

# The Pediatric Palliative Care Program

Provider Manual for Home Health Agencies



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DEPARTMENT OF HEALTH

# The Pediatric Palliative Care Program: Provider Manual

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## Purpose and Mission

### PURPOSE

This Pediatric Palliative Care Program (PPCP or the “Pedi Pal”) Provider Manual was developed to provide you, a Home Health Agency provider, with the information and tools you need to participate in this program. This manual is supplemental for use in conjunction with the [Department of Vermont Health Access Provider Manual](#).

This manual guides your Home Health Agency through the requirements for participation in the PPCP and ongoing delivery of services required by the Centers for Medicare and Medicaid Services in the approved waiver.

Delivery of PPCP services is a team effort. Use the manual and form templates to orient staff members to the program, standards, roles and responsibilities, and involve them in delivery of PPCP services to the participants and families enrolled in PPCP.

As a pediatric palliative care team within your agency, you may work to:

- Coordinate care amongst providers
- Optimize symptom control
- Optimize functional status when appropriate
- Promote the highest quality of life for patient and family
- Educate patients and family to promote understanding of the underlying disease process and expected future course of the illness
- Establish an environment that is comforting and healing
- Plan for transition to the appropriate level of care in a timely manner
- Assist actively dying patients and their families in preparing for and navigating death
- Serve as educators and mentors for staff
- Promote a system of care that fosters timely access to palliative care services

### MISSION

To provide comprehensive interdisciplinary care to children and their families by addressing their physical, emotional, spiritual, and cultural needs while helping them to maintain their goals with hope as the driving force to achieve the best quality of life throughout living, dying, and grieving.

## Section 1: Program Background and Overview

### Section 1: PROGRAM BACKGROUND AND OVERVIEW

The **Pediatric Palliative Care Program** is for children with Medicaid who are living with serious illness. The PPCP is administered through the Vermont Department of Health Children with Special Health Needs and made possible through Vermont's [1115 Demonstration Waiver](#). The program offers the following services to children who are Medicaid members diagnosed with a life-limiting illness that is expected to be terminal before adulthood (age 21).

1. Care Coordination
2. Family Training
3. Expressive Therapy
4. Skilled Respite
5. Family Grief Counseling/Bereavement Counseling

Over the last two decades there has been growing concern that children with a life-limiting illness do not always receive the care they need to alleviate associated physical, emotional and psychosocial pain. In 2010, the Federal Government amended the Patient Protection and Affordable Care Act (PPACA), adding the Concurrent Care for Children Requirement (CCCR), requiring state Medicaid programs to pay for both curative/life-prolonging treatment and hospice services for children under the age of 21 who qualify. Although this law allows children to receive curative treatments while still electing the hospice benefit, it does not change the traditional hospice eligibility criteria, specifically that a physician certify that the eligible person is within the last 6 months of life, should the disease or condition follow its normal course. Many children living with chronic illness experience an undulating illness pattern during which they have periods of extreme illness followed by months, sometimes years, of being well. Prognosticating life-expectancy in children and adolescents, especially for those with chronic complex conditions is challenging, thus making the determination for hospice life-expectancy often unrealistic.

Recognizing that children living with a life-limiting illness and their families need additional support, Centers for Medicare and Medicaid (CMS) approved the amended Vermont Medicaid Global Commitment Demonstration in 2011 which allows for pediatric palliative care services for Medicaid children in Vermont who are eligible, without the determination of a 6-month life expectancy or having to forgo life-sustaining treatments.

The PPCP is based on the principle that if curative treatment is provided along with compassionate, palliative care, there can be an effective continuum of care throughout the course of the medical condition. The objective will be to minimize the use of institutions, especially hospitals, and improve the quality of life for the child or adolescent and their family in the local community.

The PPCP was launched in August 2012.

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The 1115 Global Commitment Demonstration is available at [https://humanservices.vermont.gov/sites/ahsnew/files/doc\\_library/VT-GCH-STCs-with-Attachment-Q-03-07-23.pdf](https://humanservices.vermont.gov/sites/ahsnew/files/doc_library/VT-GCH-STCs-with-Attachment-Q-03-07-23.pdf)

## Section 2: Definitions and Acronyms

### Section 2: DEFINITIONS AND ACRONYMS

*World Health Organization (WHO) Definition of Palliative Care for Children:* Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:

- Is the active total care of the child's body, mind and spirit, and also involves giving support to the family
- Begins when illness is diagnosed, and continues regardless of whether or not a child receives treatments directed at the disease
- Demands that health providers evaluate and alleviate a child's physical, psychological, and social distress
- Requires a broad interdisciplinary approach
- Includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- Can be provided in tertiary care facilities, in community health and hospice centers, and in children's homes
- Should be developmentally appropriate and in accordance with family values

This document uses the following definitions:

*Adulthood:* People who are 21 years of age or greater.

*Agency:* A Medicaid-approved Home Health Agency that is contracted with DVHA to provide direct care services to the child and family, and that subcontracts with the necessary service providers to ensure the care plan objectives are met.

*Care Plan:* A family-centered written plan that is developed by the Care Coordinator with input from the interdisciplinary team and the family to address all relevant aspects of a child's health and socialization needs. It is based on the findings of the child and family's assessments and defines specific service and treatment goals and objectives; proposed interventions; and the measurable outcomes to be achieved.

*Curative Treatment:* Care intended to eliminate the disease and promote recovery.

*Family Unit:* Refers to the child and the family. Family is defined as the people who provide physical, psychological, spiritual, and social comfort to the child, regardless of genetic relationship. Families may include, but are not limited to, parents, step-parents, siblings, legal guardians, grandparents, relatives, household members, and friends providing care for the child, and other people considered "family" by the child.

*Intake and Needs Assessment:* A comprehensive assessment/screening for services conducted by a trained nurse or social worker, with input from the child and family to determine the child's level of functioning, current resources, and additional services needed. The intake and needs assessment will be used to inform and create the palliative care plan.

## Section 2: Definitions and Acronyms (cont'd)

*Interdisciplinary:* An integrative model wherein people from multiple disciplines work together in addressing a common challenge. This model can be seen as overlapping circles (as in a Venn diagram) where each specialty maintains its own identity while also sharing some common methodologies and assumptions with other disciplines in the web.

*Life-Threatening Conditions (LTC):* A medical condition that, in the opinion of the child's primary treating health care provider, carries a prognosis of death that is highly probable to be before the child reaches age 21. Synonymous with life-limiting illness.

*Medical Necessity:* Care and services as defined in the [Social Security Act Section 1905\(a\)](#).

*Pediatric/Child:* A child or youth less than 21 years of age.

*Prior Authorization:* Process of clinical review for specific services by Medicaid prior to their being approved and implemented.

*Nurse Program Coordinator:* A registered nurse, employed by the State of Vermont/Children with Special Health Needs, who provides oversight of the program, and technical assistance to delivering agencies.

*Service Provider:* A person or agency that provides a service specific to this program, i.e., Care Coordination, Expressive Therapy, Respite, Family Training, and/or Bereavement Counseling.

This document uses the following acronyms:

**CMS** – Center for Medicare and Medicaid

**CSHN** – Children with Special Health Needs

**DVHA** – Department of Vermont Health Access

**IDT** – Interdisciplinary Care Team

**LTC** – Life-threatening Condition

**NOD** – Notice of Decision

**PPCP** – Pediatric Palliative Care Program

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Definition of Medical Assistance is available at [ssa.gov/OP\\_Home/ssact/title19/1905.htm](http://ssa.gov/OP_Home/ssact/title19/1905.htm)

## Section 3: Participating Agency Requirements

### Section 3: PARTICIPATING AGENCY REQUIREMENTS

Participating agencies are contracted Medicaid providers, with training in pediatric palliative care, and capable of providing the broad scope of services to support the PPCP including:

- Delivery of services to children in their homes residing in Vermont
- Phone consultation with a nurse or physician available 24 hours/day, 7 days/week
- Interpreter services in person or telephonic for the participant and family, if needed. \*Please see Interpreter resources section in the General Billing and Forms Manual, Section 4.8.4 and 4.8.5.
- Maintenance of current list of Agency employed/contracted persons who deliver services to PPCP families including appropriate credentials as defined in this manual
- Responsibility for employees and contracted service providers
- Encourage and support direct care staff in pediatric palliative care educational opportunities
- Supervision and training to staff with limited pediatric palliative care experience

#### 1. Pediatric Palliative Care Competencies

All Agency staff providing direct care will complete pediatric palliative care education within their first year of providing services. Examples of competencies include:

- Complete Pediatric End-of-Life Nursing Education Consortium (ELNEC) curriculum, or equivalent training, prior to caring for children enrolled
- Attend PPCP-endorsed trainings and continuing educational opportunities, online or in-person, to enhance knowledge in the field

#### 2. Medical Record Maintenance

The member's central chart should include documentation of:

- The Family-Centered Care Plan per Agency standards and [Medicaid Rule](#).
- Services including goals, frequency, interventions, and outcomes
- 24/7 triage nurse calls, including member's name, date, time, issue, resolution (including advice given, redirection, or other) and answering nurse's name
- Confidential information in compliance with Agency standard policies, state and federal laws and regulations, including HIPAA requirements

#### 3. Service Utilization Documentation

- Documentation of PPCP services should be integrated within the agency's current system in order to maximize continuity of care with all other services being provided
- PPCP specific services should be uniquely identified within charting for audit purposes
- Specific documentation requirements pertaining to certain services (i.e. Skilled Respite and Bereavement Counseling)
- Utilization data will be obtained quarterly by CSHN

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Medicaid Rule is available at <https://humanservices.vermont.gov/rules-policies/health-care-rules>

\* Interpreter services info: <http://vtmedicaid.com/assets/manuals/GeneralBillingFormsManual.pdf>

## Section 3: Participating Agency Requirements (cont'd)

### 4. Collaboration with CSHN Program Coordinator

- Ensures timely communication with newly enrolled families as well as implementation of PPCP services
- Identifies need for additional training, support, education to PPCP providers in timely manner and problem solve collaboratively
- Includes submission of Monthly Service Reports (Appendix E for links to fillable forms)

### 5. Participation in Quality Improvement

Families will be offered multiple opportunities to participate in surveys that will both collect data for palliative care research as well as provide direct feedback regarding their satisfaction with the program. These surveys will be administered and analyzed by CSHN at the Vermont Department of Health. Additional data collection and survey projects may pull from claims databases or review agency charts. For example, to measure the frequency and impact of hospital admissions for PPCP enrolled children.

Home health agencies offering PPCP services will participate in quality improvement projects and data collection as necessary to monitor, analyze and improve program outcomes.

### 6. Agency-Based Interdisciplinary Team (IDT) Meetings

- Conducted and documented every 30 to 60 days, dependent on caseload and acuity.
- Includes at least 2 members of the IDT caring for each child
- Addresses program operations and reviews the PPCP IDT script (Appendix D) for each enrolled member.
- Includes the PPCP Coordinator as needed to provide support, resources, and/or education

### 7. Physician/Clinical Provider Orders for PPCP Services

- With the exception of *Skilled Respite*, no other PPCP services require a physician order as they are not skilled nursing or rehabilitation services



## Section 4: Service Descriptions and Provider Qualifications

### Section 4: SERVICE DESCRIPTIONS AND SERVICE PROVIDER QUALIFICATIONS

The Agency must provide all of the following services using either employees or contractors of the Agency:

- Comprehensive care coordination by a nurse trained in palliative care
- Family Training to address teaching, educational, and support needs identified with the family
- In-Home Respite Care and coordination of Out-of-Home Respite Care (if prior approved and available)
- Expressive Therapies including Art, Music, Play, Dance Movement, and Child Life specialty services
- Family Grief Counseling/Bereavement Counseling for family and other primary caregivers, as applicable
- **Independent providers outside of the Home Health Agency will not be allowed to bill individually for PPCP services on a fee-for-service basis.**

#### Care Coordination

Care coordination allows for coordinated services and community supports to work with the child and family towards better health outcomes and to prevent unnecessary hospitalization. By acting as the “key person” for the family unit and maintaining communication across the interdisciplinary team, the palliative care coordinator can facilitate and guide appropriate service coordination on behalf of the child and family.

#### Qualifications

Agency employed/contracted registered nurse, experienced in working with children living with chronic illness, and who has completed a Pediatric Palliative Care Education Curriculum recommended and/or approved by the PPCP Program (i.e. ELNEC) in person or on-line. With approval from the Nurse Program Coordinator, other healthcare providers can provide care coordination under the direction of a registered/licensed nurse.

#### Goals

- Ensure a family-centered, culturally informed system of care by coordinating services provided to the child and family
- Integrate child and family’s goals with medical objectives to assist the participant in successfully and safely living in the community
- Assess the child’s home and community environment on an ongoing basis to determine if it is safe and conducive to successful implementation of the PPCP
- Collaborate and coordinate with medical, psychosocial, state plan, and community services
- Coordinate and communicate with the multidisciplinary team for effective medical and palliative care management of the child
- Develop and implement a comprehensive care plan that responds to social, emotional, spiritual, physical and economic issues that affect the child and family’s quality of life.
- Data collection as required for quality improvement and ongoing program development

### Care Coordination (cont'd)

#### Responsibilities

- Schedule first face-to-face visit within 7 days of Home Health Agency receiving intake (exceptions may be made to accommodate the child and family's request)
- Coordinate palliative care services and ensure services are implemented as authorized
- Develop a written care plan incorporating the key elements related to palliative care (Appendix B)
- Visit the home monthly to evaluate progress towards meeting the goals established in the Care Plan
  - Telephonic monthly management may be considered if a child has been stable with no changes for 90 days and mutually agreed upon by the family and Care Coordinator, but with a minimum of in-person home visits at least once every 90 days
- Anticipate *on average* up to 4 hours per month of care coordination dependent on diagnosis, needs, acuity, etc. (although time may be flexed from month to month in order to meet family's needs)
- Review Care Plan regularly per [Medicaid Rule 7401](#) or more often as indicated by a change in the participant's condition
- Coordinate care conferences collaboratively with the child's primary care pediatrician/lead physician as needed to ensure goals of care and continuity are being maintained
  - ~Communicate with all medical care providers and the family unit to achieve integration of needs and medical treatment goals
  - ~If appropriate, accompany family unit to appointments, as necessary to facilitate communication and support goals
- Coordinate care during transition periods, such as hospitalization, discharge, rehabilitation, out of state visits, etc.
- Assist the family unit in understanding recommended changes to the medical regimen as they occur and continuously review and update the goals of care as needed
- Create written after hours action plan (who to call) with family and ensure they have an accessible copy
- When necessary, collaborate with additional service providers (i.e. CSHN, CIS, school) involved in the child's care to ensure goals of care are optimized across the care continuum

#### Communication with the PPCP Nurse Program Coordinator

- Act as primary communicator between the Agency and PPCP Nurse Program Coordinator
- Communicate challenges in family engagement, changes in health status, etc. in a timely manner
- Submit a Monthly Service Report (Appendix E) and an annual care plan to the PPCP Nurse Program Coordinator. Monthly IDT meetings with the PPCP Nurse Program Coordinator present may be used in place of monthly service reports.

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Medicaid Rule 7401 can be found at

<https://humanservices.vermont.gov/sites/ahsnew/files/documents/MedicaidPolicy/HCARAdopted/Covered-Services-Rules-07302021-scrubbed.pdf>

## Section 4: Service Descriptions and Provider Qualifications (cont'd)

### Expressive Therapy

Therapeutic interventions are aimed at assisting children and their families to meet the challenges of their experience through professionally led creative and kinesthetic treatment modalities. Therapeutic and age-appropriate communications may be used to:

- Promote optimal development
- Present information
- Plan and rehearse useful coping strategies for medical events
- Work through feelings about past or impending experiences
- Support development of therapeutic relationships between children, siblings, and parents to support family involvement in each child's care

### Qualifications

Agency employed/contracted credentialed professional, experienced in working with children living with chronic illness, who has completed a Pediatric Palliative Care Education Curriculum recommended and/or approved by the PPCP Program (i.e. ELNEC) in person or on-line.

See *Appendix C: Approved Expressive Therapy Providers* for a complete list of accepted credentials.

### Family Training

Training and instruction for family members and caregivers by a nurse to best support and empower families with skills and knowledge so they can be more self-sufficient and confident in caring for their child. This training will likely be provided by the Palliative Nurse Care Coordinator, but additional training by a provider with specialized expertise may be necessary in some situations.

- Educational/counseling needs are routinely assessed and reassessed throughout care and treatment
- When educational needs are identified, they are incorporated into the plan of care
- Educationally appropriate materials (written, online, oral) will be provided to meet the needs identified in the assessment process

The following is a list of common issues to be addressed, depending on the patient's unique clinical circumstances:

- Pain and symptom management, including side-effect management
- Advance care planning and advance directives
- Anticipated future medical needs
- What to expect in the normal course of the disease
- Signs/symptoms of approaching death
- Medical procedures, home or hospital, and medical equipment

### Qualifications

Agency employed nurse, experienced in working with children living with chronic illness.

- Strongly recommend completion of a Pediatric Palliative Care Education Curriculum recommended and/or approved by the PPCP Program (i.e. ELNEC) in person or on-line.

### Family Grief/Bereavement Counseling

Anticipatory counseling is offered to the child and/or family by a certified or licensed professional trained in grief counseling. Counselors take care to address the physical, psychological and spiritual issues associated with the child's complex picture for which curative treatment may fail, is not possible, or because an early death is likely.

#### Service Specifics and Requirements

- Services prior to the child's death are fee-for-service
- Formal counseling may continue up to 6 months after the child's death providing services are started prior to child's death
- Up to 6 units of service may be billed on final claim to cover services during bereavement period
- Bereavement Service Log will be maintained and submitted to PPCP Nurse Program Coordinator 7 months after the death of the child

#### Qualifications

Agency employed/contracted licensed professional who meets qualifications listed below.

- Strongly recommend completion of a Pediatric Palliative Care Education Curriculum recommended and/or approved by the PPCP Program (i.e. ELNEC).

Preferred Providers include:

- Certified Hospice and Palliative Social Worker (CHP-SW)
- Advanced Certified Hospice and Palliative Social Worker (ACHP-SW)
- Most appropriate licensed professional from the PPCP team employed/contracted through the agency

Or those listed in the Department of Mental Health Medicaid Manual (Effective Jan. 2004):

- Licensed psychiatrist in Vermont
- Licensed psychologist in Vermont
- A professional nurse holding a M.S. in Psychiatric/Mental Health Nursing from a university with an accredited nursing program, licensed in Vermont.
- Licensed Clinical Social Worker in Vermont
- Licensed Mental Health Counselor in Vermont
- Persons with a minimum of a Master's level degree in a human services field approved by the clinical or medical and executive director as qualified to provide clinical assessment services.

#### Bereavement Service Documentation

Documentation of all bereavement services rendered to the family after the child's death must be maintained in the bereavement log (Appendix E) and submitted to the PPCP Nurse Program Coordinator upon completion of the service (approximately 7 months after the child's death).

### Skilled Respite Care

Respite is intended to provide short-term relief for family members from the demanding responsibilities of caring for a child with a complex medical condition, or for the family to attend to personal or other family needs. Skilled respite provides an alternative to institutionalization. Clinically eligible children may qualify for up to 5 days of respite per 6 months.

All of the following care must be present to meet the medical eligibility requirement:

1. A skilled care need that exceeds what a personal care attendant or family managed respite provider can provide; and
2. Without the support of skilled nursing services, institutionalization would be required due to the complexity or intensity of medical needs.

### Qualifications

Agency employed/contracted Registered Nurse, Licensed Practical Nurse, or Licensed Nursing Assistant, experienced in working with children living with chronic illness, and with skills necessary to match the needs of the child in order to maintain their health and safety.

- Strongly recommend completion of a Pediatric Palliative Care Education Curriculum recommended and/or approved by the PPCP Program (i.e. ELNEC)

If In-home Skilled Respite does not meet the family's needs, out-of-home Skilled Respite may be approved by the PPCP Nurse Program Coordinator and provided by an approved facility in coordination with DVHA.

### Rules and Requirements

- Prior authorization may occur on an as-needed basis (i.e. family obligation) or in anticipation of need (i.e. near end-of-life) as requested by the Palliative Nurse Care Coordinator to the PPCP Nurse Program Coordinator
- More than one providertype (RN, LPN, LNA) may provide respite, but not simultaneously
- Children and adolescents receiving skilled respite services may also receive other authorized PPCP services at the same time (i.e. grief counseling)
- A qualified medical provider working in their scope of practice (MD, DO, APRN, PA) must provide orders to support nursing interventions submitted to the Home Health Agency as with other skilled service requirements per Regulations for the [Designation and Operation of Home Health Agencies](#).

### Skilled Respite Care Service Documentation

Documentation should be in compliance with Regulations for the Designation and Operation of Home Health Agencies, and may include specifics such as the following:

- Reason for in-home skilled respite care
- Vital signs (as appropriate)
- Observations of the patient's condition
- Services provided to the patient
- Medications given and the patient's response
- Treatments completed and the patient's response
- Contacts made to the hospice and/or attending physician
- New or changed orders received
- Family response to care (as indicated)
- Detailed plan to return to routine home care when appropriate
- Interventions used to achieve palliation of physical or emotional symptoms

Designation and Operation of Home Health Agencies can be found at

[https://dail.vermont.gov/sites/dail/files//documents/Regulations\\_Designations\\_operations\\_Home\\_Health\\_Agencies.pdf](https://dail.vermont.gov/sites/dail/files//documents/Regulations_Designations_operations_Home_Health_Agencies.pdf)

## Section 5: Program Operations

### Section 5: PROGRAM OPERATIONS PROCESS

#### SUMMARY

1. Referral from primary pediatrician or a subspecialist overseeing their care made to PPCP Nurse Program Coordinator at CSHN
2. Program eligibility determined
3. Voucher entered by PPCP Nurse Program Coordinator into Medicaid Management Information System
4. A copy of the eligibility letter is sent to the referring provider, member, and designated home health agency
5. PPCP Coordinator reassessment of eligibility completed annually

#### REFERRAL

- A PPCP-specific Referral Form must be submitted to PPCP Nurse Program Coordinator by the member's primary care provider or subspecialist over-seeing their care
- Inquiries may be made from other state or community programs, however completion of the Referral Form by a MD/NP/PA regarding clinical diagnosis of a life-limiting condition and other eligibility criteria will still be required
- Referring provider will be notified promptly by PPCP Nurse Program Coordinator if additional information is needed to complete the program eligibility process

#### PROGRAM ELIGIBILITY

- Program eligibility is determined by the PPCP Nurse Program Coordinator based on basic eligibility requirements and Level of Care documentation as described on the Referral Form, as well as medical documentation that supports the qualifying clinical diagnosis and need for palliative care
- Determination will be made by PPCP Nurse Program Coordinator within 14 calendar days of receiving the Referral Form if all necessary information is included
- Family and referring provider will be notified of the child's program eligibility status by receiving a copy of the eligibility letter

#### AUTHORIZATION OF SERVICES

- Services are authorized at the same time a child is determined program eligible to prevent any delay in provision of services
- For children who are clinically eligible, PPCP services are automatically authorized via voucher entered in the MMIS by the PPCP Nurse Program Coordinator and services remain open for the duration of the child's enrollment in the PPCP
- Skilled Respite is authorized on an as needed basis to children who are clinically eligible and requires a prior authorization (See Section 4: Service Descriptions and Provider Qualifications)
- The PPCP Nurse Program Coordinator will reassess eligibility annually.

## Section 5: Program Operations (cont'd)

### HOME HEALTH AGENCY ENROLLMENT

- PPCP Nurse Program Coordinator will fax the referral, eligibility letter, and supporting documents to the intake department of the designated Home Health Agency immediately upon authorizing services
- PPCP Nurse Program Coordinator will also contact the Agency PPCP Lead to notify them of a newly enrolled member
- With the exception of Skilled Respite, PPCP services **do not** require orders submitted to the Home Health Agency

### HOME HEALTH AGENCY IMPLEMENTATION OF SERVICES

- The Home Health Agency will attempt to make contact with the family within 2 business days of receiving the intake information
- Once the Palliative Nurse Care Coordinator is identified, he/she is expected to notify the PPCP Nurse Program Coordinator
- The Palliative Nurse Care Coordinator will visit the child and family within 7 calendar days – document reason in patient's chart if this does not occur (i.e. family request)
- If the Home Health Agency does not have adequate information based on the intake process to make the initial visit, it is the Home Health Agency's responsibility to follow up with the PPCP Nurse Program Coordinator immediately
- Hospitalization at the time of enrollment will not be a barrier to admitting a child and initiating any non-duplicative PPCP services.

### CARE PLAN IMPLEMENTATION

- Developed by the Palliative Nurse Care Coordinator in collaboration with IDT, including but not limited to Medicaid PPCP authorized services
- Reflects services that will be provided, including the anticipated frequency
- Implemented by the Palliative Nurse Care Coordinator in accordance with the scope and frequency approved in the plan
- Re-evaluated regularly with family input and by the IDT to meet the evolving needs of the child and family
- At a minimum, the PPCP plan of care will be completed annually and updated as needed
- Upon completion and when updated, a copy of the PPCP plan of care will be submitted to the PPCP Nurse Program Coordinator

### OPERATIONS

- The Nurse Care Coordinator will visit and communicate with the family as described, with intermittent telephonic visits as needed based on the child's condition
- Agency IDT Meetings and outside Multidisciplinary Team Meetings will be coordinated as defined under the Care Coordinator's responsibilities
- Family satisfaction with PPCP services will be assessed via survey, frequency determined by PPCP Nurse Program Coordinator
- A redetermination of eligibility is completed annually by the PPCP Nurse Program Coordinator
- A strong line of communication will be maintained between the Care Coordinator and the PPCP Nurse Program Coordinator including monthly updates

## Section 5: Program Operations (cont'd)

### ANNUAL ELIGIBILITY REASSESSMENT

- Annual eligibility reassessment will be completed by the PPCP Nurse Program Coordinator
- For ongoing eligibility, children must meet all criteria with level of care and status of qualifying clinical diagnosis taking into consideration significant positive change in health status, clinical history over the previous year, and interdisciplinary team input
- If there has been no change or improvements to the child's qualifying condition, a notice of decision will be mailed to the family and the PPCP provider/team
- If there have been changes or improvements to the child's qualifying condition, the PPCP Nurse Program Coordinator will outreach appropriate medical providers, typically the child's PCP or specialist, to further evaluate eligibility
- If unable to approve eligibility after clinical review and outreach to medical provider, the family will be contacted and given the opportunity to submit evidence of ongoing eligibility prior to termination of services
- When a child is determined ineligible for continued PPCP services, the family will receive a letter re: notice of decision and outlining appeal rights

### DISCHARGE AND DISENROLLMENT

- Discharge refers to discontinuing PPCP services at the agency level. Disenrollment occurs when a child is no longer medically eligible for the PPCP and is determined by the Nurse Program Coordinator at CSHN.
- When a child is discharged from the PPCP, the Home Health Agency should follow their standard procedures and protocols for discharge from the Agency.
- Discharge should be discussed with the Nurse Program Coordinator. If applicable, a discharge plan should be established with an adequate timeline to close services provided by PPCP team members, including a warm hand-off to additional community services, as necessary.
- A child may be discharged from the agency for any of the following reasons:
  - Parent/guardian request;
  - Disenrollment from the program;
  - When the child turns 21 years old;
  - If the child is no longer eligible for Medicaid;
  - If the participant/family home environment poses a health and/or safety risk to the providers and attempts at remediation are unsuccessful;
  - Is no longer a resident of the State of Vermont; or
  - If death occurs.
- A child will be disenrolled from the PPCP if they no longer meet eligibility criteria
- Children previously discharged or disenrolled in PPCP services may be re-referred by way of the standard referral procedure.

### EVALUATION

- The PPCP may participate in both state and national evaluation projects to measure outcomes and family satisfaction
- Annual Agency Review and Provider Needs Assessment will be completed as requested by the PPCP Nurse Program Coordinator

Designated home health agencies will participate in quality improvement projects and data collection as necessary to monitor, analyze and improve program outcomes.



## Section 6: Billing, Coding, and Reimbursement

### Section 6: BILLING, CODING, AND REIMBURSEMENT

- Medicaid is the payor of last resort and requires a denial from the member’s primary insurer prior to reimbursement for services
- All claim forms **must** include the primary diagnosis ICD-10 code for which the member qualified for the PPCP in order to be processed
- All services must be billed using the appropriate Revenue Code on a UB-04 form
- See the [Medicaid Provider Manual](#) for additional billing questions
- See Appendix A for Service Reimbursement Rates
- For billing questions, call Gainwell Provider Services: 800.925.1706

Service	Revenue Code	Procedure Code	Additional Information
Care Coordination	580 Home Health – Other visits, General	G9006 Coordinated care fee, home monitoring	<ul style="list-style-type: none"> <li>• Based on Needs Assessment</li> </ul>
Expressive Therapy	562 Home Health – Medical Social Services, Visit charge	G0176 Activity therapy, such as music, dance, art or play therapies not for recreations, relative to the care and treatment of patient’s disabling mental health problems per session, 45 mins or more	<ul style="list-style-type: none"> <li>• Based on Needs Assessment</li> </ul>
Skilled Respite	660 Respite Care, General For RN or LPN	T1005 Respite care services, up to 15 minutes	<ul style="list-style-type: none"> <li>• Based on medical necessity and prior auth</li> <li>• No more than 12 hours (48 units) may be billed in a 24 hour period unless respite is delivered in an approved facility.</li> </ul>
	669 Respite Care, Other For HHA/LNA		
Family Training	589 Home Health – Other visits, Visit charge	G0164 Skilled services of an LPN or RN in the training and/or education of a patient or family member, in the home health or hospice setting, each 15 minutes	<ul style="list-style-type: none"> <li>• Based on Needs Assessment</li> </ul>
Family Grief/Bereavement Counseling	561 Home Health – Medical Social Services, General	99510 Home visits for individual, family, or marriage counseling	<ul style="list-style-type: none"> <li>• Must be initiated prior to member’s death</li> <li>• Fee-for-service prior to member’s death</li> <li>• May bill for 6 units of service on final bill to cover services during bereavement period</li> </ul>

Medicaid Provider Manual: <http://vtmedicaid.com/assets/manuals/GeneralBillingFormsManual.pdf>

## Section 7: Important Contacts

### Important Contacts

#### ***PPCP Nurse Program Coordinator***

Phone: (802) 865-1312

Fax: (802) 863-6344

#### ***Vermont Department of Health Children with Special Health Needs***

280 State Drive

Waterbury, VT 05671-8360

Voice: 802-863-7200

In Vermont 800-464-4343

Fax: 802-865-7754

TTY/TDD: Dial 711 first

#### ***Department of Vermont Health Access***

280 State Drive

NOB 1 South

Waterbury, VT 05671-1010

Phone: (802) 879-5900

#### ***Palliative Care Team at the University of Vermont Medical Center (UVMHC)***

Medical Center Main Campus

111 Colchester Avenue

Burlington, VT 05401

Phone: (802) 847-8888

\*After hours, call Provider Services @ UVMHC and ask for the Palliative Care Clinician on-call

#### ***Lebanon Palliative Care Program at Dartmouth Hitchcock Medical Center (DHMC)***

Dartmouth Hitchcock Medical Center

One Medical Center Drive

Lebanon, NH 03756

Phone: (603) 650-5402

Fax: 603-640-6850

#### ***Vermont Ethics Network***

61 Elm Street

Montpelier, VT 05602

Phone: (802) 828-6445

Email: [ven@vtethicsnetwork.org](mailto:ven@vtethicsnetwork.org)

## Communication Summary

### COMMUNICATION SUMMARY

- Please use this as a quick reference only - further details are outlined in the PPCP Provider Manual

**PURPOSE:** To summarize communication expectations thereby preventing gaps in care

**OBJECTIVE:** Ensure fluid and timely communication between the:

- Home Health Agency and enrolled family
- Home Health Agency and PPCP Nurse Program Coordinator

**The PPCP Nurse Program Coordinator is responsible for the following:**

- ✓ Processing Provider Referral
- ✓ Determining Program Eligibility
- ✓ Creating a PPCP voucher in the Medicaid system
- ✓ Submitting appropriate enrollment documents to HHA Intake Department for enrollment of child

**Once the Intake Department has received the enrollment documents →**

**The HHA is responsible for the following:**

- ✓ Attempting contact with the child/family within **2 business days** to:
  - Acknowledge receipt of information
  - Notify that enrollment within the agency is underway
  - Provide name of child's Palliative Nurse Care Coordinator
  - Schedule first face-to-face visit within **7 calendar days**
- ✓ Notifying the PPCP Nurse Program Coordinator at CSHN of the designated Palliative Nurse Care Coordinator
- ✓ Follow-up with PPCP Nurse Program Coordinator after first face-to-face visit
- ✓ Submitting Monthly Services Reports and annual care plans to the PPCP Nurse Program Coordinator at CSHN
- ✓ Review of care plan with PPCP Nurse Program Coordinator at CSHN annually and as needed.
  - When in doubt, call the PPCP Nurse Program Coordinator at (802)865-1312

# The Pediatric Palliative Care Program: Provider Manual

## Appendix A: Reimbursement Rates

Service	Revenue Code	Unit	Rate (February 2023)
Care Coordination	580 Home Health – Other visits, General	Unit = 15 minutes	\$/Unit = 17.60 (\$70.40/hr)
Expressive Therapy	562 Home Health – Medical Social Services, Visit charge	Unit = 45 min or more	\$/Unit = 143.33
Skilled Respite	660 Respite Care, General For RN or LPN	Unit = 15 min Up to a maximum of \$828.00 per 24 hours	RN or LPN \$/unit = 11.25 (45/hr)
Skilled Respite	669 Respite Care, Other For HHA/LNA	Unit = 15 min Up to a maximum of \$828.00 per 24 hours	LNA or HHA \$/unit = 6.00 (24/hr)
Family Training	589 Home Health – Other visits, Visit charge	Unit = 15 min	\$/unit = 17.60 (\$70.40/hr)
Family Grief/Bereavement Counseling	561 Home Health – Medical Social Services, General	Unit = 1 visit	\$/Unit = 143.33

\*Rates effective as of February 15, 2023

## Appendix B: Key Elements of Care

1. **Goals of Care** – Explicitly outlines what the child and family’s philosophy of care is at the time (i.e. cure-directed treatments, considered interventions, avoid hospitalizations, etc.). This can and will change over time and therefore should be re-visited regularly as needed and with changes in the child’s status (both improvements and declines in health).
2. **Decision-Making/Advanced Care Directives (ACD)** – Discuss who is the primary decision maker (child, biological parents, foster guardian, etc.). Does the child have a COLST (Clinician Orders for Life Sustaining Treatment) or advanced care directives? This can and will also change over time. ACD and Resuscitation orders may not be discussed early on in working with a family, but should be introduced as early as possible. This is where EOL planning and funeral planning would be documented, if appropriate.
3. **Pain & Symptom Management** – Include documentation of any scales being used to measure pain or symptoms. Even stating pertinent negatives is valuable in tracking a child’s care over time. This is where the emergency symptom plan is documented.
4. **Child & Family Support** – Include any elements that are particularly important to each child and family, such as consideration to cultural or spiritual beliefs, siblings, contextual challenges that may be barriers to providing care (transportation, housing, etc.).
5. **Interventions** – Discuss action items carried out to address needs of child and family.
6. **Outcomes** – Discuss outcome of the action items and if they were successful, unsuccessful, on-going, etc.

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## Appendix C: Approved Expressive Therapy Providers

Modality	Accepted Credentials	Credentialing Board
<b>Child Life</b>	Certified Child Life Specialist (CCLS)	Child Life Council, Inc. 11821 Parklawn Drive, Ste 310 Rockville, MD 20852-2539 Ph 1-800-252-4515 Fax 301-881-7092 <a href="http://www.childlife.org">http://www.childlife.org</a>
<b>Art Therapy</b>	Registered Art Therapist (ATR) Registered Art Therapist Board Certified (ATR-BC) Certification for Art Therapy Supervision (ATCS) *Master's level graduates being supervised maybe considered	Art Therapy Credentials Board, Inc. 3 Terrace Way Greensboro, NC 27403-3660 Toll Free 877.213.2822 Ph 336-482-2856 Fax 336-482-2852 <a href="http://www.atcb.org">http://www.atcb.org</a>
<b>Play Therapy</b>	Registered Play Therapist (RPT) Registered Play Therapist Supervisor (RPT-S) *Master's level graduates being supervised maybe considered	Association for Play Therapy, Inc. 3198 Willow Avenue, Suite 110 Clovis, CA 93612 Ph 559-294-2128 Fax 559-294-2129 <a href="http://www.a4pt.org">http://www.a4pt.org</a>
<b>Music Therapy</b>	Music Therapist, Board Certified (MT-BC) *Master's level graduates being supervised maybe considered	Certification Board for Music Therapists 506 E. Lancaster Avenue, Suite 102 Downington, PA 19335 Ph 610-269-8900 or 800-765-2268 <a href="http://www.cbmt.org">http://www.cbmt.org</a>
<b>Dance Movement Therapy</b>	Registered Dance/Movement Therapist (RDMT) Board Certified Dance/Movement Therapist (BC-DMT) *Master's level graduates being supervised maybe considered	American Dance Therapy Association 10632 Little Patuxent Parkway, Suite 108 Columbia, MD 21044 Ph 410-997-4040 Fax 410-997-4048 <a href="http://www.adta.org/">http://www.adta.org/</a>
<b>Expressive Arts Therapist</b>	Registered Expressive Arts Therapist (REAT) *Master's level graduates being supervised maybe considered	International Expressive Arts Therapy Association PO Box 320399 San Francisco, CA 94132 Ph 415-522-8959 <a href="http://www.ieata.org/index.html">http://www.ieata.org/index.html</a>

### MONTHLY PATIENT REVIEW

- **PATIENT NAME**
- **ANY CHANGE IN PROVIDERS ON PALLIATIVE CARE TEAM**
- **RN CARE COORDINATOR VISIT SINCE LAST IDT MEETING:**
  - TELEHEALTH VISIT
  - IN PERSON VISIT
  - EMAIL/TEXT
  - ATTEMPTED CONTACT WITH NO REPLY
- **CODE STATUS**
- **EMERGENCY PLAN/AFTER HOURS PLAN IN PLACE**
- **ER VISITS SINCE LAST IDT MEETING:**
  - DATE
  - REASON
  - DISPOSITION
- **HOSPITALIZATION SINCE LAST IDT MEETING:**
  - DATE
  - PLANNED OR UNPLANNED
  - REASON
  - DISPOSITION
- **UPCOMING APPTS**
- **MEDICATION CHANGES**
- **MAIN SYMPTOMS REQUIRING MANAGEMENT**
- **CHANGE IN CONDITION**
- **PSYCHOSOCIAL UPDATES**
- **EXPRESSIVE THERAPY UPDATES/NOTES**

## Appendix E: Links to PPCP Fillable Forms

- [Interdisciplinary Team Meeting Notes](#)
- [Plan of Care](#)
- [Monthly Service Report](#)
- [Intake and Needs Assessment](#)
- [Bereavement Log](#)
- [Expressive Therapy Referral Form](#)
- [Additional Services Request Form](#)
- [Care Conference Meeting Note](#)