

End of Life Issues for Pediatric Patients in the Emergency Department

Purpose: The goal of palliative, end-of-life, and bereavement care for children and their families is to provide them with the best care and support possible and to do so reliably and consistently, no matter how or where a child is cared for.

Background: The instinctive response and clinical objective for providers of pediatric emergency care is the preservation of life, sparing no expense or effort in the avoidance of death. However, death is an infrequent but inevitable part of providing care to acutely ill and injured children. Management of the issues and circumstances surrounding sudden and unexpected loss can be particularly challenging.

The diagnosis of a child's life-threatening medical condition often launches the child and family into a complex and confusing world of technologically sophisticated treatments, arcane terminology, and highly specialized personnel and organizations.

Do Not Resuscitate (DNR) Orders

- Staff should screen chronically and critically ill children and families for the presence of a DNR order.
- Children may wear alert jewelry indicating medical information and the presence of a DNR order if family members are not present.

Staff Training and Preparation

- ED staff members are trained to recognize children and families for whom the goals of care should be reconsidered.
- Procedures are in place for arranging care and consultations to support clinicians, children, and families in end of life issues.
- ED staff members have been provided training and assistance in developing skills in communicating bad news, discerning child and family wishes and concerns, and respecting dignity through their language and other behavior.
- ED staff members are aware of practices for limiting life-support interventions.
- Resources and procedures available to help staff cope with the stresses of caring for critically ill and injured children.

Communicating with Families

Preparation

- Understand that respectful and clear communication is an essential professional obligation.
- Plan with members of the care team for the delivery of bad news, including the words, the tone, the time, and the place. Have information that is as complete as possible.
- Anticipate that reactions will vary, but be prepared to deal with shock, grief, anger, panic, and other strong emotions.

- Have someone trained to respond to the family's emotional and practical needs who is ready to stay with the family.
- Try to have both parents present, if clinical and family circumstances permit, and ask if they would like their child or others to be present. If the answer is yes, plan for someone to accompany the child if he or she chooses to leave.
- Find a private, quiet place where everyone can be seated comfortably and you can make eye contact with the family members and touch them if that seems supportive.
- Have a trained translator present if necessary.
- Consider taping the conversation and providing the tape to the family.

Conversation

- Indicate at the start that the news is not good.
- Show your concern, empathy, and respect for the child and family.
- Listen carefully.
- Try to get an early sense of the family, including what they already know and how they express themselves. Adjust the style and content of communication—including the use of physical contact—accordingly. Use the everyday language of the family rather than the everyday language of clinicians, except when clinical terms are likely to be helpful.
- Consider using sketches and diagrams to support explanations of the diagnosis and prognosis.
- Seek guidance from families about the amount and specificity of information they want, and let them control the pace and flow of information insofar as possible.
- Allow time for families to absorb and process information.
- Assess (if the child's condition permits) whether discussion of options, goals, and plans should be initiated or postponed to a defined later time.
- Check family members' understanding of what they have heard and assess what needs to be repeated or reinforced during this or later conversations.
- Reassure families that it is normal to be emotional, confused, or overwhelmed.
- Provide written information and suggest other information resources.
- Offer to help parents prepare for talking with their child if the child is not present
- Encourage parents to write down questions as they arise, so that they can be discussed later.
- Respect parents' need for hope and reassurance but avoid evasions or deceptions that may undermine trust and prevent emotional and other preparation for what lies ahead.

Follow-up

- Arrange for further discussions as appropriate, including with the child (if he or she was absent), siblings, and others.
- Document the conversation (in addition to documenting diagnosis and prognosis) as a guide for future discussions.
- Reflect on the conversation and what might be done better in the future.

(Adapted from IOM, 1997)

Joint Commission Standards:

RI.1.3.5 pastoral care and other spiritual services

RI.1.2.7 The health care organization addresses care at the end of life. The Commission explains the intent of this standard as covering

- provision of appropriate treatment for any primary and secondary symptoms, according to the wishes of the patient or the surrogate decision maker;
- aggressive and effective management of pain;
- sensitive issues such as autopsy and organ donation;
- respect for the patient's values, religion, and philosophy;
- involvement of the patient and, where appropriate, the family in every aspect of care; and
- attention to the psychological, social, emotional, spiritual, and cultural concerns of the patient and the family.

Sources:

- When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families
Board on Health Sciences Policy Institute of Medicine. 2003
- Core Curriculum for Pediatric Emergency Nursing. ENA 2009
- Wright, J. End of Life Care in Emergency Medical Services for Children.