Cardiology Fellowship Manual

Goals & Objectives
-Palliative Care-
Welcome

Overall Goals and Objectives for Your Palliative Care Rotation: Director – Meaghan Weaver, MD

Module 1. What is Pediatric Palliative Care?
Module 2. Delivering Bad or Sad News
Module 3. Discussing Prognosis
Module 4. Care Goals – to include code status discussion and advanced care planning
Module 5. What is Hospice?
Module 6. Family Decision Making and Patient Centered Care
Module 7. Integrative Therapies
Module 8. Pain – All Sorts of Pain
Module 9. Treatment of Respiratory, GI, Neurologic, Dermatologic Symptoms
Module 10. Existential and Spiritual Distress – with a focus on cultural respect
Module 11. Recognizing and Preparing for Imminent Death
Module 12. Resiliency and Professional Growth
Module 13. Grief and Bereavement

Relevant topics we will naturally engage as part of the rotation:
1. Interdisciplinary team synergy – strength in team vs individual care models
2. Responding to strong emotions in self and others
3. Decision-Making tools (let’s review trach decisional guide; family decisional tools, caring decisions book, etc, etc)
4. Honoring child voice (regardless age of the child)
5. Medical ethics
6. Defining and maintaining professional and personal boundaries
7. Signs, symptoms, and interventions for withdrawal (and prevention of withdrawal!)
8. Consultation etiquette
9. Grandparent and sibling experience
10. The nature of suffering
11. Validated symptom scales used longitudinally
12. Quality of life metrics
Welcome to Hand in Hand Team rotation!

The Hand in Hand (Palliative Care Service) is a consult team available to all patients at Children’s Hospital and Medical Center. A consult includes a full assessment of the patient’s pain and other symptoms, diagnosis, and treatments implemented. The consult assesses not only physical symptoms, but also emotional and psychosocial and spiritual distress. Each new consult receives a full needs assessment with the empowerment for the family to prioritize their self-perceived care needs across domains. The patient is usually offered varied modalities of treatment, pharmacologic as well as integrative therapies. The service is designed as an interdisciplinary and integrative practice model through collaboration with other disciplines such as Spiritual Care, Social Work, Case Management, and Child Life. A main intention for you joining our interdisciplinary team meetings is for exposure to collaborative patient care informed across disciplines.

Our care philosophy is to provide expert supportive care earlier in the disease process, with the goal of improving quality of life throughout. End of life care is also managed, when indicated, or the Hand in Hand team assists in seamless transition of care if possible to the patient’s home with hospice support.

Please review these resources:
https://getpalliativecare.org/whatis/pediatric/
https://www.youtube.com/watch?v=bEx-n9sDFd8
https://couragousparentsnetwork.org/

While attendance at a couple of our meetings and rounding even for a full month will not make you an expert in palliative medicine, it is our belief that such exposure will give you important skills to take with you and a deeper knowledge of a growing field dedicated to care of the seriously ill. We celebrate that palliative care is a PRIMARY care work with subspecialty teams available for support.

Again, welcome! Please check out our website at

We are grateful for your time with us this month; we look forward to learning together with and from you.

Hand in Hand Team

Overall Goals and Objectives for Your Rotation

Aim – This elective will provide you with opportunities to join an interdisciplinary team in providing whole-person palliative care for children facing life limiting or life threatening illnesses.

Objectives –
- Medical knowledge
  - Recognize suffering to include physical (pain and distressing symptoms) and psychosocial, spiritual, and emotional layers
  - Identify pharmaceutical and integrative therapy methods to manage complex symptoms to include chronic and acute pain, dyspnea, intractable nausea, seizures, and end of life symptoms
  - Understand philosophies regarding patient-provider communication and ethical principles relevant to decision making
- Patient Care –
  - Foster learning from various interdisciplinary team members (child life, healing touch practitioner, social worker, nurses, case manager) to recognize collaborate dynamics of palliative care
  - Participate in mentored goals of care conversation and care plan development with patients and families
- Professionalism
  - Demonstrate compassion, empathy, integrity, respect, and altruism
  - Maintain professional boundaries
  - Reflect on the need for “care for the caregiver” (self-care) as part of professionalism and resiliency; learn about various self-care approaches to prevent compassion fatigue and to foster mindfulness in medicine

Methods
- Medical Knowledge
  - Complete suggested readings
  - Participate in teaching sessions
  - Proactively engage in literature searches and evidence-based practice recommendations

Patient Care
- Evaluate patients with life limiting and life threatening illnesses
- Communicate with patients and families regarding goals of care

Evaluation
- Global performance evaluation with interdisciplinary team member input (100%)

Scheduled Activities
- Inpatient rounds, interdisciplinary clinic, consult visits, case conferences and care meetings, didactic teaching sessions, research mentorship
Module 1. What is Pediatric Palliative Care?

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<tr>
<td>Define pediatric palliative care (PPC) as a set of tasks</td>
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<td>Identify predictable opportunities for palliative care intervention at different stages of disease</td>
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<td>Describe when and how to utilize a subspecialty palliative care team</td>
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<td>Evaluate myths and assumptions about PPC</td>
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<table>
<thead>
<tr>
<th>Lecture – “What is Pediatric Palliative Care and Why Does It Matter?”</th>
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<tbody>
<tr>
<td>Readings –</td>
</tr>
<tr>
<td>2. Contemporary Pediatric Palliative Care: Myths and Barriers to Integration in Clinical Care. Friedrichsdorf SJ, Current Ped Reviews 13(1).</td>
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<th>Activity –</th>
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<tr>
<td>1. Please look up the following two organizational definitions of palliative care –</td>
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<tr>
<td>• World Health Organization</td>
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<tr>
<td>• Center to Advance Palliative Care</td>
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<tr>
<td>For a patient that we see together today, I would like for you to please summarize (conversationally) how that patient’s care did or did cover the domains of palliative care upheld by those organizational definitions.</td>
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<tr>
<td>2. Please know that at the end of the rotation together, I will ask you to please share in writing your own personal definition of palliative care as you feel could apply to your unique patient population in the future (reflective task not cerebral task).</td>
</tr>
<tr>
<td>3. Please review the Needs Assessment form for new palliative care consultations; after a few days with the team – you will be asked to review this form with a new consultation family and to present the needs at our Thursday afternoon interdisciplinary team meeting to witness interdisciplinary care responses</td>
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Fun Activity –
Did someone say “Ocean Guided Imagery Postcard”? – be ready for sand and sun!
Module 2. Delivering Bad or Sad News

Objectives –
- Remain open to improve in capacity for delivering bad or sad news in a compassionate, honest and direct manner as part of the physician role.
- Demonstrate knowledge of the key steps for delivering bad news.
- Conduct an appropriate opening of a discussion when bad or sad news will be presented.
- Competently deliver bad or sad news with honesty and compassion.
- Appropriately conclude a discussion of bad or sad news with formulated follow-up care plan.
- Respond to patient emotion and attend/recognize own emotion.

Lecture – Instead of a lecture, please watch the five videos on this link:
http://vitaltalk.org/topics/disclose-serious-news/

Readings –

Activity –
1. Complete the Table 2 Survey from the S-P-I-K-E-S protocol.
2. Utilize S-P-I-K-E-S at mutual communication encounter and discuss together your personal sense of outcome/impact -- you will use a self-assessment survey.
3. Discuss practice of “tracking and responding to an emotion” based on shared case.

Fun Activity –
Aromatherapy Day!
Module 3. Discussing Prognosis

Objectives –
- Learn that you MUST ask permission from the person to whom you are communicating the news; check in as a dignifying commitment
- Detail reasons for communicating prognosis
- Describe methods for communicating prognosis
- Understand methods to elicit goals of care while revealing prognosis

Lecture – “Communication and Planning”

Readings –

Activity –
1. Think of a patient case you currently follow with a certain prognosis --- we will together map out prognosis impact using triangulated lens of provider, parent, and child (notice the readings for today each represent one of those lenses) --- we will discuss the communication needs, support needs, and mutual protectionisms of each stakeholder
2. Let’s discuss unique prognostic needs of children according to developmental stage; be ready to review Erikson’s Developmental Theory and Fowler Spiritual Development; let’s talk about support for prognostic understanding specific to each stage
3. Write down what 3 top qualities of prognostic communication families seek. . . we will then discuss what the evidence reveals consistently to be the Top 3 across diagnoses.
4. Consider this talking map: http://vitaltalk.org/guides/discussing-prognosis/

Fun Activity –
Labyrinth Relaxation Day!
Module 4. Communication About Care Goals – to include code status and advanced care planning

Objectives –
- Review goals of care language specific to your patient population
- Discuss how code status and advanced care planning fits into goals of care
- Recognize the provider-patient relational context of goals of care conversations

Lecture – Instead of a lecture, please watch the three videos on this link:
http://vitaltalk.org/topics/reset-goals-of-care/

Readings –

Activity –
1. Review of Ask-Tell-Ask approach
2. Review case study and decipher opportunities/time points for longitudinal goals of care conversation content
3. Review this video about making a recommendation re: CPR; let’s then discuss documentation of code status conversational content
4. Review advanced care planning documents to include Voicing My Choices, My Wishes, and Five Wishes – discuss design of each and evidence-based of patient and family receptivity

Fun Activity –
Tibetan Music Bowls!
Module 5. What is Hospice?

Objectives –
- Differentiate between hospice care and palliative care
- Discuss concurrent insurance care model for children enrolling on hospice
- List what services home hospice does and does not provide for children and families

Lecture – Instead of powerpoint lecture, we will review the biomedical and psychosocial cases of current home hospice patients

Readings –
1. Understanding hospice – an underutilized option for life’s final chapter, NEJM 357(4).
2. Casarett DJ, Quill, TE. “I’m not ready for hospice”: strategies for timely and effective hospice discussions, Ann Intern Med 146(6)(2007), 443-449

Activity –
1. Visit Josie Harper House or attend hospice home visit with Dr Weaver

Fun Activity –
Haiku-Writing Day!
## Module 6. Family Decision Making and Family Centered Care

### Objectives –
- Define family centered care
- Learn the four key principles in family centered care
- Describe strategies for delivering effective family centered care in pediatric palliative care
- Understand and reduce barriers to family centered care

### Lecture – “Family Centered Care”

### Readings –

### Activity –
1. For one of our active cases, map out how each of the four key principles in family centered care applies to the current patient case

### Fun Activity –
Office Yoga!
Module 7. Integrative Therapies

Objectives –
- Describe how integrative medicine strategies can enhance care for children with life-threatening conditions.
- Practice relaxation and mental imagery (RMI) exercise.
- Review importance of safe and effective integrative medicine modalities to improve pain and symptom management as well as quality of life for seriously ill children.

Lecture – “Integrative Modalities”

Readings –
1. Please review the intranet-based hospital policies and educational handouts on:
   - Healing touch
   - Massage therapy
   - Aromatherapy
   - Gentle Yoga
   - Tai Chi
   - Qi Gong
   Note that the reference list for these policies are extensive; you are welcomed to further your reading on this topic at your interest level.

Activity –
1. Please plan to invest a morning or afternoon shadowing the massage therapist and/or healing touch practitioner and/or yoga instructor --- I will be interested to learn your honest impressions on: 1) the patient’s experience; 2) the family’s experience; 3) your experience.
Module 8. Pain – All Sort of Pain

Objectives –
- Differentiate neuropathic, visceral, inflammatory, musculoskeletal, and somatic pain
- Develop a step-by-step treatment approach for each of the above-listed pain categories
- Describe options for procedural pain interventions at our hospital
- Evaluate the 4 WHO-Principles of acute pediatric pain management
- Discuss the palliative care concepts of Total Pain and Multimodal Analgesia
- Determine the nature of functional chronic pain ---- and realize that opiates are NOT indicated in this setting

Lecture 1 – “Multimodal Analgesia”
Lecture 2 – “Neuropathic Pain”

Readings –
1. We will review the pain content from the Textbook of Interdisciplinary Pediatric Palliative Care

Activity –
1. Taking a real-life example of a patient currently followed with multiple pain factors and pain etiologies; differentiate a pain plan
2. If you are interested, we can practice opioid conversion calculations if these are not comfortable or familiar to you fully (How to convert a morphine PCA to oral dilaudid? How do you transition from oral morphine to a fentanyl patch?, etc, etc)
3. Please find a media article on the state of the current opiate epidemic; please review the opiate agreement document with me and practice presenting it in a normalized way; discuss the realities of safe prescribing and close monitoring for substance abuse or diversion. Please do read the CDC Opioid-Prescribing Guideline.
4. Let’s talk about how end of life pain management is unique and different from acute pain management or even chronic pain management.

Fun Activity –
Paper Crane Origami Art
### Module 9. Treatment of Respiratory, GI, Neurologic, Dermatologic Symptoms

#### Objectives –
- Evolve into a symptom management ninja 😊 This module is a whirlwind, which we won’t tackle all in one day but will target as we see the various symptom during your rotation. Basically, name a symptom and we will “rock it” with discussion on how to treat that symptom.

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<thead>
<tr>
<th>Lecture 1 – “Treatment of Respiratory Symptoms” = secretions, dyspnea, etc</th>
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<td>Lecture 2 – “Treatment of GI Symptoms” = ileus/bowel obstruction, constipation, nausea, etc</td>
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<tr>
<td>Lecture 3 – “Treatment of Dermatologic Symptoms” = intractable pruritis, pressure sores</td>
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<tr>
<td>Lecture 4 – “Management of Neurological, Emotional, and Behavioral Symptoms” = terminal anxiety, seizures, delirium, hallucinations, depression, irritability</td>
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*Note – I will focus the lecture portion of our discussions on end of life symptom management

#### Readings –
1. I have folders of articles on each symptom; rather than type them out here --- we will review the literature and evidence behind each symptom intervention as we encounter that symptom when seeing patients together

#### Activity –
1. Pick THREE validated symptom reporting scales (try to find patient-reported outcome scales in addition to proxy-reported outcome scales) for EACH symptom that could be used to track intervention impact longitudinally
2. Consider together how each symptom translates into an impacted quality of life
3. Start to draw out the pathway of symptoms --- so, not “nausea = zofran” but actually contemplate out the etiology of that nausea’s origin and a targeted intervention specific to that etiology; we’ll practice drawing symptom maps together
4. The wound care team has given permission for you to visit with them one morning or afternoon to learn more about dermatologic symptom intervention options with hands-on review of wound care supplies for pressure sores, etc

#### Fun Activity –
A Review of Relaxation Apps (pick a favorite of the ones we use with patients)
Module 10. Existential and Spiritual Distress – with a focus on cultural respect

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<tbody>
<tr>
<td>▪ Differentiate how does spirituality differ from religion</td>
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<tr>
<td>▪ Describe spiritual assessment tools and their application in palliative practice</td>
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Lecture 1.

<table>
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<tbody>
<tr>
<td>1. The Role of Spirituality in Healthcare; Proc (Bayl Univ Med Center) 14(4). C. Puchalski.</td>
</tr>
<tr>
<td>2. Cultural and religious considerations in pediatric palliative care. Palliat Support Care 11(1);47-67. L. Wiener</td>
</tr>
<tr>
<td>3. The Spiritual Assessment. AAFP 86(6) == please that the the spiritual assessment tools are available in this article</td>
</tr>
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Activity –

1. Please review the validated spiritual assessment tools (FICA, HOPE, Open Invite) and prepare to discuss your impressions of each tool
2. Consider questions that may inquire about spirituality; questions of meaning, joy, comfort, strength – reflect upon these in your own personal life (private exercise; you are not required to report back on these but I am also happy to be available if you wish to share your reflections)
3. Please plan to spend time with one of the hospital chaplains (they welcome you!) to witness spiritual care of a patient you currently follow

Fun Activity –

Team Dance Party (you get to pick the patient’s room)!
Module 11. Preparing for and Responding to Imminent End of Life

Objectives –
- Define the end-of-life period
- Describe the tasks necessary for managing pain and distress at end of life
- Identify important issues that require careful communication and planning
- Describe the essential components of good care at end of life
- Describe terminal emergencies and appropriate treatment

Lecture 1. “Death Be Note Proud: Preparation for a Loved Child’s Imminent Death”

Readings –
1. Gone From My Sight Care Booklet – also, Transitions folder

Activity –
1. Consider please to participate in hand and foot molds at the time of death for a child or the washing/preparing of a child’s body with the nurses for transfer after time of death
2. Please participate in debriefing sessions with the palliative care team during your rotation
3. I have certain practices and reflections at time of a child’s death; will share these with you as appropriate

Fun Activity –
Poetry book
Module 12. Resiliency and Professional Growth

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<tr>
<td>■ Understand how self-care is a core competency in pediatric palliative &amp; end of life care</td>
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<tr>
<td>■ Recognize what triggers stress, compassion fatigue, and burnout</td>
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<tr>
<td>■ Develop a self-care plan that not only reduces stress but also fosters personal growth and well-being</td>
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<tr>
<th>Lecture 1. “Because Self Care is Everything But Selfish; finding ways to care well for others by honoring your own wellness and your family’s well-being”</th>
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<tr>
<td>1. Consider confidentially completing the PRO-QoL scale to assess for your own self wellness: <a href="http://www.proqol.org/ProQol_Test.html">http://www.proqol.org/ProQol_Test.html</a></td>
</tr>
<tr>
<td>2. Early afternoon! You get to pick a day this week to have an early afternoon for a self-care activity – exercise, time with your family or friends, delicious food, anything other than reading a module 😊</td>
</tr>
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Module 13. Grief and Bereavement

**Objectives** –
- Review theories of grief and misconceptions
- Understand grief in children and identify developmentally appropriate support strategies
- Understand grief related to the loss of a child and strategies at address grief in families

**Lecture 1. “Grief and Bereavement”**

**Readings** –

**Activity** –
1. Discuss the current hospital approach to bereavement support for families
2. Review triaging for levels of complicated grief in bereaved family members and interventions accordingly
3. Consider your own personal practice to care for bereavement families
4. Review Grief’s Journey and Centering Corporation websites; consider visiting either
5. Please plan to meet with Child Life to review sibling support for bereaved siblings
6. Dr Weaver recently wrote a paper on using storybooks to support bereaved family members; happy to discuss this approach