

UCSF Benioff Children's Hospitals

Pediatric Oncology Nurses and Palliative Care

Caring for our Kids

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“To cure sometimes, to relieve often, to comfort always.”

Edward Trudeau

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Common Starting Ground


What is Palliative Care?

- Interdisciplinary
- Starts at diagnosis
- Concurrent care
- Sees the child as part of a family unit
- Prevents and addresses suffering & distress
 - Physical
 - Emotional
 - Psychologic
 - Existential
 - Resource


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What is under the umbrella?




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Primary vs. Specialty



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Role of Hem/Onc RN

Champion Advocate

- Symptom Assessment
 - Pain
 - Nausea/Vomiting
 - Dyspnea
 - Fatigue
 - Sleep disturbance
 - Constipation/Diarrhea
 - Cough
 - Worry
 - Dry Mouth
 - Anorexia
 - Sadness
- Assess Understanding of Illness
 - Reason for admission
 - Hopes for short term
 - Compare family timeline with team timeline
 - Elicit worries
- Facilitate Communication
- Care Coordination

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Role of Bedside RN with Palliative Care Team

- Provide eyes and ears on the patient and family
- Assist in integrating complex symptoms to develop plan of care
- Reassessment of changes to plan of care
- Serve as a voice of reality
- Communicate when family in distress
- Communicate plan of care to oncoming shifts/continuity

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Approach to Suffering



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Physical Suffering

- Pain
 - Procedural Pain
 - Visceral pain
 - Cancer pain
 - Neuropathic Pain
- Pruritus
- Nausea
- Constipation
- Bowel obstruction
- Dyspnea
- Eliciting perception and tolerance of symptoms
- Non-pharmacologic management
- Pharmacologic recommendations
- Family support
- Staff Support

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Psychological Suffering

- Delirium
- Anxiety
- Fear
- Depression
- Coordination with Psychiatry, Social Work
- Open discussion about death
- Supporting control as able
 - Advance Care Planning
 - Advance Directives
 - Death preferences
 - Life celebration/funeral
- Identifying family supports
- Bereavement care

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Existential Suffering

- "Why me?"
- "Why did I go through that?"
- "Why am I sick/dying/suffering?"
- Create a safe space
 - Listening presence
- Affirmation of life value
- Support in communicating with peers
- Legacy projects
 - Video recordings
 - Art/Music Therapy
 - Letters to family/friends
- Psychotherapy

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Spiritual Suffering

- Can present as anxiety
- Under assessed
- Impacts other realms of suffering
- Acknowledgement
- Assessment
- Consult with Spiritual Care Services
 - Interdisciplinary assessment
 - Invite to family meetings, rounds
- Identification of rituals
- Coordination with clergy

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Specialty Palliative Care Team

Words are our tools, family meetings are our procedures

Added layer of support	Research agenda	Expertise <ul style="list-style-type: none"> • Communication • Care Coordination • Decision Making Support • Symptom management
Quality improvement	Advocacy	Education <ul style="list-style-type: none"> • Local • Community • Hospices

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Advocating for a Consult

When to get Palliative Care team involved

Family support	Uncertainty around prognosis	Uncertain goals of care
Grief/loss of normal child	Refractory symptoms	Need for home resources
Spiritual or existential distress	Staff support	

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Initial Consult

Why we aren't the "Get the DNR team"

1. Tell us about your child, what is s/he like as a person?
2. What is your understanding of your child's illness?
3. In light of your understanding, what's most important to you?
4. What are you hoping for? What are your worries?
5. How do you maintain your strength?

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What do we do after each question?



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Talking about Scary Stuff

<ul style="list-style-type: none"> ▪ Ask what families have heard from the team ▪ Hopes ▪ Worries ▪ Naming emotions ▪ "Other parents I have cared for have said..." 	<ul style="list-style-type: none"> ▪ "Loving parents..." ▪ "I wonder..." ▪ "I wish..., but at this stage it is not possible..." ▪ "It is clear...AND I/we worry..."
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Share the burden of guilt

↑ Collaboration	<p>"We recommend ___"</p> <p>"Treatment options include ___. Since our goal is ___, we would suggest ___"</p>	↓ Burden
	<p>"What would you like us to do?"</p> <p>"Do you want us to give antibiotics?"</p> <p>"Do you want us to do resuscitate him?"</p>	

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Local Resources

- CCS Pediatric Palliative Care Waiver

<http://www.dhcs.ca.gov/services/ppc/Pages/default.aspx>

- | | |
|---|--|
| ▪ Services | ▪ Eligibility |
| <ul style="list-style-type: none">• Care Coordination• Expressive Therapy<ul style="list-style-type: none">– Art therapy– Music therapy– Massage therapy• Symptom Management• Resource support• Family counseling | <ul style="list-style-type: none">• 11 Counties<ul style="list-style-type: none">– Alameda, Fresno, Marin, San Francisco, Santa Clara, Santa Cruz, Sonoma• Under 21yo• Full scope/no share of cost Medi-Cal• Eligible kids identified by SW, RN, MD; Needs MD to sign eligibility form. |

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Local Resources

George Mark Children's House



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Bereavement Services

Who will be there for the family?

- | | |
|---|---|
| <ul style="list-style-type: none">• Community and Family support• Individual/Group Counseling<ul style="list-style-type: none">• Through local hospices• Pro-bono counselors• Hospital Specific• Camp Erin: https://moyerfoundation.org/camps-programs/camp-erin/• Individual/Group Counseling<ul style="list-style-type: none">• Through local hospices (Hospice by the Bay: http://hospicebythebay.org/types-of-care/grief-support/) | <ul style="list-style-type: none">• Pro-bono counselors (Inquire at with hospital's Palliative Care team)• Hospital Specific: Stanford (http://www.stanfordchildrens.org/en/service/bereavement); BCH Oak (https://www.childrenshospitaloakland.org/main/departments-services/palliative-care-program-154.aspx)• Kara Grief Support: https://kara-grief.org• Josie's Place: http://www.josiesplace.org/josiesPlace-Program_Services.html |
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Further Reading

National Institute of Nursing Research (NINR)

Information for nurses and providers on the role of pediatric palliative care: <https://www.ninr.nih.gov/newsandinformation/conversationsmatter/bcpproviders>

Quick Sheet from NINR: https://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/NINR_508c_AtaGlance.pdf

Nausea Guidelines: Oncology Nurse Society guidelines for management of CINV. <https://www.ons.org/practice-resources/pep/chemotherapy-induced-nausea-and-vomiting/chemotherapy-induced-nausea-and-0>

[Teaching Sheets on Palliative Care Topics from Hospice and Palliative Nurse Association](#)

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Santucci, G. (Ed.). (2017). *Core Curriculum for the Pediatric Hospice and Palliative Nurse* (2nd ed). Oxford.

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For Parents

[Center to Advance Palliative Care](#): Introduction to pediatric palliative care, services provided, and role of the team in supporting families

[Courageous Parents Network](#): Parent designed videos and guides to dealing with having an ill child, communication, decision making, stress, worry and the role of a palliative care team

[NINR Introduction to Pediatric Palliative Care](#)

National Institute of Nursing Research. (2015, November) *Parent's Perspectives on Pediatric Palliative Care*. Retrieved from https://www.ninr.nih.gov/sites/default/files/NINR_508c_FamilyStories_0.pdf

Pediatric Palliative Care, brochure from NINR: [English](#), [Spanish](#)

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