

Pediatric Palliative Care Referral Criteria

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.

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General Referral Criteria

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

Automatic Referral

One or more of the following:

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

Suggested Referral

- 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

Malignant Disease Criteria

Presence of malignant disease with any one of the following:

Automatic Referral

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

Suggested Referral

- 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

Pulmonary Criteria

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

Automatic Referral

- 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

Suggested Referral

- 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

Genetic Criteria

Presence of any of the following:

Automatic Referral

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

Suggested Referral

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

Neurologic/Neuromuscular/Neurodegenerative Criteria

Presence of at least one of the following:

Automatic Referral

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

Suggested Referral

- Static encephalopathy
- Intellectual Disability with Cerebral Palsy with comorbidities
- Severe anoxic brain injury (not neonatal)

Metabolic/Inclusion Disease Criteria

Presence of any one of the following:

Automatic Referral

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

Suggested Referral

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

Infectious Disease Criteria

Presence of one of the following:

Automatic Referral

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

Suggested Referral

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

Orthopedic Criteria

Presence of one of the following:

Automatic Referral

- Thanatophoric dwarfism

Suggested Referral

- Severe progressive scoliosis
- Severe forms of dwarfism

Renal Criteria

Presence of one of the following:

Automatic Referral

- Neonatal polycystic kidney disease

Suggested Referral

- Renal failure, not transplant candidate

Gastrointestinal Criteria

Presence of chronic gastrointestinal dysfunction with one of the following:

Automatic Referral

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

Suggested Referral

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

Neonatal Criteria

Presence of one of the following:

Automatic Referral

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

Suggested Referral

- VLBW infants

Cardiac Criteria

Presence of one of the following:

Automatic Referral

- 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

Suggested Referral

- Complex congenital heart disease
- ECMO candidate
- Severe myocarditis

Intensive Care Criteria

Presence of one of the following:

Automatic Referral

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

Suggested Referral

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

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