



# Supporting Children and Families at a Child's End of Life

## Pediatric Palliative Care Pearls of Anticipatory Guidance for Families

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### KEYWORDS

• End of life • Palliative • Pediatrics • Hospice • Mental health provider

### KEY POINTS

- Use the child's signs and symptoms as a guide to prognostication.
- Continue to empower the parental role, as this is a unique gift only they can offer.
- Help prepare patients and families for what they may see, hear, and experience during the dying process.

### INTRODUCTION

A child's death has been described as the *ultimate loss*,<sup>1</sup> and preparing for this often seems unnatural and illogical. Mercifully, pediatric deaths are relatively uncommon; however, given this rarity, health care providers are often unfamiliar and uncomfortable with supporting the dying child. Pediatric death occurs under different circumstances, ranging from acutely in the neonatal period to perhaps expectedly as a young adult from a congenital life-limiting disease, thus requiring different skill sets for preparation and anticipatory grieving for families.<sup>2</sup> This article seeks to provide clinical pearls from pediatric palliative care providers to help patients and families process and prepare for a child's death.

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Disclosure Statement: Neither L. Humphrey nor B. Lockwood have any financial or other affiliations to disclose at this time.

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Child Adolesc Psychiatric Clin N Am 27 (2018) 527–537

<https://doi.org/10.1016/j.chc.2018.05.003>

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## EDUCATING PATIENTS AND FAMILIES ABOUT PALLIATIVE CARE

Case: Your patient, Daniel, a 21-year-old with hypoplastic left heart syndrome status post a Fontan procedure, now has severe ventricular dysfunction and is being considered for heart transplantation. The primary team consults palliative care. You have known this patient for multiple years due to his depression and anxiety. He asks to speak to you because he is worried that “the death doctors are coming to talk me out of a heart transplant.”

Pediatric palliative care is the medical specialty that addresses the many stressors experienced by pediatric and young adult patients with life-threatening conditions. It addresses physical symptoms (eg, pain, nausea, insomnia), spiritual, and psychosocial stressors that can negatively impact quality of life. Additionally, palliative care seeks to ensure that the patient and caregivers have maximal comprehension of their health issues and medical choices, and that the health care team understands the patient’s hopes and seeks to align patient goals with medical interventions as able. There can be discordance between hopes and what medicine can offer. In these cases, palliative care partners with the patient, family, and the health care team for optimal communication and decision making. At times, patients may transition to hospice care, a specific type of palliative care that provides end-of-life care for the dying patient that still attends to the many domains of care, including physical, psychological, social, spiritual, and cultural.

## ACCEPTING THE DEATH OF A CHILD

Case: Susie is a 16-year-old girl with high-risk acute myelogenous leukemia who received stem cell transplantation 3 weeks ago. Her single mother sits vigilant at Susie’s bedside in the pediatric intensive care unit. She was transferred 1 week ago due to renal and respiratory failure prompting need for continuous dialysis, intubation, and mechanical ventilation. Susie has not shown signs of clinical improvement. You have been consulted to provide support and help her mother “comprehend and accept” her daughter’s mortality risk.

Letting go of the goal for cure and moving toward hope for a comfortable death is an extremely challenging transition for patients, families, and health care providers. Caregivers may have difficulty understanding why previously effective therapies are no longer beneficial. They also struggle with the emotions of failing their child. As providers, you can help guide families through this transition from *life preservation*, preventing the loss and prolonging the life of their child, to *letting go*, recognizing the inevitable death and shift in focus to the child’s needs and well-being.<sup>3</sup>

There are a number of factors that influence parental readiness for their child’s death. The perspective of *letting go* is supported by certainty that the child cannot be cured, perception of suffering with visible symptom burden, an ability to separate their own needs from their child’s, and the ability to parent meaningfully.<sup>3</sup> Some caregivers can transition to death acceptance solely through these exposures and capacities; others can with additional clinical support. There are also caregivers who may never be able to transition from a goal of cure to a goal of comfort.

Each type of caregiver requires a different supportive approach. The caregiver who independently transitions will benefit from reassurance that there is emotional and practical reinforcement from the health care team. For those who transition with support, techniques such as motivational interviewing can be transformational. Clinician

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