Introducing Pediatric Palliative Care

The goal of pediatric palliative care:

Enhance the quality of life of patients and families facing serious illness

Goals of Palliative Care

• Decrease suffering by offering ‘total care’ addressing patient and family’s physical, emotional, and spiritual needs
• Coordinate communication between families and the care team
• Communicate with and advise families as they make difficult decisions about a child’s continuing medical care
• Reduce unnecessary emergency room visits and hospital admissions
**Patient-Centered Care**

- Focus on patient’s needs
- Emotional support and education for the child and family members, including siblings
- Symptom management
- Inpatient counseling and outpatient therapy for patient and family
- Case management, coordination of care

**Impacts of Serious Illness on the Family System**

- Congenital vs. Acquired Illness
- Appreciating the Grief of a Million Losses
- Longer-term arc of chronic illness
  - Years, decades of living with illness

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**Figure 1: Palliative Care Integration in the Disease Trajectory**

*Graph showing the integration of palliative care within the disease trajectory.*

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## Children Living with Serious Illness

<table>
<thead>
<tr>
<th>Age</th>
<th>Developmental Milestones</th>
<th>Impacts of Serious Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant/Toddlers (0-2 years)</td>
<td>Security, attachment, trust</td>
<td>Lack of bonding, socialization, “untouchable,” fear of strangers, developmental delays</td>
</tr>
<tr>
<td>Preschoolers (2-5 years)</td>
<td>Autonomy, sense of self, magical thinking</td>
<td>Isolation from peer communities, impeded socialization, behavior, fear of medical providers</td>
</tr>
<tr>
<td>School-agers (5-11 years)</td>
<td>Sense of purpose, social improved decision-making</td>
<td>Learning delays (school), separation from peers, body image, lacking medical knowledge, extracurricular limits</td>
</tr>
<tr>
<td>Adolescents (12-18 years)</td>
<td>Independence, invincible, need for peers, thinks abstractly</td>
<td>Body Image, feeling left out, depression, limited social networks, lack of purpose, loss of abilities</td>
</tr>
</tbody>
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## Integrating Holistic Family Care

- What’s the bigger picture?
- Patient – Caregiver – Siblings – Extended
- Reinstating “parenting,” routines
- Normalizing experience
- The “Shadow” of illness

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## Spiritual Assessments

- Spiritual Generalists vs. Spiritual Specialists
- Assessment Model
  - Love (Community, Connection)
  - Hope (Meaning, Perspective, Purpose)
  - Faith (World View, Religion, Prayer)
  - Virtue (Ethics, Morality, Integrity)
  - Beauty (Renewal, Art, Creativity, Joy)

Supporting Spiritual Care Needs

<table>
<thead>
<tr>
<th>Age</th>
<th>Developmental Needs</th>
<th>Spiritual Needs</th>
<th>Spiritual Tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant/Toddlers (0-2 years)</td>
<td>Security, attachment, trust</td>
<td>Safety, Nurture, Love</td>
<td>Learn Trust</td>
</tr>
<tr>
<td>Preschoolers (2-5 years)</td>
<td>Autonomy, sense of self, magical thinking</td>
<td>Awe, Trust, Entering Story</td>
<td>Imagination, Explanation, Curiosity, Wonder</td>
</tr>
<tr>
<td>School-agers (5-11 years)</td>
<td>Sense of purpose, social, improved decision-making</td>
<td>Justice, Myth/Logic</td>
<td>Concept of ‘God’</td>
</tr>
<tr>
<td>Adolescents (12-18 years)</td>
<td>Independence, invincible, need for peers, thinks abstractly</td>
<td>Question and Doubt; Purpose</td>
<td>Personal ‘mythos’; Differentiated Spirituality</td>
</tr>
</tbody>
</table>

From Hospital to Home

• What equipment do they need?
• What appointments need to be scheduled?
• What resources would make their life easier?
• What kind of support do they have at home?
• What can help them stay organized?
• How can we support the whole family?
• What can improve their quality of life?

Engaging Wonder

• Developmentally appropriate play
  – Drawing, coloring, artwork for expression and a window into the world of Wondering
  – Puppets, Stuffed Animals
  – Toys as objects of conversation through play
  – Environmental curiosity, wondering
• “Tools” of the trade
  – Apps
  – Books
  – Playdoh, crayons, paints, and a willingness to TRY
3 Key Components of Understanding Death

**Irreversibility** – once something is dead it will not come alive again

**Non functionality** – all internal and external function has stopped

**Universality** – all living things will eventually die

Understanding these components is affected by a child’s... 
- Developmental Stage
- Previous Experiences
### Children's Understanding of Death

<table>
<thead>
<tr>
<th>Age</th>
<th>Developmental Milestones</th>
<th>Understanding of Death</th>
<th>Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant/Toddlers (0-2 years)</td>
<td>Security, attachment, trust</td>
<td>No understanding, but reacts to separation and parental anxiety</td>
<td>Cuddle, keep routines</td>
</tr>
<tr>
<td>Preschoolers (2-5 years)</td>
<td>Autonomy, sense of self, magical thinking</td>
<td>Death is not permanent</td>
<td>Simple explanations, appropriate phrases</td>
</tr>
<tr>
<td>School-aged (5-11 years)</td>
<td>Sense of purpose, social, improved decision-making</td>
<td>Begin to understand death is possible and irreversible</td>
<td>Honest explanations, permission to cry and share feelings</td>
</tr>
<tr>
<td>Adolescents (12-18 years)</td>
<td>Independence, invisible, need for peers, thinks abstractly</td>
<td>Understands implications of death, acknowledges life is fragile</td>
<td>Communication, good listener</td>
</tr>
</tbody>
</table>

### The Ethics of Truth Telling

- When is it right to tell a child what's happening to their body?
- Is there ever a time that it is ok NOT to tell a child?
- How should those situations be handled?
- Ethics, Morality, and the right to autonomy
  - Consent vs Assent; Age of Understanding
  - The Private Worlds of Dying Children
    - Myra Bluebond-Langner

### Talking to Children about Death

- Active Listening
  - Learn what the child knows already
- Help eliminate fears and misconceptions
  - Provide concrete and honest explanations
- Provide information, comfort, and understanding.
  - Validate child's feelings
- Use Child Friendly Language
  - Confusing phrases: went to sleep; Passed away; gone to heaven; ‘lost’
Explaining Death to Children

- Give clear and simple explanations.
  - The baby died. Her body stopped working.
- Use the words dead or dying.
  - They are less likely to lead to misconceptions.
- Listen and be prepared for questions.
  - Answer questions honestly.
  - Say, “I don’t know.” if you do not know the answer.

Care Planning

Bereavement and the Family

- Important to support the family as a whole
  - And the individuals in their unique needs, losses
- Grief: More than stages
- Grief, Mourning, and Loss
- Setting up “good” grief
Long-term Bereavement Care

• Support Groups
• Individual counseling (effects of long-term serious illness on the family)
• Remembering, Celebrating