

PEDIATRIC PALLIATIVE CARE WAIVER TRANSITION RESOURCE GUIDE



A guide to help payers, providers, and other stakeholders in pediatric palliative care (PPC) navigate the transition from the PPC waiver program (Partners for Children) to the Medi-Cal state benefit for home-based palliative care services (SB 1004)

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Section 1 | INTRODUCTION

This *Pediatric Palliative Care Waiver Transition Resource Guide* was developed by the Coalition for Compassionate Care of California (CCCC) in response to California's January 1, 2019, transition for the provision of pediatric palliative care services from a waiver program to a pediatric palliative care Medi-Cal state benefit. The guide is intended to support managed care plans and providers as they navigate this change and to ensure a smooth transition for the pediatric members being served under the waiver. We want to acknowledge the Department of Health Care Services (DHCS), Medi-Cal managed care plans, pediatric palliative care providers, and numerous clinicians and other stakeholders throughout the state for their valuable input.

This online resource guide should be considered a living document as we continue to work with the DHCS to clarify remaining discrepancies and questions related to the new state benefit. CCCC will actively update this resource guide as we learn more from DHCS and other stakeholders involved in the delivery of community- and home-based pediatric palliative care.

If you have questions about home-based pediatric palliative care in California that are not answered in this resource guide or have suggestions for other resources that should be included in this guide, please email CCCC's Program Director for Pediatrics at agarzon@coalitionccc.org. If you would like to be added to our distribution list to receive alerts when we release updates to this resource guide, please email info@coalitionccc.org.

Who should use this online resource guide?

This guide will be useful to:

- Home health and hospice agencies currently delivering pediatric palliative care or those who have an interest in developing a community-based pediatric palliative care program
- Medi-Cal Managed Care Plans (MCPs)
- Referring providers
- Coalitions or organizations supporting or representing children who may benefit from pediatric palliative care
- Anyone looking to better understand pediatric palliative care – i.e. state health care departments, payers, community stakeholders, etc.

Section 2 | OVERVIEW + TRANSITION

As of January 1, 2019, California's Pediatric Palliative Care (PPC) waiver and the Partners for Children pediatric palliative care program have been discontinued. The California Department of Health Care Services (DHCS) is committed to delivering pediatric palliative care services under Medi-Cal fee-for-service and managed care plans. This section of the resource guide provides an overview of the PPC waiver and Partners for Children, and the transition plan being implemented by DHCS under Senate Bill 1004 and EPSDT (Early and Periodic Screening, Diagnosis, and Treatment).

Background on the Pediatric Palliative Care Waiver/Partners for Children

Pediatric palliative care (PPC), provided concurrently with life-prolonging or curative treatment, enhances patient care and quality of life, with measurable improvements to the physical and emotional well-being of children and their families. The American Academy of Pediatrics recommends that PPC, as defined by the Institute of Medicine (IOM), begin upon the diagnosis of a child's life-threatening condition, and continue for the duration of the disease and alongside curative care or life-saving treatment, and that it be included in both public and private insurance plans.¹

California was one of the first states to respond to the need for comprehensive pediatric palliative care. The Nick Snow Children's Hospice and Palliative Care Act of 2006 (Assembly Bill 1745) required the California Department of Health Care Services (DHCS) to submit a Medicaid (or Medi-Cal as it's referred to in California) Home and Community-Based Services (HCBS) waiver that would enable eligible children and their families to receive in-home palliative care services during the course of the child's illness, while concurrently pursuing curative treatment for the child's life-limiting or life-threatening medical condition.

The waiver was first approved as a pilot project in December 2008, and established the Partners for Children (PFC) Program within the Service of Care Division (SCD) of DHCS. The first children to participate in PFC were enrolled in March 2009. The waiver was based on the principle that if curative treatment is provided along with palliative care irrespective of life-expectancy projections, there can be an effective continuum of care throughout the course of the participant's medical condition. Under the waiver, children had access to an array of home-based palliative care services, including intensive care coordination, pain and symptom management, expressive therapies (i.e. massage, art, music, and child-life), and family counseling, without electing to receive hospice care. Services were provided by licensed hospice and home health agencies.

PPCW/PFC Eligibility

To qualify for the PPC waiver, children had to be younger than 21 years, have full-scope Medi-Cal, and have a qualifying life-limiting condition. In addition, children had to meet the Level of Care determination, which required that a referring physician assert that in the absence of waiver services the child's condition and stage of progression put them at risk of being hospitalized for at least 30 nonconsecutive days in the coming year. However, children enrolled in the PPC waiver program were not required to meet hospice eligibility life-expectancy requirements. Notably, the eligibility criteria for the PPC waiver were broader than those for the federal concurrent care benefit, which requires that children have a life-expectancy prognosis of likely less than six months to live should the disease follow its normal course.

Outcomes

The PPC services offered under the waiver proved to be beneficial for children throughout the progression of their condition, with even greater efficacy for children with less severe disease progression. These results further demonstrate the benefits of introducing PPC services earlier on in the continuum of care.² PPC services such as

enhanced family-provider communication and coordination of social and community supports were independently shown to improve the family experience. In addition, the PPC waiver services demonstrated success in reducing caregivers' stress and worry related to their child's care, in building the confidence of the caregiver in their ability to provide care in the home, and in reducing children's pain as observed by their caregiver.³ Notably, two independent studies conducted by the UCLA Center for Health Policy Research authenticated high levels of family and staff satisfaction with the PPC waiver program among diverse families and children and a wide range of service providers.

The PPC waiver program also demonstrated notable reductions in days spent in the hospital, expenditures per enrollee, and improvements in families' quality of life.³ The provision of caring, supportive services for children in their homes offered families relief and alternatives to 911 calls, emergency department (ED) visits, and unnecessary hospitalizations while reducing lengths of stay, which consequently resulted in substantial cost avoidance. A 2015 study demonstrated:

- A nearly 50% reduction in the average number of inpatient days per month, from 4.2 to 2.3.
- A significant drop in average hospital length of stay from 16.7 days to 6.5 days (more than a 60% reduction).
- A strong trend in reducing 30-day readmission rates, from 45% of readmissions to 37%.
- Net savings – after deducting program costs – of \$3,331 per enrollee per month.³

Transition of PPC Services to Medi-Cal Benefit

In March 2017, new Conflict of Interest (COI) guidelines from the Centers for Medicaid and Medicare (CMS) prohibited any agency responsible for care coordination and case management from also providing direct care services. These new requirements proved to be too restrictive to allow home-based providers to continue providing PPC under the waiver. With funding from the California Health Care Foundation (CHCF), the Coalition for Compassionate Care of California (CCCC) convened stakeholder groups to brainstorm solutions to the challenges posed by the new Conflict of Interest guidelines. Despite the recommendations that stemmed from the stakeholder meetings, CMS declined to modify the guidelines, and in 2018, DHCS, in communication with CCCC and other stakeholders, made the decision to not pursue renewal of the PPC waiver and to work with providers to deliver comparable PPC services to children and their families under Medi-Cal.

SB 1004/EPSDT

California Senate Bill 1004 (SB 1004), implemented on January 1, 2018, required DHCS to establish a framework for Medi-Cal beneficiaries of all ages to receive palliative care services. The initial All Plan Letter (APL) developed to support implementation of SB 1004 under Medi-Cal Managed Care was initially adult-centric, but on December 7, 2018, the APL was amended to include eligibility requirements and language specific to children. It went into effect on January 1, 2019, and requires the provision of home-based palliative care services to eligible pediatric patients whether they are enrolled with a managed care plan or are under Medi-Cal fee-for-service.

DHCS revised and published [APL 18-020: Palliative Care](#) and [NL 16-1218: Palliative Care Options for CCS Eligible Children](#) to guide plans and providers through the transition and ensure that California children and their families continue to have access to critical home-based PPC services.

For more information on services covered by SB 1004, please see the FAQ section in this resource guide, or refer directly to [APL 18-020](#) published by DHCS.

Section 3 | UNDERSTANDING ADULT & PEDIATRIC PALLIATIVE CARE

Palliative care is person- and family-centered care, meant to relieve suffering and enhance the quality of life for patients living with life-threatening or life-limiting conditions. The goal of palliative care for both adult and pediatric populations is the same: bridging the gaps in healthcare to fulfill unmet physical, emotional, spiritual, and concrete needs for patients with serious illness. Though the intent is the same, the delivery of palliative care for pediatric patients may appear different than the delivery of palliative care for adults. Providers of home and community-based adult palliative care should anticipate caring for children at times, in part due to the relative scarcity of pediatric palliative care services in the United States.

Referral

Adult patients referred to palliative care most often have oncologic diagnoses.⁴ In contrast, pediatric patients referred to palliative care have a much broader range of diagnoses—including neurological, oncological, metabolic, chromosomal, cardiological, respiratory and infectious diseases, etc.—many of which are considered rare diseases.⁵ The most common conditions seen by pediatric palliative care teams are severe neurologic impairment. Specifically, 41% of pediatric palliative care patients have genetic/congenital conditions and 39% carry a diagnosis of neuromuscular disorder, while only 20% have cancer.⁶ In pediatrics, much more so than in the adult population, patients face a great deal of uncertainty with a life-limiting or -threatening diagnosis.

The medical complexity and uncertainty which these children face may complicate the palliative care referral process. In some cases, the provider or health plan may not have experience recognizing the medical need for palliative care in children. In others, there may not be a home- or community-based provider willing to accept a pediatric patient with an unfamiliar or rare diagnosis. Further, anecdotally, pediatricians often play a role in providing primary palliative care for their patients and may be hesitant to involve a subspecialty palliative care team to assume that role.

Relationship with Patient, Family, and Community

Palliative care providers treating adult patients often communicate directly with the patient and/or a limited number of adult caregivers. Because children are often referred for palliative care at a very young age and may survive for a long time, pediatric palliative care requires a more longitudinal relationship with both the patient *and* the patient's family, which may include siblings and extended family members.

The care network for children extends to include school, developmental supportive services (Regional Center, Blind Babies, PT/OT), tertiary children's hospital providers, home shift nursing, and community groups. Pediatric physicians and palliative care providers will benefit greatly from being aware of community resources and family connections and using those to best support the needs of the child.

Psychosocial Needs of the Provider

While caring for patients with serious illness can be difficult, some providers find caring for pediatric patients with life-threatening or life-limiting illness uniquely challenging. The unnatural nature of pediatric death can be uncomfortable for providers who are not familiar with caring for children. Even experienced palliative care providers have reported that they are not sure what to say to the family of a child with an advanced illness, or how to communicate directly with the child. Resources are available to aid in navigating this discomfort; Jordan et. al.⁷ provide helpful recommendations for communicating with families in the context of pediatric palliative care in their paper "Top Ten Tips Palliative Care Clinicians Should Know About Caring for Children".

Psychosocial Needs of the Patient and Family

PPC providers must navigate important and sometimes difficult conversations with patients across a wide range of ages and developmental abilities. The American Academy of Pediatrics (AAP) encourages the child's participation in developmentally- and age-appropriate conversations about their illness and treatment options, including conversations about burdens and benefits of management options.⁸ Providers must consider the unique psychosocial challenges that patients at every age may face and take care to ensure that conversations with the patient are developmentally appropriate.⁹ While pediatric patients should be involved in conversations about their care to the extent possible, most conversations will take place with the child's guardian(s). PPC providers should also take care to acknowledge any unmet psychosocial needs of siblings, as related to the patient's illness.

Interdisciplinary/Transdisciplinary Team

A PPC team may have more members than an adult palliative care team. A comprehensive PPC team may consist of a child-life specialist, a pediatric mental health specialist, a pediatric grief specialist, a massage therapist, an art or music therapist, and a care coordinator in addition to the physician, nurse practitioner, RN, chaplain, social worker, and pharmacist.^{7,9,10} Because many members of a PPC team are part-time, each person on the *interdisciplinary* team should expect their work to be *transdisciplinary*. For example, an RN should be familiar with child-life practices and aware of the social work plan for the child so that he or she can be working towards the goals of those two team members even when they are not present.

Clinical - Pain & Symptom Management

Many of the symptom management medications that are used in palliative care are the same for pediatric and adult patients. While safety and efficacy of opioids have largely not been tested in clinical trials for pediatric patients, standard dosing guides are available for common symptoms, including pain. Weight-based dosing should be used for pediatric patients. Using age- and development-appropriate tools for pain and symptom assessment is critical to ensure symptoms are managed properly. Adequate pain management is paramount, as untreated pediatric pain can lead to chronic pain in later years. Pain and symptom management resources are listed in the Resources section of this guide.

Clinical - Medical Technology

The majority of children receiving palliative care require the use of some type of medical technology. This may include life-prolonging interventions such as feeding tube placement, oxygen delivery devices, tracheostomy, ventilator, and IV therapies (including TPN).⁶ Providers of PPC should familiarize themselves with this technology, using the child's primary care or subspecialty physician team as a resource when needed.

Clinical - Duration of Palliative Care

The median duration of palliative care for pediatric patients is longer than for adult patients.⁴ Unlike adult patients, 70% of pediatric patients are alive one year after initiating palliative care.⁶ For this reason, PPC providers should expect to develop a longer-term relationship with the child and his or her family.

Clinical - Prognostic Uncertainty

In pediatrics, many patients are diagnosed with their life-limiting illness at a very early age, and it is unclear how this diagnosis may affect their lives in the future, as some of these diseases are so rare that we do not know the natural course of the disease, and also because children often surprise us with their ability to adapt and to recover from life-threatening or -limiting condition, such as traumatic brain injury. It can, therefore, be difficult to predict what a child's disease course and trajectory may be in the future, and the role of pediatric palliative care is often times to support families through this uncertainty.⁶ PPC providers can support patients and families by ensuring repeated goals of care conversations over time to promote the best quality of life.

Section 4 | MEMBER REFERRAL AND PPC ELIGIBILITY GUIDELINES

Please note that these guidelines should not be used as criteria for referral for office-based or inpatient palliative medicine consultation. In addition, this document is meant to provide direction in thinking about the benefit that a patient might receive from home-based palliative care under SB 1004. It is not intended to be a strict guideline, and clinical judgment must be applied to each case.

Step 1:

Qualifying medical eligibility criteria for pediatric patients under 21 years of age is on page 5 of California's [All Plan Letter 18-020 \(Palliative Care\)](#). It is important to note that pediatric patients do **NOT** have to meet the eligibility criteria for adults outlined in sections I.A. and I.B. beginning on page 3 of the APL.

The family and/or legal guardian must agree to the provision of pediatric palliative care, and there must be documentation that the patient has a life-threatening diagnosis. This can include but is not limited to:

1. Conditions for which curative treatment is possible, but may fail (e.g., advanced or progressive cancer or complex and severe congenital or acquired heart disease); or
2. Conditions requiring intensive long-term treatment aimed at maintaining quality of life (e.g., human immunodeficiency virus infection, cystic fibrosis, or muscular dystrophy); or
3. Progressive conditions for which treatment is exclusively palliative after diagnosis (e.g., progressive metabolic disorders or severe forms of osteogenesis imperfecta); or
4. Conditions involving severe, non-progressive disability, or causing extreme vulnerability to health complications (e.g., extreme prematurity, severe neurologic sequelae of infectious disease or trauma, severe cerebral palsy with recurrent infection or difficult to control symptoms).

Step 2:

There should be an indication that medical services are needed in the home setting. This might be indicated by:

1. Emergency department visits for medical issues that could have been prevented or that could have been treated with an outpatient office visit.
2. Hospitalizations that were not planned and might have been prevented by education on recognition of symptoms and early intervention to prevent progression or by better adherence to the medical plan of care.
3. Frequent missed medical appointments.
4. A caregiver who is having difficulty navigating the complex medical system and coordinating the care of the patient. This might be more common in patients who have multiple subspecialists.
5. A caregiver who is able to identify that having home-based palliative care prevents trips to the emergency department or hospital.
6. Significant dependence on medical technology such as a central line or respiratory support (CPAP, BiPAP, or, ventilator)
7. Social barriers that are present and preventing optimal medical care. These might include but are not limited to:
 - a. Issues with transportation to visits
 - b. Difficulty understanding complex care instructions. A language barrier is one potential source of this type of issue
 - c. Significant caregiver stress
 - d. Significant financial stress

Step 3:

The need for home-based services frequently increases as a patient’s medical condition becomes more severe and the patient has more symptoms. The need is also more likely for patients experiencing new symptoms or a decline in condition.

Diagnoses Frequently Associated with Significant Symptom Management Needs	
Neoplasms	<ul style="list-style-type: none"> • Stage 3 or 4 • Any neoplasm not responding to conventional protocol (at least one relapse) • Central nervous system tumors
Cardiac	<ul style="list-style-type: none"> • Major cardiac malformations for which surgical repair is not an option or awaiting surgery or transplant • Severe anomalies of aorta and/or pulmonary arteries • Heart failure
Pulmonary	<ul style="list-style-type: none"> • Cystic Fibrosis with multiple hospitalizations or emergency department visits in the previous year • Pulmonary hypertension • Refractory pulmonary hypertension • Pulmonary hemorrhage • Chronic or severe respiratory failure
Immune	<ul style="list-style-type: none"> • AIDS with multiple hospitalizations or emergency department visits in the previous year • Severe Combined Immunodeficiency Disorder • Other severe immunodeficiencies
Gastrointestinal	<ul style="list-style-type: none"> • Chronic intestinal failure dependent on TPN or awaiting transplant • Other severe gastrointestinal malformations • Liver failure in cases in which transplant is not an option or awaiting transplant
Renal	<ul style="list-style-type: none"> • Renal failure in cases in which dialysis, transplant are not an option, or awaiting transplant
Neurologic	<ul style="list-style-type: none"> • 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/hypoxic-ischemic encephalopathy (HIE) with recurrent infections or difficult-to-control symptoms • Batten Disease • Severe neurologic sequelae of infectious disease or trauma
Metabolic	<ul style="list-style-type: none"> • 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
Neuromuscular	<ul style="list-style-type: none"> • Muscular dystrophy requiring ventilatory assistance (at least nocturnal BiPAP) • Spinal muscular atrophy, type I or II • Other myopathy or neuropathy with severity that meets Level of Care criteria as defined by the State
Other conditions that meet Level of Care criteria, including but not limited to:	<ul style="list-style-type: none"> • Severe epidermolysis bullosa or severe osteogenesis imperfecta • Post-organ transplant with complications • Congenital infection with severe sequelae (e.g. CMV, HSV, toxoplasmosis)

Section 5 | DEVELOPING BENEFIT AND PAYMENT OPTIONS

Medi-Cal Managed Care Plans (MCPs) and PPC providers have multiple options when negotiating payment arrangements for home-based PPC services and MCPs have some discretion on expanding some benefits. The two primary options are a **bundled service rate** or a **fee for service payment** structure.

Comparable Pediatric Palliative Care Waiver Benefit Under Medi-Cal

The PPC waiver provided children with life-limiting or life-threatening conditions access to a robust array of in-home pediatric palliative care services, which significantly improved their overall health and well-being. The PPC waiver also proved to be fiscally responsible, dramatically reducing healthcare costs through a reduction in ED visits, hospitalizations, and length of stay. Following the decision in the summer of 2018 to not renew the PPC waiver, DHCS committed to working with MCPs and community-based PPC providers to develop a comparable array of services under Medi-Cal.

The table below indicates which PPC services are currently covered by Medi-Cal, including those that are defined and/or delivered differently under the Medi-Cal benefit than they were under the PPC Waiver benefit.

PPC Waiver Services Covered by Medi-Cal		
	Yes	No
Pain and symptom management	X	
Personal care services	X	
Family counseling*	X	
Care coordination*	X	
Family training*	X	
Respite care in and out of home		X
Expressive therapies (art, music, and massage)		X
24/7 palliative care phone consultation access		X

*Defined/delivered differently under Medi-Cal

Family counseling – Services are available through the member’s MCP, the county mental health plan, and/or social services benefits as psychotherapy, bereavement counseling, and medical social services, as noted in the [DHCS PPC Waiver FAQ](#) document.

What is different: Under the PPC waiver, families received 22 hours of anticipatory grief and bereavement counseling from a Licensed Clinical Social Worker (LCSW), Associate Clinical Social Worker (ACSW) supervised by an LCSW, Marriage, and Family Therapist (MFT), or Licensed Psychologist. Services were available in-home

or in the individual provider setting and accessible to the family for up to one year following the death of the child. Families whose counseling needs exceeded those available under the PPC waiver could access additional services through existing state plan services.

Care coordination – Coordination of care is available in MCPs and by the PPC provider. Care coordination is available in Regular Fee-for-Service (FFS) Medi-Cal to the extent that the PPC service provider will work to coordinate the specific service(s) they are providing, but is not a separate billable service as it was under the waiver. Care coordination may be less intensive in FFS Medi-Cal because there are no managed care supports. Beneficiaries enrolled in managed care receive the care coordination services provided by the MCP.

What is different: *Under the PPC waiver, families received a minimum of 4 hours of care coordination per month depending upon the individual/family needs, and the Care Coordinator met with the family unit at least once a month, typically in their home.*

The Care Coordinator provided coordination of a multifaceted array of services to enable the participant to receive all medically necessary care in the community with the goal of avoiding institutionalization in an acute care hospital. Additionally, a key function of the Care Coordinator was to assume a large part of the burden of responsibility, otherwise placed on the parents, for condensing, organizing, and making accessible to providers, critical information that is related to care and necessary for effective medical management.

Services were provided by a registered nurse or a medical social worker with a Masters in social work and a minimum of three years of pediatric clinical experience, plus a minimum of one year of clinical end-of-life experience.

Family training – Although family training is not a Medi-Cal covered service, a similar service is covered through the Palliative Care Assessment and Consultation by the beneficiary’s care team. The consultation aims to collect both routine medical data and additional personal information such as patient goals. Topics may include, but are not limited to:

- Treatment plans, including palliative care and curative care
- Pain and medicine side effects
- Emotional and social challenges
- Spiritual concerns
- Patient goals
- Advance directive, including Physician Orders for Life-Sustaining Treatment (POLST) forms
- Legally recognized decision maker

The assessment includes the beneficiary and/or his or her representative in the development of the plan of care. The plan of care is designed to meet the physical, medical, psychosocial, emotional, and spiritual needs of the beneficiary. The plan of care will also address other issues such as medication services and allied health.

What is different: *Under the PPC waiver, family training was a designated service by an RN for the family unit, the family’s circle of support, or other potential caregivers of waiver service recipients. Training included instruction about end-of-life care, palliative care principles, care needs, medical treatment regimen, use of medical equipment, and how to provide in-home medical care to best meet the needs of the participant.*

Expressive Therapies (art and music) – Although art and music therapy are not Medi-Cal covered services, EPSDT allows for both art and music therapy under their Behavioral Health Treatment (BHT) requirement. Some PPC patients may also be eligible for BHT through EPSDT. Please refer to the [APL 18-006, Responsibilities for Behavioral Health Treatment Coverage for Members Under the Age of 21](#) for more information, including eligibility requirements.

***What is different:** Under the PPC waiver, all enrollees had access to child life specialists, art therapists, music therapists, and massage therapists for up to 60 hours every 90 days. Sessions were billed in 45-minute increments, with up to three units allowed per day.*

24/7 palliative care phone consultation access – Although 24/7 palliative care phone consultation access is not a Medi-Cal covered service, many MCPs have nurse advice lines available. Nurses answering calls to the advice line are not required to have palliative care experience, and may not be trained in pediatrics. Nurse advice lines may not be available at all for patients receiving PPC under Medi-Cal fee-for-service.

***What is different:** Under the PPC waiver, provider agencies were required to provide phone consultation on a 24-hour basis, 7 days a week by a Registered Nurse (RN), with pediatric palliative care experience preferred.*

Payment Structures for Delivering PPC Under Medi-Cal

The Center to Advance Palliative Care (CAPC) has developed a [table of palliative care payment models](#), which outlines the pros and cons with regard to fiscal impact, administrative responsibilities for contracting and operations, and additional factors such as partnering organizations. It also includes operational examples.

In addition, the California Health Care Foundation funded the development of online [SB 1004 Implementation Resources](#) for agencies providing palliative care services for adults. These resources may prove helpful to MCPs and PPC providers in developing payment and delivery contracts for children under SB 1004 and EPSDT; however, in using these resources, it is critical to keep in mind that the differences between pediatric and adult palliative care, the differing eligibility criteria for children under SB 1004, and the PPC waiver services not currently covered by Medi-Cal, which have proven to be instrumental in improving well-being and quality of life for children and their families, and cost-effective.

Bundled Case Rate

A monthly **bundled service rate** or case rate provides MCPs and PPC providers with greater flexibility to develop a benefit package that is comparable to the PPC waiver. MCPs and PPC providers have the opportunity to work together develop a comprehensive list of services and billing codes that go beyond those required under SB 1004. A bundled rate allows the MCP to better predict costs and eliminates the administrative hassle for both MCPs and PPC providers in the code-by-code authorization and billing process. Additionally, a bundled rate may allow for the provision of additional services like expressive therapies and respite care which, under the PPC waiver, were shown to significantly increase family/caregiver's confidence in caring for their child, improve sleep patterns, reduce stress and worry, and enhance quality of life for the child and family.

A case rate is typically based on prior and/or projected utilization, delivery and cost of an agreed upon menu of home-based pediatric palliative care services and may be tiered based on the level of care considerations. A list of specific services that must be provided to patients under that rate would be outlined in the contract and would include, at a minimum, all required services under SB 1004. MCPs have the discretion to cover services that were available under

the PPC waiver and the flexibility to pay for those services either under the bundled case rate, as fee-for-service, or on a case-by-case basis in accordance with their prior authorization policies and procedures.

Under the PPC waiver, Medi-Cal developed separate billing codes for designated PPC waiver services. While **these rates are no longer active**, the table below provides information as to the reimbursement for PPC services under the waiver including those services not covered by Medi-Cal. This information may provide a starting point for conversations between MCPs and PPC providers exploring options for developing a bundled case rate structure.

Codes Under PPC Waiver (No Longer Active)				
Procedure Code	Description	Provider Qualification	Old Rate (NO LONGER ACTIVE)	Limits
G9001	Coordinated care fee, initial rate	Care Coordinator: Registered Nurse or Medical Social Worker (with at least a Master’s degree) and <ul style="list-style-type: none"> · A minimum of three years clinical pediatric experience · A minimum of one year clinical end-of-life care experience · End of Life Nursing Education Consortium (ELNEC) or equivalent training within the last five years 	\$1,000	Initial. One time payment for at least 22 hours of initial assessment services.
T2022	Monthly Case management , per month		\$229.17 per month	4 – 8 hours /per month
T2025	Administrative Fee , per month		\$300 per month	Once per month
G9012	Supplemental Other specified case management, per hour		\$45.43 per hour	Additional, after 8 hours per month, up to 60 hours each 90 days of additional care coordination
H0045	Respite care services, out of home , per diem		Congregate Living Health Facility: Staff available with pediatric care experience	Three levels: Level 1 - \$91.28 per 24 hrs Level 2 - \$358.97 per 24 hrs Level 3 - \$490.60 per 24 hrs

Codes Under PPC Waiver (No Longer Active)				
Procedure Code	Description	Provider Qualification	Old Rate (NO LONGER ACTIVE)	Limits
T1005	<p>Respite Care services in home, up to 15 minutes</p> <p>Intermittent or regularly scheduled temporary care and supervision provided to an individual in their home</p>	<p>Agency Registered Nurse, Licensed Vocational Nurse, Certified Home Health Aide: Pediatric experience and education standard</p> <p>Individual Registered Nurse, Licensed Vocational Nurse: Pediatric experience and education standard and training and expertise provided by Home Health/Hospice Agency and/or other trained family members (individual Medi-Cal provider number required)</p>	Ranges from \$4.72 - \$10.14 per 15 minutes (based on who's providing service)	Up to 30 days combined in and out of home, per annum
S5111	Family Training ; per session.	Agency Registered Nurse; Individual RN meeting waiver standards of participation (individual Medi-Cal provider number required)	\$45.43 (when provided by HHA/HA) \$35.77 (when provided by individual nurse practitioner billing independently)	Up to 100 hours per year
G0176	Expressive Therapies , per unit	Agency hire/contract - Child Life Specialist, Art Therapist, Music Therapist, Massage Therapist: Appropriate certification or registration; Experience with children who have complex medical conditions	\$35.00 per 45 minute unit. Up to 3 units billed daily.	Up to 60 hours every 90 days
X9508	Family Counseling (Bereavement)	Agency Licensed Psychologist, Licensed Clinical Social Worker or Marriage and Family Therapist	\$50.87 per unit	22 units

Medi-Cal Codes for Pediatric Palliative Care

DHCS has developed a service code crosswalk, which designates state and national Medi-Cal service codes that can be used to authorize and bill for core PPC services previously available under the PPC waiver. **The usefulness of the codes below are limited by the lack of direction around the number of units allowed for each code and how often each code can be used.**

The below is directly from the DHCS Service Codes, to be posted to the DHCS website shortly.

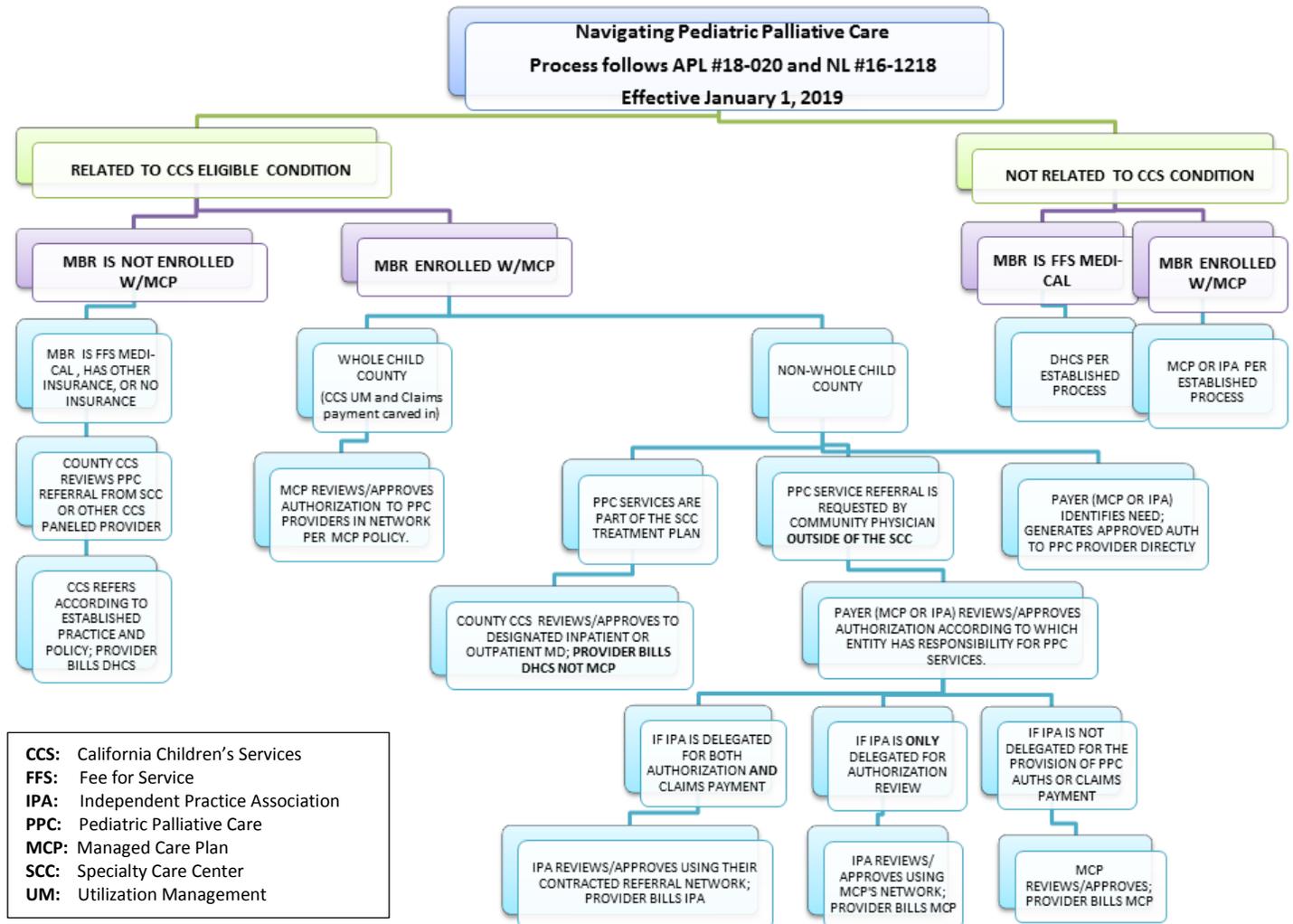
Palliative Care Service Codes

Medi-Cal providers, including hospice agencies that are compliant with the provisions of HSC 1747.3, may provide palliative care services and bill using the appropriate CPT codes that reflect the appropriate level of care provided along with ICD-10 code Z51.5. Below is a list of palliative care services and corresponding billing codes:

Palliative Care Services	Billing Codes
Advance Care Planning	CPT Code 99497 (reimbursable twice a year before TAR) and 99498 (reimbursable once a year before TAR)
Palliative Care Assessment and Consultation Inpatient/Outpatient (I/O)	CPT codes 99251-99255
Palliative Care Assessment and Consultation (H)	CPT codes 99341-99350
Pain and Symptom management (I/O)	Pharmacy benefit
Pain and Symptom management (H)	Pharmacy benefit
Plan of Care (I/O)	CPT codes 99251-99255
Plan of Care (H)	CPT codes 99341-99350
Care Coordination (H)	CPT 99490, 99491
Nursing Services (H) Home Health Aide	HCPCS codes G0299, G0162, G0300, and G0156
Psychosocial Services	CPT code 90832, (psychotherapy) HCPCS G0155 (clinical social worker)
Discharge Planning (I) Discharge Planning (H)	CPT codes 99238 and 99239 CPT codes 99341 - 99350
Physical therapy (H/Hospice)	HCPCS code G0151
Occupational therapy (H/Hospice)	HCPCS code G0152
Palliative Care team (I/O)- qualified health professional (QHP)	CPT codes 99366 and 99368
Chaplain services/Spiritual support	Only as a hospice benefit. Not billable for palliative care services.
Note: I=inpatient, O=outpatient, H= home	

Section 6 | NAVIGATING PEDIATRIC PALLIATIVE CARE POST-WAIVER: A VISUAL GUIDE

The flowchart below is a high-level visual for navigating pediatric palliative care under SB 1004. Please note that the process for determining CCS eligibility are outside the scope of this flowchart—wherever “CCS condition” or “CCS eligible condition” are noted, assume that CCS eligibility has already been established.



Section 7 | FREQUENTLY ASKED QUESTIONS

PPC Waiver

1. What is the difference between the Pediatric Palliative Care (PPC) waiver and the Partners for Children (PFC) program?

The PPC waiver was a federal Home and Community Based Services 1915(c) waiver which authorized the Department of Health Care Services (DHCS) to develop a home-based Medi-Cal pediatric palliative care program called Partners for Children (PFC). Throughout this document, we use the term “PPC waiver” in reference to both the PPC waiver and its service program, Partners for Children (PFC).

2. What services were offered under the pediatric palliative care (PPC) waiver?

The PPC waiver program provided comprehensive access to pediatric palliative care in a home/community-based setting. Referrals to the program were managed by a CCS Nurse Liaison in each participating county.

- Care Coordination – RN or social worker supported family in coordination of medical and palliative care services at home, clinic, school, and other settings. The care coordinator, also sometimes referred to as the nurse case manager, often accompanied family to clinic visits and visited patient if hospitalized to ensure smooth coordination of care between all teams.
- Expressive Therapies – creative art, music, massage, and child-life 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 anticipatory grief and bereavement for caregivers, as needed
- Pain and Symptom Management
- 24/7 nurse line

Please refer to “Developing Benefit and Payment Options” section of this resource guide for more details.

3. What were the criteria for eligibility for the Partners for Children waiver program?

To be eligible for the PPC waiver program, children had to live in a participating county, be CCS and full-scope Medi-Cal eligible, be under 21 years old, and meet Level of Care determination, which required that the referring provider assert that in the absence of waiver services the child’s condition and stage of progression put them at risk of being hospitalized for at least 30 non-consecutive days in the coming year.

4. Are MCPs required to cover the same services that were available under the PPC Waiver?

No. The services covered under SB 1004 are not the same as the services that were available under the PPC waiver. Most notably, the provision of expressive therapies and respite care is not mandated by DHCS, but DHCS encourages and allows Managed Care Plans to authorize additional palliative care services, including expressive therapies and respite care, at their own discretion and cost.

Under SB 1004, there are **seven** palliative care services that Medi-Cal requires when determined to be medically necessary for eligible patients.

- Advance Care Planning
- Palliative Care Assessment and Consultation
 - Including family training
- Plan of Care
- Palliative Care Team

- DHCS recommends that the palliative care team include, but not be limited to, a doctor of medicine or osteopathy, a registered nurse, a licensed vocational nurse or nurse practitioner, and a social worker. They also recommend that a chaplain be included in the team, but do not reimburse for chaplain services. Other pediatric palliative care team members may include a massage therapist, expressive art and music therapists, child-life specialists, complementary medicine therapies, and personal home health aides at the discretion of the MCPs and provider agencies.
- Care Coordination
 - Available through MCPs and through PPC provider.
 - For fee-for-service Medi-Cal, care coordination is only available to the extent that the PPC provider coordinates the services they are providing, but it is not a separately billable service
 - 24/7 nurse advice lines are available through most MCPs.
 - The primary goal of care coordination under SB 1004 is for continuous assessment of needs and ensuring implementation of the plan of care. This is in sharp contrast to care coordination under the PPC waiver program, where the care coordinator was responsible for organizing a multifaceted array of services and assumed a large part of the burden of responsibility, otherwise placed on the parents, in condensing, organizing, and making accessible to providers critical information that was related to the patient’s care and necessary for effective medical management of the life-limited or life-threatening illness.
- Pain and Symptom Management
- Mental Health and Medical Social Services
 - Including anticipatory grief, bereavement, counseling and family counseling

Please refer to “Developing Benefit and Payment Options” section of this resource guide for more details.

5. What cost analysis data is available to demonstrate the fiscal impact of PPC waiver services?

An analysis of the data from the Partners for Children waiver pilot program^{2,3} showed a significant decrease in health care spending for children participating on the waiver program due primarily to a reduction in admissions, hospitalizations, and lengths of stay, resulting in a net savings of \$3,331 per month per enrollee. The program demonstrated:

- A nearly 50% reduction in the average number of inpatient days per month, from 4.2 to 2.3.
- A significant drop in average hospital length of stay from 16.7 days to 6.5 days (more than a 60% reduction).
- A strong trend in reducing 30-day readmission rates, from 45% of admissions to 37%.

6. What were the qualifying criteria for hospice and home health agencies to provide PPC under the PPC waiver program?

Agencies were required to be a Medi-Cal Provider and complete provider training offered by DHCS prior to providing services under the PPC waiver. In addition, participating agencies were required to provide:

- Phone consultation on a 24-hour basis, 7 days a week by a Registered Nurse (RN), with pediatric palliative care experience preferred;
- Interpreter services for the participant and family;
- Continuum of PPC waiver services

Provider agency direct care staff qualifications varied based on the service, but all positions required pediatric care experience. Clinical staff were required to have a minimum of three years clinical pediatric experience, one year clinical end of life care experience, and provide proof of completion of the End of Life Nursing Education Consortium (ELNEC) or equivalent training within the previous five years or within one year of beginning to provide services.

Find more information in this resource guide under “Developing Benefit and Payment Options.”

California Children’s Services (CCS) and Managed Care Plans (MCPs)

7. What is the role of the California Children’s Services (CCS) program within the Department of Health Care Services (DHCS)?

The CCS program is administered as a partnership between county health departments and DHCS. Through this program, from birth through 20 years old, children who meet the clinical and financial eligibility requirements can receive diagnostic and treatment services, medical case management, and physical and occupational therapy services related to their special health needs. Typically, county staff performs all case management activities for eligible children residing within their county, including determination of program eligibility, evaluation of needs for specific services, referral to appropriate provider(s), and authorization for medically necessary care. The Medi-Cal program, administered by DHCS, reimburses care related to their CCS-eligible conditions either directly or through the Medi-Cal managed care system, with some exceptions. For example:

- If the child is enrolled with a **Whole Child Model** Medi-Cal managed care plan (MCP), CCS is integrated. The county CCS staff still determine eligibility, but the MCP administers authorization, care coordination, case management, and claims payment.
- If the child is enrolled with a **non-Whole Child Model** Medi-Cal MCP, CCS is carved out, not integrated. CCS determines eligibility and has case management, referral, and authorization responsibility, and the Medi-Cal program reimburses care. The MCP is generally responsible for reimbursing and authorizing medical care that is **not related** to the child’s CCS-eligible condition. However, **MCPs are responsible for the provision of home-based PPC services, whether the care is related to the CCS condition or not.**
- If the child has a CCS-eligible condition, has full scope Medi-Cal, and is not enrolled with a Medi-Cal MCP, they are considered “Medi-Cal fee-for-service (FFS).” CCS determines eligibility and administers all the case management and referral and authorization components of the program, and the state Medi-Cal program reimburses the care.
- If the child is not eligible for Medi-Cal but otherwise meets the financial and clinical criteria, they are considered “CCS-Only.” CCS determines eligibility and administers case management, authorization, and referrals. Care is funded by both the state and the county.

8. What is the distinction in the roles that CCS and MCP play with respect to Pediatric Palliative Care?

CCS is responsible for PPC services for CCS-eligible patients when those services are part of the Special Care Center (SCC) treatment plan. MCPs are responsible for PPC services for all of their enrolled members, including those who are CCS-eligible, regardless of whether the PPC services are related to their CCS condition. With the exception of Whole Child Model counties, the MCP has responsibility for ensuring access to PPC services that are requested/identified outside of the SCC treatment plan. DHCS will be issuing a clarification to NL 16-1812 to further distinguish responsibilities between CCS and the MCP with respect to the SCC. In the meantime, please refer to the flow chart in this guide on “Navigating PPC Post-Waiver” for a visual representation of the role of the MCP and CCS in PPC.

PPC Providers

9. What home health and hospice agencies participated in the PPC waiver and what counties did they serve?

Until its expiration on December 31, 2018, the following counties were actively participating in the PPC waiver program: Alameda, Los Angeles, Marin, Monterey, Orange, San Francisco, Santa Clara, Santa Cruz, and Sonoma. Coastal Kids Home Care served Santa Clara, Santa Cruz, and Monterey counties; Hospice by the Bay (By the Bay

Kids) served Alameda, Marin, San Francisco, and Sonoma counties; Providence TrinityKids Care served Los Angeles and Orange counties; and Libertana Home Health served Los Angeles County. Previously, Fresno, San Diego, and Ventura counties had participated in the PPC waiver program but were not active at the time of its expiration. Participating providers in these counties included Libertana Home Health (Ventura) and Hinds Hospice (Fresno).

10. Do MCPs have established credentialing criteria for PPC providers in order to be contracted in their network?

Each MCP will likely share the same credentialing criteria but they may differ in the standards they set specific to palliative care services. For example, some MCPs require any provider of palliative care, pediatric or adult, to be Joint Commission-certified. While this may be important to ensure quality of care, there are many counties throughout the state without a Joint Commission-certified agency, and many counties where the volume of patients, specifically pediatric patients, is not high enough to meet the Joint Commission criteria for certification. Providers in these counties should not be excluded from contracting with plans to provide palliative care. Typically, MCPs will have exceptions to ensure access to care and supporting policies for monitoring quality of care. PPC providers should ensure that the staff has training in the clinical and psychosocial care of pediatrics, including information on how pediatric palliative care differs from adult palliative care. DHCS recommends that MCPs contract with providers with current pediatric palliative care training.

11. Where can MCPs find a list of qualified pediatric palliative care providers by county and setting (i.e. hospitals, clinics, hospices, home health agencies)?

CCCC is not aware of a list of qualified pediatric palliative care providers in California. Hospice agencies providing palliative care (under the SB 294 pilot program) are required to register with the state, but home health agencies providing palliative care are not required to register. The Center to Advance Palliative Care (CAPC) has created a national provider directory (getpalliativecare.org) in which any agency or health system providing palliative care can self-register, but that registry is not verified or comprehensive. CCCC has made an effort to identify and share PPC Medi-Cal provider contact information with MCPs whenever possible, and this effort is ongoing.

Authorization and Eligibility

12. What are the age criteria for pediatric palliative care?

Patients are eligible for pediatric palliative care from birth up until their 21st birthday.

13. Are services authorized fee-for-service or as a bundled per patient per month service rate?

Billing arrangements are made between each provider and MCP. Some plans may choose to allocate a per-patient-per-month rate to the provider and allow the provider to care for the patients as necessary. Other plans may choose to pay for PPC services as fee-for-service based on the exact care provided to the patient. The payment guideline in the “Developing Benefit and Payment Options” section of this resource guide is a great tool for navigating these conversations on both the plan and provider side.

14. Is there guidance on how long authorization for PPC is valid and how often to review?

Authorization for pediatric palliative care services under the PPC waiver program was granted for up to six months, depending on the county. MCPs establish their own policies but it is recommended that an authorization period of six months to one year would not overburden providers or plans with frequent re-authorizations requests. While the condition of children receiving home-based palliative care may progress or stabilize, the children’s eligibility and need for PPC services typically remains constant throughout the course of their condition.

15. Who is responsible for determining eligibility for home-based palliative care services for pediatric members?

The referring provider should ensure that the patient meets eligibility criteria for pediatric palliative care before referring the patient (see APL 18-020 and the “Guideline for Consideration of Referral to Home-based Palliative Care” section of this resource guide for eligibility criteria). Once a referral has been made to the MCP, the plan is responsible for determining which services are approved for that patient on the basis of medical necessity. The referring provider can help this process by providing as much detailed information about the child’s condition as possible in their referral to the MCP.

16. Who is responsible for authorizing and paying for home-based palliative care services for pediatric members?

The flowchart in the “Developing Benefit and Payment Options” section of this resource guide is a great tool to determine whether the MCP, CCS, or Medi-Cal is responsible for authorizing palliative care services for pediatric members. Conversation is ongoing with DHCS to achieve clarity regarding delineation of responsibility between MCPs and CCS.

17. Are pediatric members required to meet the general eligibility criteria outlined in Section 1.A of APL 18-020 (Palliative Care) or just the pediatric-specific criteria outlined in Section 1.C?

Pediatric members do not need to meet the general eligibility criteria outlined in Section 1.A of APL 18-020 or the disease-specific criteria in Section 1.B of the APL. Pediatric members must only meet the pediatric-specific eligibility criteria outlined in Section 1.C of the APL 18-020. Please see the “Member Referral and PPC Eligibility Guidelines” section of this guide for consideration of referral to pediatric home-based palliative care.

Training and Other

18. What training and resources are available on pediatric palliative care for utilization management, care coordination, and other clinical MCP staff?

Several national organizations have published thorough pediatric palliative care resources. The Center to Advance Palliative Care (CAPC), the National Hospice and Palliative Care Organization (NHPCO), the End-of-Life Nursing Education Consortium (ELNEC), and the American Association for Hospice and Palliative Medicine (AAHPM) are among the organizations that have published information on what to consider when defining PPC functions on a care team and information about how care is delivered. Please see the resources section at the bottom of this guide for more sources of information.

19. If an MCP chooses to cover expressive therapies and/or respite care, what guidance is available on how to bill for those services?

If an MCP chooses to cover expressive therapies and respite care, the MCP should provide a framework to bill for these services. Each provider should work with that plan to determine the best way to be reimbursed for the services. Codes that existed under the PPC waiver for expressive therapies (e.g., G0176) may still be active in the HCPCS. Please refer to “Developing Benefit and Payment Options” section of this resource guide for more details.

EPSDT

20. What is EPSDT?

EPSDT stands for “Early and Periodic, Screening, Diagnosis, and Treatment.” This benefit is mandated by the federal government to be provided by state Medicaid, or Medi-Cal in California, for eligible children and youth through age 20. EPSDT requires that states provide medically necessary health care services to correct or ameliorate health conditions, even when the service may not be covered in the state’s Medicaid benefit.

21. How does EPSDT apply to pediatric palliative care?

The EPSDT benefit includes shift nursing in the home, which is the most frequent use of this benefit by agencies providing pediatric palliative care. According to the All Plan Letter on EPSDT, 18-007, the benefit also includes case management services meant to assist patients and families in gaining access to necessary medical, social, educational, and other services. These case management services are often available through the MCP, but if appropriate case management services are not already available, the MCP must arrange and pay for them. EPSDT also mandates that the MCP covers non-emergency medical and non-medical transport when necessary for patients to receive medically necessary covered services and when ordered by a qualified clinician. EPSDT may cover art and music therapy for children receiving PPC as part of the Behavioral Health Treatment (BHT) requirement. Please refer to [APL 18-006](#) for eligibility requirements.

22. Does EPSDT cover expressive therapies and respite care?

Art and music therapies may be covered under EPSDT, per [APL 18-006](#). Respite care, child life services, and massage therapy are not covered by EPSDT or Medi-Cal. Coverage of those services is at the discretion of the MCPs and is not available to fee-for-service Medi-Cal beneficiaries.

Even though most expressive therapies and respite care are not paid for by the state or covered under the EPSDT benefit, some plans and providers are finding other ways to pay for the services. Health plans may choose to provide the home health or hospice agencies with a per-patient-per-month reimbursement for each pediatric patient receiving palliative care, which could allow the provider to allocate funds to expressive therapies or respite care. Alternatively, some agencies may receive philanthropic funds that allow them to continue providing expressive therapies and/or respite care. Please refer to the guideline for referral to pediatric home-based palliative care on page 9 for more information.

23. Who can answer questions about EPSDT Private Duty Nursing (PDN)?

DHCS has created an email inbox specifically for questions about EPSDT PDN and Pediatric Day Health Care. They can be contacted at epsdt@dhcs.ca.gov.

Section 8 | RESOURCES

California

[Department of Health Care Services, All Plan Letter 18-020: Palliative Care](#)

[Department of Health Care Services, Number Letter 16-1218: Palliative Care Options for CCS-Eligible Children-Revised:](#)

A third DHCS update of this document is pending. This resource guide will be updated with the most current version when it becomes available.

National

[National Consensus Guidelines for Quality Palliative Care, 4th Ed:](#) Primarily geared towards adult palliative care, but pediatric-specific guidelines and recommendations are peppered throughout.

[CAPC Resources on Payment for Palliative Care:](#) Not specifically for pediatrics, but several great resources for palliative care payment models.

[CAPC Pediatric Palliative Care Field Guide:](#) A gold mine of information and other resources for everything related to pediatric palliative care.

[NHPCO Pediatric Concurrent Care:](#) Covers palliative care as well as hospice care and details about the provision for concurrent care in the ACA.

[AAHPM Pediatric-Hospice and Palliative Medicine Competencies](#)

[ELNEC Pediatric Palliative Care Training Program:](#) Free online training modules

Pain and Symptom Management

[Webinar - Little People Big Pain: Overcoming obstacles to pain management in children](#)

[WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses](#)

Hunt, M.O., Protus, B.M., Winters, J.P., and Parker, D.C. (2014) [Pediatric Palliative Care Consultant: Guidelines for Effective Management of Symptoms](#). HospiScript, a Catamaran Company, Dublin, Ohio.

Wolfe, J, Hinds, P, Sourkes, B (2011) [Textbook of Interdisciplinary Pediatric Palliative Care \(1st Ed\)](#), Elsevier, Philadelphia, PA.

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- ¹⁰ <https://getpalliativecare.org/whatis/pediatric/the-pediatric-palliative-care-team/>