LIVE IN-PERSON AND VIRTUAL ACTIVITY

End-of-Life Nursing Education Consortium Pediatric Palliative Care

May 22-23, 2025

Children's Hospital Colorado
Medical Conference and Education Center
Aurora, Colorado

Provided by:
Children's Hospital Colorado
Pediatric Palliative Medicine

Children's Hospital Colorado

End-of-Life Nursing Education Consortium Pediatric Palliative Care

Overview

The End-of-Life Nursing Education Consortium (ELNEC) Project is a national and international end of-life/palliative care educational program administered by City of Hope (COH) designed to enhance palliative care in nursing.

Since 2000, ELNEC is a collaboration between City of Hope, Duarte, CA and the American Association of Colleges of Nursing (AACN), Washington, DC. ELNEC is the world's leading nursing education initiative focused on improving the care of patients with serious illness and their families. Since its inception, this model academic-practice partnership between AACN and the City of Hope has reached healthcare professionals in all 50 states and over 100 countries around the world.

Target Audience

This activity was developed for healthcare professionals to provide a more thorough understanding of how the end of a child's life impacts families, friends, and caregivers.

Who should attend?

- Undergraduate and graduate pediatric nursing faculty
- CE providers and staff development educators working in-pediatric settings
- Hospice nurses
- Homecare nurses
- APRN/staff nurses working in pediatric acute care settings (i.e. oncology, medical/surgical, palliative care settings, NICU, PICU, clinics, etc.)

Other members of the pediatric interdisciplinary team are welcome to attend, with the understanding that the curriculum is written by nurses for nurses.

Learner Outcome

After attending this event, participants will report increased knowledge related to providing evidence-based care for patients, as well as emotional and spiritual support to caregivers and survivors.

Agenda

Thursday, May 22, 2025

7:30 a.m.	Check in and breakfast
7:55	Welcome and Opening Remarks
8:00	**Introduction to Peds Palliative Care** Dora Mueller, MSPC, BSN, RN, CHPPN
9:00	**Symptom Management** Kristen Eisenman, MD, MSPC
10:30	Break
10:45	**Ethical Issues** Curtis R. Coughlin II, PhD, MBE, HEC-C Brian Jackson, MD, MA, HEC-C
11:45	Lunch
12:30 p.m.	**Sudden and Traumatic Death** Andy Krack, MD Casey Plank, CCLS Danny Nguyen, BSN, RN, CPN
1:30	**Communication** Rachel Rusch, LCSW, MSW, MA, APHSW-C
3:00	Break
3:15	**Loss, Grief, and Bereavement** Jenn Flaum, LCSW, MBA
4:15	Questions and Answers, Evaluation, and Wrap-up
4:30	Adjourn

Friday, May 23, 2025

7:45 a.m.	Check in and breakfast
7:55	Welcome and Opening Remarks
8:00	**Perinatal and Neonatal Palliative Care** Ashley Spalla, MSN-Neonatal Nurse Practitioner, RNC-NIC
9:00	**Cultural and Spiritual Considerations** Sara Reynolds, MDiv, BCC Rev. Jennifer Hill, MDiv
10:00	Break
10:15	**Pain** Jennifer Fanelli, MSN, APRN, CPNP-PC
11:45	Lunch
12:30 p.m.	**Family Panel** Rachel Rusch, LCSW, MSW, MA, APHSW-C
1:30	**Final Hours** Jenny Sheperdigian, MSPC, RN, CHPPN
2:30	Break
2:45	**Caring for Ourselves** Adam B. Hill, MD
4:15	Questions and Answers, Evaluation, and Wrap-up
4:30	Adjourn

Location

In-person Learners

Children's Hospital Colorado
Anschutz Medical Campus
Medical Conference and Education Center – 2nd Floor
Mt. Princeton Conference Room
13123 East 16th Avenue, Aurora, Colorado 80045

Virtual Learners

Zoom link: *https://us06web.zoom.us/j/83771140142*

Continuing Education Credit

Registration, **attendance**, sign-in and submission of the **evaluation**, including a written response to questions related to any change in practice that you may make as a result of learning that took place at this activity, are required for successful completion and receipt of the certificate of attendance. Claim only those hours you attend.

Attendance

Learners are required to sign-in for this NCPD activity to verify participation in the program.

Signing-in: Sign-in opens 30-minutes prior to the event. There are two sign-in options:

1. Text the attendance code below to 720-790-4423 or
2. Enter the attendance code below at ce.childrenscolorado.org/code

Attendance Code: **ELNEC25**

Evaluation

To obtain your NCPD certificate, the on-line **evaluation must be completed by midnight, Friday, June 6, 2025**. After completing the evaluation, you will be prompted to claim your NCPD credits. Any questions or concerns with access should be directed to ce@childrenscolorado.org.

Credit

Nursing: Children's Hospital Colorado is approved with distinction as a provider of nursing continuing professional development by Colorado Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation. This educational activity for 14.5 nursing contact hours (5/22 - 7.75 hours; 5/23 – 6.75 hours) is provided by Children's Hospital Colorado.

Others: A general certificate of attendance will be provided to all other attendees.

Financial Disclosure

Planners, faculty, and others in control of content (either individually or as a group) have no relevant financial relationships with ineligible companies.

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Children's Hospital Colorado

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END-OF-LIFE NURSING EDUCATION CONSORTIUM
Advancing Palliative Care

Pediatric Curriculum

MODULE 1

INTRODUCTION TO PEDIATRIC PALLIATIVE CARE

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Learning Objectives

At the completion of this introductory module, the participant will be able to:

- Describe the philosophy, principles, and roles of pediatric palliative care.
- Describe the role of the nurse in providing quality palliative care for children and families.
- Identify the role of collaboration within interprofessional team members while implementing pediatric palliative care.
- Recognize the various perspectives and impacts that having a child with serious illness may have on others.
- Discuss the unique aspects of suffering for children and families facing a life-threatening illness or event.

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NCP [National Consensus Project] Guidelines

Domain 1: Structure and Processes of Care

- Principles and practices can be integrated into any health care setting
- Delivered by all clinicians & supported by PC specialists who are part of an IDT
- Begins with a comprehensive assessment and emphasizes:
  - Patient [child] & family engagement
  - Communication
  - Care coordination
  - Continuity of care across health care settings

NATIONAL CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE

NCP, 2018

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Definition of Pediatric Palliative Care (PPC)

- Palliative care for children aims to improve quality of life for the patient and the family. This is done through expert management of pain and other physical symptoms such as shortness of breath, nausea, vomiting, and anxiety. It is also done through emotional, spiritual and other support services to help the patient and family cope with the roller coaster of emotions that result from dealing with a serious illness or condition (AAP, ND).

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Health and Well-Being of America's Children and Youth

- 14.4 % live in poverty
- 5% are not insured
- 14.6% live in food insecure housing
- 6 per 1,000 12-17 year olds were victims of serious violent crimes
- 16% of 12-17 year olds had at least one major depression episode

Childstats.gov, 2020; FIFCFS, 2020

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Facts about Pediatric Deaths in America

- Approximately over 42,000 children died in 2020 [neonate to 19 years of age]
- 21,467 deaths occurred in children under age 1 year
- 80% die in acute care settings

Heron, 2019

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Trends in Pediatric Palliative Care

- Children with serious illness and complex health care needs are living longer.
- Numbers of children with serious illness that could potentially benefit from PPC continue to increase.
- Early involvement of PPC allows for rapport building and establishing family driven, value-based care as the palliative care team journeys with patients and families facing an uncertain future that may include death.
- PPC teams have increased over the past decade, but expansion is essential to include all pediatric hospitals, general hospitals where children are cared for and community-based care settings.

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Palliative Care Is:

- Appropriate at any stage in a serious illness
- Provided over time to patients based on their needs and not their prognosis.
- Offered in all care settings
- Focused on what is most important to the patient, family, and caregiver(s)
- Interprofessional

NCP, 2018

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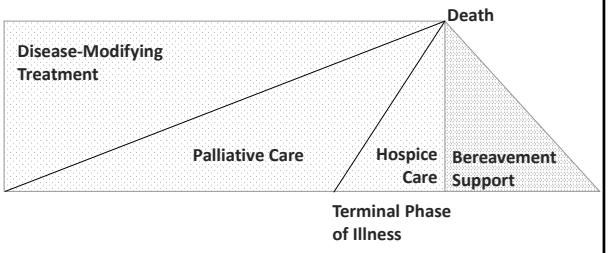
Palliative Care



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What is Hospice?

- Hospice care is a medical benefit covered by Medicaid and private insurances
- Patients with a life-expectancy of 6 months or less
  - *"Would you be surprised if this child died in the next 6 months?"*

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Why Hospice?

- Benefits:
  - Nursing care
  - Medical equipment
  - Pain and symptom management
  - Home based social work
  - Chaplain and hospice aid services
  - Respite care
  - Home delivery of many medications
  - Allows the child to stay home for care
  - Bereavement support for the family after the death
  - Additional support to the family in their home

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Changing the Landscape of Pediatric Palliative Care

- Affordable Care Act
  - Section 2302: Concurrent Care for Children Requirement (CCCR)
  - Removed the prohibition of receiving curative treatment for any eligible child with Medicaid or Children's Health Insurance Program (CHIP)
  - To be eligible
    - < 21 years of age
    - Physician certifies the child is within the last 6 months of life
    - Entitled to any other services to which the child is entitled under Medicaid for treatment of the terminal condition

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Pediatric Palliative and Hospice Care

- Philosophy of care
- Goals of care

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Differences between Adult Palliative Care and Pediatric Palliative Care

- Patient/Overall Caseload
- Team Members
- Developmental Stages
- Decision Making
- Communication
- Bereavement
- Etiology/disease trajectories
- Medication options
- Treatment options
- Documentation
- Resources

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Principles of Hospice & Palliative Care for Children

- Child and family are unit of care
- Adolescents and young adults have distinctive needs
- Holistic care
- Interdisciplinary
- Education and support of child/family
- Bereavement support

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Stop and Consider: Aurie and referral to Palliative Care

- 6 years old, diagnosed with glioblastoma (GBM)
- Aurie has 2 younger siblings.
- Providers recommend a palliative care consult during hospital stay.
- Her mother is overwhelmed and asks what this means. “My grandfather had hospice care just days before he died”. She shares. “Is Aurie dying?”

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Models of Pediatric Palliative Care

- Hospital-based programs
- Free-standing facility
- Hospice-based programs
- Community agency or long-term care facility

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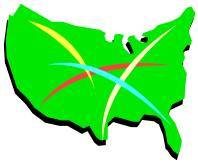
Death and Dying Disparities

- Child perspective
- Family perspective
- Sibling perspective
- Grandparents perspective
- Community perspective
- Schools



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Developmental Issues in Pediatric Palliative Care

- Comprehension
- Communication
- Fears
- Development theories & tools
- Child's need to protect family

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Stages of Development

- Infancy
- Toddler
- Preschool age
- School age
- Adolescence

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Stop & Consider: Loren and Developmental/ Family Issues

- 7 year old, home schooled, diagnosed at 7 months with sickle cell disease
- Raised by single mother, has two older brothers
- Has had 2 TIAs; awaiting stem cell transplant
- ED/pediatric unit visits increase for pain management
- Admitted, as earlier in day, mom found Loren combative, disoriented, possible seizure

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Barriers to Quality Care at the End of Life

- "Children should not die!"
- Uncertainty of prognosis
- Delayed access to hospice/palliative care
- Death denial
- Overtreatment
- Communication breakdown
- Insensitive to cultural concerns
- Lack of adequate education
- Other limitations

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Hope Within Pediatric Palliative Care

- Meaning of hope
- Hope vs. despair
- Role of hope

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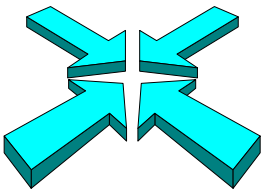
Model of Quality of Life (QOL)

- Physical Well-Being
- Psychological Well-Being
- Social Well-Being
- Spiritual Well-Being



City of Hope, 2020

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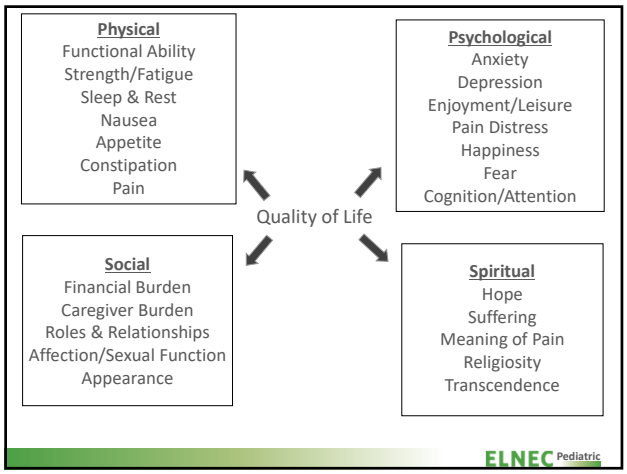

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Integrative Therapies Used to Improve Quality of Life

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Nurse's Role in Pediatric Palliative Care

- Anticipating
- Preventing
- Treating
- Promoting
- Advocating
- Being present
- Nursing: The safety net
- Redefining hope

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The Impact of Losing a Child

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Learning Objectives

At the completion of this module, the participant will be able to:

- Identify common symptoms in children with life-threatening illnesses.
- Identify potential causes of symptoms.
- Describe assessment of these symptoms.
- Describe interventions that can prevent or diminish symptoms.

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NCP Guidelines

NATIONAL CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE

- *Domain 2: Physical Aspects of Care*—the IDT endeavors to relieve suffering and improve quality of life
- *Domain 3: Psychological & Psychiatric Aspects of Care*—the IDT has knowledge and skills to assess and support mental health issues, and addresses emotional distress and quality of life for child/adolescent & families
- *Domain 4: Social Aspects of Care*—the IDT has the skills and resources to identify and address, the social factors that affect the child/adolescent and family quality of life and well-being

NCP, 2018

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Section I: Introduction to Symptom Management

- Symptoms throughout illness and at end of life are multidimensional
- Family-Centered
- Interprofessional

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General Principles

- Establish clear goals of care
- Focus on psychological/emotional, spiritual, and social suffering
- Child's report is the "gold standard"
- Use developmentally appropriate language
- Anticipate, educate and discuss potential symptoms
- Consider early referral to palliative care

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Establishing Goals of Care

- Focus on improved QOL and decreased suffering
- Identify and address symptoms of most concern
- Symptom management should be driven by family's goals of care for the child
- Interventions must be compatible with understanding of where the child is in the disease trajectory

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Suffering

- State of distress that threatens or disrupts the intactness or integrity of the child
  - Lasts until threat is gone or integrity is restored
  - Subjective experience differing amongst individuals
  - Suffering in the child results in family suffering

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Anticipate, Educate and Communicate

- Educating families on potential symptoms help to reduce anxiety, stress, and unwanted admissions
  - Empower families with methods to treat symptoms
  - Provide 24/7 support to manage symptoms

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Addressing Symptoms in End-of-Life/Palliative Care

- Prevent and manage symptoms
- Assure comfort and meaning
- Prioritize symptoms and provide anticipatory guidance
- Open communication and access to HCP may lead to positive parental satisfaction with symptom experience

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Key Nursing Roles

- Assessment
- Child/family advocacy
- Pharmacological treatments
- Non-drug treatments
- Teaching
- Non-judgmental support

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Assessment and Management

- Continuous assessment
- Symptom onset, severity & effect on quality of life
- Diagnostic testing
  - Not 'if' but 'why'

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Symptom Overview

- Neurological
- Respiratory
- GI Symptoms
- Fatigue
- Psychological

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Section II

Neurological

- Autonomic dysregulation
- Dystonias
- Restlessness/agitation
- Insomnia
- Delirium

Respiratory

- Dyspnea
- Terminal respiration

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Autonomic Dysregulation or Dysautonomia

- Autonomic nervous system instability
  - Vital sign instability (B/P, HR, RR, temp)
  - Altered perception of pain (irritability)
  - Sleep/wake disturbances
- At risk: TBI, CNS malformations, encephalopathy
- Management: treat symptoms, beta blockers, clonidine, opioids, benzodiazepines, gabapentin

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Dystonia

- Repetitive and sustained contracture of muscles
- Complications: pain, severe scoliosis, contractures, dislocation of joints, dysphagia, GI dysmotility
- Management:
  - Pharmacologic: levodopa, baclofen, botox, benzodiazepines
  - Non-pharmacologic: PT/OT, positioning, splints, massage

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Restlessness/Agitation

- Provide routines, comfort and support
- Decrease stimulation
- Pharmacologic
- Non-pharmacologic

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Insomnia

- Causes
  - Unrelieved symptoms (pain, dyspnea, anxiety, depression, fears)
  - Alterations in circadian rhythm
  - Medication side effects or withdrawal
- Interventions
  - Non-pharmacological
  - Pharmacological (treat underlying pain or symptom, melatonin, trazodone, zolpidem, benzodiazepines, antihistamine)

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Delirium

- Definition
  - Disturbance of consciousness (attention and awareness) **and** cognition (memory, orientation, language, perception)
- Acute onset, fluctuating course
- Cause:
  - Underlying disease process
  - Side effects of treatment
  - Highly abnormal environment

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Assessment of Delirium

- Assessment
  - Often under recognized
  - Cornell Assessment of Pediatric Delirium (CAP-D): pediatric screening tool
  - Consult child psychiatry to assist with diagnosis
- Risk factors:
  - Significant developmental delay
  - Supplemental oxygen/mechanical ventilation
  - Preschool children

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Treatment of Delirium

- Treatment
  - Treat the underlying cause for the delirium (e.g., infection, pain, dyspnea)
  - Reduce iatrogenic factors (e.g., avoiding restraints, encourage mobilization)
  - Optimize environment
  - Medication (quetiapine, risperidone, olanzapine)

Joyce et al., 2015; Thom, 2017

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Dyspnea

- Definition
- Associated diseases
- Causes

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Assessment of Dyspnea

- Assessment
  - Subjective report
  - Clinical assessment
  - Physical examination
  - Diagnostic tests

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Treatment of Dyspnea

- Treating symptoms or underlying cause
- Pharmacologic treatments
- Other treatments
  - Oxygen/bipap
  - Blood transfusions
  - Thoracentesis
  - Endobronchial laser therapy

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Treatment of Dyspnea (cont)

- Non-pharmacologic
  - Pursed lip breathing
  - Energy conservation
  - Fans, elevation
  - Counseling
  - Other

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Terminal Respirations

- Agonal or Cheyne-Stokes breathing
- Use an anti-cholinergic medication for excess secretions
- Provide family support

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Section III

Gastrointestinal Symptoms

- Anorexia and cachexia
- Constipation
- Vomiting and nausea

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Anorexia and Cachexia

- Anorexia: loss of appetite, usually with decreased intake
- Cachexia: lack of nutrition and wasting
- Risk factors:
  - Prematurity
  - Disease related
  - Psychological
  - Treatment related

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Assessment of Anorexia and Cachexia

- Weight loss, muscle wasting, decreased strength, bowel sounds, and growth curve %
- Impact on function and QOL
- Calorie counts/daily weights
- Pre-albumin vs. albumin

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Treatment of Anorexia and Cachexia

- Dietary consult/intervention
- Medications
- Parenteral/enteral nutrition

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Feeding at End of Life

- Education as artificial nutrition at EOL may increase suffering
- Offer favorite foods, but educate families about disease process
- Forcing intake orally or artificially may cause additional suffering

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Constipation

- Definition
- Prevention is key
- Discussion may be difficult with child/adolescent

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Etiology of Constipation

- Disease related: Obstruction, tumor progression, electrolyte imbalances, spinal cord compression, other intestinal conditions (Crohn's, abdominal tumor), dehydration
- Treatment related: Opiates, anticholinergics, vinca alkaloids, diuretics, and other medications, radiation
- Inactivity, low fiber diet

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Assessment of Constipation

- Bowel history
- Abdominal assessment
- Rectal assessment
- Medication review

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Treatment of Constipation

- Medications
- Dietary/fluids
  - Popsicles
  - Clear sodas
  - Jello
- Other approaches

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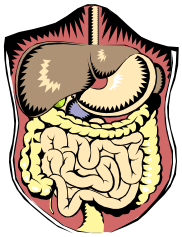
Nausea and Vomiting

- Overview
- Gastrointestinal Causes
- Metabolic Causes
- CNS Causes
- Treatment Causes
- Other



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Assessment of Nausea and Vomiting

- Clinical/physical exam
- History
- Lab values
- BARF scale
- Minimize suffering

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Pharmacologic Treatment of Nausea and Vomiting

- 5-HT3 receptor antagonists
- Anticholinergics
- Antihistamines
- Steroids
- Prokinetic agents
- Other

Chrastek & van Breemen, 2019; Collett & Chow, 2019; Haskamp & Lafond, 2016

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Non-Drug Treatment of Nausea and Vomiting

- Distraction
- Dietary
- Small/slow feeding

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Section IV: Symptom Management

- Fatigue

Psychological

- Depression
- Anxiety

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Fatigue

- Subjective, multidimensional experience of exhaustion
- Commonly associated with many diseases
- Impacts all dimensions of quality of life

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Causes of Fatigue

- Disease related
- Psychological
- Treatment related

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Assessment of Fatigue

- Subjective
- Objective
- Laboratory data

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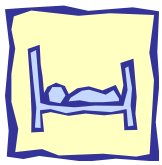
Treatment of Fatigue

- Pharmacologic
- Non-pharmacologic
  - Rest
  - Energy conservation
  - PT/OT
- Neonates



Haskamp & Lafond, 2016;
O'Neil-Page et al., 2019; Yennurajalingam & Bruera, 2015

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Depression

- Common in children and adolescents
  - Does not always manifest same as adult depression
  - Often unrecognized and undertreated
- Prevalence:
  - Higher in adolescent females than males
  - More common in prepubertal boys than girls

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Risk Factors of Depression

- First degree family history of depression
- Chronic illness
- Traumatic brain injury
- Poor coping skills
- Caregiver/child conflict
- Academic difficulties
- History of anxiety disorders, substance use disorder
- History of abuse, neglect, or early loss

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Clinical Manifestations (Depression)

- Depressed or irritable mood
- Diminished interest or pleasure
- Change in appetite or weight
- Sleep disturbance
- Physical symptoms (pain, GI disturbances, fatigue)
- Psychomotor agitation or retardation
- Feelings of worthlessness or guilt
- Impaired concentration and decision making
- Recurring thoughts of death or suicide

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Suicide Assessment

- National Emergency
- Screening tools
- Risk Assessment
- Intervention

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Causes of Depression

- Disease related
- Psychological
- Treatment related

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Treatment of Depression

- Pharmacotherapy
- Psychotherapy
  - Cognitive-behavioral therapy
  - Grief/psychiatric counseling/therapy
  - Draw on strengths
- Combination therapy
  - Pharmacotherapy plus psychotherapy

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Anxiety: Definition/ Assessment

- Definition
- Assessment
  - Physical symptoms
  - Psychological symptoms
  - Behavioral symptoms
  - Assess for presence of uncontrolled symptoms/fears

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Treatment of Anxiety

- Maximize symptom management
- Empathetic listening
- Assurance and support
- Relaxation/imagery
- Medications

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Conclusion

- Goals of Care guide symptom management
- Multiple symptoms common
- Interprofessional team approach
- Pharmacologic and non-pharmacologic options
- Be open and honest
- Advocate, support, and educate

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1

Learning Objectives

At the completion of this module, the participant will be able to:

- Define the role of the nurse in supporting ethical practice in palliative care for children.
- Discuss ethical issues and dilemmas that may arise in the care of children with serious illness.
- Describe advanced communication techniques and their role in preventing ethical dilemmas.
- Apply ethical principles utilized in addressing palliative care dilemmas, including models for case presentation and use of ethics committees.
- Define moral distress and its effect on nursing care.

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2

NCP Guidelines

- *Domain 8: Ethical and Legal Aspects of Care*
  - Legal considerations: Attention is paid to the rights of children and adolescents in decision making.
  - Assessment: The child's or adolescent's views and preferences for medical care, including assent for treatment (when developmentally appropriate), are assessed, documented, and given appropriate weight in decision making.

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NCP, 2018

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3

Standards of Professional Nursing Practice

- ANA Code of Ethics
- Nurse Practice Act
- Standards for professional organizations

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4

Overview of Ethics in Pediatric Palliative Care (PPC)

- Understanding Ethics
- Nurses Role in addressing ethical issues
- Decision Making and Communication
- Common Ethical Issues and dilemmas
- Applications of Ethics in Practice
- Organizational Ethics
- Moral Distress

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5

Understanding Ethics

- What ought to be
- Determining the best course of action
- Ethical issues are inevitable
- Societal changes

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6

Ethical Principles

- Autonomy
- Beneficence
- Non-Maleficence
- Justice

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Nurse's Role in Addressing Ethical Issues

- Promoting family-centered care
- Respecting preferences
- Role models of clinical proficiency, integrity, and compassion
- Balancing competing objectives

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Issues of Communication and Shared Decision Making

- Capacity
- Consent
  - Children are "legally" capable of giving consent at age 18
- Confidentiality

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Issues of Communication and Shared Decision Making (Cont.)

- Assist the child to develop an awareness of the nature of the illness
- Disclose the nature of the treatment, what the child is likely to experience
- Assess the child's understanding of the situation and forces influencing their response
- Solicit a willingness to undertake the proposed treatment

Lafond & Kelly, 2019

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Issues of Communication and Shared Decision Making (Cont.)

Disclosure

- Revealing information about the child's illness
- Care is improved by open and honest communication
- Children have a right to be offered developmentally appropriate information
- Request to withhold information must be carefully considered
- A child's Right Not to Know

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Common Ethical Issues and Dilemmas

- Prolongation of life
  - Curative intent
  - Acute therapeutic care
  - Life sustaining treatments (LST)

Jonsen et al., 2015;
Prince-Paul & Daly, 2019

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Common Ethical Dilemmas (cont)

- Redirection of care (toward comfort)
  - NOT withholding or withdrawing
- Prolonging Life: Balancing benefits vs burdens
- Curative focused training – What does "do everything" mean?

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Common Ethical Dilemmas (cont.)

- Special Circumstances – Redirection of Care with Neonate

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Common Ethical Dilemmas (cont.)

Important distinctions between acronyms:

- Do Not Attempt Resuscitation (DNAR)
- Allow Natural Death (AND)

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Common Ethical Dilemmas (cont.)

- Futility – requires goals to be clearly stated
  - An intervention that can definitively not accomplish the intended goal
- Potentially Inappropriate Treatment
  - More common
  - Treatments have some chance of accomplishing the goal, but competing ethical considerations justify not providing the intervention

Miller-Smith et al., 2019

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Common Ethical Dilemmas (cont.)

- Medical aid in dying
- Euthanasia
- Hastening death
  - Principle of double effect

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Cassandra C

https://www.youtube.com/watch?v=-j-dQWoloDg
(Video: 4:00 min)

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Cassandra C

- 17-year-old Connecticut young woman diagnosed with Hodgkin's Lymphoma in 2015
- Placed into custody of Dept. Children and Families was taken to the hospital for treatment.
- Against her wishes underwent placement of a port and chemotherapy.
- Case went to court, ruled the department was NOT violating her rights. She had hx of runaway while at home so did not have the maturity to make her own medical decisions. Went to state supreme court

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Cassandra C

- Lived at the hospital for 6 months.
- 2016 disclosed she had a mass on her lungs and was undergoing alternative treatments.
- As an adult, she did eventually agree to more chemo, immunotherapy, and other treatments, but the cancer metastasized.
- During illness, gave birth to twins who were 19 months old when she died May 14, 2020 at age 22.

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Cassandra C

"My daughter was very intelligent and liked by many teachers and peers, but she was denied many of the joys of being a teenager. I raised her to be a fighter, and that she was. She went through hell. She never had a life. She never had a chance. I hold every doctor and nurse who touched her, the DCF, the courts– I hold everyone is responsible."

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Issues of Justice in Palliative Care

- Provision of quality palliative care
- Costs of palliative care

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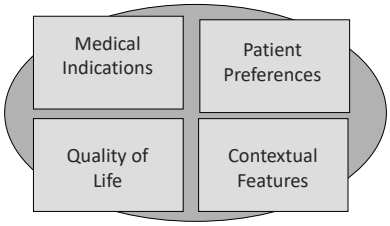
Facilitating Ethical and Legal Practice

- The Four Box Method



Jonsen et al., 2015

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Box 1: Medical/ Clinical Indications

- Indications for and against the intervention
  - Interdisciplinary team input
  - Medical specialists
- Reflect the goals of care
- Common ethical dilemmas

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Box 2: Patient/ Family Preferences

- Parents as moral and legal agents
  - Determine relevant weight of parenteral preferences and child's best interest
- Principle of respect for persons
  - Autonomy, privacy, veracity
- Assess child/family understanding
- POLST

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Box 2 (cont.): Patient/Family Preferences

Advance Care Planning

- Promote ongoing conversations with patient, family and team
- Cultural, spiritual, ethnic, and age-related differences
- Interdisciplinary
  - Child Life Specialists, Social Workers, Chaplains
- *My Wishes ™/Voicing My Choices ™/Five Wishes ™*

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Box 3: Quality of Life (QOL)

- Evaluation of prior QOL
- Expected QOL with and without treatment
- Common ethical dilemmas addressing QOL

Jonsen et al., 2015

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Box 4: Contextual Features

- Social, legal, economic and institutional circumstances
- May involve issues of justice
- Research in pediatric palliative care

Jonsen et al., 2015

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Managing Disagreement

- Intra-Family
  - Parent-child conflict, Parent-Parent
- Minors
- Legal issues, etc.
- Family-physician
- Physician-nurse

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Parental Insistence on Treatment

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Parental Insistence on Treatment

Baby K. case (1994): Baby K was anencephalic but was put on a respirator in the delivery room. Her mother refused to permit a DNR order, much less removal of the respirator. She was firmly committed to the position that God would heal her child. Baby K was eventually discharged to a nursing facility. She was readmitted to the hospital several times for treatment of respiratory distress. The hospital asked for an order from the court stating that it did not have to provide extraordinary medical treatment to this hopeless case. The court found that the federal Emergency Treatment and Active Labor Act, which requires any hospital to provide essential care to emergency admissions, applied to Baby K, and the hospital could not refuse to treat her in the emergency department. The trial judge's decision was upheld when the hospital appealed to the United States Court of Appeals for the Fourth Circuit. Baby K finally died in the pediatric nursing home at age 14 months, still on full life support.

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Organizational Ethics & Legal Practices

- Organizational ethics
- Ethics committees and consultation
  - Education
  - Policy development
  - Case consultation

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Preventative Ethics

- Early identification of issues
- Know the natural history illnesses
- Solicit patient/family wishes
- Cultural and spiritual assessment
- Communication skills

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Moral Distress

- Occurs when there is conflict between ethical principles and external forces
- Nurses are advocates for quality patient/family care

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Common Causes of Moral Distress

- Clinical situations
  - Unnecessary treatment, inadequate informed consent, incompetent providers
- Factors internal to caregiver
  - Perceived powerlessness, lack of knowledge about alternatives, fear of reprisals
- External factors in the situation
  - Work environment/culture, legal/regulatory issues, co-worker issues

Whitehead et al., 2015

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Significance of Moral Distres

- For Nurses
  - Physical and emotional symptoms
  - Loss of capacity for caring
- For Patients
  - Inconsistent and less attentive care
- For Organizations
  - Employee dissatisfaction, increase turnover

Dudinski, 2016; Sauerland, et al., 2015

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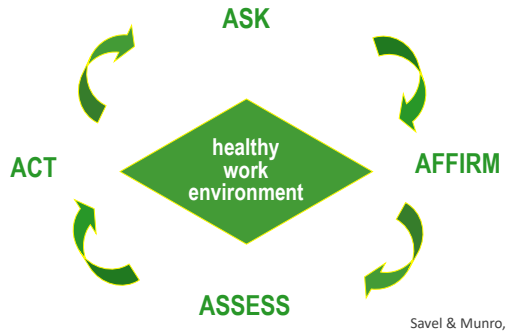
AACN'S 4 A's Model



Savel & Munro, 2015

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ASK

- Am I feeling distressed or showing signs of suffering?
- Am I observing symptoms of distress within my team?
- Have coworkers, friends, or family members noticed these signs and behaviors in me?

GOAL: You are aware of moral distress

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AFFIRM

- Your distress
- Commitment to take care of yourself
- Validate your feelings and perceptions
- Professional obligation to act

GOAL: You make a commitment to address moral distress (don't ignore it)

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ASSESS

- What is the source of the distress?
- Determine the severity
- Contemplate your readiness to act
- The 4 R's
  - Relevance, risks, rewards, roadblocks

GOAL: You establish an action plan

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ACT

- Anticipate setbacks
- Maintain desired change
- Continue to evaluate

GOAL: You preserve your integrity and authenticity

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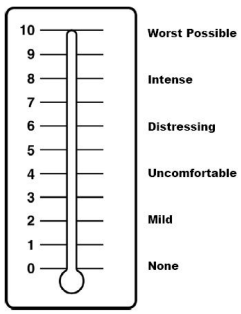
Moral Distress Thermometer



Wocial & Weaver, 2013

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Dealing with Moral Distress

- Self awareness
- Self care
- Focus on changes in the work environment that preserve moral integrity
- Three levels of intervention:
  - Patient care
  - Unit/team culture
  - Organization

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Conclusion

- Engage in a process of ethical discernment
- Apply principles of ethics
- Use ethical process to seek balance in decision-making
- Advocate for children and families

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END-OF-LIFE NURSING EDUCATION CONSORTIUM
Advancing Palliative Care

Pediatric Curriculum

MODULE 3

SECTION I
COMMUNICATION

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1

Learning Objectives

At the completion of this module, the participant will be able to:

- Summarize three aspects of excellent ongoing communication with the interprofessional team, the child, and the family throughout palliative care.
- Identify important elements of effective communication in the pediatric palliative care setting.
- Describe steps in communicating bad news.

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NCP Guidelines

- *Domain 4: Social Aspects of Care*
  - Palliative care addresses environmental and social factors that affect patient [child] and family functioning and quality of life.
  - The palliative care interdisciplinary team (IDT) partners with the child and family to identify and support their strengths and to address areas of need.
- Communication is applied across all the domains of the NCP guidelines

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NCP, 2018

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Section I: Overview of Communication

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4

The Power of Words

"Words are better and worse than thoughts, they express them and add to them; they give them power for good or evil; they start them on an endless flight, for instruction and comfort and blessing, or for injury and sorrow and ruin."

Tyron Edwards (1809-1894)

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Key Components of Communicating with Patients and Families

- The care of a child is a family experience, especially related to end-of-life care. The role of communication becomes more crucial to palliative care as it includes imparting necessary medical information and options, so children and families may make informed decisions related to care.

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Tasks of Communication

- Interpersonal relationship-building
  - Mutual respect
  - Trust
  - Empathy
- Information exchange
- Collaborative decision-making
- Identify communication style of patient/family
- Consider culture

Lafond & Kelly, 2019

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Methods of Communication

- Verbal
- Nonverbal
- Written
- Play

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Opportunities in Communicating with Children/Families

- Nurses are key witnesses and the "constant" at the bedside; identify those who could benefit from palliative care
  - Ask how much child/family want to know
  - Collaborative decision making
  - Be aware that illness can strengthen or weaken relationships
  - Base communication with children on developmental age

Lafond & Kelly, 2019; McDaniel & Desai, 2019

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Ethical Conversations: Providing Accurate & Ethically Sound Information

Conversations about:

- Plan of care
- Ability to return to a normal life
- Prejudices among providers regarding quality of life
- Forgo treatment
- Burdens versus benefits
- Plans for comfort and palliative care

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Starting the Conversation

- Set the right atmosphere
- Does the child/family want to talk?
- If so, encourage child/family members to talk
- Acknowledge feelings
- Be silent

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The Importance of Silence and Listening

- Starts with an open mind
- Sensitive listening
- Occurs at 5 levels
  - Hearing
  - Understanding
  - Retaining information
  - Analyzing
  - Actively empathizing

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Factors Influencing Communication

- Child / Family
- Society / Cultural
- Healthcare Professional

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Family Factors Influencing Communication

- Child/family unit
  - Family systems
  - Levels of comprehension
  - Interpretation of information
  - Existing coping skills
  - Need for hope

Dahlin & Wittenberg, 2019;
Duncan & Kobler, 2016

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Family Factors Influencing Communication (cont.)

- Siblings
  - Anxiety
  - Loss
  - Guilt/shame/blame
  - Plan of care for siblings

Battista & LaRagione, 2019;
Limbo et al., 2019

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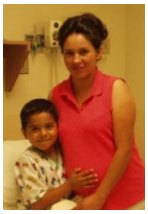
Family Factors Influencing Communication (cont.)

- Financial/educational
- Physical limitations/environment/ sleep deprivation
- Language/communication ability



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Family Factors Influencing Communication (cont.)

- Coping with loss
  - Family dynamics
  - Denial
  - "Hiding" information/feelings to protect family members
  - Spirituality
  - Anticipatory grieving

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Cultural Factors Influencing Communication

- Culture pervades/invades human behavior
- Hierarchical structure
- Cultural humility

Cormack et al., 2019;
Rosa & Morin, 2017

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Healthcare Professional Factors Influencing Communication

- Fear or lack of confidence/training in how to communicate bad news
- Personal experiences
- Ethical issues/concerns

Lafond & Kelly, 2019
Prince-Paul & Daly, 2019

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Section II: Communication Techniques: Giving "The Words"

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Communication Techniques/ Examples in Palliative Care

- Build trust
- "Warning shot"
  - *" I regret that I have some difficult news to share with you"*
- Acknowledge emotions
  - *"I see this is very upsetting to you"*
- Legitimize normalcy of reaction
  - *"Anyone receiving this news would be upset"*
- What is under the emotion?
  - *"What worries you the most?"*
- Empathy
  - *"I can not imagine how overwhelming this is"*
- Strengths/coping
  - *"Where do you find your strength?"*
- Use silence

Childers et al., 2017; Vital Talk, 2019

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Communication Techniques/ Examples in Palliative Care (cont.)

- Check that your message has been heard
  - *"What have we not talked about today that is important to you?"*
- Use the "D" word
  - *"Because you are so ill, I believe you are dying."*
- Expect conflict
- Summarize/restate your understanding
  - *"Let me double-check that I understand what you said."*
- Provide support
  - *"I am here to work with you and support you."*
- Use nonverbals

Duncan & Kobler, 2016; Vital Talk, 2019

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Delivering Difficult News

- Steps:
  - Find out what they know/want to know
  - Plan what to say/use simple language
  - Establish rapport
  - Be sensitive/respectful
  - Control the environment
  - Set aside time/turn off pagers
  - Acknowledge and reflect on your own discomfort

Gentry, 2016

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Listen With Parent's Ears

What HCP Says	What Patient Hears
His creatinine is better.	He will get well.
She is stable today.	She is getting better.
We have an experimental treatment.	This new therapy will cure my child.
Do you want us to do CPR?	You think CPR will help.
Do you want us to "do everything" for your child?	Doing everything means you think my child will survive and get well.

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Family Meetings

- Child may attend (if appropriate)
- Family members
- Appropriate clinicians (best to include primary care along with palliative care)
- Goal to enhance communication

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Helpful Tips for Talking with Children

- Child life specialist
- Appropriate language for developmental age
- Begin with non-threatening topic
- Listen actively/observe non-verbals
- Ask child what he/she knows
- Give valid choices
- Respect opinions
- Allow time to plan

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Communicating with the Child with Developmental Disabilities

- Identify unspoken wishes
- Invite others to assist with decision-making
- Listen, talk, develop trust and rapport
- Introduce advance directives early
- Recognize differences and similarities

Gentry, 2016

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Family Meetings: Video

Family Conferences for Serious Illness: A Clinician's Guide

http://vitaltalk.org/topics/conduct-a-family-conference/

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Children's Books to Facilitate Talking About Death

- *The Invisible String*
- *Gentle Willow: A Story for Children about Dying*
- *When Someone Dies: A Child-Caregiver Activity Book*
- *The Fall of Freddie the Leaf*
- *Goodbye Mousie*
- *I'll Miss You, Mr. Hopper (Sesame Street)*

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Healthcare Professional's Role in Framing Conversations

- Anticipate difficult questions and statements
- Familiarize yourself with natural responses to devastating news
- Acknowledge your own feelings

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Language

Unclear/Distressful	Helpful
It's time to pull back.	Let's think about/discuss discontinuing treatments which are not providing benefit or causing more symptoms.
There is nothing more we can do.	We may consider changing the goals of care. Let's review the goals of care to see if any of them have changed.
A miracle may turn things around.	In my experience, I have not seen a child in this situation survive.

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Language

Avoid	Helpful Phrases
It was a blessing…	May I just sit here with you?
You have other children to think about.	Is there anyone I can call for you?
I know how you feel.	What might be helpful to you at this time?
This will make you a better/stronger person.	Would you like me to talk with your other family members, or be there with you when you talk with them?

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"I Wish" and "I Worry"

- *"I wish"* statements demonstrates empathy, but also addresses limits of treatment(s)
  - *"I wish we had a chemotherapy treatment that would cure your child's cancer."*
- *"I worry"* shares concern without stating with certainty that something will or will not occur.
  - *"I worry that the chemotherapy treatments will not work."*
- Denotes empathy and aligns with the patient/family

Partain & Strand, 2018

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Articulating Empathy: NURSE

- **N**aming
- **U**nderstanding
- **R**especting
- **S**upporting
- **E**xploring

http://vitaltalk.org/guides/responding-to-emotion-respecting/

Back et al., 2008

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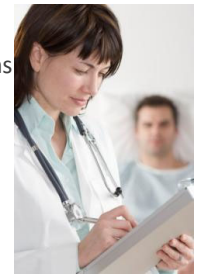
Semantics

- Use the "D" (death/die) word
  - Caregivers need concrete terms
  - Eliminate vague/confusing messages



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Team Communication

- Intra-team communication is essential
- Should be collaborative
- Should be effective and frequent
- Document
- Expect conflicts
- Ethical emphasis

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Communication with Team Members who are Unfamiliar or Reluctant to Consult with Palliative Care

- Honor the relationship providers have with their patients
- Maintain professional relationship
- Be specific about the reasons for the "ask."
  - *"The nurses in the NICU believes that Sydney is in pain."*
  - *" Sydney's mother is very upset, and she believes her daughter is suffering."*
- Palliative care can support the work of providers

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Summary

- Communication is a complex process
- Should be individualized
- Advocate for the child's and family's best interest
- Child and family have a primary role in the plan of care
- Promote clear open communication
- Ongoing assessment of communication

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Let's Practice

- Thomas, 16 year old, with osteosarcoma with mets
- Informed today by oncologist that there are no other treatments available
- Hospice recommended
- You arrive to work shortly after the family was informed and you enter the room

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1

Learning Objectives

Upon completion of this module, the participant will be able to:

- Define loss, mourning, grief, and bereavement.
- Distinguish between different types of grief.
- Describe three tasks of grief and list factors that significantly affect the grief process.
- Define personal death awareness and cumulative loss associated with professional caregiving.
- Identify four systems of support the nurse can access to assist in coping with death anxiety and loss.

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2

NCP Guidelines:

NATIONAL CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE

- *Domain 3: Psychological & Psychiatric Aspects of Care*
  - Child/parent support related to a change in prognosis, anticipatory grief, loss, and emotional responses related to coping with advanced illness and end of life
- *Domain 7: Care of the Patient Nearing the End of Life*
  - Patient/family needs must include assessment of family risk for prolonged grief disorder
  - Bereavement support available to family & care team for minimum of 13 months after death

NCP, 2018

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3

Loss, Grief, and Bereavement

- America is a death-denying society
- Affects the family unit, community and healthcare providers
- Grief is an individual process
- Honor cultural traditions

Limbo et al., 2019

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Definitions

- Loss is the absence of a possession or person
- Grief is the emotional response to loss
- Mourning is the outward, social expression of loss
- Bereavement includes grief and mourning
- Strongly influenced by culture

Corless & Meisenhelder, 2019;
Limbo et al., 2019

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5

Models / Theories of Grief

- Stage/phase or medical models
  - Criticism of these models
- Grief work theories – relearning the world
  - Relinquish attachment to the deceased
  - Adjust to life without the deceased
  - Develop a new relationship with the deceased

Kissane & Zaider, 2015; Limbo et al., 2019

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Grief Work

- Not orderly or predictable
- Begins before death
- Task-oriented
- No one "gets over it"
- Leads to living with the death
- Healing occurs when the pain is less

Battista & LaRagione, 2019; Limbo et al., 2019

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7

Grief as Relearning the World

- Relearning physical surroundings
- Relearning social surrounding
- Relearning aspects of the self
- Relearning the relationship with the child

Limbo et al., 2019

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8

Anticipatory Grief

- Definition
- Actual or fear of potential loss(es)
- Children's responses to the illness is a form of their anticipatory grief
- Grief interventions
- Does not lessen intensity of grief after death

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9

Complicated Grief

- More intense and longer in duration than expected
- Types of complicated grief
  - Chronic
  - Delayed
  - Exaggerated
  - Masked
- Risk factors
- Chronic sorrow

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Special Circumstance - Perinatal and Neonatal Loss

- Medical management
  - Lactation consultant/postpartum care
- Psychological and social care
- Disenfranchised grief

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Factors Affecting the Grief Process

- Individual factors
  - History and relationship
  - Previous experience with death
  - Developmental level
  - Personality and coping style

Limbo et al., 2019

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12

Factors Affecting the Grief Process (cont.)

- Environmental factors
  - Deceased child's role in the family
  - Family characteristics
  - Cultural/socialcharacteristics
- Situational factors
  - Characteristics of the child's illness/death
  - Involvement in the illness/death-related events

Limbo et al., 2019

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13

Circumstances Where Special Care May Be Needed

- Sudden or traumatic death
- Suicide, homicide
- Multiple losses
- Unresolved grief from prior losses

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14

STOP & Consider

- Heather gave birth 12 hours ago to a healthy baby girl.
- She just learned from her husband that her father and young son, who were on their way to the hospital to visit the new baby, were killed in a motor vehicle accident.
- Heather's mother was also in the car and had minor injuries.
- You are Heather's nurse. Where would you begin?

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15

Effects of Grief on the Dying Child

- Related to personal awareness
- Range of feelings
  - Anger
  - Anxiety
  - Sadness
  - Loneliness
  - Fear

Limbo et al., 2019

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Effects of Grief on the Parents/ Caregivers

- Relationship is like no other
- Responsible for protecting child
- Mother and father have unique experiences
- Special at-risk parents

Limbo et al., 2019

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Effects of Grief on Siblings

- Loss is three-fold
- Sibling needs
- Difficulty transitioning back to "normal" life
- Validation of sibling grief

Limbo et al., 2019; Lövgren et al., 2016; Rosenberg et al., 2015

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Effects of Grief on Grandparents

- Source of strength
- Grief is two-fold, for the parents and the child

Limbo et al., 2019

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19

The Nurse's Unique Role in Grief and Bereavement Assessment/Management

- Provide reassurance and validation of feelings
- Utilize interdisciplinary team

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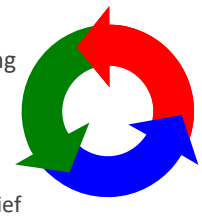
Grief Assessment

- Who: child, family, significant others
- When: time of diagnosis – ongoing process
- Grief assessment includes
  - Interdisciplinary approach
  - Assess for factors which affect grief and complicated grief



Chovan, 2019;
Corless & Meisenhelder, 2019; Limbo et al., 2019

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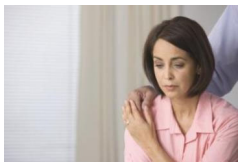
Grief Interventions: Parents/ Caregivers

- Before death
  - Communication
  - Evaluate helpful support
  - Memories
  - Funeral planning



Limbo et al., 2019;
Meisenhelder & Gibson, 2015

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Bereavement Interventions: Parents/ Caregivers

- Follow-up by HCPs
  - Bereavement follow-up phone calls
  - Meeting with child's doctor
- Identify support systems
  - Social support
  - Refer to support groups
- Allow time to talk about feelings, normalize grief

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Grief Interventions: Children

- Interventions match developmental level
- Involve/include in funerals, memorial services
- Address fears, listen/reassure
- Allow to express grief/validate feelings
  - Model grief behavior
- Provide opportunities to remember

Limbo et al., 2019

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Grief Interventions: Family

- Provide presence
- Active listening, touch, silence, reassurance
- Follow-up bereavement phone calls
- Identify support systems
- Make referrals, as appropriate
- Normalize & individualize the grief process
- Actualize the loss & facilitate living without the deceased

Limbo et al., 2019

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Grief Interventions: Schools

- Preparing students
  - Understand what the bereaved child wants their peers to know
  - Provide guidance of what to say/do
- Peer death
- Staff support

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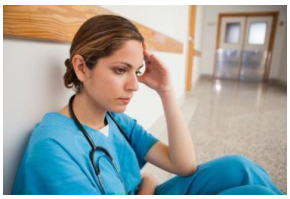
Impact on Nurse

- Emotional Burden
- Importance of support/ resources
  - Death Anxiety
- Grief response is individual
- Defenses



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Cumulative Loss

- Succession of losses experienced by nurses
- May not have time to resolve losses before another loss occurs
- Caregiver suffering
  - Moral distress *and* grief
  - Bearing witness to others' suffering

Limbo et al., 2019;
Vachon et al., 2015

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I was required to confront my own pain in nursing and the pain of those around me. The challenge was to create some distance from the pain, yet remain caring and human.

~ Beth Perry Black

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Nursing Differs From Other Professions

- Competence in caring distinguishes nursing from other professions.
- Presence provides to patients and their families:
  - Confirmation
  - Nurturing
  - Compassion

Borneman & Brown-Saltzman, 2019;
Coyle & Kirk, 2019

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However...

- The labor of healthcare is stressful
- Stress is an assumed cost of doing our work and interpreted as the individual's responsibility to counter it
- Yet, we don't do it…It feels natural to care for others, but difficult to nurture ourselves

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Interventions For Healthcare Professionals

- Formal/informal support systems
- Needs of the healthcare provider
- Mentorship
- Spiritual support
- Education in end-of-life/palliative care
- Self-care

Limbo et al., 2019

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Conclusion

- Nursing care does not end with the death
  - Loss, grief, and bereavement need to be assessed with ongoing intervention
- Utilize expertise of interdisciplinary team
- Nurses must recognize and respond to their own grief

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Find Own Meaning & Purpose

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Pediatric life limiting metabolic disorder

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END-OF-LIFE NURSING EDUCATION CONSORTIUM
Advancing Palliative Care

Pediatric Curriculum

PERINATAL PALLIATIVE CARE

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Perinatal Palliative Care Key Messages

- A unique aspect in the field of maternal fetal medicine.
- Appropriate for babies with a range of serious and life-limiting illnesses including those with prognostic or diagnostic uncertainty or could survive into the NICU and beyond.
- Simultaneously prepares families to say "hello" and "good-bye" to their baby.
- There are many barriers that impede the availability of and access to perinatal palliative and end-of-life care.
- Communication is critical and unique skills in verbal and non-verbal communication, listening, and presence are critical in caring for families facing a potentially life-threatening fetal condition.
- Ethical issues and dilemmas are inherent in this level of care.
- Can facilitate adaptation to loss and greatly relieve suffering in the perinatal settings by focusing on end-of-life needs.

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Section I:
Introduction
Standards of Perinatal Palliative Care

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NCP Guidelines (4th edition)

The NCP domains can guide perinatal palliative care

- Domain 1: Structure and Processes of Care
- Domain 2: Physical Aspects of Care
- Domain 3: Psychological & Psychiatric Aspects of Care
- Domain 4: Social Aspects of Care
- Domain 5: Spiritual, Religious, and Existential Aspects of Care
- Domain 6: Cultural Aspects of Care
- Domain 7: Care of the Patient Nearing the End of Life
- Domain 8: Ethical & Legal Aspects of Care

NATIONAL CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE

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Perinatal Palliative Care

- **Perinatal palliative care (PPC)** refers to a coordinated care strategy that comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early infancy.

ACOG, 2019

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Standards of Professional Practice

- AAP - American Academy of Pediatrics
  http://www.aap.org
- ACOG – American College of Obstetricians & Gynecologists
  https://www.acog.org/
- NAFTNet – North American Fetal Therapy Network
  https://www.naftnet.org/
- NANN - National Association of Neonatal Nurses
  http://www.nann.org/
- NHPCO – National Hospice and Palliative Care Organization
  https://www.nhpco.org/
- PLIDA- Pregnancy, Loss and Infant Death Alliance
  https://www.plida.org/

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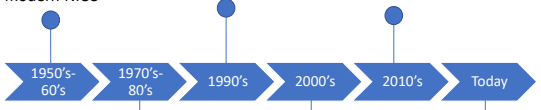
History of Perinatal Palliative Care

- Birth practices more family centered
- Formation of modern NICU

Advances in technology

- 2015 – NANN
- 2017 – AAN
- 2019- ACOG/AAP



- Duff & Campbell
- Baby Doe Case
- AAP position on newborn ethics

Increased awareness

PPC is an important standard of care focused on maximizing quality of care and comfort for newborns

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Key Components of PPC

- Interdisciplinary team approach
- Provided alongside life-sustaining or disease-directed treatments
- Appropriate for babies with a range of serious and life-limiting illnesses including those with prognostic or diagnostic uncertainty or those who could survive into the NICU and beyond
- Informed decision-making guidance
- Provide infants dignity and comfort
- Maximize quality of time
- Seamless continuum of care for families
- Simultaneously preparing families to say "hello" and "good-bye"

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Key Components of PPC (cont.)

- Pre-planning of baby's birth with family-centered care discussions including:
  - Potential limitations and anticipated transition points
  - Survival expectations
  - Appropriate fetal interventions
  - Risk of prematurity or fetal death
  - Comfort-care focused vs planned neonatal resuscitation and interventions
  - Meaning of quality of life for family
  - Wishes/Hopes and Fears/Concerns
  - Continuation or termination of pregnancy

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Which Families Benefit from PPC Consultation?

- Severe, life-limiting anomalies
- Anomalies severe enough to increase the risk for a long, complex hospital stay
- Termination of pregnancy
- Considering comfort care following delivery
- Those with uncertainty

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Cultural/Spiritual Considerations in PPC

- Cultural preferences
- Religious affiliations
- Support available

"When a clinician strives to be emotionally, spiritually, and psychologically grounded and healthy, in turn, the patients and families they serve have a higher chance of experiencing holistic care"

Limbo & Wool, 2016

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Maternal Perspectives of PPC

- Perinatal palliative care is welcomed by parents
- Families appreciate expert and personalized care from an interprofessional team
- Encourage the “normal” within the extraordinary
- Provide appropriate choices to support informed decision-making and autonomy
- Identified legacy opportunities from diagnosis to birth
- Promote opportunities for hope during a difficult pregnancy

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Quality Predictors of Parental Satisfaction

N = 405 parent responders to "The Voice of Parents" survey

- Overall, 80.2% of parents in this study reported satisfaction with PPC
- Parents in the study reported valuing:
  - Compassionate care from their health care team
  - Having physicians take the time to talk with them in a respectful way, listen to parents, and incorporate parents' perspectives and decision-making
  - Addressing parents' bereavement from time of diagnosis through pregnancy and after birth/death

Wool & Wool, 2020; Wool et al., 2018

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Introduce Case Study

https://www.youtube.com/watch?v=ToNWquoXqJI&t=1s

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Case Study – Road to the Diagnosis

- Mother: Deidrea
  - 32-year-old; G1P0, 20+2 weeks; husband T.K.
  - Expecting boy – parents plan to name him Thomas
- Scheduled OB visit
  - Ultrasound revealed fetal abnormalities
  - NIPT (non-invasive prenatal testing) identified high risk Trisomy 13
  - Referral to maternal fetal medicine (MFM)
- MFM visit:
  - Extensive ultrasound confirmed anomalies
  - Met with genetics counselor
  - Amniocentesis confirms Trisomy 13
- Follow-up MFM visit:
  - Explanation of findings from fetal MRI and ECHO with additional ultrasound
  - Family care conference with MFM, neonatologist, cardiologist, and palliative care

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Section II: Perinatal Care Decision Making

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Paths to Diagnosis

- Prenatal genetic testing
- Fetal Imaging
  - Ultrasound
  - Fetal MRI, fetal echo
- Referral to maternal fetal medicine, fetal surgeons, neonatology, and pediatric specialists

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Prenatal Genetic Testing

- Timeframe
- Screening vs. diagnostic
- Limitations
- Declining
- Genetic Counseling

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Fetal Imaging

- Routine ultrasound in OB office
- Additional imaging based on suspected diagnosis
  - Repeat ultrasound
  - Fetal MRI
  - Fetal echo

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Guidelines for care following suspected or confirmed diagnoses

When parents face unexpected outcomes from prenatal testing or imaging, the following should be offered:

- Referral to pediatric specialists and tertiary center for delivery
- Counseling regarding family education and preparation
- Obstetric management recommendations
- Availability of adoption or pregnancy termination
- Perinatal palliative care services and comfort care for delivery of child with diagnosis or fetal presentation expected to be incompatible with long-term survival

ACOG & SMFM, 2017

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"Why Did This Happen to Us?"

- Many family's first question
- Followed by:
  - *"What can we do about it?"*
  - *"Will it happen again?*

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Communication Strategies in Perinatal Palliative Care

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"You can talk all you want about what's wrong with my baby, but I'm going to tell you right now I won't hear a word. I'm just too sad today."

~ Parent prior to a planned family care conference

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Words Matter – Disclosing Diagnoses

- *"We're sorry we're here today. I know this is not what you imagined for this pregnancy or for your baby."*
- Consider terms such as "serious condition"
  - Avoid "Lethal" or "Incompatible with Life"
  - *"We know that babies with this condition typically do not survive."*
- Counseling should focus on salient prognostic features
- Provide prognosis in general terms versus specific times
  - *"Weeks to months"* versus *"2 weeks"*
- Following delivery of diagnosis, it may be appropriate to allow time for the family to process information

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Offering Pausing Spaces

- Slowing pace of conversation to offer protective respite
- Giving permission to stop the conversation at any time
- *"We've just covered a lot about your baby. I'm wondering, what do you need to happen next?"*

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Strong Emotions in Perinatal & Neonatal Settings

- Hope
- Peace
- Obtaining sense of control
- Love
- Disappointment
- Grief
- Guilt
- Anger
- Physical Exhaustion
- Fear
- *What would you add?*

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Statements for Articulating Empathy NURSE(S)

www.vitaltalk.org

- **N**aming: *"It sounds like you are frustrated."*
- **U**nderstanding: *"This helps me to understand what you are thinking."*
- **R**especting: *"I can see you have really been trying to follow our instructions."*
- **S**upporting: *"I will do my best to make sure you have what you need."*
- **E**xploring: *"Could you say more about what you mean when you say that…"*
- **S**ilence

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Staying Connected when Expectations Differ

- *"Help me to understand"*
- *"I'm curious about…"*
- Avoid using the word "but" and replace it with "and"
- Explore what "do everything" means to the parent
- *"Our team strives to care for families in ways that are most meaningful to them, and we are very open to learning when we have fallen short of expectations. When you are ready, can we talk further about your request?"*

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Communication Strategies

- Using the "W" words may be helpful when expectations differ
  - *"I wish"* – aligns the provider with the parent's hopes even while focusing on realistic goals
    - *"I wish the genetic testing would have given us better news."*
  - *"I wonder"* – allows the provider to introduce another idea or option
    - *"I wonder if you've thought about what you want to do if the genetic testing confirms the diagnosis?"*
  - *"I worry"* – provides space for the provider's concerns
    - *"I worry her heart is not getting better and she will die."*

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Defuse Conflicts www.vitaltalk.com

1. Notice the conflict
2. Find a non-judgmental starting point
3. Listen to their story first
4. Identify what the conflict is about, and articulate it as a shared interest
5. Brainstorm options
6. Look for options that recognize the interests of all involved
7. Remember that some conflicts cannot be resolved

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Establishing Goals of Care

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Prenatal Decision-Making

Discussions and decision-making guided by:

- The certainty of the diagnosis
- The certainty of the prognosis
- The meaning of that prognosis to the parents
  - Ability to adapt, cope, live with death of a child vs. survival of a disabled child
  - Influenced by faith and cultural values

Fry et al., 2020

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Introducing the Role of Palliative Care

- *"Palliative care is consulted when a baby is diagnosed with a serious medical condition. We're here to help support you and your family in making medical decisions given the information we know about your baby."*
- Introduction into a conversation of choice
  - *"These decisions are incredibly personal"*
  - *"We want to help you make the right decision for you and your family."*

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Establishing a Relationship

Learning more about our parents:

- *"Have you chosen a name for your baby, and if so, may we use his/her name as we talk and plan together."*
- *"In order for us to best support you, it is helpful for us to know what support systems you have in place as a family. Who do you turn to for support? Who helps you to make decisions?"*
- *"Can you share about an experience in the past that you have had to make difficult decisions? "*
- *"Help me to know how your family found their way through previous losses (deaths)."*
- *"Given what you've heard from the cardiologist, what are you hoping for today? What worries you?"*

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Parental Factors Which May Impact Decision-Making

- Cultural, spiritual, social, and/or ethical values
- Family characteristics:
  - Family dynamics
  - Previous experiences (i.e., history of infertility, miscarriage, early infant loss)
  - Financial
  - Need for relocation for treatments, monitoring
  - Health of the mother
  - Beliefs on what defines a "good parent"
  - Expecting multiples
  - Surrogacy
  - Adoption

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Goals of Care

- Create a plan reflecting the parents' preferences for their baby's care
  - May take days or weeks to develop
  - Determination of best interest for the baby
  - Weigh treatment benefits and burdens
  - Plan may include labor/delivery preferences and after-birth care
  - Collaboration with specialists is ideal (MFM, Cardiology, etc)
  - How does the plan change in the event of an Intrauterine Fetal Demise (IUFD) or premature birth?

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Goals of Care [cont.]

- Full-Interventions vs. Wait-and-See Approach vs. Comfort Care approach vs. Pregnancy Termination
  - Are there limitations to the interventions the family wishes to pursue?
  - Recognize shifting goals and needs as the baby's living unfolds
    - *"We will work together to make decisions and plans for your baby but will always use your baby as the guide as to what we pursue when he/she arrives."*
    - *"When you think about this pregnancy and your baby, what is most important to you?"*
- Timing and Method of Delivery
  - What do these options look like? Are they realistic options for the family?

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Spectrum of Care Options

Life Sustaining Interventions	Wait and See	Comfort Care Approach
C-section for fetal distress		No c-section for fetal distress
Intubation	Positive Pressure Ventilation	Monitoring vs. no monitoring
Chest compressions	NICU admission	Routine resuscitation (drying, oral suction, stimulation)
Resuscitation	Non-invasive testing	Swaddling
Medications	Palliative Procedures	Warming
NICU Admission		Holding
Long term ventilation		Medications to ease pain
Invasive testing		Oxygen
Surgery		

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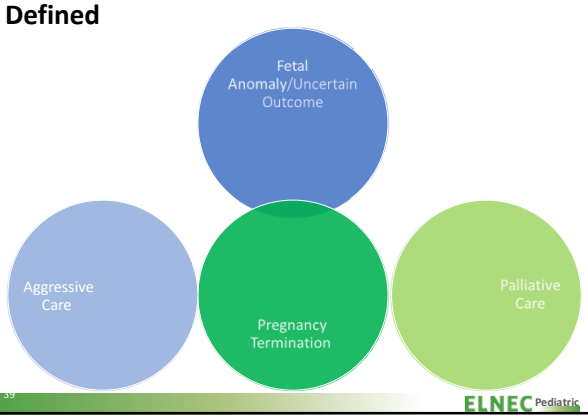
Options for Families May Not Be Clearly Defined



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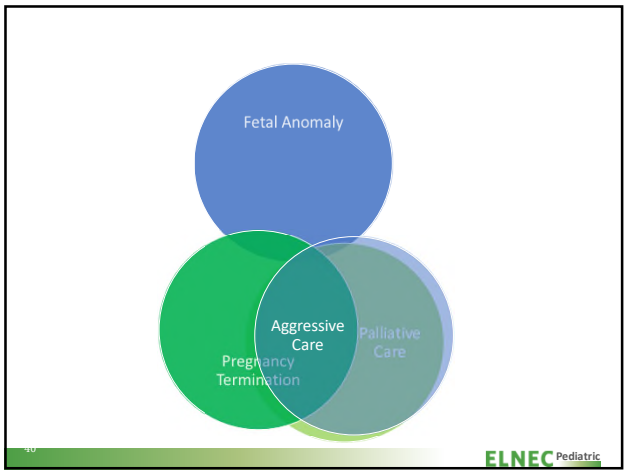

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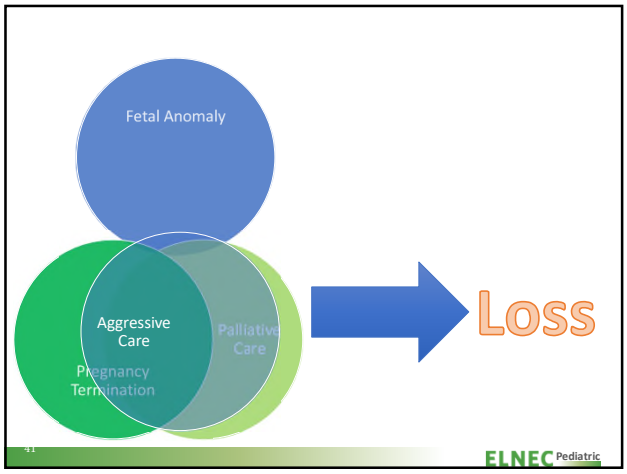

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Ongoing Assessment of Parents' Understanding

- *"What did the cardiologist tell you about the recent ECHO?"*
- *"Can you share with me what you heard from the neurologist after they reviewed the fetal MRI?"*
- *"Knowing what we have talked about today, can you share with me what you anticipate to happen next?"*
- *"Knowing what the neonatologist shared today, what do you hope for?"…"What worries you?"*
- *"Is there information you feel would be helpful to you in making these decisions?"*

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Termination of Pregnancy

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Pregnancy Termination

- Definition
- Maternal indications
- Fetal indications
- Pregnancy termination gestational age parameters vary in each US state or may not be permitted in some states
- Termination may be offered as treatment option as part of non-directional counseling by OB/MFM
- Words matter: “abortion” versus “pregnancy termination”

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Termination of Pregnancy

- Dilation and evacuation (D&E)
  - Cervical dilation and removal of uterine contents in an OR
  - Genetic testing
  - Pathology studies
- Induction of Labor (IOL)
  - Medications used to induce labor
  - Genetic testing
  - Autopsy

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Creating a Birth Plan

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Components of Birth Plan

- Overall goal of care for labor & delivery
- Fetal monitoring
- Preferred site & mode of delivery
- Fetal interventions and medications
- Parents' preference re: presence of family members
- Desired memory-making activities or rituals
- Cultural and spiritual considerations
- End-of-life care

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"This is a special kind of nesting I can do to prepare for my son."

~ A mother during a prenatal planning conversation

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Opening Section of Birth Plan

- Parents' overall goals (eg. To minimize suffering and spend as much time with baby as possible)
- Baby's gender & chosen name
- Parents & siblings names
- EDC: If planned, date of induction or C-section
- OB/MFM Name(s)

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Labor and Delivery

- Fetal monitoring during labor
  - External vs Internal
  - Frequency and timing
  - Intervening (or plan to not intervene) with fetal distress
  - Parents staying informed of baby's status
- Routine pain management options (epidural) and laboring/ induction process
- Mode and site of delivery
- Intervention plan in the event of maternal implications
- Would parents like to "cut the cord"
- Cord blood samples for genetic testing, if desired/recommended

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Neonatal Interventions and Medications

- Intended resuscitative measures/code status
- Location of initial care/resuscitation (i.e., mother's chest, radiant warmer)
- Anticipated medical interventions, such as:
  - Ventilation/airway management
  - Pain & symptom management (pharm & non-pharm)
  - Nutrition/hydration (IV/NG placement)
  - Lab testing (including genetic testing), imaging
  - Routine newborn procedures/screening
- Preferred location for the baby's care
  - Transfer to NICU/Transition to post-partum/Stay with mom

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Siblings and Extended Family and Friends

- Sibling needs and involvement
- Communication plan with family/friends
- Timing and location if family/friends will be present/visit

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Desired Memory Making or Rituals

- Desired mementoes
- Photography
- Hand/feet prints or molds
- Rituals

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Cultural/Religious Care Considerations

- Some end-of-life care choices are not valued or permitted in certain cultures/religious traditions, for example:
  - Decision to not initiate feedings
  - Planned end-of-life extubation
  - Viewing/holding body after death
  - Taking photographs/memory-making activities
- All cultures/religious traditions also have important practices that should be followed during end-of-life
- Critical to learn parents' cultural/religious preferences and incorporate into the birth plan/communicate to teams

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End-of-Life Care

- End-of-life care
  - Preferred location for baby's dying and death
  - Funeral director chosen by family
  - Autopsy or post-mortem biopsy/genetic testing
  - Organ or tissue donation plans
- Contact information for key team members

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Once a Birth Plan is Completed

- Dissemination of birth plan
- Designation of key point person for the parents
- Consider reaching out to parents just prior to planned delivery date to check in, assess for additional needs or changes to their plan

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Support During Pregnancy

- Unexpected news about the baby
- Shock and trauma
- Need for rapid decision-making vs. time for preparation and goal setting
- Emotions
- Navigating social relationships
- Impact on extended family and siblings
- Care coordination

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Intertwining Grief and Hope

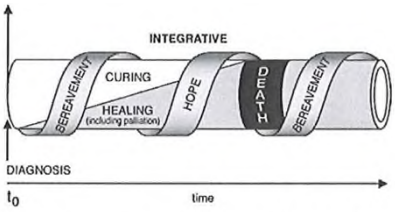

Figure 1. Integrative model of curing and healing. Copyright 2010, Jay Milstein. Modified by Rana Limbo and Kathie Kobler. Used with permission.

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Acknowledging Hope for a Miracle

- Portrayal of 'miracle' babies in the news & social media
- Expectation of a divine miracle based upon religious beliefs
- Often belief in a miracle is strongly held by other family members, who may have not received the same medical information as the parents
- Assess if the parents are hoping for a miracle, and the meaning of that miracle to them
- Provide balanced, non-judgmental response
- *"Thank-you for sharing the miracle you are hoping for. What else do you hope for? And what else?"*

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Case Study – After the Diagnosis

- Parents aware of prognosis, *"Where do we go from here?"*
  - *"What is most important to you and for Thomas?...What worries you and for what are you most hopeful?...If you know that Thomas' life will be shortened, what might you want this time to look like?"*
- Hopes:
  - Meet and hold him; to become a mom
  - Meet extended family
  - Thomas' comfort
  - Take him home
- Considerations:
  - What plan of care would be recommended for Thomas and his family?
  - What are next steps?

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Section III: When Baby Arrives

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Upon Admission to L&D Through Delivery

- Relationship-focused approach to care
  - Provide continuity of care within the team as possible
  - Provide warm handoff between teams
- Coordination to ensure seamless transition from the maternal-fetal team to postpartum, neonatal or hospice care teams
- Review birth plan and wishes with family
- Review counseling and plan including assessing and honoring family values, expectations, and goals
- Fostering capacity to revisit/shift goals as baby's birth and living unfold

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Coordinating Birth and Transitions of Care

- Comfort care birth
  - Labor and delivery
  - Fetal monitoring
  - Possibility of intrauterine death during labor
  - Baby may or not be born alive
  - Parental request to "cut the cord" or request for delayed cord clamping

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Managing Care After Birth

- Baby's needs and physical responses leading the way to planning and supportive care
- Anticipate symptoms baby may experience and prepare for potential interventions accordingly
- Continue reassessment and intervention as baby passes critical transition points
- Organize care to promote family-centered care, honoring parents' values, wishes and preferences

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Nursing Plan of Care Considerations

- Level of intervention at birth, if liveborn
  - Routine or simple resuscitative measures (drying, suction airway)
  - Baby given to mom/parent to hold immediately after birth vs after initial care provided
  - Frequency and duration of newborn assessment
- Comfort measures
  - Skin to skin
  - Swaddle, warmth
  - Breast feeding

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Transition to Comfort Care Only

- Who needs to be in the room at time of extubation/redirection of care to comfort only.
- Do not assume that once the baby is extubated, the baby will immediately stop breathing. While we may not expect the baby to breathe for a "long" period of time, this can vary.
- If the baby continues to breathe on their own after extubation, discuss a plan with family about having a staff member stay with them or check in per their preference.

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Medications for Symptom Management

- Opioid for dyspnea
- Benzodiazepine for restlessness/agitation
- Tylenol or Sucrose drops for discomfort
- Review doses and have available at birth

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Assessing Symptoms

- Physical assessment of baby
  - Retractions
  - Nasal flaring
  - Restlessness
  - Color
- A trial of medication is helpful
  - Morphine used for dyspnea and other pain
  - Lorazepam used for anxiety and restlessness
- Emotional assessment of parents

Choosing Thomas

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Nursing Plan of Care Considerations

- Spiritual plan or rituals
- Support and privacy
- Memory making
  - Build a Bear heartbeat, handprints, footprints, molds, photos, blankets, clothing
  - Opportunities for meaningful moments: playing special music, board books for reading, giving bath, skin-to-skin holding

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Baby Footprints

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Baby & Family Ink Prints

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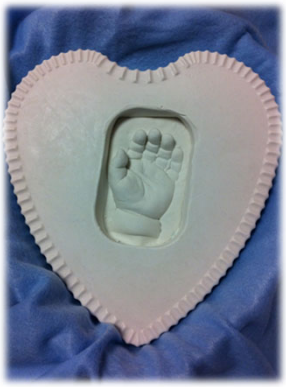
Plaster Molds



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Imprint Mold with Instructions for Teaching Staff

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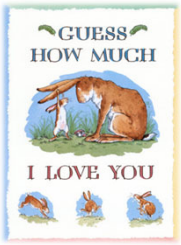
Reading Special Books



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"Wait, Why is She Still Alive?"

- Growing awareness of baby's relative stability
- Important next questions
  - Reframing goals
  - Shift in site of care
  - What should be added to baby's care
  - Reassess appropriate location for the baby
  - Who else should be involved in baby's care
- Comfort-focused interventions continue
  - Warm blanket if baby is becoming "cool"
  - Food/drink for parents/mother

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Choosing the Location of Continued Care

- Timing of exploring, *"Would you like baby to go home?"*
- Interdisciplinary team collaboration
- Hospital
  - Transfer to another unit/Can they stay on mother baby unit
  - NICU admission to continue comfort-focused care/symptom management only until discharge when home palliative care can be arranged
- Home
  - Pediatric Palliative Care or Hospice Care
  - Inpatient hospice or free-standing hospice home in community
- Assess for houselessness
  - Community resources and hospice possibilities

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Coordination of Care & Discharge Planning

- Engaging community pediatric palliative/hospice services
- Pediatrician involvement
- Be prepared and flexible
- Celebrate the life versus waiting for the death

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Case Study – After the Birth

- Teams aware of birth plan and parents' wishes
- Thomas immediately placed in Deidrea's arms, brisk cry and breathing on room air
- Thomas discharged to home on hospice when Deidrea released to home 50 hours after his birth
- *Case Considerations/Discussion*

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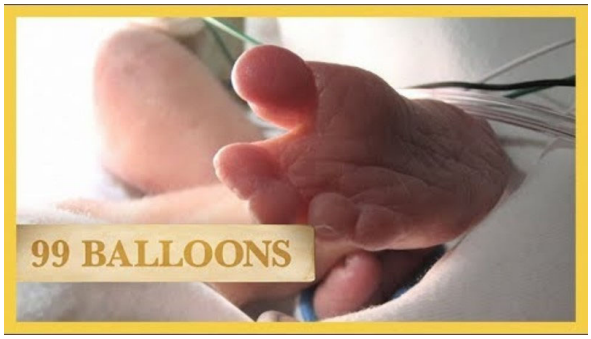
99 Balloons



https://www.youtube.com/watch?v=th6Njr-qkq0

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Care After the Death

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Care Following the Death

- Bereavement-focused care for parents, siblings, extended family
- Memory-making, ritual, faith traditions
- Care of body after death
- Honoring family's time with baby after death
- Anticipating parting from baby's body
- Mother's transition to home and postpartum care needs
- Bereavement follow-up

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Care Following the Death – Fostering Family Bonds

- Respecting a family's time with the baby
  - Cooling blankets/mattresses
- Cultural/religious practices
  - *"Please help me to know if your family has special preferences for how we should care for your baby's body."*
- Memory making
  - Involvement of siblings
- Expect BIG emotions
  - Use of self, including silence and presence, for support
  - Showing emotion is okay

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Care Choices Following the Death

- Diagnostic testing/autopsy
- Genetics counseling
- Organ donation

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Care After Death – Care of the Body

- Various options for families
- Often institution specific
- Dependent on family wishes
- Consider cultural/ religious preferences
- Consider financial issues/support
- Examples-
  - Hospital cremation
  - Funeral home arrangements
  - Transporting baby's body home

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Care of the Mother Following the Death

- Routine postpartum care/what to expect
- Lactation suppression
- Bereavement milk donation (initiation of milk supply for purposes of donation is desired by some families)
- Bereavement support/follow-up care including postpartum depression screening plan

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Perinatal Bereavement

- Perinatal loss
  - Death of a baby via ectopic pregnancy, miscarriage, stillbirth and neonatal or infant death
- Grief and memories begin with prenatal diagnosis
  - Anticipatory grief, loss of expected healthy baby
- Constant wonder who their baby would have been
  - "What would he be doing at this age?"
  - "What would he be like?"
  - "What would be his favorite food or toy?"
  - "What would be his first word?"
  - "What would he look like?"
- Loss of future

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Perinatal Bereavement (cont.)

- Unique characteristics of PPC bereavement
  - Isolation and abandonment
  - Disenfranchised grief
  - Attachment syndrome
  - Paternal bereavement
  - Subsequent pregnancies
  - Death of multiples

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Perinatal Bereavement (cont.)

- What is most helpful?
  - "Holding space" or "Compassionate silence"
  - Resources
  - Condolence cards
  - Follow-up calls
  - Bereavement assessments
  - Support groups (online or in person)

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Case Study – After the Death

- Thomas dies at 5 days old
- Parents participate in ritual of bathing and clothing him
- Memory making
- Funeral
- Bereavement support

- *Case Considerations/Discussions*

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Section IV: Implementing Perinatal Palliative Care

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Implementing Perinatal Palliative Care Strategies Without a Formal Team

- Partners in care (hospital team): Identify stakeholders
  - Maternal-Fetal Medicine Team
  - NICU Team
  - Labor and Delivery/Mother Baby Team
  - Palliative Care (Adult or Pediatric)
  - Parent
  - Administrator

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Defining Team

Who to include [if available]:

- Physicians
- Advanced Practice Providers (NP/CNS/PA/Midwives)
- Nurses
- Social Workers
- Child Life
- Art/Music Therapists
- Spiritual Providers
- Bereavement Specialists
- OT/PT/Speech
- Bereaved parents
- Community Hospices

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Community Partnerships

- Provide educational opportunities for community hospice/home care partners
  - Policies
  - Procedures
  - Provider support
  - Psychosocial support
- Community relationships
  - Hospice/Home Care
  - Schools
  - Churches

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Common Challenges in Perinatal Palliative Care

- Environment of care and potential bias of staff
  - "Life saving interventions" at all cost?
  - Family makes thoughtful decisions based on their values, not "our" values
  - Importance of supporting family values
- Family expectations
  - Potential birth plan changes as labor progresses and family changes their minds
    - *"It is different now that they are born"* or "*I love her so much now"*

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Common Challenges in Perinatal Palliative Care

- Societal expectations
  - *"Doing everything"*
  - *"Won't they die anyway?"* or *"Why are you doing this to them? Are they suffering?"*
  - *"I could never do that…"*
- Financial/regulatory constraints
- Self- and team-care
- Ethical issues

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Common Ethical Dilemmas in Perinatal Palliative Care

- Diagnostic, prognostic, and therapeutic uncertainties for the unborn fetus
- Margin of viability and perinatal resuscitation decisions
- Level of intervention – trials of therapy vs. withholding or withdrawing of treatment
- Health care professional moral distress
- Personal values regarding termination of pregnancy

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Clinical Ethics Model

- What are the ethical concerns in this situation?
- Which norms and standards are applicable (legal, ethical, professional practice)?
- Which strategies are permissible?
- Recommend which strategy is the best (or the least bad)
- What follow-up is necessary?

Carnevale et al., 2020

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Section V: Self-Care and Resilience in Perinatal Palliative Care

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Impact of End-of-Life Care Provision

- Daily bearing witness to others' suffering in our work brings out our own feelings
- Burnout from emotional exhaustion and depersonalization
- Compassion fatigue and burnout in Pediatric Palliative Care providers
  - Clinical experiences
  - Emotional depletion
  - Physical exhaustion
  - Experiences of personal loss
  - Distressed about coworkers

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Impact of Caring for the Dying

- Unique opportunity for meaning-making, cultivating spiritual life, reflect on own mortality
- Experiences of personal growth for pediatric clinicians
  - New or altered life perspectives
  - Enhanced personal resources
  - Benevolence

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Self-Inventory

- Know oneself to support personal and professional well-being
- Self reflection/questions
- Take time for reflective practice
- Cleansing breaths
- Self Inventory [of what you are feeling in the moment]

Kolber, 2020

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Assessing Boundaries

- What is the level of my attachments to the families in my care?
- Do concerns about my perinatal families and neonates occupy my thoughts when I'm at home?
- Have I worked extra shifts or visited on days off so I could be with a patient/family?
- What shakes or unsettles me? What interrupts my sleep or keeps me awake at night?

Kolber, 2020

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Three Good Things

- N = 32 NICU healthcare professionals participated in a 14 day online "Three Good Things" intervention survey, responding to two questions:
  - *What are the three things that went well today?*
  - *What was your role in bringing them about?*
- "Three Good Things" exercise acknowledges the importance of self-care and appears to promote well-being for healthcare professionals.

Rippenstein-Leuenberger et al., 2017

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Processing Impactful or Challenging Care Experiences

- Exercise self-compassion
- Give yourself grace
- *"I don't know; Let me check; I'll get back to you"*
- Ask for help
- Attend to your own needs
  - Debrief with colleagues
  - Think about how the situation has impacted you
  - Make space to process feelings
  - Reflect on lessons learned

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Team Well-Being

- When impactful clinical events occur, opportunities for reflection and acknowledgement are beneficial:
  - Focused debriefing led by professionals trained in group processing facilitation
  - Formal critical incident review
  - Team ritual to acknowledge or mark impactful clinical experiences.

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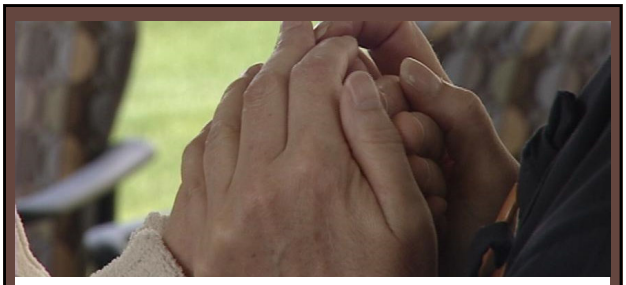

Blessing of the Hands

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Summary

- Perinatal Palliative Care is relationship based
- Family decisions are based on clinical information and what that means for each individual family and their values
- Goal is to support the family and baby
  - Symptom management
  - Psychosocial support
  - Flexibility
- Acknowledge the duality of grief and joy at the birth of their baby
- Self awareness
  - Care of self
  - Bias
  - Meaning of the work

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Thank You

In A Week (110 days later)

In a week you were going to be born.
Instead, on a day in late September I held your birth and death in the same breath. We did what every parent dreams of-take their child's pain away. We washed you in tears and wrapped you in arms made more tender than we'd known possible. Your whole life was 90 minutes. Your whole life was love.

Into the bend of the river as far as we can go
John Mayer

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1

Learning Objectives

At the completion of this module, the participant will be able to:

- Identify dimensions and influence of culture and spirituality on pediatric palliative care.
- Discuss cultural and spiritual factors which may affect the ability to communicate effectively with patients and families facing the end of life.
- Identify the components of a cultural and spiritual assessment of children and families.
- Recognize the value of interprofessional care in respecting cultural and spiritual diversity.

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NCP Guidelines

NATIONAL CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE

- *Domain 5: Spiritual, Religious, and Existential Aspects of Care*—Palliative care IDT serves each child/ family in a manner that respects their spiritual beliefs and practices; but, are also respectful when the child/ family declines to discuss their beliefs or accept spiritual support.
- *Domain 6: Cultural Aspects of Care*—IDT members to provide assessment and respect of values, beliefs & traditions related to health, illness, caregiver roles & decision making to provide culturally sensitive palliative care.

NCP, 2018

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3

If the World Was a Village of 100 People

- By 2060, marginalized groups will comprise close to 65% of the US population

Vespa et al., 2020

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Culture

- Security, integrity, belonging
- Child's experience
- Social beliefs
- Ethnic identity/evolving

Cormack et al., 2019

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End-of-Life Care

- Has its own cultural and spiritual considerations
- Examine personal cultural and spiritual beliefs, values, and principles
- Never assume

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Components of Culture

- Ethnic identity
- Race
- Gender
- Age

7

Components of Culture (cont.)

- Differing abilities
- Sexual orientation
- Financial status
- Place of residency

8

Components of Culture (cont.)

- Child's role
- Education level
- Social consideration

9

Religion and Spirituality

- Religion and spirituality are not the same
- Religion: beliefs, rituals, system of faith/worship
- Spirituality: Individualized, search for meaning & purpose, feeling of interconnectedness

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Spirituality

- Addressing spirituality in pediatric palliative care
  - "If you are not providing good spiritual care, you are not providing good palliative care."
- Communication and understanding is essential in addressing spiritual needs with families:
  - About anger towards God/Higher Being or Power
  - Feelings of blame/regret
  - Forgiveness

Ferrell et al., 2016

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Spiritual Assessment

- Formal (assessment tools)
  - FICA
  - SPIRIT
- Informal
  - In your worst moments, what gives you strength?
  - What has been helpful in the past when things are difficult?

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Striving to Understand Culture: A Process

- All terms & definitions about culturally appropriate care involve self-awareness and an openness and respectfulness for each other.
  - Cultural humility
  - Cultural competence
  - Cultural sensitivity
- Striving to understand the importance of culture in healthcare is a process, not an endpoint.

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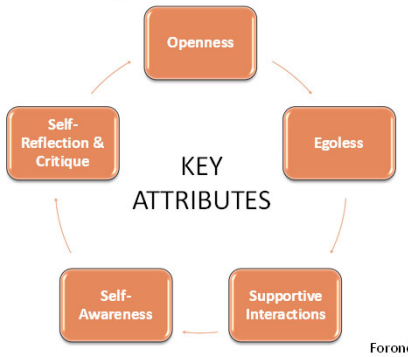
Cultural Humility



Foronda et al., 2016

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Cultural Competence

- Cultural awareness
- Cultural knowledge
- Cultural skill
- Cultural encounters
- Cultural desire

Cormack et al., 2019

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Cultural Sensitivity

- Culturally competent nursing care includes sensitivity to issues related to age, race, ethnicity, gender, sexual orientation, social class, economic factors, spirituality/religion, and other factors cited previously.
- Interprofessional team resources may include
  - Social worker
  - Chaplaincy/Pastoral care/Shamans or other spiritual leaders
  - Interpreter services
  - Child life specialists
  - Interpreter services
  - Child life specialists

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Components of Cultural Assessment

- Child/adolescent/family
- Self-identification
  - Birthplace
  - Ethnic identity
  - Decision-making
  - Language and communication

Cormack et al., 2019

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Components of Cultural Assessment (cont.)

- Community
  - Religion
  - Spirituality/rituals
  - Food preferences/prohibitions
  - Economic situation/support system
  - Health beliefs regarding death, grief, pain

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Components of Cultural Assessment (cont.)

- Nurse and Interprofessional Team
  - Self assessment
  - Cultural beliefs of co-workers
  - Cultural competence

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Cultural Considerations of Communication

- Comfort level
- Use of interpreters
- Conversational style
- Effective communication

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Cultural Considerations of Communication (cont.)

- Personal space
- Eye contact

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Cultural Considerations of Communication (cont.)

- Touch
- Time orientation
- View of healthcare professionals
- Learning styles

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Role of the Family

- Who makes decisions?
- Who is included in discussions?
- Is full disclosure acceptable?

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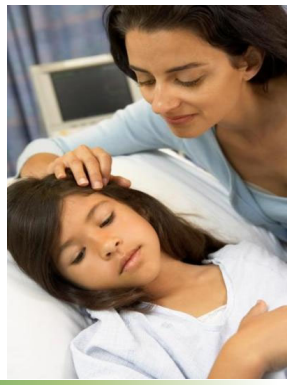
Know your region/area



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Conclusion

- Many dimensions of culture
- Major influence on end-of-life care
- Self-assessment of culture, including spirituality
- Interprofessional care facilitates culturally sensitive care

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1

Learning Objectives

At the completion of this module, the participant will be able to:

- Identify barriers to adequate pain relief in pediatric palliative care.
- List components of a thorough pain assessment.
- Describe pharmacological and non-pharmacological therapies used to relieve pain in children.
- Discuss the role of the nurse involved with pain assessment and management in serious illness.

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National Consensus Project for Quality Palliative Care Clinical Practice Guidelines

Domain 2: Physical Aspects Of Care

- Guideline 2.1: The **palliative care interdisciplinary team** (IDT) endeavors to relieve suffering and improve quality of life, as defined by the patient and family, through the safe and timely reduction of the physical symptoms and functional impairment associated with serious illness.
- Guideline 2.2: The IDT assesses physical symptoms and their impact on well-being, quality of life, and functional status .

NATIONAL CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE

NCP, 2018

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SECTION I: Introduction to Pain in Pediatric Palliative Care

Section 1:

- Definition of Pain
- A subjective response
  - Pain is "what the child says it is…"
- Can be acute, chronic, or a combination both
- Influenced by many factors
- Treated using a multidimensional approach

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Types of Pain

- Nociceptive Pain
- Neuropathic Pain
- Procedural Pain

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Concept of Total Pain

- **Physical Pain**
  - Pain due to disease location
  - Other symptoms (ie, nausea)
  - Physical decline & fatigue
- **Spiritual pain**
  - Religious/faith, anger at God
  - Meaning of life & illness
  - Why me?
  - Why my child?
- **Psychological Pain**
  - Grief, depression
  - Anxiety, anger
  - Change in appearance
- **Social**
  - Relationships with family/friends
  - Role in the family
  - Financial problems

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Scope of the Problem

- Pediatric pain experience
  - Children of all ages
  - Healthy children and those with serious medical illnesses
  - Effect of pain on Quality of Life

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Barriers to Pain Relief

- Healthcare professionals
- Healthcare Systems
- Patients/ Families

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Myths Related to Pain and Pain Management in Pediatrics

- Respiratory Depression
- Substance Use Disorder (SUD)/Addiction
- Children playing/sleeping do not have pain
- Pain indicates worsening of disease or approaching death

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Facts About Childhood Pain

- Opioid addictions are rare
- Repeated exposure to painful procedures leads to increased anxiety and perception of pain
- Children as young as 3 years old can use pain scales

Hockenberry et al., 2019; O'Brien & Root, 2019

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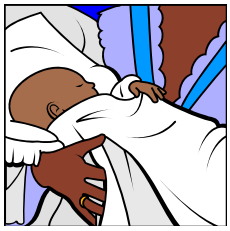
Myths Related to Neonatal/Infant Pain

- Incapable of feeling pain
- Immature nervous system
- Incomplete myelinization
- No memory
- Analgesics unsafe



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Facts About Neonatal/Infant Pain

- Pain perception occurs early in life
- Neonates exhibit physiologic and behavioral cues
- No risk of addiction
  - Tolerance & physical dependence can occur

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Impact of Pain

- What is it like to have a child in pain?
  - Sense of helplessness
  - Unprepared/ unknowledgeable
  - Horrible/ frightening
  - Wish for relief, even if it means death

Mariyana et al., 2018

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Pediatric Pain Experience

- Acute onset illness/ trauma or chronic medical condition
- Hospitalization (ER, PICU, general admission)
  - Challenges to pain management
- Minor injury/ accidents/ or common childhood illness
  - Home pain management

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Special Populations in Pain Management

- Complex Chronic Conditions associated with pain
- Traumatic Injury/ post-surgical
- Pre- or non-verbal children
- Non-English-Speaking patients/ families

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Special Populations (Cont.)

- Cancer pain
  - Disease, treatment, & procedure related
- Chronic non-malignant pain
  - Sickle cell disease, diabetes, rheumatoid arthritis, HIV, cystic fibrosis, neurological degenerative diseases

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Special Populations (Cont.)

- Sickle cell
  - Numerous complications of SCD result in pain
  - Vaso-occlusive crisis, priapism, dactylitis, splenic sequestration, spinal cord compression, and avascular necrosis of joints

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Special Populations (Cont.)

- Musculoskeletal/rheumatic
  - Juvenile Primary Fibromyalgia
  - Juvenile Idiopathic Arthritis
  - Complex Regional Pain Syndrome

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Special Populations (Cont.)

- Neurocognitive impairment
  - Pain experience
  - Pain indicators
  - Assessment
    - Knowing child
    - Recognizing patterns
    - Intersubjective process with HCP

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Section II: Assessment of Pain in Pediatric Patients

- Multidimensional Assessment
- Assessment Tools
- Communicating Assessment

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Multidimensional Assessment

- Self-report/parent-report
- Intensity
- Quality
- Pattern
- Aggravating/alleviating factors
- Medication history
- Impact on quality of life

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Assessment

- Types of assessment
  - Self-report
  - Behavioral
  - Physiologic
  - Proxy report
- Use of scales

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Reassessment of Pain

- Changes in pain
- Changes in analgesic regimen
- Assess consistently and at appropriate time intervals post intervention
- Use of diaries

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Neonatal/Infant Pain Assessment Tools

- CRIES Neonatal Postoperative Pain Measurement Score
- Premature Infant Pain Profile (PIPP)
- Neonatal Infant Pain Scale (NIPS)
- Neonatal Pain Agitation and Sedation Scale (NPASS)

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Pain Assessment Tools

- Pre-verbal / nonverbal (examples)
  - FLACC
  - Pain Observation Scale
  - Modified Objective Pain Score
  - Non Communicating Children's Pain Checklist (NCCPC)

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Self-Report Pain Intensity Scales

- FACES Pain Scale-Revised (FPS-R)
- OUCHER
- VAS (Visual Analog Scale)
- Verbal Report Scale

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Tools for Initial Overall Pain Assessment

- Brief Pain Inventory
- Parent/Child Total Quality Pain Instruments
- Neuropathy Pain Scale
- Adolescent Pediatric Pain Tool

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Communicating Assessment

- Document clearly in chart
  - Assessment
  - Intervention
  - Re-assessment
- Establish pain care plans

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Section III – Pharmacological Therapies in Pediatric Palliative Care

- Analgesics
- Adjuvants
- Adverse effects and Complications
- Titration
- Rotation
- Equianalgesia

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Pain Management

- Severe pain is a medical emergency
- Rapid assessment and treatment is imperative
- Provide an interprofessional care plan including family

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WHO Two-Step Analgesic Stepladder

- Start with an analgesic with a strength appropriate to assessed pain severity
  - Mild Pain: Provide non-opioid pain management with a mild analgesic(s) (acetaminophen, NSAIDs)
  - Moderate to Severe Pain: Patients may be started on a combination of acetaminophen and/or NSAIDs with an opioid

O'Brien & Root, 2019; WHO, 2019

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Analgesics
Acetaminophen/NSAIDs

- **Acetaminophen**
  - Useful for mild pain, anti-inflammatory action
  - Works synergistically with morphine
- **NSAIDs**
  - Can be used in mild, moderate, acute, or chronic pain alone
  - Use in severe pain in combination with opioid ± adjuvant
  - Useful in treatment of bone pain

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Analgesics

- Management of NSAID side effects
  - Gastric irritation, heart burn, ulceration, and bleeding
  - Use gastroprotective medications for prolonged use
  - Effect on platelet aggregation: short-acting, reversible
  - Renal effects: rare, insufficiency and nephrotoxicity can occur with prolonged high doses

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Analgesics

Tramadol

*** Should not be used in those < 12 years**

- FDA warning: no use with history of obesity, OSA, severe lung disease for those < 18 years of age
- Beneficial for neuropathic pain
- Weak opioid
- Adverse effects include: dizziness, hypoglycemia
- Lowers seizure threshold

Hauer & Jones, 2019

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Analgesics (cont)

- Combination products
  - Hydrocodone – acetaminophen (Lortab®, Vicodin®, Norco®)
  - Oxycodone – acetaminophen (Percocet®)
- Concern for acetaminophen overdose
- Concern for masking a fever
- Limits use of acetaminophen alone

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Analgesics (cont)

- Opioids
  - Morphine is gold standard
    - Variety of routes, formulations
    - Large body of research
    - Used for moderate to severe/intractable pain
  - Fentanyl
    - Used in anesthesia, procedural sedation
    - Severe pain
    - Patch has been found useful in some cancer and chronic non-malignant pain

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Analgesics (cont)

- Opioids
  - Hydromorphone
    - More potent than morphine
    - Alternative to morphine or oxycodone
  - Methadone
    - Used in chronic and neuropathic pain
    - Long half-life; longer time to steady state
      - Make dose adjustments q 3-7 days to allow assessment of each dose escalation and avoid overdosing

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Opioids in Neonatal Population

- Reduce clearance of majority of opioids
- Prolonged half-life
- Accumulation

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Adjuvant in Pediatric Pain Management

- Adjuvant/ co-analgesic: Medications use in combination with opioids to enhance analgesia or treat specific types of pain
- Neuropathic adjuvants:
  - Anticonvulsants
  - Antidepressants

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Adjuvants for Neuropathic & General Pain

Neuropathic & General Pain

- Anesthetics: lidocaine, ketamine, propofol
- Corticosteroids: dexamethasone
- Anxiolytics: lorazapam, diazapam, midazolam
- Barbiturates: phenobarbitol, pentobarbital
- Sedative: dexmedetomidine (Precedex®)

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Analgesic Side Effects

- Constipation: prevention is KEY!
  - Miralax, senna and ducosate sodium, casanthranol and ducosate sodium, bisacodyl, mag citrate
- Sedation: tolerance within a few days
  - Precedes respiratory suppression; use monitor

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Analgesic Side Effects (cont.)

- Urinary retention: oxybutynin
- Nausea/vomiting: zofran, promethazine hydroxyzine
- Pruritus: diphenhydramine, hydroxyzine, low-dose naloxone gtt

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Opioid Risks: Definitions

- Substance-use disorder (SUD)
- Tolerance
- Physiological dependence

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Respiratory Suppression

- EXCEEDINGLY RARE
- Decreased depth and rate of respiration, increased sedation
- Use reversal drugs with caution

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Procedural Pain Management

- Topical anesthetics
- Procedural sedation

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Titration of Pain Medications

- Conduct thorough pain assessment
- Provide PRN dose of medication
- Reassess in 15 min if IV/SC, 30 min if PO
- In no relief, give another PRN dose
- Repeat until pain relieved
- Calculate dose needed for PCA/sustined prep
- Notify physician/APRN if requiring frequent bolus doses or change in quality of pain

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Tapering Opioids

- Goal: avoid opioid withdrawal
- Recommended for patients who have required routine doses of opioids for ≥ 5-7 days
- Elicit help from pharmacist for wean schedule
  - Create a calendar for family to follow
  - Wean schedule often determined by the length of time and dose of opioids

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Tapering Opioids (cont.)

- Monitor for return of pain
- Monitor signs and symptoms of withdrawals
  - Runny/stuffy nose, diarrhea, abdominal cramping, nausea/vomiting
  - Return to dose prior to onset of symptoms

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Opioid Rotation & Equianalgesia

- Changing from one opioid to another:
  - When pain is not well managed despite increasing opioid doses
  - Intolerable side effects to an opioid
- Equianalgesia must be considered when changing opioids as each opioid has a different potency
- Failing to consider equianalgesia is a leading cause of inconsistent pain control and oversedation

Portenoy et al., 2020

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Equianalgesia

- Calculate total amount of meds in past 24 hours
- Make appropriate equianalgesic conversions
  - Decrease equianalgesic dose by 25-50% to account for cross tolerance
  - If pain is not controlled prior to conversion, increase calculated equianalgesic dose by 15 – 30%

Paice, 2017; Portenoy et al., 2020; Treillet et al., 2018

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Equianalgesia Opioid Conversion Chart

Medication	PO	IV
Morphine	30mg	10mg
Oxycodone	20mg	NA
Hydromorphone	7.5mg	1.5mg
Fentanyl	NA	0.1mg

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Let's Practice: Conversion Example

- Child is currently on a morphine PCA pump with basal 25mg IV q 24 and has received five 1mg PRN doses. Convert this to an oral equivalent:
  - Total 24 hr dose = 30 mg (25 + 5)
  - 30mg IV multiplied by conversion of 3 = 90mg PO
- Convert oral morphine to oral dilaudid:
  - Oral morphine 90mg/24 hrs.
  - 30 mg PO morphine= 7.5 mg hydromorphone(30/7.5 = 4)
  - 90mg morphine = 22.5 mg hydromorphone X 25% for cross tolerance = 16.9 mg hydromorphone/day
  - 2.5 mg q 4 hrs PRN pain

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Section IV: Principles of Pediatric Pain Management

- Around the Clock Dosing
- Stay Ahead of the Pain
- Routes of Administration
- Nonpharmacological techniques
- Pain at End-of-Life
- Nursing role

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Around the Clock Dosing

- Opioids should be given on scheduled basis
  - Provide adequate PRN doses for breakthrough pain
  - Maintain stable analgesic blood levels
  - Designed to control baseline pain

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Stay Ahead of Pain

- Individualize based on level of pain, prior experience with opioids, and desired activity level
- Frequently assess pain level and adjust treatment plan as necessary
- Pain crisis - rapid titration to comfort is imperative

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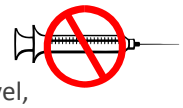
Route of Administration



- Least invasive route
- Consider age, developmental level, cooperation, temperament
- Traumatic administration can lead to under-reporting, poorly controlled
- Use interprofessional team (pharmacist, child life)

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Route of Administration (cont).

- Oral/Transmucosal
  - Long-acting preps
  - Breakthrough IR preps
- Transdermal
  - Limited use in escalating pain
  - Treat with additional analgesics until peak onset is reached with initial placement

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Routes (cont.)

- Topical
- Intravenous/Subcutaneous
- Intraspinal/epidural

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Non-Pharmacologic Pain Management

- Parental presence
- Visualization/guided imagery
- Deep breathing
- Massage
- Heat/Cold
- Positioning
- Physical therapy
- Meditation
- Play therapy
- Reiki
- Hypnosis
- Aromatherapy
- Music
- Hydrotherapy
  - Consult child life, social work, rehab for assistance

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Non-Pharmacologic Techniques for Neonates/Infants

- Modify environment (minimize light and sound, temperature)
- Minimize sleep interruptions
- Oral sucrose
- Swaddling/holding and rocking
- Music
- Infant massage

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Pain at the End-of-Life

- Practical treatments in the home
- Dosage of opioids
- Renal function
- Accumulation of metabolites

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Pain in Dying Children

- 47% of children dying of cancer experience a "great deal" or "a lot of pain" at end of life
- Inadequate pain relief hastens death
- What role does spirituality/religion play in suffering at the end of life?

Ferrell et al., 2016

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Pain versus Suffering

- Influenced by existential distress, fear of dying, and grief
- Affects quality of life (QOL) dimensions

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Intractable Pain

- Palliative chemotherapy
- Radiation therapy
- Therapeutic nerve blocks
- Epidural/intrathecal infusions

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Palliative Sedation

- Communication with family
- Goal of sedation
- Treatment
- Comfort measures

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Role of the Nurse in Pain Management

- Advocacy
- Competency
- Awareness

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Summary

- Pain must be assessed and managed consistently
- Interprofessional management
- Golden rules
  - "If it would hurt you, it hurts them"
  - Approach the child with the same respect you would an adult
  - Requires trust and cooperation

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END-OF-LIFE NURSING EDUCATION CONSORTIUM
Advancing Palliative Care

Pediatric Curriculum

MODULE 8

Final Hours in Pediatric Palliative Care

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Video Clip from Grey's Anatomy

https://www.youtube.com/watch?v=VSjdbWRrA-g

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Learning Objectives

Upon completion of this module, the participant will be able to:

- Discuss the role of the nurse at the time of a child's death.
- List physical signs and symptoms of the dying process.
- Identify physical, psychological, social, and spiritual needs and interventions for an imminently dying child and family.
- Describe supportive interventions when caring for the dying child and his/her family.

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NCP Guidelines

- *Domain 7: Care of the Patient Nearing the End of Life*
  - Care provided to child/adolescent and their families near the end of life, with emphasis on the days leading up to and just after the death.
  - Comprehensive assessment & management of pain and other physical symptoms
  - Assessment & management of social, spiritual, psychological, and cultural aspects of care as the child/adolescent nears death.
  - IDT provides appropriate education to the child/adolescent, family and/or other caregivers about what to expect near and immediately following the patient's death.

NCP, 2018

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Pediatric Dying and Death

- How children die
- Final hours: significant moments for child and family
  - Preparing for death, saying goodbyes, memory-making
  - Assess final wishes

Battista & Santucci, 2016

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Pediatric Death is a Unique Experience

- No typical pediatric death
- Developmental issues
- Family is the unit of care
- Interdisciplinary team approach

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Role of the Nurse in the Final Hours

- Advocate
- Support
- Educate
- Coach
- Interdisciplinary team collaboration

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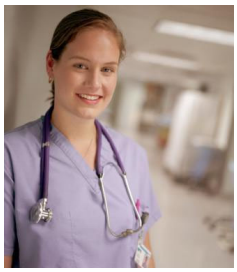
Role of the Nurse in the Final Hours (cont.)

- Be present
- Physical care
- Spiritual comfort
- Honor culture
- Memory-making



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Communication in Final Hours

- Provide information in simple terms, based on readiness
- Child's awareness of death
- Presence

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The Dying Child

- Awareness of dying
- Disclosure

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The Family

- Parents/Caregivers
- Siblings—involve a child life specialist
- Extended family

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Location of Death

- Hospital
- Home
- Physical environment
- Changes should be avoided

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Special Considerations for Home Care

- Referral to home care/hospice
- Relationships/communication
- Flexibility and reliability
- Assess goals of child/family

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Education About Final Hours

- Empowerment
- Signs, symptoms of dying process
- Family involvement

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The Imminently Dying Child

- Estimating prognosis
- Organ/tissue donation
- Signs/symptoms only a guideline
- Dying process

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Psychosocial and Spiritual Issues

- Fear
- Psychosocial assessment
  - Social withdrawal
  - Decreased attention span/ability to concentrate
  - Gradual loss of consciousness
- Withdrawal
- Spiritual assessment
  - Near death awareness

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Family Practice/Ritual

- Family may have cultural or religious practices surrounding death and dying
- Always ask about preferences—don't assume
- Rituals

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Assessing/Managing Physical Symptoms

- May occur months, weeks, days, or hours before death
- Evaluate the degree of distress
- Comfort is the primary focus of care
  - Evaluate benefit of providing interventions which may be disruptive (i.e., monitoring V/S, blood work)
- Interprofessional approach

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Physical Symptoms

- Onset
- Confusion, disorientation, delirium
- Weakness, fatigue
- Pain changes
- Restlessness and/or terminal agitation

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Physical Symptoms (cont.)

- Alertness/sleep changes
- Temperature changes
- Gastrointestinal changes
- Decreased oral intake

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Physical Symptoms (cont.)

- Incontinence or urinary retention
- Seizures
- Breathing pattern changes
- Vital sign changes
- Continued assessment is important

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The Death Vigil

- Family presence
- Common fears
  - Not "being there"
  - Painful death
  - Time of death
  - Giving "last dose"

McHugh & Buschman, 2016;
Stajduhar & Dionne-Odom, 2019

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Death: When the Time Comes

- Signs and symptoms
- Parental presence or absence
- Death pronouncement

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Communicating the Death

- Grief
- Interprofessional team approach

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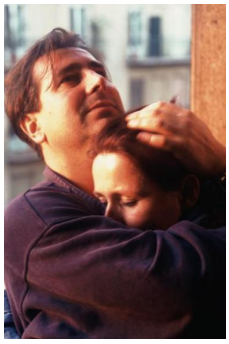
After the death- What can you do?



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Care Following Death

- Removal of tubes, equipment
- Bathing and dressing the child's body
- Encourage family participation
- Respect cultural preferences

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Care Following Death (cont.)

- Compassionate/sensitive removal of body
- Rigor mortis
- Embalming
- Siblings
- Funeral home

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Care Following Death (cont.)

- Assistance with calls, notifications
- Destroying medications
- Autopsy

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Care Following Death (cont.)

- Assisting with arrangements
- Initiating bereavement support

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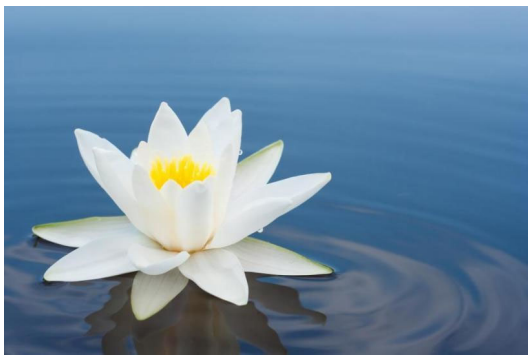

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