

Case 1: Anticipated death on the newborn unit

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

	Patient issues	Family issues	MD issues	Nurse/RT/etc. issues
1 Anticipating the end	Can he drink/eat? Hunger Discomfort from CHF, resp distress Temperature control	Is he in pain? Is he hungry? Will he starve to death? Will he have trouble breathing? How will I cope with my grief/emotional pain? How will my family/friends respond? What will death look like? Religious rites / prayers.	Can he suck / swallow Risk of early CHF/ cyanotic heart? Pain? Excessive secretions? Are the orders entered (including limits) and clear?	Vital signs Monitoring What limits to interventions are ethically and legally permissible (and family has given clear indication for)?
Useful questions and phrases for the family	I'm doctor _____. I'll be available all evening and all night. My job is to make sure that Logan is comfortable. Babies with Logan's problems have under-developed brains. His may not be developed enough to be able to suck and to swallow. We would never prevent any baby from drinking or feeding. If his body wants to eat and he wants to suck, we should absolutely let him. Let's offer him some sugar water. If he'll take it, great! If not, even a little sugar water on a pacifier may make him more comfortable.			

	<p>If he sucks well, there is no reason not to let him drink from a bottle or from the breast, if you would like to try.</p> <p>We want our staff and you to be able to concentrate on Logan and not on any monitors. Just let us know if you see anything that makes you worried. One of us will be in to check on him every _____ minutes (negotiable).</p> <p>What spiritual or religious support will be important for you? Can I call them for you?</p>			
	Patient issues	Family issues	MD issues	Nurse/RT/etc. issues
2. Pain, discomfort, dyspnea	<p>If CHF, may have dyspnea. If retained lung fluid, may have dyspnea</p>	<p>How will we know if he has pain or trouble breathing?</p> <p>Will the medicine you are giving him for his pain or distress cause him to stop breathing?</p> <p>....perhaps a discussion of the Principle of Double Effect</p>	<p>Dosing and route of opioids. Morphine</p> <p>Initial dose: 0.15 to 0.3 mg/kg /dose PO or SL q 3 hours.</p> <p>= 0.3mg to 0.6mg (I would choose 1 mg/ml and give 0.3mg as a first dose, give an extra 0.1 in 20 minutes if distress continues, then give the effective dose every 3 hours as needed. Call if not enough.</p> <p>Blow-by oxygen for comfort?</p> <p>Oral or SL: -----></p> <p>IV or sub-Q (less desirable) 0.05 to 0.1mg/kg</p>	<p>Recognizing pain or distress (Grimacing, whining Tachypnea, retractions, flaring, grunting)</p> <p>What is the largest volume that can be delivered sub-lingually?</p> <p>If oral or sublingual</p> <p>HOW SUPPLIED: Most concentrated: Morphine 20mg/ml (too concentrated for babies) Morphine 2mg/ml (10mg per 5 ml cup) (would mean 0.15 ml as first dose) (sub-linguals need to be given more slowly, 2 or 3 drops at a time) Morphine 1mg/ml injection (can be used in a pinh) p.o. or sub-lingual</p>
Useful questions and phrases for the family	<p>We will watch closely for any signs that Logan is having trouble breathing. What did you see that shows you he is/might be uncomfortable?</p> <p>At the doses we are using, the effect of the medicine will relieve pain and shortness of breath with very little, if any, effect on his breathing. Older children who can talk often wake up and say, "thanks".</p> <p><i>Even if it were to require large doses of medicine to control his discomfort, if our reason is to lessen his distress, it is permissible both legally and morally to use a medicine that MAY have an unwanted side effect (if we are using it for the right reason). We never use medicine to decrease his breathing.</i></p>			
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<p>3. I's & O's of dying</p> <p>May include:</p> <p>Secretions, noisy breathing</p> <p>Nausea, vomiting (unlikely in this case)</p> <p>Bleeding (unlikely in this case)</p>	<p>Sensation of choking? Feelings of dyspnea?</p>	<p>Why is his breathing so noisy? Is he drowning? Should he be suctioned? Should he be on monitors?</p>	<p>Noise vs. distress. Is there fluid overload?</p> <p>Drugs: Glycopyrrolate 0.04-0.1 mg/kg PO 0.004 – 0.01 IV, SC comes 0.2mg/ml for this 2 kg baby: would give 0.1 mg or 0.5 ml</p> <p>Atropine: 0.01 to 0.02mg/kg PO or SL Comes 0.4mg/ml, so give For this 2 kg baby would give 0.04 mg Or 0.1 mg sub lingual</p>	<p>Should I suction him?</p> <p>More aggressive suctioning may cause rebound and may be more obnoxious than a little bit of noise.</p> <p>Nasal bulb syringe suction may be well tolerated</p>
<p>Useful questions and phrases for the family</p>	<p>The noises you hear are just normal saliva and a little mucous that is in his nose and throat. If it appears to be causing him distress we can use some medicine to make them a little drier and less noticeable.</p>			

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<p>4. Seizures, agitation, myoclonus (unlikely in this case)</p>				
<p>Useful questions and phrases for the family</p>				
	Patient issues	Family issues	MD issues	Nurse/RT/etc. issues
<p>5. Last breaths</p>	<p>Comfort, color</p>	<p>Comfort, color Will we know when the end is near? Did we do the right thing? Did we</p>	<p>Will I know when the end is near? Will the medicine I order cause his</p>	<p>Will I know when the end is near? Will the medicine I administer cause his</p>

		make the right decisions? What if I'm not there at the end (unwillingness to leave the bedside)?	death? How do I tell the family he is gone? Don't increase dosing of medicine without objective increase in distress.	death? When Logan dies, is it okay for me to tell the family?
Useful questions and phrases for the family	At some point, his breathing will become irregular. There may be times of faster breathing, and some long pauses in his breathing and even some gasping sounds. Don't be at all surprised if you think he has taken his last breath, but then after a long pause he breathes again.			
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6. After the death	Dignity, respect	Dignity, respect How long can he stay with us? What about our religious ? Anticipatory grief	Gift of life? Autopsy? Pronouncing the death. Documentation of the death. (Documentation must be explicit and hands on, check eyes, listen to heart for 2 minutes)	Anticipatory grief. What else could/should I have done?
Useful questions and phrases for the family	I'm so glad for him, that you were able to be here and hold him. You made very wise choices for him. If love alone could have saved him... I wish there had been something else we could have done. I, we will never forget your baby.... Phrases to avoid: He's in a better place. Leave organ donation conversation to the trained staff.			

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