

EXPERIENCES

These are examples and not an all-inclusive list of experiences of which a child may have in order to be considered for PIC:TFK services.

- New diagnosis of life-limiting/ life-threatening disease or condition
- New secondary condition/diagnosis
- Uncertainty regarding prognosis
- Poor response to usual treatment methods or burden of treatment outweighing benefit
- Complex pain or symptom management needs
- Uncontrolled symptoms
- Difficulty managing stress, fear, and other emotions (siblings and caregivers too) due to the child's condition(s)
- Considerations regarding the continued use of the medical nutrition and/or hydration
- Family with limited social supports
- Family and/or sibling stress
- Issues at school (sibling too)
- Caregiver Role Strain (due to own decline in health, child growing/aging, etc)
- Multiple members of family unit have physical/behavioral conditions
- Do Not Resuscitate (DNR) order considered or other ethical consideration
- Complex care coordination
- Presence of other social/economic factors that may lead to poor health outcomes

SERVICE UTILIZATION

These are examples and not an all-inclusive list of observed service utilization activities that a child may be using in order to be considered for PIC:TFK services.

- Three or more hospitalizations within 6-months
- Three or more emergency department visits within 6-months
- Prolonged hospitalization for >3 weeks
- Multiple medications
 - Three or more medications
 - Medication prescribing from more than one physician
 - Antipsychotics/anxiolytics in concurrent use with any other medication
- Ongoing revisions in medications/dosages
- Three or more specialists/therapy visits routinely

ASSESSMENT

These are examples and not an all-inclusive list of findings that may be present in a child in order to be considered for PIC:TFK services.

- Positive indicator on a pain survey/assessment
- Low score on a quality of life survey

To refer a patient or for more information, call the patient's CMS Health Plan Care Manager.

Adapted from the Massachusetts Department of Public Health Pediatric Palliative Care Network (PPCN) Referral Guidelines.



Partners in Care: Together for Kids Identification Tool for Providers



The Partners in Care: Together for Kids Program is a palliative care program that provides additional support services to children enrolled in the CMS Health Plan who have a life-limiting/threatening illness, as certified by their primary care or specialty physician.

Use this tool as a guide for identifying children in Florida who may benefit from the services provided by the Partners in Care: Together for Kids (PIC:TFK) Program.

ELIGIBILITY CRITERIA

Must be a Children's Medical Services (CMS) Health Plan enrollee who:

- Resides in a PIC:TFK service delivery area
- Is diagnosed with a life-limiting/threatening condition
- Resides in a community setting (e.g. home, group home)

CONDITIONS AND SYMPTOMS

These are examples and not an all-inclusive list of conditions and symptoms of which a child may have in order to be considered for PIC:TFK services.

Cardiopulmonary

- Single ventricle cardiac physiology
- Severe Pulmonary HTN
- Ebstein's Anomaly
- Eisenmenger's Syndrome
- Hypertrophic Cardiomyopathy
- Hypoplastic Left Heart
- Ongoing discussion of cardiac transplant
- Combination of cardiac diagnosis with underlying neurologic/ chromosomal diagnosis
- Complex Congenital Heart Disease
- Severe Myocarditis
- VACTERL/VATER Syndrome

Gastrointestinal

- Multi-visceral organ transplant under consideration
- Biliary atresia
- Total aganglionosis of colon
- Progressive hepatic or uremic encephalopathy
- Feeding tube under consideration for any neurological condition
- Long-segment Hirschprung's
- Short-gut syndrome with TPN dependence
- Severe feeding intolerance (autonomic enteropathy/chronic intestinal pseudo-obstruction)

Congenital & Genetic

- Renal agenesis/dysgenesis, aka "Potter Syndrome"
- Asphyxiating Thoracic Dystrophy, aka "Jeune Syndrome"
- Muscular Dystrophy
- Epidermolysis Bullosa
- Trisomy 13, aka "Patau's Syndrome"
- Trisomy 18, aka "Edward's Syndrome"
- DiGeorge Syndrome
- Larsen Syndrome
- Rett Syndrome
- Rare chromosomal anomalies with known poor neurologic prognosis

Infectious Disease & Immunology

- HIV/AIDS
- Severe Combined Immune Deficiency
- Congenital CMV/toxo with neurological sequelae
- Severe encephalitis
- Severe immunodeficiency syndromes, particularly those for which BMT is a consideration (intestinal pseudo-obstruction)

Malignant Disease

- Progressive metastatic cancer
- Bone marrow/stem cell transplant
- Diffuse Intrinsic Pontine Glioma
- Stage 4 Neuroblastoma
- Relapse following stem cell/bone marrow transplant
- 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

Metabolic

- Krabbe Disease
- Mucopolysaccharidosis, aka "Hunter's/Hurler's Disease" or "Sanfilippo Syndrome"
- Lipidosis, aka "Niemann-Pick disease" or "Fabry disease"
- Menkes Disease
- Pompe Disease
- Sandhoff Disease
- Severe mitochondrial disorder
- Severe metabolic disorders for which BMT is a therapeutic consideration
- Peroxisomal Disorders

Neonatal

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

Neurologic, Neuromuscular, Neurodegenerative

- Paraplegia/quadriplegia
- Progressive Neurodegenerative Conditions
- Leukodystrophy
- Friedrich Ataxia
- Congenital Hereditary or Progressive Muscular Dystrophy
- Retinal dystrophy in systemic or cerebroretinal lipidosis, aka "Batten Disease"
- Brain Reduction Syndromes (i.e., cephalo)
- Persistent Vegetative State
- Severe Traumatic Brain Injury
- Static encephalopathy
- Severe anoxic brain injury
- Agenesis of the corpus callosum
- Lennox-Gastaut Syndrome
- Cerebral Palsy
- Subarachnoid Hemorrhage
- Neurofibromatosis

Orthopedic

- Thanatophoric dysplasia
- Severe progressive scoliosis
- Severe forms of dwarfism (i.e., Skeletal Dysplasia)
- Osteogenesis Imperfecta (Type II and above)

Pulmonary

- Cystic Fibrosis
- Bronchiolitis Obliterans
- Pulmonary Atresia (especially if associated with hypoplastic pulmonary arteries)
- Central hypoventilation syndromes
- Chronic ventilator/CPAP/BiPAP dependence

Renal

- Neonatal Polycystic Kidney Disease
- End-stage Renal Disease
- Renal Failure, not transplant candidate