

**Policy Title:** Palliative Care - Counseling and Support Services and Health Home Care Management

**Policy Number:** CW0015

**Effective Date:** December 1, 2021

**Last Revised:** November 2022

**Applicable to:** Children's Waiver Home and Community Based Services (HCBS) Providers and Health Home Care Managers (HHCMs) serving Children's Waiver enrolled and eligible participants that have a terminal illness or a life-threatening illness and meet the requirements below.

**Background:**

Palliative Care Counseling and Support Services has historically supported family members facing the terminal diagnosis of their child/youth who was enrolled in the Children's Waiver. As of December 1, 2021, families may receive Palliative Care Counseling and Support Services up to six (6) months after the passing of the enrolled participant and/or Health Home Care Management services for one (1) additional month following the passing of a participant enrolled in the Children's Waiver. Palliative Care Counseling and Support Services must be provided by a professional with experience or education in grief and loss counseling, per the [Children's HCBS Manual](#).

**Counseling and Support Services** provide help for participants and their families to manage and cope with the diagnosis and grief related to the participant's end-of-life experience. Children/youth with a terminal or life-threatening illness, and their families, cope with grief and loss in a variety of ways and may need various kinds of support over time, including counseling, support groups, and other services.

**Note:** These services can be offered at any point after a Children's Waiver participant is diagnosed with a terminal or life-threatening illness.

When an enrolled participant is disenrolled from Medicaid services or is deceased, Medicaid services typically end because payment of the service is predicated upon the Medicaid enrollment. However, Counseling and Support Services may continue after the participant's passing.

- ❖ Families may receive Palliative Care Counseling and Support Services under either the Medicaid State Plan Hospice authority or Counseling and Support Services under the Children's Waiver, so long as the services are not duplicative.
- Counseling and Support Services are available for those participants in receipt of hospice care through a hospice provider under the State Plan. Counseling and Support Services are included as a component of the hospice service for those participants who are receiving services with a hospice care provider. For information regarding Counseling and Support hospice services under the Medicaid State Plan authority, please see the policy guidance: <https://www.emedny.org/ProviderManuals/Hospice/PDFS/Hospice%20Manual%20Policy%20Section.pdf>
- This policy outlines the Counseling and Support Services under the Children's Waiver. Palliative Care Counseling and Support Services are intended to provide continued support even after the passing of the participant. ***The service must be added to the***

**service plan and the begin date of service must occur prior to the participant's passing. The claim must be submitted within 30 days of the participant's death.**

**Purpose:**

This policy provides guidance to Children's Waiver HCBS Providers and HHCMs regarding the requirements for delivering and documenting Palliative Care - Counseling and Support Services for families of children and youth with a qualifying illness i.e., terminal or life-threatening illness, who is enrolled in the Children's Waiver.

**Policy:**

The Children's Waiver Palliative Care Counseling and Support Services **and** Health Home Care Management are intended to support the caregivers, siblings, and other family members after the passing of an eligible and enrolled Children's Waiver participant.

**A. Counseling and Support Services Component:**

Palliative Care Counseling and Support Services are delivered to a participant and their family to cope with and prepare for the end-of-life experience. To address the need for families to receive support prior to and after the passing of their child, Counseling and Support Services are now available for up to six (6) months after the passing of the enrolled participant.

Palliative Care Counseling and Support Services can be delivered:

1. To the participant with a terminal or life-threatening illness **and** the participant's identified family members prior to the passing of the participant, to assist with managing the diagnosis,

**AND/OR**

2. To the participant's identified family after the passing of participant, if the HCBS providers service plan and the care managers plan of care (POC) denotes the service as outlined below.

To receive Palliative Care Counseling and Support Services after the passing of the eligible and enrolled participant, the family must initiate the service **prior to** the participant's passing. A determination of the needed services and request by the family must be made as part of the HCBS plan for the provider to bill the service, which includes counseling for up to six (6) months after the passing of the participant. Additionally, the six (6) months of counseling must be documented in the participant's Health Home or Children and Youth Evaluation Services' (C-YES) POC.

**Determination of Counseling and Support Services Needs**

The Palliative Care Counseling and Support Services provider must conduct an **initial need assessment** to determine the needs of the participant and their family while considering the social, spiritual, and cultural factors that may impact their ability to cope with the participant's terminal or life-threatening illness diagnosis and death. This review should be incorporated into the provider's service plan<sup>1</sup> that outlines the frequency, scope, and duration of counseling to be provided **and** should also be incorporated into the HH/C-YES care management POC. For

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<sup>1</sup> Please refer to the [HCBS Plan under the 1915c Children's Waiver](#) guidance for additional information

families to receive Counseling and Support Services after the passing of their child/youth, the service must be included in the care manager's POC prior to the participant's passing.

To enhance engagement with, and support for, the family, care managers should have at least 2 documented discussions with the family to identify their needs, even if the family ultimately chooses not to use the Counseling and Support Services after the child/youth passes away. The conversations should include care management roles as well as incorporating the needs assessment for Counseling and Support Services by a licensed mental health practitioner. These needs may not be apparent prior to experiencing a loss, but they should be incorporated into the POC and billed in compliance with the billing guidance in section C below. Counseling and Support Services and post-mortem service plans should be updated regularly and be incorporated into the final POC. The Care Manager should ensure that the provider implements the service plan.

### **Examples:**

#### Services Plan:

- 1) Palliative Care Counseling and Support Services will be provided bi-weekly to the participant for 3 months with family involvement to develop coping strategies regarding the terminal diagnosis of the participant. Continued counseling for the family will be reviewed and determine based on their needs.
- 2) Palliative Care Counseling and Support Services will be provided bi-weekly for up to six months to the participant's family following the passing of the participant.

#### Plan of Care:

- 1) Palliative Care Counseling and Support Services will be provided bi-weekly for the participant for 3 months with family involvement to address coping strategies regarding the terminal diagnosis.
- 2) Palliative Care Counseling and Support Services will be provided bi-weekly for up to six months to the participant's family due to the passing of the participant.

The **Palliative Care HCBS Provider** will utilize the following to assist with the Counseling and Support Services review and development of the service plan:

#### Determination of Counseling and Support Services Needs

The participant is determined to have a terminal illness or a life-threatening illness and the participant and/or family members have at least one of the following as determined by a qualified provider\*:

- 1) a degree of anxiety and depressive responses and triggers of such responses
- 2) other affective responses such as guilt and helplessness
- 3) somatic concerns and dysregulation
- 4) psychiatric symptoms including orientation and mental status, PTSD (post-traumatic stress disorder) in both full-blown and partial forms, and suicidal ideation (\*That a qualified provider who has appropriate licensure to diagnose within their scope of practice or recommend referral to such an appropriate provider)
- 5) self-esteem issues
- 6) effects on the individual's ability to work or perform major life tasks
- 7) effects on the management of family relationships, including the relationship to spouse or partner, to other children/youth, and to the extended family

Counseling and Support Services should incorporate guidance that accounts for:

- the nature and degree of involvement in interpersonal relationships outside the family
- the meaning framework or structure in which the family is embedded and its current power
- the degree to which the family is able to invest emotional energy in life tasks and the type of life tasks that are engaged

For family members, the relationship to the terminally ill participant and the Counseling and Support Services needs are reviewed in relation to:

- 1) the ability to cope with the terminal diagnosis and management of treatment
- 2) the degree of preoccupation with the diagnosis and the illness
- 3) the degree of guilt, helplessness, or ability to manage the illness
- 4) the extent in which the illness is impacting the functioning, activities, and daily life needs for the siblings, caregivers, and other family members

For family members, the relationship to the deceased participant and the Counseling and Support Services needs are reviewed in relation to:

- 1) the degree of preoccupation with memories and thoughts of the deceased
- 2) the extent to which the description of the deceased is characterized by an inability or unwillingness to express the personal feelings brought about by the death
- 3) the degree of idealization of the deceased
- 4) the report of psychological conflict or contradictions in the relationship
- 5) the degree and type of positive affect and emotion
- 6) the degree and type of negative emotion toward the deceased
- 7) the degree of closeness or distance from the relationship and experience of the deceased
- 8) the affective experience when discussing the deceased (e.g., a parent who might say, "I always feel guilty thinking about how my son died")
- 9) the presence of previously described grief phases of shock, seeking reminders of the deceased, disorganization, and restoration of a coherent life flow the manner in which the deceased is memorialized both publicly and within the family

Social, spiritual, and cultural factors that may impact a family member or other individual's ability to cope with the participant's death may include, but are not limited to:

- History of previous losses
- Religion
- Family problems
- Community
- Financial and/or legal concerns
- Communication issues
- Drug and alcohol abuse
- Health concerns
- Mental health issues
- Presence or absence of a support system
- Feelings of despair, anger, guilt, or abandonment

These issues may not be readily apparent during the initial Counseling and Support Services review but must be considered and should be incorporated into the provider's service plan.

The broad elements of comprehensive psychological and emotional care include the following:

- Evaluation of the child/youth's psychological status and identification of psychological symptoms or disorders

- Provision of appropriate psychotherapy, psychotropic medications, or behavioral interventions as an integral part of the participant's overall care
- Advice for the participant's physician, parents, and others on additional strategies or steps that they can take to manage or minimize emotional distress
- Evaluation of the participant's parents and siblings (and sometimes other family members) for psychological symptoms
- Referral as appropriate to support groups for ill children/youth, healthy siblings and parents that allow them to share experiences in living with serious illness
- Counseling and Support Services for the family after the participant's death

## **B. Care Coordination Component: Medical Notifications and Related Tasks**

In addition to (but not contingent upon) Children's Waiver Counseling and Support Services, the family may receive Health Home care management services for an additional one (1) month after a participant in the Children's Waiver passes away, in accordance with this policy. Care Management is intended to assist with provider notifications and managing discontinuation of services after the participant's passing.

When a participant dies, particularly a participant who was terminally ill or had a life-threatening illness, families are often too emotionally stressed and overwhelmed to perform the multiple notifications and service discontinuations needed. Medically complex children/youth often have 10 to 15 medical specialists, 2 to 3 Durable Medical Equipment (DME) and supply vendors, 1 or 2 different pharmacies or specialty pharmacies, private duty nurses, and/or multiple agencies, and various school contacts. In addition, the family needs to notify the Local Department of Social Services (LDSS), the insurance carrier, and/or Medicaid Managed Care Plan (MMCP). The Health Home care manager (HHCM) can assist with these tasks to support the family.

The POC, developed by the HHCM, should include the medical notifications and other related tasks that need to occur in the 30 days after the participant passes.

**Care Management activities** may include but are not limited to:

- Contacting all DME<sup>2</sup> providers to determine whether the equipment is owned or rented
  - If owned, (if parent chooses) arrange removal from home
  - If rented, arrange for pick-up by vendors
  - If borrowed, arrange for item[s] to be returned to owner
- Arranging for all disposable supplies to be donated and transported (since vendors are prohibited from taking back supplies)
- Notifying all nursing / home care providers, including Fiscal Intermediary agencies
- Notifying all physicians and pharmacies
- Contacting school district / Committee on Special Education (CSE) team, Early Intervention Program (EIP) and/or therapy providers
- Notifying LDSS, MMCP, and insurance carrier [if applicable]
- Notifying Office for People With Developmental Disabilities (OPWDD) [if applicable]
- Removing Environmental Modifications – there are often items such as chair lifts or wheelchair ramps that families want removed from their homes, and they may want to know how / where to sell their modified vehicle.
- Assisting with locating funding for final expenses
- Providing linkage to bereavement groups and/or sibling support groups as well as ensuring that Counseling and Support Services continues under the waiver/hospice benefit

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<sup>2</sup> Please refer to the [DME Manual](#) for more guidance and information

- Notifying personal contacts as requested

These needs may not be readily apparent during the initial needs assessment but should be incorporated into the Health Home or C-YES POC.

### **Plan of Care**

The care management [POC](#) must indicate the specific services that will be provided (including post-mortem Counseling and Support Services and assistance with medical notifications), individuals who would receive the services, and the frequency, scope, and duration of the services. The POC should be reviewed and updated up until the participant's death to support any changes in the family's needs. The Care Manager should ensure that any Counseling and Support Services is delivered in a manner consistent with the POC in effect at the time of the participant's death.

The POC must reflect the needs of the family and services that the provider will deliver to the family within the scope of the HCBS definition as outlined in this policy and HCBS Manual.

### **Example:**

#### Plan of Care:

- 1) Palliative Care Counseling and Support Services will be provided by the Health Home care manager for one month after the passing of the participant to assist with medical notification and other related tasks for the family
- 2) Palliative Care Counseling will be provided bi-weekly by the HCBS provider for up to six months to the participant's family due to the passing of the participant

### **C. Billing Component**

Palliative Care Counseling and Support Services must be provided by a professional with experience or education in grief and loss counseling, per the [Children's HCBS Manual](#). Assistance with medical notifications and other related tasks must be provided by a Health Home or C-YES Care Manager. Billable services must be documented in the Service Plan, including the needs assessment, and in the Plan of Care.

#### Palliative Care Counseling:

1. When serving the participant to manage and cope with their diagnosis, billing will occur in 30-minute increments.
2. When serving the participant's family after their passing, a *one-time* claim for payment for Counseling and Support Services must be submitted with a date of service prior to and within 30 days of the participant's passing.
  - a. The rate includes the Counseling and Support Services needs assessment and up to six (6) months of counseling after the passing of the participant.

#### Health Home Care Management

1. Claims for payment for Health Home care coordination provided during the month of the participant's death must be dated prior to and submitted within 30 days of the participant's passing. Please note a claim with a date *after* the participant's death cannot be submitted.
2. Add the member's monthly billing instance to the Medicaid Analysis Performance Portal Health Home Tracking System (MAPP HHTS) to indicate that a billable Health Home service was provided during that member month.
3. The separate Health Home upstate/downstate rate code based upon acuity (below) is allowed for an additional unit to be billed along with the regular Health Home PMPM

within 30 days of the participant's passing. This claim will not be reflected within the MAPP HHTS.

4. This additional rate code will allow for the additional month of care coordination for the month after the child/youth's passing to assist the family as outlined above.
5. The member's segment within the MAPP HHTS must be ended with the last day of the month in which the member passed.

Service	Rate Code	Procedure Code	Unit Measure	Unit Limit
Palliative Care Counseling and Support Services	8017 – Counseling	90832	30 minutes	Limited to the lesser of 10 units per month or 120 units per calendar year
Bereavement Assessment and Counseling	7952 – Assess/Counseling	96156	Needs assessment and up to six (6) months of Counseling and Support Services	1 unit/calendar year Per member
Health Home Care Management Based Upon Acuity	7946 – HH Upstate <sup>3</sup> Low 7947 – HH Upstate Med 7948 – HH Upstate High 7949 – HH Downstate <sup>4</sup> Low 7950 – HH Downstate Med 7951 – HH Downstate High	96156	Care Coordination for one (1) month	

Please refer to the [Children's HCBS Manual](#) for additional information regarding Counseling and Support Services under the Children's Waiver. For additional information on billing, please refer to the [Billing and Coding Manual](#).

<sup>3</sup> Upstate: all states that do not fall into the 'downstate region'

<sup>4</sup> Downstate: 5 boroughs of New York City, counties of Nassau, Suffolk, Westchester, Rockland, Putnam, Orange, Dutchess, Sullivan and Ulster