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.

These clinical practice guidelines describe generally recommended evidence-based interventions for the evaluation, diagnosis and treatment of specific diseases or conditions. The guidelines are: (i) not considered to be entirely inclusive or exclusive of all methods of reasonable care that can obtain or produce the same results, and are not a statement of the standard of medical care; (ii) based on information available at the time and may not reflect the most current evidenced-based literature available at subsequent times; and (iii) not intended to substitute for the independent professional judgment of the responsible clinician(s). No set of guidelines can address the individual variation among patients or their unique needs, nor the combination of resources available to a particular community, provider or healthcare professional. Deviations from clinical practice guidelines thus may be appropriate based upon the specific patient circumstances.