

Pediatric Palliative Care Referral Criteria

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The following criteria have been suggested, or are in actual use, at leading palliative care centers for initiating a palliative care referral. Some hospitals use these criteria for internal marketing, while others have established them as defining criteria for automatic referral.

General Referral Criteria

Presence of a chronic, complex or life-threatening illness/condition

AND

one or more of the following:

- Conflicts regarding use of medical nutrition/hydration in cognitively impaired, seriously ill or dying patients

➔ Automatic

OR

- New diagnosis of life-limiting or life-threatening disease
- Three or more hospitalizations within 6 months
- Difficult pain or symptom management
- Patient, family or physician uncertainty regarding prognosis
- Family with limited social supports
- AND (Allow Natural Death)/DNR order or other ethical conflicts
- Complex care coordination and/or homegoing needs
- Prolonged hospitalization for > 3 weeks
- Need for hospice resource utilization

➔ Suggested

Pediatric Palliative Care Referral Criteria

Malignant Disease Criteria:

Presence of malignant disease with any one of the following:

- Progressive metastatic cancer
- Bone marrow/stem cell transplant
- Diffuse intrinsic pontine glioma
- Stage IV neuroblastoma
- Relapsed malignant disease following stem cell/bone marrow transplant

➔ Automatic

OR

- Any newly diagnosed malignant disease with an EFS of <40 % with current therapies
- Any relapsed malignant disease
- Metastatic solid tumors
- New diagnosis with complex pain or symptom management issues

➔ Suggested

Pulmonary Criteria:

Presence of compromised pulmonary status with any one of the following:

- Patients with CF considering lung transplant/at the time of transplant
- Patients with CF with FEV1<30%
- Patients with CF with vent dependence or those ineligible for lung transplant
- Bronchiolitis obliterans

➔ Automatic

OR

- Patients with CF with multiple hospitalizations
- Patients with CF with pain, dyspnea or other symptoms who would benefit from symptom management
- Central hypoventilation syndromes
- Patients who are chronically ventilator dependent

➔ Suggested

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Genetic Criteria:

Presence of any of the following:

- Trisomy 18, 13, 15
- Asphyxiating thoracic dystrophy
- Severe forms of osteogenesis imperfecta (type 3 or 4)
- Potter Syndrome
- Epidermolysis Bullosa

➔ Automatic

OR

- Rett's Syndrome
- Other rare chromosomal anomalies with known poor neurologic prognosis

➔ Suggested

Neurologic/Neuromuscular/Neurodegenerative Criteria:

Presence of at least one of the following:

Automatic

- Progressive neurodegenerative conditions
- Muscular Dystrophy
- Spinal Muscular Atrophy
- Severe Traumatic Brain injury
- Persistent Vegetative State
- Batten Disease
- Metachromatic Leukodystrophy/ALD
- Brain reduction syndromes:
 - Anencephaly
 - Hydranencephaly
 - Lissencephaly
 - Severe schizencephaly

➔ Automatic

OR

- Static encephalopathy
- MRCP with comorbidities
- Severe anoxic brain injury (not neonatal)

➔ Suggested

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Metabolic/Inclusion Disease Criteria:

Presence of any one of the following:

- Krabbe's disease
- Hunter's / Hurler's disease
- Niemann- Pick disease
- Menke's disease
- Pompe Disease
- Sanfilippo syndrome
- Tay Sachs disease
- Fabry's disease
- Sandoff's disease

➔ Automatic

OR

- Severe mitochondrial disorder
- Severe metabolic disorders for which BMT is a therapeutic consideration

➔ Suggested

Infectious Disease Criteria:

Presence of one of the following:

- HIV/AIDS resistant to antiretrovirals
- Severe Combined Immune Deficiency

➔ Automatic

OR

- Congenital CMV/toxo with neurological sequelae
- Severe encephalitis
- Severe immunodeficiency syndromes, particularly those for which BMT is a consideration

➔ Suggested

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Orthopedic Criteria:

Presence of one of the following:

- Thanatophoric dwarfism



Automatic

OR

- Severe progressive scoliosis.
- Severe forms of dwarfism



Suggested

Renal Criteria:

Presence of one of the following:

- Neonatal polycystic kidney disease



Automatic

OR

- Renal failure, not transplant candidate



Suggested

Gastrointestinal Criteria:

Presence of chronic gastrointestinal dysfunction with one of the following:

- Multi-visceral organ transplant under consideration
- Biliary atresia
- Total aganglionosis of colon
- Progressive hepatic or uremic encephalopathy



Automatic

OR

- Feeding tube under consideration for any neurological condition
- Long-segment Hirshsprung's
- Short-gut syndrome with TPN dependence
- Severe feeding intolerance (autonomic enteropathy/chronic intestinal pseudoobstruction)



Suggested

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Neonatal Criteria:

Presence of one of the following:

- Extreme prematurity with concomitant severe BPD, Grade IV IVH, PVL, etc.
- Severe birth asphyxia
- Hypoxic ischemic encephalopathy (moderate to severe)

➔ Automatic

OR

- VLBW infants

➔ Suggested

Cardiac Criteria:

Presence of one of the following:

- Single ventricle cardiac physiology
- Severe pulmonary hypertension
- Down syndrome with significant cardiac abnormality
- Ebstein's anomaly
- Eisenmenger's syndrome
- Cardiomyopathy: hypertrophic or severe dilated
- Pulmonary atresia (especially if associated with hypoplastic pulmonary arteries)
- Ongoing discussion of cardiac transplant
- Combination of cardiac diagnosis with underlying neurologic/chromosomal diagnosis

➔ Automatic

OR

- Complex congenital heart disease
- ECMO candidate
- Severe myocarditis

➔ Suggested

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Intensive Care Criteria:

Presence of one of the following:

- Prolonged or failed attempt to wean mechanical ventilation
- Multi-organ system failure
- Compassionate extubation
- Severe head injury following NAT



Automatic

OR

- PICU stay longer than two weeks
- Irreversible brain injury that will impact functional status
- Immersion injury



Suggested