

5.2 Communication

Communicating honestly with a seriously ill child and their family about prognosis and expected disease trajectory is central to excellence in palliative and end-of-life care. Honest prognostic discussions, as difficult as they are, allow the child and family to anticipate what they will likely experience and empowers them to make effective decisions about their ongoing care. Engaging in these discussions also enables the clinician to explore the family's goals, needs, hopes and fears.

No parent enjoys talking about the possibility/likelihood that there is no further curative treatment available for their child; however, research has taught us that parents want to have these honest discussions with their clinicians.¹ At times, non-verbal communication is more important than verbal communication. Silence and being present, accessible and approachable are all very important skills for effective communication in pediatric palliative care.

Advance Care Planning

Advance Care Planning (ACP) is necessary for any child with advanced cancer. It requires effective communication to clarify the goals of care and establish agreement on appropriate interventions for the child as prognosis changes. Ideally, ACP discussions should happen early and in a non-urgent fashion to help parents digest complex end-of-life decision-making. ACP should be implemented even though it is difficult to exactly predict the timing of death.

Important topics to review in ACP include:

1. Seriousness of illness and disease progression
2. Expected course, treatment options and risk/benefits to each
 - a. Treatment options may include palliative chemotherapy, palliative radiation, antibiotics, blood replacement products
 - b. How long to continue on, and when to limit certain aspects of, the treatment plan
 - c. Will treatment prolong life but at a cost of suffering? Will treatment prolong life and improve quality of life?
 - d. Benefits and impact of artificial nutrition and hydration at end of life
 - e. Reassurance that the child will be offered fluids and foods by mouth for comfort providing ability
3. Focus on minimizing distress and easing suffering
 - a. Review of pain medications and adjuvants
4. Family-centered care and the focus on siblings
5. Resuscitation
6. What does death look like (please refer to [Sub-Section 5.5 End of Life](#))

Resuscitation

Resuscitation status is a small but integral part of ACP. Discussions about resuscitation should be incorporated into the larger issue of goals of care, as the benefits of cardiopulmonary resuscitation (CPR) when goals become focused on optimizing comfort are dubious. Parents typically obtain their information about resuscitation from the media. Some parents have expressed worry that “Do Not



Resuscitate” (DNR) means “Do Not Treat”; they may have the misperception that if a DNR is in place, their child will not have access to pain and symptom management and other aspects of supportive care, leading to increased suffering.

Important considerations when communicating about resuscitation include:

1. Ensure you lead discussions about resuscitation with open-ended questions versus asking parents if they want a DNR. Open-ended questions allow for a deeper and meaningful understanding of what a DNR is and is not. It is important to remember that every parent would do anything and everything to save their child.
2. CPR will not save the child dying from cancer.
3. Parents need to understand the futility of attempting resuscitation in a child dying of a malignant disease. They require support and guidance from the medical team to appreciate the pain and suffering (both for the child and family) that often come with resuscitation attempts in a child with advanced cancer and the parental distress of actively withdrawing life-sustaining treatment.
4. It is crucial to emphasize to parents what WILL be provided (oxygen, medications to keep their child comfortable and ongoing care and support), not just discuss what we will NOT do.

References

1. Mack JW, Wolfe J, Grier HE, Cleary PD, Weeks JC. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *J. Clin. Oncol.* Nov 20 2006;24(33):5265-5270.

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Record of Updates

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