

Module 8: Final Hours in Pediatric Palliative Care

Supplemental Teaching Materials/Training Session Activities

Module 8

Table 1: Symptoms of Impending Death and Interventions/Teaching Points

Symptoms	Possible Causes	Interventions/Teaching Points
Profound progressive weakness	<ul style="list-style-type: none"> • Hypoxia • Progressive disease • Malnutrition 	<ul style="list-style-type: none"> • Will require additional assistance with all or most of care • Ensure bedside commodes, hospital beds and other adaptive equipment are available
Sleeping much of the time	<ul style="list-style-type: none"> • Hypoxia • Progressive disease 	<ul style="list-style-type: none"> • Rule out cause of oversedation
Little interest in food and drink	<ul style="list-style-type: none"> • Decreased need for food as the body naturally begins to conserve energy. 	<ul style="list-style-type: none"> • Older children have indicated this is not experienced as hunger or thirst. • Dehydration is a natural comfort measure as the body cannot process feeds/fluids effectively. • If the child shows interest in PO feeds, allow for small frequent feeds as tolerated. Do not force a child to PO feed when imminently dying.
Difficulty swallowing	<ul style="list-style-type: none"> • Increased secretions • Profound weakness • Decreased alertness 	<ul style="list-style-type: none"> • Do not force food/fluids • If interested in PO feeds, provide small frequent feedings • Elevate head of bed when PO feeds are attempted
Urinary incontinence, or retention	<ul style="list-style-type: none"> • Opioids • Neurological compromise • Urinary obstruction 	<ul style="list-style-type: none"> • Opioid rotation • Crede's maneuver (apply manual pressure over the lower abdomen to promote emptying of the bladder) • Bladder decompression via catheterization or placement of a Foley catheter • Use of diapers to protect bed linens, if appropriate. • Change linens and cleanse child frequently to maintain comfort and protect skin.
Oliguria or anuria	<ul style="list-style-type: none"> • Renal insufficiency • Dehydration • Impending death 	<ul style="list-style-type: none"> • Prepare the family for impending death, although in children death may not occur for 24-96 hours
Changes in	<ul style="list-style-type: none"> • Progression and imminent 	<ul style="list-style-type: none"> • Use of opioids for signs of dyspnea or distress

respiratory rate & pattern Cheyne-Stokes	death	<ul style="list-style-type: none"> • Use of benzodiazepines if agitation noted • Prepare family for end of life, although may be hours to days before death
Noisy breathing, airway secretions	<ul style="list-style-type: none"> • Described as the death rattle • Primary lung disease • Brain tumors • Unable to maintain one's own secretions 	<ul style="list-style-type: none"> • Child is often unconscious or unaware of his/her surroundings and therefore not viewed as uncomfortable to the child. Compare this to snoring; snoring does not bother the person who is sleeping, only those around them. • Treatment: scopolamine patch, hyoscyamine gtts, glycopyrrolate, limit or hold fluids/feeds • Reposition the patient, elevate head of bed • Minimize deep suctioning
Mottling and cooling of skin	<ul style="list-style-type: none"> • Poor perfusion and decreased circulation 	<ul style="list-style-type: none"> • Use light covers
Mental status change, such as delirium, restlessness, agitation, and coma Disorientation to time with increasingly short attention span	<ul style="list-style-type: none"> • Disease progression • Opioids • Opioid toxicity • Metastatic disease to brain • Persistent hypoxia 	<ul style="list-style-type: none"> • Haloperdol, risperidone for delirium • Assist with orientation of time by placing a clock at bedside, opening blinds/windows or keeping lights on during the day and closing at night. • Short conversations, anticipate repeating

Of note:

- These symptoms are merely guidelines and allow for anticipatory guidance for families, but not all children will experience each of these symptoms prior to death.
- Anticipatory guidance is critical for each of these symptoms. Educating families on the signs and symptoms of impending death is crucial to their awareness and allow for preparation.
- Typically, a child will die of respiratory failure followed by cardiac failure. This is different than an adult's death. Therefore, heart beats can remain relatively strong up to the point of death in many children. Therefore, the child's respiratory rate will typically become slow and irregular before changes are noted in the heart.

References:

- Berry, P., & Griffie, J. (2019). Planning for the actual death. In: B.R. Ferrell and J.A. Paice (Eds.), *Oxford textbook of palliative nursing*, 5th edition (Chapter 33, pp. 420-431). New York, NY: Oxford University Press.
- Wolfe, J (2011). Easing distress when death is near. In: J.Wolfe, P.S. Hinds and B.M. Sourkes (Eds), *Textbook of interdisciplinary pediatric palliative care* (Chapter 36, pp. 368-385). Philadelphia, PA: Elsevier/Saunders.