



Pediatric Concurrent Care: Advocating for Private Insurance Coverage Toolkit

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Background

Concurrent care enables children with a life-limiting diagnosis to continue to receive disease-directed treatment along with hospice care, avoiding the impossible choice between these two types of care.

On March 23, 2010, the Patient Protection and Affordable Care Act (ACA) was signed into law enacting a new provision, [Section 2302, termed the "Concurrent Care for Children" Requirement \(CCCR\)](#). CCCR requires state Medicaid and Children’s Health Insurance Program (CHIP) to pay for both disease-directed treatment and hospice services for children under the age of 21 who qualify.

Prior to the ACA, both children and adults had to have (1) a six-month prognosis and (2) forego any disease-directed, curative treatments to enroll in hospice. With concurrent care, pediatric patients must still meet the six-month prognosis, but do not have to choose between disease-directed, curative care and hospice care. Disease-directed treatments are any therapies, medications, equipment, or modalities related to the serious illness which may postpone a child’s death. The exact definition of what a private insurer uses for disease-directed care may vary by insurer.

Despite the advancement of concurrent care with Medicaid and CHIP, private insurers (e.g., commercial insurance, employer-sponsored insurance) are not required to cover disease-directed services along with hospice care. However, this does not mean private insurers will never cover the services, and some already have benefits in their plans to cover concurrent care. As a provider, you can provide support to the patient and family to advocate for a private insurer to cover both hospice and disease-directed services in tandem.

The purpose of this toolkit is to inform providers about how to work with private insurance companies to advocate for coverage of concurrent care for pediatric patients, but it is not a guarantee of coverage. Through this toolkit, hospice staff will learn how to discuss the importance of concurrent care with insurers, how to set expectations with families, the language insurers may use, and examples of working with private insurance companies.

As always, if you have questions about pediatric concurrent care, please reach out to NHPKO’s Pediatric Advisory Council at pediatrics@nhpco.org.

Setting Expectations with Patients and Families

When beginning the process of working with private insurance to provide concurrent care, it is imperative to include the patient and family in the process. For most patients and families, concurrent care is a new concept. Staff will need to work with them to let them know what they can expect regarding insurance, equipment, and treatment. Generally, providers can follow three steps when setting expectations with patients and families: (1) assess the situation, (2) discuss any needs, discrepancies, and issues with the patient and family, then (3) bill the private insurance based on the first two steps. Below is a list of considerations when discussing concurrent care with families:

Equipment and Supplies

■ Assess

- Determine what, if any, equipment and supplies are already in the home.
- Equipment may be covered under concurrent care, meaning paid for by the private insurer, then the family should continue to contact the durable medical equipment (DME) company as established. If the hospice will be covering the DME, then the hospice team will coordinate/help with ordering equipment and supplies.
 - If the hospice is coordinating and covering equipment, it may require a new contract with the company.
 - If changing the DME provider, the child's current equipment need to be picked up and replaced with equipment provided by the DME company with whom the hospice has a contract. This switch of equipment can be burdensome to families.
- Decide what equipment can be ordered from a DME company and what equipment is specialized for pediatric patients.
 - Specialty items will have to be reviewed with insurance companies, which may require a review of concurrent care and what is covered.
 - Many DME companies may not carry a large stock of pediatric equipment and supplies. It is important to know what the company the hospice contracts with can provide for any pediatric patients.

■ Discuss

- Many families are used to supplies coming in large quantities to cover a month of needs. If the hospice team orders in smaller amounts, it is important to explain this to families.
- It is also important to review specifics of brands and sizes to make sure families know items may be different.

■ Bill

- Determine if the family would like to be provided with the same brand items. It is possible brand names may differ based on formulary and non-formulary items determined/covered by the hospice.
- If the items are covered in the hospice plan of care, then the hospice team can work with companies on billing the hospice directly instead of the private insurance.
- Items not covered in the hospice plan of care will need to be billed to private insurance or paid for out of pocket by the family/caregiver.

Treatments and Therapies

■ Assess

- What services are being provided to the patient? Who is providing those services?
 - Smaller children may have support from organizations like Help Me Grow, Head Start, or Early Invention which will not conflict with hospice services.
- If therapies are being offered in the home from a homecare agency, find out the number of sessions left and the goal for the care. These services may have conflicting billing codes with concurrent care. If these services will be needed after hospice is started, then it is important that, prior to being admitted to hospice, the insurance company agrees to pay for both the hospice and home health services.
- Determine if therapies being provided are intended to help with activities of daily living (ADLs) or with quality of life. Some of these visits may be covered by the hospice as part of the hospice plan of care.
- If private duty services are being frequently provided to children admitted to hospice, it is important to know how many hours of care the child is receiving as well as the discipline of the caregiver providing those hours. Some insurers may question whether private duty services and hospice services are duplicative. Prior to admitting a child to hospice ensure that the insurance company is committed to continuing to pay for both the private duty services and the hospice services.

■ Bill

- If the private insurer agrees to cover the current disease-directed or cost-prohibitive treatments and therapies, the hospice should collaborate with the contracted company to ensure the services are continued and to educate the contracted company on the services that hospice is

Documentation of Discrepancies and Items not Covered

■ Assess

- Review any items, supplies, or services that will and will not be covered in the hospice plan of care and/or via concurrent care.
- It is important to document covered and non-covered items, supplies, and services in the hospice plan of care and to provide the documentation to the patient and family as well as the private insurance company.

■ Discuss

- Inform the patient and family of any non-covered items, supplies, or services.

■ Bill

- A list can be supplied to families of items and medications that will not be covered under the hospice plan of care.

Medications

NHPCO's [Determination of Hospice Medication Coverage in Children](#) provides comprehensive guidance on how to determine medication coverage.

Expectations of Private Insurance Plans

Some private insurance companies may not be familiar with concurrent care so you will need to explain the purpose and goals of concurrent care. Below is some simple language to describe concurrent care to a private insurance provider:

- Concurrent Care is a benefit that allows children to receive disease directed treatment in conjunction with hospice care. Services may include:
 - Private duty nursing
 - Hospitalizations
 - Chemotherapy
 - Radiation
 - Intensive life-preserving treatment including trach or vent
 - IV fluids and Total Parenteral Nutrition (TPN)

Understanding Private Insurance Hospice Benefits

Private insurance companies may have a hospice benefit separate from broader health insurance coverage. Instead of including hospice care within the general health insurance coverage, it is a separately managed benefit. This ensures individuals with terminal illnesses receive comprehensive care tailored to their unique needs.

A hospice benefit may include:

- A separate benefit from other medical services with different eligibility criteria and coverage limits.
- A separate network of hospice care providers.
- A dedicated claims processing center for hospice benefits.
- Additional support and resources to policyholders and their families who are receiving hospice care. This may include care coordination services, counseling, bereavement support, and access to community-based palliative care programs.

While there are benefits to a separate hospice benefit, it is important to note some of the challenges. These include:

- Potential for fragmented care navigating multiple insurance plans or networks.
- Limited provider choices within the network.
- Additional administrative complexity with a separate benefit for the policyholder and the insurance, potentially causing delays. These delays may impact prior authorizations, claims processing requirements, and/or coordination of benefits.
- Potential financial consequences with copayments, deductibles, or coverage limits.

You should work closely with patients and families, as well as insurance representatives, to ensure care recipients understand their options and make informed decisions about hospice and concurrent care benefits.

Questions to Ask

To understand what is covered under a patient's insurance, you will need to reach out to the insurance company to better understand the benefit. Below are questions you should ask an insurance company to identify what is included in the hospice benefit and if they provide concurrent services:

- What are the requirements a patient must meet to qualify for the hospice benefit?
 - Must a certification of terminal illness (CTI) be completed?
 - Who must sign the CTI?
 - Is eligibility based on prognosis or diagnosis?

- Is pre-authorization required?
- Can the hospice benefit be accessed if the patient has home health care in the home?
- If the patient wants to continue with [chemotherapy/[radiation] treatment while receiving hospice care who will pay for it?
- If the patient continues hospitalizations while receiving hospice who will pay for it?
- Is there a separate pharmacy benefit from the medical benefit that needs to be utilized for medications?
- Does the hospice benefit include coverage for respite?
 - If so, what is the criteria for accessing respite and for how long?
 - Are there limits to respite days and/or frequency?
- If the hospice is denied (pre-authorizations, coverage), what is the process for appeal?
 - Peer to Peer?
 - Appeal Letters?

Tips for Working with Private Insurance

- Contacting the parent/insured to find out if they have a case manager or connection with their insurance company is the best place to start.
 - It is recommended you document the date, time, reference number, and name of the person you spoke with should you need to follow up on any discussion.
- If an insurance case manager is involved, remain connected and provide updates for ongoing advocacy for coverage.
- Encourage parents to reach out to insurance providers to speak on their child's behalf including regarding:
 - Impact of concurrent hospice coverage on quality of life, health, and well-being.
 - Personal stories to highlight their experiences and need for concurrent coverage.

Other Considerations

- What contracts do you have in place with hospitals in the area? Will this impact coverage decisions (e.g. for general inpatient)?

Communicating with the Private Insurance

Be prepared to provide the private insurance company with examples of how providing concurrent care to the patient will positively impact quality of life, outcome measures, and reduce cost/burden to the company as well as the patient and family.

Items for Consideration:

- Intravenous medications
- Cost prohibitive items, such as medications, treatments, supplies, and services. Advocate for a carve-out (i.e., the item is not considered part of hospice and is paid through the larger health benefit) for specific items that would otherwise prevent or impact the family decision for hospice care.
- Explain that the impact of hospice care provided by an interdisciplinary team can allow for reduced emergency room visits and/or hospitalizations.
- Provide specifics to that particular beneficiary, including recent hospitalizations, emergency visits, and/or clinic visits that could have been prevented with involvement of the hospice team/care.

Communicating with private insurance companies is not typically a one-and-done conversation. Be willing to advocate for concurrent care coverage one or two items, and then plan to re-evaluate or discuss other coverage options as care continues/progresses. As you continue to work with the private insurance company, be sure to explain the impact hospice is having on quality of outcomes and potential cost reductions in total care.

Provide the private insurance company with resources explaining concurrent care and how determination of medications, supplies, and services are made. You can do so by utilizing the resources available on [NHPCO's Pediatric webpage](#).

Examples of Successes:

- Intravenous (IV) administration: Some hospices have been successful in obtaining a contractual agreement with private insurance company to "carve out" all IV fluids (IVF) and TPN. This means that if a patient is admitted to hospice services and requires IVF, the private insurance company will cover (i.e., paid) the cost of those items outside of the hospice reimbursement.
- Private insurance companies may agree to coverage of certain items for a defined period of time (e.g., 30-60-90 days) from the admission date of hospice services to allow the team, patient, and family time to transition.
- When a patient is hospitalized within your hospice's service area, reach out and discuss coverage of the hospitalization with the private insurance. If the hospice determines the hospitalization is outside of the hospice plan of care, advocate and explain why it is important for the hospice team to stay involved. The benefit of the hospice staying involved could be (1) reducing hospital days (goals of care discussions), (2) continuity of care/ease of discharge back home, (3) involvement of hospice interdisciplinary team to provide supportive services to the whole family, such as siblings at home who are unable to visit the hospital, counseling, bereavement support.

Resources and Templates

Additional NHPCO Resources:

- [Tips for Adult Providers Caring for a Pediatric Patient](#)
- [Standards of Practice for Pediatric Palliative Care](#)
- [Determination of Hospice Medication Coverage in Children](#)
- [Concurrent Care for Children Implementation Toolkit](#)
- [Palliative Care Resource Series](#) – requires an NHPCO membership

Appendix:

- A. Insurance Verification Checklist
- B. Letter of Medical Necessity Checklist
- C. Letter of Medical Necessity Template

Appendix A

Insurance Verification Checklist

Patient Name: _____

Patient Date of Birth: _____

Patient Zip Code of Home Address: _____

Insurance Company Name: _____

Insurance Company Phone Number: _____

Insurance Company Fax Number: _____

Benefit Information:

Effective Date (start date of insurance coverage): _____

Type of Plan: HMO PPO Medicaid Medicaid Managed Care

Is [ORGANIZATION] in Network: YES NO

If NO, can we apply to become in-network: YES NO

If NO to in-network, what is out of network coverage: _____

Coverage Year (if different than calendar year): _____

Costs:

Deductible: Individual _____ Family _____

% Covered after deductible: Individual _____ Family _____

Out of Pocket Maximum: Individual _____ Family _____

Is there a lifetime maximum? YES NO

Hospice Benefit Coverage:

Is pre-authorization required? YES NO

What is the fax number for authorization? _____

Is it a per diem rate or reimbursement of services provided? _____

What is required to access the hospice benefit? Two doctors' signatures CTI Prognosis of 6 months or less

What is included in the medical hospice benefit? _____

Is there a pharmacy benefit? YES NO

- If yes, contact pharmacy customer service to review medications
- Meds will fall into the following categories: Covered- no co-pay, covered with co-pay required, requires prior authorization for coverage, not covered

■ **Hospice Codes:**

- In home: S9126, Q5001
- Inpatient: Q5006, Q5005 (for respite, and GIP)
- IMPORTANT: SOME PRIVATE INSURANCE COMPANIES HAVE A SEPARATE RESPITE BENEFIT THAT COVERS MORE THAN 5 DAYS.

Hospice Benefit - additional questions to consider:

Can hospice benefit be accessed if patient has home health care in the home?

YES NO

Can family continue aggressive chemo treatment that insurance will cover while still receiving hospice care?

YES NO

Hospitalization? YES NO

Does insurance have a separate respite benefit? YES NO

If yes, what is the time frame allotted by this benefit? _____

If hospice is denied, what is the process for appeal? _____

Is there a minimum or maximum number of visits allotted per month? YES NO

Is there a Home Infusion benefit? YES NO

Can it be used in conjunction with hospice? YES NO

Palliative Care Coverage:

MD/APN coverage (codes depending on Service Site)? _____

What is the time limit allotted under the authorization? _____

When do we need to re-authorize for services? _____

Are we limited to a certain number of visits? YES NO

If yes, how many? _____

Appendix B

Letter of Medical Necessity Checklist

- 1. Patient Information:**
 - Full name of the patient
 - Date of birth
 - Address
 - Contact information
- 2. Medical Provider Information:**
 - Your full name
 - Your title
 - Contact information
 - Medical facility or practice name
- 3. Date:**
 - Include the date when the letter is written.
- 4. Recipient Information:**
 - Full name of the person or department responsible for reviewing the request
 - Title
 - Name of the medical facility or insurance company
 - Address
- 5. Subject:**
 - Clearly state the purpose of the letter, such as "Letter of Medical Necessity for Pediatric Hospice Care"
- 6. Patient's Diagnosis and Medical History:**
 - Specify the patient's primary diagnosis
 - Provide a brief medical history, including relevant details about the progression of the illness
- 7. Current Medical Condition:**
 - Describe the patient's current medical condition, emphasizing symptoms, pain levels, and any distressing factors
- 8. Prognosis:**
 - Explain the prognosis, including the expected course of the illness and the estimated life expectancy
- 9. Rationale for Pediatric Hospice Care:**
 - Clearly articulate the reasons why pediatric hospice care is medically necessary for this patient
 - Discuss how hospice care aligns with the goals of providing comfort, dignity, and quality of life
- 10. Symptom Management:**
 - Describe the specific symptoms that require management through hospice care
 - Explain how hospice services will address pain control and symptom relief
- 11. Interdisciplinary Care Team:**
 - Highlight the importance of the interdisciplinary approach in pediatric hospice care
 - Mention the collaboration between medical, nursing, psychosocial, and spiritual support teams
- 12. Home Setting:**
 - Explain the preference for hospice care to be provided in the home setting
 - Emphasize how this environment will contribute to the patient's well-being
- 13. Supporting Documentation:**
 - List and attach relevant medical records, test results, and any other supporting documentation that validates the need for hospice care
- 14. Contact Information and Availability:**
 - Provide your contact information and express your availability to offer additional information or clarification as needed
- 15. Closing and Signature:**
 - Express gratitude for the recipient's attention
 - Include a professional closing and your signature if sending a hard copy

Appendix C

Letter of Medical Necessity Template

REMEMBER: This is the start of a letter, make sure to personalize the letter to reflect your patient's specific situation! Explain the carve outs needed to provide care for the child.

[Your Name]

[Date]

[Your Title]

[Your Contact Information]

[Recipient's Name]

[Recipient's Title]

[Medical Facility or Insurance Company Name]

[Address]

Subject: Letter of Medical Necessity for Pediatric Concurrent Care

Dear [Recipient's Name],

I am writing to advocate for the immediate consideration and approval of pediatric hospice care for my patient, [Patient's Name]. As the primary healthcare provider for [Patient's Name], I have carefully assessed their medical condition and determined hospice care is the most appropriate and compassionate option to ensure their comfort, dignity, and quality of life during this challenging time.

[Patient's Name] is a [age]-year-old child suffering from [diagnosis or medical condition], which has reached an advanced and irreversible stage. Despite all efforts to manage symptoms and provide curative treatments, [he/she] continues to experience significant pain, discomfort, and distress. The trajectory of [Patient's Name]'s illness indicates a limited life expectancy, and the focus of care has shifted to providing comfort and support for both the patient and their family.

Hospice care is essential in addressing the unique physical, emotional, and psychosocial needs of pediatric patients and their families. The interdisciplinary approach of hospice care, including specialized medical, nursing, psychosocial, and spiritual support, is crucial in maintaining the highest possible quality of life for [Patient's Name]. This approach aligns with the goals of palliative care, emphasizing symptom management, pain control, and emotional well-being.

I am requesting approval for pediatric hospice care services to be provided in the home setting to facilitate a familiar and supportive environment for [Patient's Name]. The interdisciplinary hospice team will work closely with the patient's primary caregivers to ensure a comprehensive and individualized care plan that prioritizes the comfort and dignity of [Patient's Name].

Enclosed with this letter are relevant medical records, including [list any supporting documents], which highlight the ongoing medical needs and the appropriateness of hospice care for [Patient's Name].

I appreciate your prompt attention to this matter and am available to provide any additional information or clarification required. Your approval of pediatric hospice care for [Patient's Name] will contribute significantly to the well-being of the patient and their family during this challenging time.

Thank you for your understanding and consideration.

Sincerely,

[Your Signature, if sending a hard copy]

[Your Name]

[Your Title]



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