b>Reason for consultation</b>	<p>27 year old mother, uneventful second pregnancy, now at 25+4 weeks gestation.</p> <p>The mother presented in preterm labour after she ruptured her membranes.</p> <p>Could you please meet with the family and provide your recommendations for the infant's care.</p>
<b>Role of the Trainee</b>	<p>Obtain a full history and good understanding of parents' values and beliefs.</p> <p>Provide information to the mother and discuss the options for care. Proceed towards shared decision making about the care plan for the infant.</p>

Before you meet with the mother, take time to review her medical chart (see the next 3 pages):

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**CHEO** Children's Hospital of Eastern Ontario  
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**REQUEST FOR CONSULTATION AND REPORT  
DEMANDE DE CONSULTATION ET RAPPORT**

SURNAME	GIVEN NAME & INITIALS
WARD OR DEPT	DATE OF BIRTH
STREET ADDRESS	TELEPHONE
CITY & PROVINCE	SHIP NO. & SUBSCRIB. INITIALS
TELEPHONE (HOME)	TELEPHONE (WORK)

To: Physician or Service / Au: Médecin ou Service

Date / Admission:

Reason(s) for requesting consultation/Motif de la consultation:

Please could you meet with this family and provide advices. This mother is 27 years old, now at 25+4 weeks GA, G2T0 P1L1. She had normal pregnancy and she is currently followed by MFTT. FUS was N x 2. She has protective serology, but unknown GBS. Came in TPTL with ruptured membranes and dilated cervix

Requested by: \_\_\_\_\_ for \_\_\_\_\_  
PRINT NAME SIGNATURE STAFF PHYSICIAN/MRP (most responsible physician)

Billing number: \_\_\_\_\_ Date: \_\_\_\_\_

Completed By: \_\_\_\_\_ on behalf of \_\_\_\_\_  
PRINT NAME SIGNATURE STAFF PHYSICIAN / SERVICE



Children's Hospital of Eastern Ontario  
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SUMMARY NOTES AND PHYSICIANS' PROGRESS NOTES  
NOTES SOMMAIRES ET RAPPORT D'EVOLUTION DU MEDECIN

DATE \_\_\_\_\_

UNIT N° (3 INITIALS) / UNITE N° (3 INITIALES) \_\_\_\_\_ DAY / JOUR \_\_\_\_\_ MONTH / MOIS \_\_\_\_\_ YEAR / ANNEE \_\_\_\_\_

SURNAME / NOM DE FAMILLE \_\_\_\_\_ GIVEN NAMES & INITIALS / PRENOMS ET INITIALES \_\_\_\_\_

STREET ADDRESS / ADRESSE \_\_\_\_\_

CITY & PROVINCE / VILLE ET PROVINCE \_\_\_\_\_ TELEPHONE NO. / N° DE TELEPHONE \_\_\_\_\_

NEXT OF KIN / PARENT PROCHE \_\_\_\_\_ OHP N° / N° OHP \_\_\_\_\_ SUB INITIALS / INITIALES \_\_\_\_\_

DATE & TIME / DATE ET HEURE	PROBLEM No. Problème N°	NOTES
22/12/2010		Admission Note (MFTT team)
		27w.o. Coz to P. An L1 — G1 2007 at 29 weeks now 25 <sup>th</sup> weeks GA. otherwise healthy.
		Admitted for Preterm labor and PROM.
		Pregnancy: ⊕ no GD, no PIH no other complications no drugs, no alcohol, no meds was on vitamins supp.
		Fus 7 weeks eye opposite. 18 weeks ⊕ malplac.
		Serology Hep B ⊖ Rubella ⊕ immune. Blood group A+ antihbep ⊖. CBS ?
		Current issues:
		Started to feel contractions after dinner. Took ibuprofen, then felt water loss. No fever, no fluency. No bleeding. No signs of infection.
		Exam cervix 3-4cm. FHR ⊕ Contractions 4-5 min ~ 1 min length with pain.
		Preterm labor + PROM.



## Appendix B

### Procedural Form: Key Components of a Medical Encounter

\*Note: this is a guideline of steps, they are not necessarily sequential. Many steps occur or re-occur throughout the whole encounter

#### ANTENATAL CONSULTATION

**Preparation:**

1. Identification of the reason for consultation and clarify the range of prognosis according to the expected gestational age prior to meeting with parents.
2. Review the maternal chart.
3. Discuss the plan with the obstetrical team (including fetal ultrasound result and estimated fetal weight).
4. Find a time and quiet place to make parents comfortable and allow for questions (30-60 minutes).
5. Try to have both parents present at the consultation (may need to schedule appointments). Appropriately inquire about the father's/partner's presence/absence (if applicable).

Steps	Further Explanation
<p>* <b>Welcome to parent(s) &amp; introduce yourself.</b></p> <p>* <b>Introduce other attendees as needed</b> (e.g. trainees, etc...).</p> <p>* <b>Welcome to others</b> (e.g. grandparents, acquaintances, etc ...) and inquire about the appropriateness of their presence in the room based on the parent(s)' wishes. Clarify their relationships to parents.</p>	<p>To establish trustful and supportive relationship and to introduce your role.</p> <p>To introduce others' role(s).</p> <p>To acknowledge that the situation is very sensitive and delicate and give the parents the opportunity to freely express their feelings or to have the support that they would like.</p>
<p>* <b>Inquire about the baby's name and refer to the baby's name.</b></p> <p>* <b>Understand and acknowledge the parent(s)' concerns.</b></p> <p>* <b>Be honest. Admit uncertainty when present.</b></p> <p>* <b>Maintain eye contact.</b></p> <p>* <b>Demonstrate compassion and empathy.</b></p> <p>* <b>Recognize the parent(s) wish.</b></p> <p><i>"I'm sorry to be meeting you in this difficult circumstance. However, I am here because there is a risk that [Name] may come early."</i></p>	<p>To show compassion and empathy by acknowledging that the situation is very sensitive and delicate.</p> <p>To establish a trustful relationship.</p>
<p>* <b>Introduce the agenda for the initial meeting.</b></p> <p>* <b>Use an open ended question to create the agenda according to the parent(s) needs.</b></p>	<p>To explain the specific steps during the interview.</p> <p>To reinforce the shared decision making process.</p>
<p>* <b>Build upon and evaluate the parent(s)' knowledge base, level of understanding, values, beliefs and preferences for participation in the decision making</b> by using an open ended question.</p> <p><i>"How I can help you to better understand the situation and to make plans for [Name]?"</i></p>	<p>To clarify if parent(s) have preferences or wishes as to what should be done for their infant in term of saving life, quality of life and suffering, since this will influence how you are going to discuss issues with them.</p> <p>To allow the parent(s) to "drive" the interview so you can go at their pace and level of understanding.</p>

Steps	Further Explanation
<p><b>* Verify parent(s) perspectives</b> by using open-ended questions.</p> <p><i>"What is your experience with premature infants?"</i></p> <p><i>"What are your worries for [Name], if is going to be born in the next few days?"</i></p> <p><i>"How can I support you?"</i></p>	<p>To understand parents' perspectives and to be able to adjust what you are going to discuss accordingly to parents' worries, questions and needs.</p>
<p><b>* Clarify incomplete components of medical and social history.</b></p> <p><i>"I reviewed your chart and I understand that... (Summarize briefly the information), but I would like to clarify some information..."</i></p>	<p>To gather information that could influence decision, prognosis, and care plan.</p>
<p><b>* Transitional signal</b> toward discussion about consequences of prematurity</p> <p><i>"My goal in the next minutes is to share with you information that may help you understand the situation."</i></p> <p><i>"The information that I am going to discuss may be difficult to hear, but it takes into account your whole situation."</i></p>	<p>To prepare parent(s) about the information they will hear because it could be difficult for them to hear.</p>
<p><b>* Share the information with parent(s) using short sentences and simple, non-medical terminology.</b></p> <p><b>* Acknowledge our prognostic limitations and the limits of the meaning of statistics.</b></p> <p><b>* Allow silence and time as often as needed.</b></p>	<p>To avoid long monologue and to allow parent(s) to integrate information.</p> <p>To use parent(s)' knowledge base, and respect the parents preferences about the type of information they wish to hear</p> <p>To ensure parent(s)' gain sufficient understanding about: survival, long term outcomes, short term complications and the hospital stay.</p>
<p><b>* Evaluate parent(s)' understanding frequently and make readjustments as necessary. Offer time for parent(s) to ask questions as often as possible.</b></p> <p><i>"May I ask you to summarize what I told you?"</i></p> <p><i>"Is there anything else you need to know or understand better?"</i></p>	<p>To evaluate their understanding and competency for decision making and voluntarism (freedom to consent without undue third party influence).</p>
<p><b>* Observe parent(s) reactions and listen to the way the parents describe the situation.</b></p> <p><b>* If you can identify them, you can name them:</b></p> <p><i>i.e. Anger: "You seem upset by that ..."</i></p> <p><b>* Acknowledge, validate and support parent(s) emotions.</b></p> <p><i>"Your emotions/reactions, are more than understandable"</i></p> <p><b>* Allow them to keep some realistic hope (2 scenarios):</b></p> <p><i>"The days and weeks that you gain for [Name], will give them greater chances of survival and better long term outcome."</i></p> <p><i>"[Name] needs to be delivered early so they will have a better chance of survival and less of a chance to develop complications."</i></p> <p><b>* Offer support to parent(s) all along the encounter.</b></p> <p><i>"We know that this is very difficult for you. Is there anything you would like me to do that would help you in a more concrete way?"</i></p> <p><i>"We will be with you all along the process...."</i></p>	<p>To acknowledge emotion by using general terms</p> <p>To demonstrate empathy by normalizing the reaction.</p> <p>To demonstrate empathy and acceptance of the parent(s) perspectives and concerns.</p> <p>To ensure that parent(s) do not feel abandoned.</p>

Steps	Further Explanation
<p><b>* Transition toward discussion about care plan.</b>  <i>"The news that I just shared with you is difficult to hear, but I need to discuss with you what can be offered to [Name] if they are born very soon."</i></p> <p><b>* Ask the parent(s) if they are comfortable with the current process or the way they are participating to the discussion.</b>  <i>"Are you comfortable to discuss now or would you prefer me to come back later?"</i></p>	<p>To prepare the parent(s) regarding their role in the decision-making if the baby is born.</p> <p>To make sure with the parent(s) that they are not too overwhelmed.</p>
<p><b>* Explain the usual care offered in that specific situation. Offer options according to the standard of care.</b></p> <p><b>* Always discuss options with parent(s) to allow them to participate.</b></p>	<p>To describe options based on the Canadian Pediatric Society statement.</p> <p>To increase their satisfaction in regards to participation in the decision making process.</p>
<p><b>* Offer a break time in order to give the parent(s) an opportunity to talk together and/or with other family members or friends and plan a follow-up meeting with them within 24 hours.</b></p>	<p>To allow the parent(s) to relieve some anxiety and decrease fatigue, so they will be able to take a step back in order to think about questions for clarification and thus make better decisions based on their own perceptions.</p>
<p><b>End of first meeting</b></p>	

<b>Follow-Up Meeting within 24 hours</b>	
<b>Steps</b>	<b>Further Explanation</b>
<p>* <b>Re-introduce yourself.</b></p> <p>* <b>Summarize previous discussion(s)/decisional care plan.</b></p> <p>* <b>Provide parent(s) the opportunity to ask any questions.</b></p>	<p>To ensure both parent(s) and medical team are at the same level of understanding.</p>
<p>* <b>Set the agenda for this meeting:</b></p> <p>Evaluate parent(s) preferences to participate in the decision making process.</p> <p>Negotiate a shared treatment plan for the care of the baby if s/he is going to be born.</p> <p><i>Use words such as: "team, shared, together" etc.</i></p>	<p>To emphasize the teamwork between parent(s) and medical team.</p> <p>To achieve the best management plan for the baby to which everyone agrees.</p>
<p>* <b>Based on the care plan decision, explain</b> what will happen to the baby in detail, including the usual behaviors of the baby, depending on the following care plan chosen:</p> <p><b>- Interventionist</b></p> <p><b>- Comfort care</b></p>	<p><b><i>In case of intensive care:</i></b> To help parent(s) understand what will happen to the baby after birth and explain that the father can follow the baby to the NICU.</p> <p><b><i>In case of palliative care:</i></b> To provide the opportunity to make sure that the parent(s) understand the decision by reviewing the dying process (if necessary). To be able to move towards clarifying end of life preferences as needed (e.g. baptism, organ donation, autopsy, etc.).</p>
<p>* <b>Obtain clear consent for the care plan.</b></p> <p><i>"Do you agree with the care plan that we made together for [Name] ...?"</i></p> <p>* <b>Empathize with parent(s) and their perspective while reaffirming care plan.</b></p> <p><i>"The decision we made is the best in the circumstances. We will make sure that [Name] ... will receive the care as we discussed."</i></p>	<p>To confirm the decision and ensure that they feel supported and secured.</p>
<p>* <b>Offer the opportunity to make any changes to the care plan now or later, recognizing there are limits.</b></p> <p>* <b>Offer the opportunity to re-discuss and information or changes of the clinical situation individually or with other supports (e.g. nurses, social work, etc.).</b></p> <p>* <b>Maintain open communication.</b></p>	<p>To acknowledge that parts of the care plan are hypothetical until the actual events occur.</p> <p>To respond to changing medical and psychosocial needs.</p> <p>To offer opportunities to be called at any time to re-visit them if they have any other questions.</p>
<p>* <b>Ask for any other questions or clarification before you leave.</b></p> <p><i>"Do you have any questions about what we have discussed today?"</i></p> <p>* <b>Close the interview by being appropriately hopeful.</b></p> <p><i>"Goodbye and we will see you again as needed."</i></p> <p><i>"We wish you the best and hope your pregnancy continues without further complications and that your baby does very well"</i></p> <p><i>"We will do our best, when [Name] is born and keep you informed at all times."</i></p>	<p>To ensure that the parents feel supported and secured.</p>