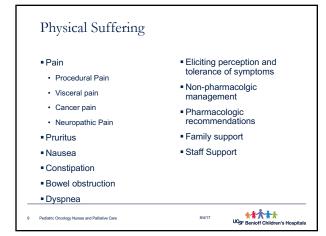


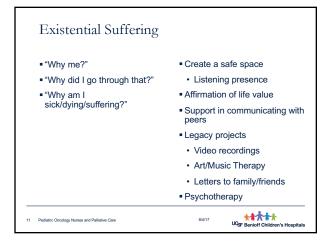
# Role of Bedside RN with Palliative Care Team Provide eyes and ears on the patient and family Assist in integrating complex symptoms to develop plan of care Reassessment of changes to plan of care Serve as a voice of reality Communicate when family in distress Communicate plan of care to oncoming shifts/continuity

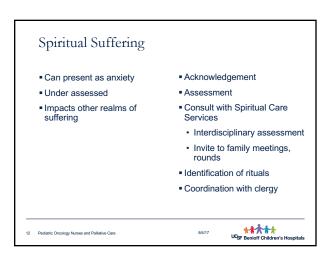
UCSF Benioff Children



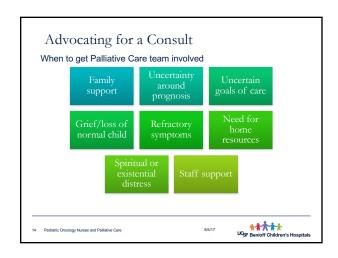


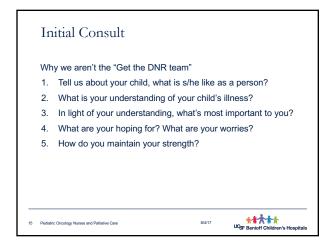




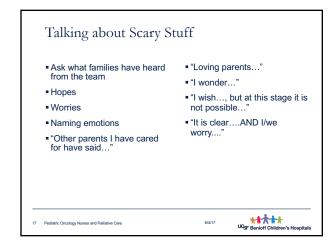


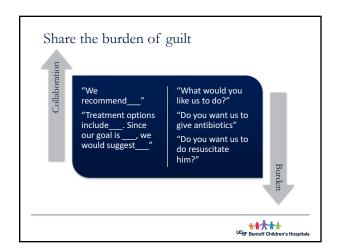














### Local Resources

CCS Pediatric Palliative Care Waiver

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

- Services
- Care Coordination
- Expressive Therapy
- Art therapy
- Music therapy
- Massage therapy
- Symptom Management
- · Resource support
- · Family counseling

- Eligibility
- 11 Counties
  - 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,



### Local Resources

George Mark Children's House





## Bereavement Services

### Who will be there for the family?

- Community and Family support
- Individual/Group Counseling
- · Through local hospices
- · Pro-bono counselors Hospital Specific
- Camp Erin: https://moyerfoundation.org/camps Kara Grief Support: https://kara-grief.org
- Individual/Group Counseling
- Through local hospices (Hospice by the Bay: http://hospicebythebay.org/types-of-care/grief-support/)
- · Pro-bono counselors (Inquire at with
- Hospital Specific: Stanford (http://www.stanfordchildrens.org/en/service/b eraevement); BCH Oak (https://www.childrenshospitaloakland.org/mai n/departments-services/palliative-care-program-154.aspx)
- Josie's Place: http://www.josiesplace.org/josieSplace-Program\_Services.html

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Rosenberg, A., Orellana, L., Ulirich, C., Kang, T., Geyer, J., Feudtner, C., . . . . Wolfe, J. (2016). Quality of Life in Children with Advanced Cancer: A Report from the PedicUEST Study. *Journal of Pain and Symptom Management*, 52(2), 244-255. http://dx.doi.org/10.1016/j.jpainsymman.2016.04.002

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# Further Reading

National Institute of Nursing Research (NINR)

ormation for nurses and providers on the role of pediatric palliative care:

Quick Sheet from NINR: https://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/NINR 508c AtaGlance.pdf

resources/pep/chemotherapy-induced-nausea-and-vomiting/chemotherapy-induce

Teaching Sheets on Palliative Care Topics from Hospice and Palliative Nurse Association

Boyce, T. L., Davis, M. M., Gerdy, C. & Pool, A. APHON Position Statement on Social Media in the Workplace. Retriev

Hecktman, H. M. (2012). Stress in Pediatric Oncology Nurses. Journal of Pediatric Oncology Nursing, 29(6), 356-361. Mooney-Doyle, K. (2006). An Examination of Fatigue in Advanced Childhood Cancer. *Journal of Pediatric Oncology Nursing*, 23(6) 305-310.

O'Shea, E. R. and Kanarek, R. B. (2013) Understanding Pediatric Palliative Care. *Journal of Pediatric Oncology Nursing*, 30(1), 34-44.

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

ous 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

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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