

Partners for Children (PFC) Waiver



Partners for Children Waiver Overview

The diagnosis and management of a life threatening condition in a child places extreme stress on the child and his/her family. Stress results from differing views of family members about how to move forward with treatment of the child's illness, inadequate pain/symptom control in the home setting, and a family being required to manage multiple appointments, equipment in the home, services, and treatment plans.

PFC, the California pediatric palliative care waiver program, provides home-based supportive palliative care services, and care coordination to children who have a California Children's Services (CCS)-eligible medical condition with a complex set of needs. The program provides an extra layer of support for the patients and their families.

The objective is to improve the quality of life for child and family and minimize the use of hospitals. An evaluation of this waiver by UCLA demonstrated very high ratings for all services by caregivers. In addition, participation in PFC reduced hospital days for participants, reduced caregiver stress/worry, and increased caregiver confidence.

PFC Services Available

- **Care Coordination** – RN or social worker to support family in coordination of medical and palliative care services, at home, clinic, school, or other settings.
- **Expressive Therapies** such as creative art, music, massage and play therapy
- **Family Training** including education and training on palliative care issues, care needs, treatments, and use of equipment
- **Respite Care** in-home and out of home
- **Family Counseling** including bereavement for caregivers, as needed
- **Pain and Symptom Management**
- **24/7 nurse line**

PFC Referral Process

Most children eligible for PFC are identified at the **special care center** where they receive treatment or by their **primary care physician**. The provider may discuss the waiver with the family, give them the family flyer, and refer them, if interested, to the Nurse Liaison at the county CCS office (CCSNL).

Other potentially eligible children may be identified directly at the County CCS office by diagnosis and hospitalizations over the past year. In this case, the CCSNL will contact the child/family to determine interest. If needed, the CCSNL will contact the child's physician to request any necessary medical documentation. A child/family might also self-refer to the waiver, in which case they would call or come to the CCS office directly and the CCSNL will notify the appropriate physician(s) and request any needed medical documentation.

If the physician determines that the child meets the **Requirements for Participation in PFC** (see below), the MD completes the **PFC Referral Form**. The referring MD/SCC staff then submits the referral form, along with medical reports substantiating the child/youth Level of Care (LOC), to the CCSNL at the CCS Office. The CCSNL and state verify no other 1915(c) waiver enrollment.

For more information, please contact the CCS Office state lead, Dr. Jill Abramson at Jill.Abramson@dhcs.ca.gov or view the website at California Department of Health Care Services.

Enrollment

To enroll in PFC, the referred child / parent meets with the CCSNL to review the waiver in more detail, sign Agreement and Freedom of Choice forms, and select a hospice or home health agency to provide PFC waiver services. The CCSNL then contacts the care coordinator at the selected hospice or home health agency to share information about the participant.

How the Child/Family Receives the Services

The PFC care coordinator from the home health or hospice agency meets with the client, family and CCSNL to develop a care plan, the Family Centered Action Plan, coordinates the supportive PFC services, and works with the caregiver to coordinate the child’s complex health and palliative care needs.

Requirements for Participation in PFC

The participant must:

- Live in a **waiver county**

Participating County CCS Contact Numbers

Fresno	559-445-3300
Los Angeles	800-288-4584
Marin	415-473-6877
Monterey	831-755-4747
Orange	714-347-0300
San Francisco	415-575-5700
Santa Clara	408-793-6200
Santa Cruz	831-763-8900
Sonoma	707-565-4500

See PFC Referral Form for specific CCSNL contact information

- Be enrolled/eligible for full scope, no share of cost **Medi-Cal**
- Be **under 21** years of age
- Have a life threatening CCS-eligible condition
- Meet **Level of Care (LOC)** criteria – individual anticipated to be in acute care hospital at least **30** non-consecutive **days** per year in the absence of waiver services

Conditions of PFC participants include

- Neoplasm, Stage 3 or 4
- Any neoplasm not responding to conventional protocols
- Central nervous system tumors
- Major cardiac malformations for which surgical repair is not an option or awaiting surgery or transplant
- Heart Failure
- Cystic Fibrosis
- Pulmonary hypertension
- Chronic or severe respiratory failure AIDS
- Severe Combined Immunodeficiency Disorder
- Liver failure in cases in which transplant is not an option or awaiting transplant
- Renal failure
- Holoprosencephaly or other severe brain malformations requiring ventilatory or alimentary support with at least four hospitalizations or emergency department visits in the previous year
- CNS injury with severe comorbidities
- Severe cerebral palsy/HIE with recurrent infections or difficult-to-control symptoms
- Severe and progressive metabolic disorders including but not limited to: leukodystrophy, Tay-Sachs disease, and others with severe comorbidities
- Mucopolysaccharidoses that meets Level of Care criteria
- Muscular dystrophy
- Spinal muscular atrophy, Type I or II
- Other myopathy or neuropathy with severity that meets Level of Care criteria below
- Severe epidermolysis bullosa
- Severe osteogenesis imperfecta
- Congenital infection with severe sequelae (e.g. CMV, HSV, toxoplasmosis)
- Post-organ transplant with complications
- Other life threatening CCS eligible conditions meet medical eligibility requirement as long as LOC is met.