

PEDIATRIC PALLIATIVE CARE REFERRAL GUIDELINE

URGENT CONSULTATION

Presence of a chronic, complex, or serious illness AND

- Progression of patient's underlying medical condition
- Moderate-severe pain and/or other symptoms (nausea, vomiting, dyspnea, etc.)
- Family faced with complex medical decision making
- Family with urgent grief and bereavement needs
- Urgent coordination of in-home palliative or hospice services needed

SUGGESTED CONSULTATION

Presence of a chronic, complex, or serious illness AND

- Mild-moderate symptom management needs
- Uncertainty surrounding prognosis
- Multiple hospitalizations in the last year
- Prolonged hospitalization
- Family will benefit from an additional layer of support
- Family will benefit from continuity across care settings
- Family will benefit from support with communication between interdisciplinary team members
- Support with complex transitions in care (Pediatric to Adult, NICU to PICU, BBCH to Home, etc.)

Common Pediatric Palliative Care Diagnoses:

(including, but not limited to)

● **Patients receiving intensive and/or long term disease directed therapies**

Examples: Complex and severe congenital or acquired heart disease, advanced or progressive cancer, cystic fibrosis, severe immune deficiencies, sickle cell disease, chronic respiratory failure, renal failure, severe gastrointestinal disorders

● **Patients with progressive medical conditions**

Examples: Progressive metabolic disorders, certain chromosomal abnormalities, severe forms of osteogenesis imperfecta, muscular dystrophy, prenatal diagnoses associated with prognostic uncertainty

● **Patients with severe, non-progressive medical conditions, causing vulnerability to health complications**

Examples: Severe cerebral palsy with recurrent infections or difficult-to-control symptoms, extreme prematurity, hypoxic or anoxic brain injury, severe neurologic sequelae of infectious disease, holoprosencephaly or other severe brain

CLINICAL PEARLS

- The Pediatric Palliative Care Team at Maine Medical Center is called the Pediatric Advanced Care Team (PACT).
- PACT Mission: The Pediatric Advanced Care Team aims to improve quality of life, strengthen communication and prognostic awareness, support decision-making, and coordinate medical and psychosocial care for patients and families facing serious illness.
- Pediatric Palliative Care is provided alongside disease-directed therapies, with a goal of initiation of Pediatric Palliative Care as early as possible in the course of illness.