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# Palliative Care: Symptom Management from the Office

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## **Preface**

This guideline is intended to apply to children of all ages. For information regarding perinatal palliative care, see Perinatal Palliative Care guideline.

## **Key Points**

- Symptoms during End of Life are usually manageable in the home with education and preparation.
- Families often reach out to the primary care provider for help even when hospice is involved.
- Make a plan and write it down with/for the family being sure to include common issues:
  - Pain
  - Gastrointestinal issues
  - Airway/breathing issues
  - Neurologic changes
- Provide prescriptions for all medications needed in the plan.
- Provide contact information on how a physician can be reached after hours.

## Definitions and History

- Advanced Directives. Documentation of a person's desires for themselves or their ward in the event that they should be unable to communicate their desires, may include but is not limited to Do Not Resuscitate (DNR) status
- CPR. Cardiopulmonary resuscitation, including chest compressions and assisted respirations
- DNAR. Do not attempt resuscitation, has been suggested as an alternative to DNR but has met with criticism due to concerns over increasing confusion.
- DNR. Do not resuscitate. Please see the Neonatal Advanced Directives and Palliative Care guideline,
- Life-limiting Condition. A medical condition that will likely result in death at a younger age than expected
- Palliative Care.
  - Palliative care provides support and assistance to families facing challenging situations and difficult decisions with regard to their child's life-limiting condition.
  - Palliative care is not intended to coerce into making any particular decision but rather to ensure that the family has all of the necessary information and support to make the decision that is best for the child and family.
- History of DNR Orders
  - In 1991, the United States Congress approved the Patient Self-Determination Act (PSDA) that allowed adults to choose advanced directives and protect providers who followed the order.<sup>1,2</sup> Medical providers are required by the act to inquire if Medicare/Medicaid patients have an order in effect and to allow them the opportunity to institute one.
  - In 1992, Sahler and Greenlaw urged the American Academy of Pediatrics to educate pediatricians about PSDA and the American College of Emergency Room Physicians issued a statement, Ethical Issues of Resuscitation, that called for physicians to know state law and patient wishes regarding DNR.<sup>3</sup>
  - In 1995, the State of Arkansas created DNR regulations for providers of emergency medical services, and in 2005 revised the DNR form that withholds all CPR measures.<sup>4</sup>

## Symptoms That Are Likely to Arise at the End of Life

- The goal of palliative care is not only to treat symptoms as they arise but also to prepare families for symptoms that may arise as the end of life nears.<sup>5</sup>
- Many families rely on their primary care provider to continue to assist in symptom management, even when they have accepted that their child has a terminal condition and chosen palliative or hospice care. Below is a list of most common distressing symptoms at the end of life.<sup>6</sup>
  - Pain: may be physical, spiritual, or psychological
  - Airway/Breathing: may be related to obstruction, secretions, poor respiratory effort, or pulmonary failure leading to air hunger and distress
  - Gastrointestinal: nausea, vomiting, constipation, decreased appetite
  - Neurologic: seizures, anxiety, depression, drowsiness, decreased level of consciousness

# Intervention

Families, as well as physicians who work in the hospice care system who traditionally treat adults, look to pediatricians as a source of information on how to manage symptoms at the end of life. Helping that physician and the child's family to have a plan for what to expect and how to manage symptoms that arise will help everyone to be more comfortable as death approaches.

- A thorough history should be obtained on every patient prior to creation of a management plan. That history should include:
  - What does the family currently understand about the disease, its typical progression, and the patient's proximity to death?
  - What symptoms are present?
  - To whom are those symptoms concerning (patient, parents, other caregivers)?
  - What has been tried to manage the symptoms?
  - What other experiences has the family had with the dying process in the past and do they have concerns about similar symptoms happening to the patient?
- Once the current symptoms have been identified, a plan can be created to manage those symptoms and to plan for other symptoms that may arise in the future.
  - Pain
    - Attempt to determine if the pain is physical, psychological, and/or spiritual - pain may be a combination
    - If psychological or spiritual needs are identified work with the family to find an appropriate therapist, counselor, religious advisor
    - Identify a pain scale/evaluation tool that will work for the patient and the caregiver
    - Utilize the World Health Organization (WHO) pain ladder as a guide for management knowing that at the end of life medication may escalate
    - Consider alternative therapies: hypnosis, acupuncture, massage, radiation therapy (for masses or bony lesions)
  - Gastrointestinal issues
    - Nausea and/or vomiting
      - Look for medications that may be causing the distress
      - Consider frequent, smaller meals
      - Consider diphenhydramine, ondansetron, promethazine, scopolamine
      - If bowel obstruction: consider octreotide, steroids, surgical intervention
      - Consider alternative therapies: hypnosis, acupuncture
  - Constipation
    - Often related to pain medications; consider starting bowel regimen when narcotics initiated
    - Consider stool softener, bowel stimulant
  - Decreased appetite
    - May be progression of disease; help families find other meaningful interactions - avoid force feeding
    - Consider megestrol or steroids
  - Airway/Breathing
    - Shortness of breath
      - Increase airflow around the patient (a fan can be very helpful)
      - Relaxation/hypnosis techniques
      - Oxygen: only if it improves patient comfort; some patients find it more distressing than helpful

- Opioids for respiratory distress
    - Oral, sublingual, or IV morphine
    - Nebulized fentanyl may also be helpful but current studies may or may not find it better than PO or IV morphine
- Secretions “Rattling”
  - Attempt to determine if it is disturbing to the patient or the family – may not need intervention if it is not bothersome to the patient
  - Consider antihistamines, glycopyrrolate, scopolamine patch
- Neurologic changes
  - Agitation/Depression
    - If patient is still communicative consider therapy/counseling
    - Benzodiazepines or antidepressants
  - Drowsiness
    - Attempt to determine cause – may be medication related vs. disease progression
    - Consider changing medications or stimulants
  - Seizures
    - Consider benzodiazepines for acute events
    - Consider anticonvulsants if recurrent

## Documentation

- A written plan should be created for the family to refer to as symptoms arise and all necessary medications should be prescribed and filled so the family has them when needed.
- Provide family with letter explaining diagnosis and current plan of care.
- Include contact information on how to reach the physician if questions arise.

## References

## References

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5. American Academy of Hospice and Palliative Medicine. What is palliative care? Glenview, IL: American Academy of Hospice and Palliative Medicine. <http://www.palliativedoctors.org/> Accessed Sep 28, 2012.
6. Cozier F, Hancock LE. Pediatric palliative care: beyond the end of life. *Pediatr Nurs* 2012;38(4):198-206.

### Additional Selected Reference

Hanks G, Cherny NI, Christakis NA, Fallon M, et al. *Oxford Textbook of Palliative Medicine*. 4th ed. New York: Oxford University Press, Inc. 2011.