

Case 1: Anticipated Death on the Newborn Unit --- Work Sheet

Julia is a 24 year old woman who gave birth at 4 o'clock this afternoon to a male baby known to have trisomy 13. She and her husband, 25 year old Todd, had extensive counseling prenatally and decided to carry the baby to delivery. Their goal is to not admit him to the ICU, but to provide him with care directed at comfort and allowing natural death to occur. At the vaginal delivery at 38 weeks, the baby weighed 2.1 kg and had APGAR scores of 7 and 8 following drying, stimulation, and brief blow-by oxygen. Exam was notable for a small head and very small eyes with colobomas of the irises, extra fingers, rocker-bottom feet, a sub-mucous cleft palate, a very small penis with non-descended testes. There was no heart murmur. The baby held a pacifier in the mouth but did not suck on it. His name is Logan.

In following the pre-natal birth plan, the nurse kept Logan in the room with the parents and did not do routine tests and interventions (glucose check, vitamin K, eye ointment), but the parents took turns holding the baby. Grandparents are anticipated to arrive later to take some pictures. The afternoon pediatric attending has already entered a "DNar/DNI order" in the chart.

You are on call on the evening shift and received the above sign-out with the advice: "Give comfort care only. This baby may survive for hours, weeks, or more. If survives beyond 2 days, will arrange for home hospice." The nurse calls you at 8 pm. The mom is now more able to talk and the parents have questions about what is likely to happen.

Your exam is as above, the baby occasionally opens his eyes briefly and he does not look at all distressed. Pulse is 130, RR 40 without grunting, flaring or retraction

	Questions	What are we worried about?	What do we say?	What do we do?
1	Anticipating the end	"The dad looks very agitated and nervous...what should we do?"		
2.	Pain, discomfort, dyspnea	"The baby looks uncomfortable"		

Author(s): CS Mott Children's Hospital Pediatric Palliative Care Team, 2010-2011.

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3. I's & O's of dying

“What if he doesn't want to drink?”

What are we worried about?

What do we say?

What do we do?

4. Seizures, agitation, myoclonus (not likely for this case)

5. Before the last breaths

“What should we be ready for?”

6. After the death

“Now what?”

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