

10 year old with advanced cancer -- Work Sheet

Annie is a 10 year old girl admitted with a recurrent, metastatic neuroblastoma. After an initial response to therapy 3 years ago, she had recurrence 4 months ago that has not responded to aggressive chemotherapy with autologous stem cell transplant and a recent phase 1 agent. She has bone pain in her chest, shoulders and back. She had severe epistaxis last week from thrombocytopenia and was briefly admitted to the PICU last week in hemorrhagic shock. With aggressive fluid management, including multiple PRBC and platelet transfusions she stabilized without requiring intubation. Scans showed marked progression of her disease.

At a team and family meeting last week, the parents decided to change goals of care to comfort. No chemotherapy options are going to be offered. The decision was made to not use TPN. Antibiotics will not be started in case of fever. Because they are divorced, mother and father have chosen to keep her in the hospital for her last days. She was transferred to a private room on the oncology ward where she has a very good relationship with several nurses.

She is expected to live for days, weeks at most. There is a DNAR/DNI 'Allow Natural Death' order on the chart. Child life and spiritual care have been involved. She likes to work on art projects when she feels good and until today has been awake for 3 or 4 hours each day. Three days ago Annie filled out a 'My Wishes' document saying she "wants to be comfortable and to not have any tubes in her nose or blood draws or needles other than through her Broviac". She has acknowledged that she is going to die and is 'only a little bit afraid'. She has told her dad she is worried about her mom.

Annie has had trouble with nausea and vomiting, incompletely controlled with ondansetron. Pain has been well controlled with the patient/parent controlled hydromorphone. She has not had constipation, and has been sleeping reasonably with a dose of IV lorazepam at night. Dexamethasone was started last week to help with bone pain, and her appetite has increased when she is awake.

Her meds include: Hydromorphone PCA at 20 mcg/kg/hour (600 mcg); with a 600 mcg bolus every 8 minutes as needed. (These are both double what they were 36 hours ago.) Ondansetron. 3mg IV q 6 hours; Diphenhydramine 25 mg IV q 6 hours prn nausea; Lorazepam 0.5 mg every 4 hours prn agitation, and qhs for sleep. Dexamethasone 20 mg IV q am. She had some facial puffiness noted earlier and IV fluids were reduced to ½ maintenance rate.

At least one parent has been at the bedside continuously. She has been receiving PRBC's every 3 days and platelets every 2 days.

You are on call this evening: You get the above sign out face to face with the additional instructions: "Annie has been fading today, will briefly open her eyes and squeeze a parent's hand" Dad is completely on board with the plan, but Mom has been tearful and less certain.

	Questions	What are we worried about?	What do we say?	What do we do?
1 Anticipating the end	“Dad is on board...mom is less certain”			

	Questions	What are we worried about?	What do we say?	What do we do?
2. Pain, discomfort, dyspnea	“Won’t those pain meds make her stop breathing?”			

3. I’s & O’s of dying Vomiting	“What can we do about the vomiting?”			
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Bleeding	“We don’t want her to bleed to death”			
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4. Seizures, agitation,
myoclonus (not likely
for this case)

Questions

What are we worried about?

What do we say?

What do we do?

5. Before the last
breaths

“What should we be ready for?”

6. After the death

“Now what?”

Cancer Case: Learning Objectives

	Trigger Qustion(s)	Learning objectives
1 Anticipating the end	“Dad is on board...mom is less certain”	<ol style="list-style-type: none"> 1. Identify the sources of distress in the patient, the family and the support staff 2. Practice using language that can comfort and reassure patients and families.
2. Pain, discomfort, dyspnea	“Won’t those pain meds make her stop breathing?”	<ol style="list-style-type: none"> 3. Assess dyspnea and pain 4. Know doses and routes of at least one opioid 5. Use phrases that can reassure the family that using an opioid is safe and appropriate.
3. I’s & O’s of dying: Nausea and vomiting	“What can we do about the vomiting?”	<ol style="list-style-type: none"> 6. Recognize treatable causes of nausea and vomiting 7. Describe at least one pharmacologic and one non-pharmacologic method to treat significant nausea and vomiting near the end of life
4.. I’s & O’s of dying: bleeding	“We don’t want her to bleed to death.”	<ol style="list-style-type: none"> 8. Describe at least one pharmacologic and one non-pharmacologic method to minimize the distress of bleeding near the end of life 9. Demonstrate language that can reassure patients or family members who are worried about bleeding
5. Before the last breaths	“What should we be ready for?”	<ol style="list-style-type: none"> 10. Explain the process for approaching patients and families regarding autopsy and gift of life.
6. After the death	“Now what?”	<ol style="list-style-type: none"> 11. Review the ‘check list’ of post-mortem care items. 12. Demonstrate language that may comfort family members after a death.