Clinician and Administrator Pediatric Concurrent Hospice Care Toolkit

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National Alliance for Care at Home

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Purpose of the Toolkit

This toolkit is designed to help hospice program clinicians and administrators understand and operationalize concurrent hospice care for children with serious or life-limiting illness. Concurrent care allows a child to receive hospice services while continuing selected disease-directed or life-prolonging treatments when those treatments are consistent with the child's goals of care.

Concurrent care must always be accompanied by informed discussion of goals of care, hospice and non-hospice care planning, clear role delineation, ongoing reassessment, and careful documentation of treatment burden, symptom benefit, and plan changes.

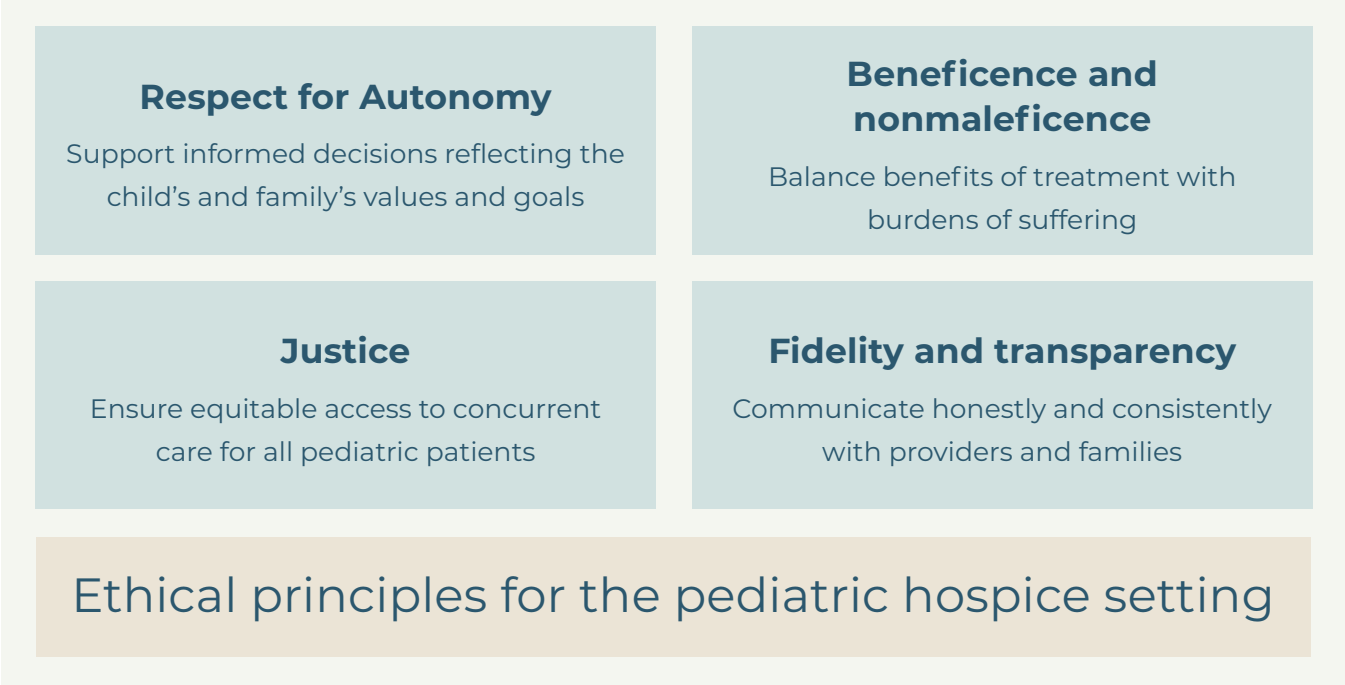
The toolkit is intended to reduce confusion, improve communication, support safe transitions across care settings, and clarify roles among providers. It is especially useful for programs building pediatric concurrent care pathways, addressing coverage questions, or training adult-focused hospice teams who may be less familiar with pediatric practice.

This toolkit should be adapted to state law, Medicaid policy, payer contracts, hospice conditions of participation, and local practice standards. It is not a substitute for legal, billing, or medical advice; rather, it is a practical framework for building policy, workflow, documentation, and operational tools.

Ethical Principles

The implementation of concurrent care in pediatric hospice settings must be grounded in core ethical principles that guide clinical decision-making and care coordination. Respect for autonomy requires that the child (when developmentally appropriate) and family are supported in making informed decisions that reflect their values, beliefs, and goals of care, without coercion or false dichotomies between treatment and comfort. Beneficence and nonmaleficence require clinicians to carefully evaluate the balance between the potential benefits of continued disease-directed treatment and the burdens it may impose, ensuring that care consistently aims to promote comfort,

quality of life, and overall well-being while avoiding unnecessary suffering. Justice underscores the importance of equitable access to pediatric hospice services, ensuring that children are not excluded due to diagnosis, treatment status, payer complexity, or socioeconomic factors. Finally, the principle of fidelity and transparency requires clear, honest, and ongoing communication among all providers and with families, including accurate representation of prognosis, treatment intent, and coverage limitations. These principles support ethical delivery that is compassionate, coordinated, and aligned with the child's and family's evolving goals.



Definitions

Concurrent care: The provision of hospice services together with disease-directed or life-prolonging treatment(s) that align with the patient's and family's goals and are allowable under payer rules.

Hospice services: Care for patients with serious, advanced, or life-limiting illness that focuses on symptom management, comfort, psychosocial and spiritual support, caregiver support, advance care planning, and care coordination. Eligibility criteria include an anticipated life duration of six months or less.

Disease-directed treatment: Treatment intended to treat the underlying disease (disease-modifying), stabilize symptoms, slow progression (life-prolonging), or improve function. Examples may include medications, transfusions, infusions, radiation, therapy, or other interventions depending on the patient's clinical situation and coverage rules.

Goal-concordant care: Health care that is aligned with the patient/family's values, goals, preferences, priorities, and informed choices. Specifically, this care reflects and supports what matters most to the patient/family.

Goals of care: The patient/family's priorities, values, preferences, and desired outcomes that guide treatment and care decisions.

Interdisciplinary team (IDT): The hospice team responsible for assessment, communication, care planning, and review of the patient's plan of care.



Policy

Federal Policy

Pediatric concurrent hospice care is defined in federal policy to address the unique clinical realities of children with serious illness, whose care needs often do not fit a linear transition from curative to hospice-focused treatment. Many children and families require both comfort-focused hospice services and ongoing disease-directed therapies simultaneously. Recognizing this, federal law established a pediatric concurrent care benefit that allows eligible children to receive hospice services without relinquishing access to curative or life-prolonging treatments. This policy is codified in Section 2302 of the Affordable Care Act (ACA), which mandates that individuals under age 21 enrolled in Medicaid or Children's Health Insurance Program (CHIP) may access both hospice care and medically necessary treatment related to the terminal condition. The TRICARE concurrent care provision similarly allows eligible children to receive both disease-directed treatments and hospice services simultaneously, supporting goal-concordant care.

Direct link: Medicaid - https://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/SMD10018.pdf

UNDERSTANDING HOSPICE AND CONCURRENT CARE

Hospice is the benefit available to eligible children with a life-limiting illness. Concurrent care is not a separate benefit; it is how the hospice benefit is paid for and delivered. Section 2302 of the Affordable Care Act (and similar pediatric provisions in TRICARE) did not create a new benefit. Instead, it allows services to be billed and paid for outside the hospice benefit, based on their goal or purpose, even when those services relate to the child's terminal illness.

To qualify for hospice, the child's life expectancy without the services provided under concurrent care should be predicted to be six months or less, if the illness runs its normal course. Children enrolled in hospice may appropriately continue therapies such as medications, infusions, enteral or parenteral nutrition, respiratory support (including oxygen or ventilation), rehabilitation services, or subspecialty care. These interventions may be essential not only for disease management, but also for maintaining comfort, preventing complications, and avoiding unnecessary hospitalizations or emergency department visits. In plain terms, pediatric concurrent care promotes access, continuity of care, and family-centered decision-making. Pediatric concurrent care allows care plans to align with evolving goals, clinical uncertainty, and the child's quality of life.



Importantly, concurrent care should not be interpreted as duplicative or conflicting service delivery. Misunderstandings at the hospital, payer, or provider level often frame concurrent care as "dual enrollment" that creates billing ambiguity. In contrast, federal intent is clear: concurrent care requires coordinated, role-defined service delivery, not duplication. Hospice programs usually retain responsibility for hospice services (including symptom management, nursing support, psychosocial care, and care coordination) while disease-directed treatments may continue under the direction of the treating medical team, provided they meet coverage criteria and align with the established goals of care.

This toolkit emphasizes that operational clarity—particularly in documentation, communication, and billing delineation—is essential to successful implementation. Clear role definition between hospice providers and treating specialists reduces confusion, prevents service overlap, and supports compliance with federal expectations.

Furthermore, pediatric concurrent care is not a program, waiver, temporary exception, workaround, or diminished form of hospice care. It is a legitimate benefit and intentional model of care grounded in the recognition that children often experience prolonged, unpredictable, and non-linear illness trajectories. Families may appropriately choose to pursue treatments that offer symptom relief, preserve function, extend life, or support meaningful experiences, even in the context of incurable, life-limiting illness.

Accordingly, federal policy affirms that hospice eligibility for children does not require the cessation of treatment, but rather the integration of supportive and disease-directed care. This approach honors the complexity of pediatric illness and reinforces a care model centered on flexibility, clinical appropriateness, and family choice.

FEDERAL RESOURCES

Resource	Use in the Toolkit	Suggested Link
ACA / Public Law text	Federal pediatric concurrent care provision and statutory background	https://www.congress.gov/bill/111th-congress/house-bill/3590/text (see Section 2302 - Concurrent Care for Children)
CMS Hospice	Hospice benefit basics, hospice levels of care, billing guidance	https://www.cms.gov/medicare/medicare-fee-for-service-payment/hospice
CMS Manuals	Medicare hospice guidance and manual references	https://www.cms.gov/regulations-and-guidance/guidance/manuals
AHRQ Care Coordination	Care planning, communication, transitions, and team-based care workflows	https://www.ahrq.gov/ncepcr/care/coordination/index.html
Medicaid Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)	Children's coverage, medical necessity, and pediatric benefit information	https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment
TRICARE	TRICARE hospice benefit allows patients <21 years to simultaneously receive medically necessary curative care	https://tricare.mil/CoveredServices/IsItCovered/ConcurrentCare

State Policy

State Medicaid programs, whether fee-for-service or managed care plans, are required to develop clear processes for concurrent care payment and care delivery (e.g., prior authorization, coverage questions, case-by-case review).

- Defined pathways for prior authorization (if applicable) that reflect the concurrent care model
- Transparent guidance on coverage responsibilities between hospice and non-hospice providers
- Mechanisms for timely resolution of coverage questions and disputes
- Structured case-by-case review processes when treatment is necessary to support comfort, function, or care goals

Additionally, states should promote collaborative, care coordination structures that encourage communication between hospice teams, treating specialists, and Medicaid (managed care) plans. Clarifying roles and expectations across providers reduces fragmentation and ensures that care remains coordinated, patient-centered, and compliant with policy.



Recognizing documented variation in state implementation, this toolkit encourages states to move toward greater standardization and transparency. Clear written policies, consistent reviewer training, and stakeholder engagement (including families and pediatric providers) are essential to reducing inequities in access and ensuring that all eligible children can benefit from concurrent care regardless of location.

Key Message: Federal policy establishes the right to concurrent care, while state policy implements that right into the benefit. Section 2302 states that State Medicaid Plans have to offer concurrent care to children, up to the age of 21, even if the State Medicaid Plan does not offer a hospice benefit for those over the age of 21. While the adult hospice benefit can be discontinued for adults (those over 21), the State has to offer hospice benefits to children under Early and Periodic Screening, Diagnostic, and Treatment (EPSDT).

STATE RESOURCES

State-specific resources may include Medicaid policy manuals, state bulletin language, pediatric hospice implementation guides, state plan amendments, and state examples of successful concurrent care programs. Because each state has a different Medicaid policy, hospice rules, and pediatric program infrastructure, hospice administrators and clinicians should acquaint themselves with potentially existing state resources:

- State Medicaid Hospice Policy
- State Plan Amendments
- State Medicaid Pediatric Concurrent Care Guidance
- State Medicaid Prior Authorization Resources
- State Hospice Association
- State Pediatric Palliative Care Network
- Children's Hospital-based Palliative Care Program
- State Children's Medicaid / CHIP Coverage Guide

A repository of state-specific resources is available here: https://pedeolcare.utk.edu/state-concurrent-care/

FEDERAL VS. STATE POLICY COMPARISON FOR PEDIATRIC CONCURRENT CARE

Domain	Federal Policy (ACA / CMS Framework)	State Policy (Medicaid Implementation)
Legal Authority	Established under Section 2302 of the Affordable Care Act; mandates concurrent care for Medicaid/CHIP beneficiaries under age 21	Defines how federal requirements are operationalized through state Medicaid plan amendments, legislation, and guidance
Core Intent	Ensure children can receive hospice services without discontinuing curative or disease-directed treatment	Payment and delivery of the federal concurrent benefit. Translate intent into workable systems that ensure access, clarity, and consistency across providers
Eligibility Standard	Based on hospice eligibility criteria with allowance for ongoing treatment intended to improve or extend life	May require interpretation of eligibility criteria; should avoid restrictive application based on adult hospice models
Role of Treatment	Permits continuation of treatments related to the life-limiting condition with hospice care	Determines which treatments are covered, how they are authorized, and under what conditions they align with concurrent care
Care Model	Emphasizes integrated, coordinated care rather than mutually exclusive services	Defines operational roles and responsibilities between hospice providers, specialists, and managed care entities
Coverage Philosophy	Supports access, continuity, and family choice	Must ensure coverage decisions reflect quality of life, functional support, and family goals, not solely disease trajectory
Medical Necessity	Broad federal allowance recognizing pediatric complexity and non-linear illness trajectories	Requires flexibility in medical necessity determinations, including approval of supportive therapies that maintain comfort and function

Domain	Federal Policy (ACA / CMS Framework)	State Policy (Medicaid Implementation)
Examples of Covered Services	Hospice services plus medically necessary disease-directed therapies	Specifies coverage for services such as medications, infusions, nutrition, respiratory support, and specialty care within state rules
Administrative Structure	Provides high-level guidance; limited operational detail	Establishes prior authorization processes, billing rules, documentation standards, and dispute resolution pathways, if applicable
Billing and Payment	Distinguishes hospice per diem from separately billable treatments	Clarifies billing responsibility and coordination between providers to prevent duplication or denial due to confusion
Provider Guidance	General federal guidance; limited specificity	Responsible for issuing provider manuals, bulletins, and training materials to ensure consistent understanding
Variation Across Jurisdictions	Intended to be uniform entitlement nationwide	Significant variability exists across states in interpretation, access, and implementation practices
Quality and Oversight	Broad oversight through CMS and federal reporting structures	Implements state-level monitoring, reviewer training, and quality assurance processes
Key Implementation Challenge	Misinterpretation as dual or duplicative care	Inconsistent application, restrictive medical necessity decisions, hospice recertification, audits, and lack of clear guidance
Best Practice Priority	Promote integrated pediatric care aligned with family-centered goals	Develop clear policies, streamlined processes, and collaborative care models to reduce barriers and inequities

Pediatric Palliative Care State and Regional Coalitions



Pediatric palliative care state and regional coalitions are collaborative networks that bring together healthcare organizations, children's hospitals, hospice agencies, clinicians, family advocates, policymakers, and community partners to improve access to and quality of pediatric palliative and hospice care. These coalitions work to address gaps in services, promote best practices, advance professional education, and support the development of care models that meet the unique needs of children with serious illnesses and their families.

For hospices, participation in a pediatric palliative care coalition can provide valuable access to clinical expertise, educational resources, mentorship, referral networks, and consultation opportunities. This is particularly important for community hospices that may care for only a small number of pediatric patients each year and may not employ dedicated pediatric specialists. Coalitions often facilitate case consultations, development of pediatric care pathways, symptom management guidance, training opportunities, policy advocacy, and partnerships between hospices and tertiary pediatric medical centers. They may also assist organizations in navigating concurrent care requirements, improving care coordination, and strengthening community resources for children with life-limiting conditions.

Common coalition activities include:

- Regional pediatric palliative care education programs
- Pediatric hospice and concurrent care training
- Hospice and non-hospice case consultation and peer support
- Development of clinical guidelines and toolkits
- Family and caregiver advocacy initiatives
- Quality improvement and research collaborations
- Legislative and regulatory advocacy – such as amending a state's Medicaid state plan (State Plan Amendment or SPA) and/or modifying the use of Medicaid waivers in the state
- Resource sharing among hospices, hospitals, and community agencies

Hospice leaders should be aware of state or regional pediatric palliative care coalitions and consider participation when available. Engagement with coalition partners can enhance organizational readiness, improve access to pediatric expertise, and support the delivery of high-quality care for children receiving hospice or concurrent care services, particularly in regions where pediatric-specific resources are limited. **See the Pediatric Palliative Care Coalition (PPCC) website for additional information:** https://ppcc-pa.org/.

Pediatric Concurrent Care Workflow

The following pediatric case examples* offer an example of an adult community-based hospice workflow in accepting and caring for a child. ***Note:** *All case examples are hypothetical scenarios and do not represent a real patient.*

CASE EXAMPLE: DANTE

Dante is a 6-year-old boy who loves to visit the park in the family wagon and to spend time with his puppy. He has progressive cardiac failure and is admitted for worsening edema, fatigue, shortness of breath, and recurrent pulmonary infections. He is not a candidate for a heart transplant. His cardiology team discusses prognosis with his parents, estimating a three-month life expectancy. The family expresses a strong desire to continue disease-directed cardiac medications in hopes of slowing progression, while also prioritizing comfort and quality of life at home.

Through his state's Medicaid program, he is enrolled in concurrent hospice care, allowing him to receive both hospice services and ongoing heart interventions. A hospice interdisciplinary team (including at minimum a nurse, social worker, chaplain, nutritionist, physical therapist, and physician) begins regular home visits. The hospice child life specialist, psychosocial consultant, and massage therapist are further consulted. They focus on symptom management (dyspnea control with opioids, antiemetics, and fatigue support), psychosocial counseling for the patient and siblings, and establishing trust.

Meanwhile, the patient continues an intravenous infusion to maximize his heart function under his cardiologist's supervision, with periodic outpatient visits. Over the next two months, his symptoms are better controlled, and he is able to attend school part-time and spend meaningful time with family and dog. As his cardiac condition progresses, the care plan gradually shifts toward comfort-only measures. The hospice team continues to work with the family on advance care planning as a longitudinal conversation. The hospice team supports the family through end-of-life decision-making and bereavement.

This case illustrates how pediatric concurrent hospice care enables children and families to pursue life-prolonging treatments while receiving comprehensive end-of-life support. Dante survived with improved life quality longer than his six-month life expectancy due to the provision of concurrent services from hospice and cardiology.

CASE EXAMPLE: MAYA

Maya is an 8-year-old girl who loves art and music. Maya was diagnosed with Batten disease, a progressive neurodegenerative disorder resulting in seizures, loss of mobility, feeding difficulties, and cognitive decline. Following several hospitalizations for aspiration pneumonia and worsening neurologic symptoms, her pediatric neurologist estimates a prognosis of less than six months. Maya lives in a rural community where the only hospice serving the area is an adult hospice that occasionally cares for children but does not employ pediatric-trained physicians or nurses.

After enrolling in hospice through her state's Medicaid concurrent care program, Maya continues to receive follow-up care from her pediatric neurologist and specialized children's hospital team. The hospice physician and nurses collaborate closely with these providers, participate in care conferences, and seek guidance regarding pediatric medication dosing, symptom management, and equipment needs. The hospice team provides regular home visits, caregiver education, symptom assessment, social work support, spiritual care, and 24-hour on-call assistance. The pediatric specialists continue to manage disease-specific recommendations, while the hospice team applies its expertise in serious illness communication, comfort-focused care, family support, and end-of-life planning.

Over time, Maya's symptoms become increasingly complex, requiring adjustments to seizure medications, nutritional support, and comfort measures. Through ongoing consultation with the children's hospital team, the hospice staff successfully manages her symptoms at home and helps the family avoid unwanted hospitalizations. As Maya's condition declines, the hospice team guides conversations about goals of care, prepares the family for end-of-life changes, and provides bereavement support after her death.

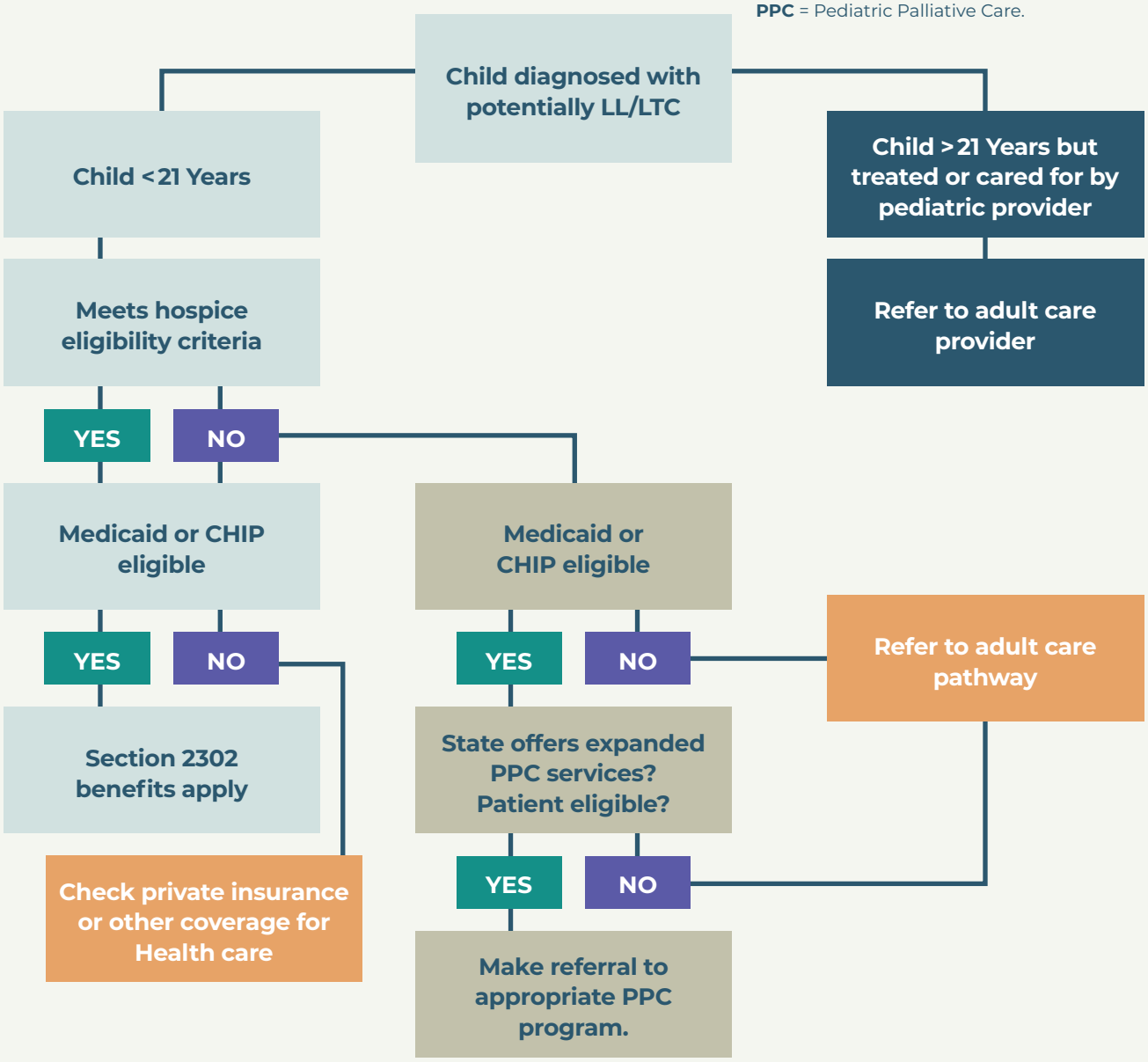
This case demonstrates that formal pediatric specialty training within the hospice is not required for every pediatric hospice enrollment. Community hospices can successfully care for children by leveraging core hospice expertise, maintaining close communication with pediatric specialists, utilizing external consultation when needed, and implementing a coordinated approach that supports both the child and family. The model emphasizes collaboration rather than replacement of specialty pediatric care and reflects how pediatric hospice services are delivered in many communities across the country.

Key workflow steps must be undertaken by an adult community-based hospice when enrolling a pediatric patient and delivering coordinated concurrent care alongside ongoing disease-directed treatment.

Step 1: Referral Intake — Receive referral from family, hospital, clinic, specialist, or community partner. Screen for serious illness, symptom burden, and hospice appropriateness. Flag potential concurrent care needs early. The referral intake includes a key decision process as shown in this figure.

Healthcare Professional and Hospice Decision Process
Section 2302 and Pediatric Palliative Care

CHIP = Children's Health Insurance Program
LL/LTC = Life-Limiting or Life-Threatening Condition
PPC = Pediatric Palliative Care.



Step 2: Benefit and Coverage Review — Confirm payer type. Determine whether the proposed treatment is covered under hospice, separately billed, or not covered. Identify authorization requirements.

Step 3: Clinical Assessment — Complete nursing and interdisciplinary assessment. Review symptoms, functional status, caregiver support, medication regimen, and treatment plan. Determine whether ongoing treatment aligns with the patient's stated goals.

Step 4: Goals-of-Care Conversation — Discuss what the patient hopes treatment will accomplish. Clarify priorities such as symptom relief, time at home, function, or life prolongation. Explain hospice support and concurrent care in plain language.

Step 5: Care Plan Development — Document the concurrent care plan. Assign responsibilities for each treatment and service. Identify symptom triggers, escalation pathways, and communication expectations.

Step 6: Admission and Service Start — Enroll the patient in hospice if eligible. Begin interdisciplinary hospice services. Coordinate with external treating providers.



Step 7: Ongoing Review — Reassess at plan-of-care intervals. Reassess after changes in condition, hospitalization, ED use, or treatment changes. Update goals and care plans as needed.

Step 8: Transition Planning — If treatment is no longer helpful or becomes burdensome, discuss stopping or modifying the treatment. If the patient's goals change, reassess hospice plan intensity and service alignment.

Roles and Responsibilities

Concurrent care requires clear role structure so that patients/families, hospitals, and payers know who is responsible for each aspect of the benefit.

Role	Core Responsibilities	Key Outputs
Hospice Administrator	Policy implementation, compliance, payer alignment, staff education, quality oversight	Agency policy, payer workflow, quality review, staff competency plan
Hospice Medical Director/Physician Designee	Clinical appropriateness, complex case review, symptom burden review, treatment burden review	Eligibility approval, clinical consultation, escalation guidance
Advanced Practice Practitioner	Comprehensive symptom assessment and management, development and implementation of the hospice plan of care, coordination with the team, communication with patients and families regarding goals of care, and support of quality-of-life-focused, goal-concordant care	Comprehensive symptom assessment and management, goals-of-care and advance care planning conversations, medication optimization, coordination, family education, hospice and non-hospice collaboration
RN Case Manager and Nursing Team	Assessment, symptom monitoring, communication, care plan updates, triage support	Care plan, symptom notes, communication log, escalation documentation
Social Worker	Caregiver burden, coping, resource linkage, goals-of-care support, family meetings	Psychosocial assessment, resource plan, family support documentation
Chaplain/Spiritual Care	Meaning-making, anticipatory grief, legacy support, cultural/spiritual responsiveness	Spiritual assessment, support plan, legacy and bereavement support
Aides/Support Staff	Observe/report changes, reinforce care plan, support comfort and routine	Visit notes, change reports, home support observations

Role	Core Responsibilities	Key Outputs
Billing/ Authorization Staff	Coverage verification, prior authorization, payer communication, financial transparency	Coverage determination notes, billing status, payer communication log
Pediatrician	Continuity, family communication, clinical guidance, coordination with hospice and specialists	Ongoing medical leadership, family support, treatment review
Medical Specialist/ Subspecialist	Manage specialty interventions, lines, drains, vents, procedures, advanced therapies	Specialty order ownership, treatment monitoring, consult guidance
Therapy Services	Services may include child life specialists, music therapy, pet therapy, art therapy, occupational/ physical therapy, nutrition, integrative therapy	Care plan with focus on child and family experience and therapeutic interventions

Hospice Clinicians

Pediatric hospice care must account for developmental differences, family-centered decision-making, and the unique emotional and clinical needs of children. Adult-trained hospice clinicians benefit from pediatric specific education and support. There should be role clarity on how each member of the interdisciplinary hospice team (including nurses, social workers, medical directors, chaplains, and aides) supports pediatric patients and their families within a concurrent care model. Team members are expected to collaborate closely to ensure that care is coordinated, compassionate, and aligned with the goals and values of both the child and the family.

To promote safe and effective care delivery, there should be structured after-hours triage guidance tailored to pediatric needs. Clinicians must be prepared to respond to a range of urgent concerns, including pain escalation, respiratory distress, seizure activity, feeding intolerance, infusion pump malfunctions, fever, caregiver distress, and equipment failures. Clear pediatric protocols help ensure timely assessment, appropriate intervention, and escalation when needed. Pediatric guidelines are intended to reduce uncertainty, support clinical decision-making, and promote consistency in care, especially during periods when pediatric specialists may not be immediately available.

Palliative Care Clinicians

Inpatient palliative programs that refer a patient to hospice can support a family's transition to hospice via communication with subspecialists and introductory family meetings. When families are balancing complex specialty treatments with hospice support, palliative clinicians often provide continuity and clinical perspective that complement hospice's home-based role.



Specialists / Subspecialists

Specialists are often the clinicians most directly responsible for lines, drains, tubes, ventilators, infusions, seizure regimens, or other advanced interventions. There should be a clear process for determining ownership of orders for these interventions. This is critical because families often experience distress when they receive conflicting instructions from multiple providers.

Ideally there is a pediatric provider responsibility matrix that clearly identifies who owns ordering and managing specialized medications, following and troubleshooting devices, deciding on ongoing need for procedures, adjusting therapy, and responding to urgent concerns. Hospice teams and specialists should communicate when disease-directed treatment continues. Clear ownership prevents delays, improves safety, and avoids the common problem of everyone assuming someone else was managing it.

Pediatricians / Primary Care Providers

Concurrent care allows the child's pediatrician to remain involved in developmental guidance and immunization schedules while the child also receives hospice support. Pediatricians should view concurrent care as a way to maintain relational continuity.

Best Practices

Care Coordination

An effective pediatric concurrent care model depends on strong care coordination. There should be a structured team for helping children safely transition across care settings (home, acute care, rehabilitation, skilled nursing, hospital, etc.) with hospice support while maintaining communication among all involved providers. A best-practice model includes a shared care plan, a symptom escalation pathway, and regular touch-base meetings between hospice clinicians, pediatric subspecialists, the primary pediatrician, and inpatient palliative care teams.

Interprofessional meetings are valuable means to coordinate care for existing patients with additional meetings when there is clinical change, caregiver distress, or treatment transition. There should be a process for rapid communication so that all providers remain aware of changes in symptom burden, medication adjustments, admissions, discharge plans, and family concerns. This can be as simple as a shared weekly update, a standardized care summary, a group (HIPAA compliant) email chain, or a designated care coordinator who communicates across teams.

Communication Standards

Concurrent care is only effective when communication is deliberate and structured.

MINIMUM COMMUNICATION EXPECTATIONS

- All treating clinicians and healthcare providers are identified.
- Responsibility for each medication or intervention is documented.
- Urgent updates have a defined communication pathway.
- After-hours escalation is clearly explained to the family.
- Care plan changes are communicated promptly.

COMMUNICATION WITH OUTSIDE PROVIDERS

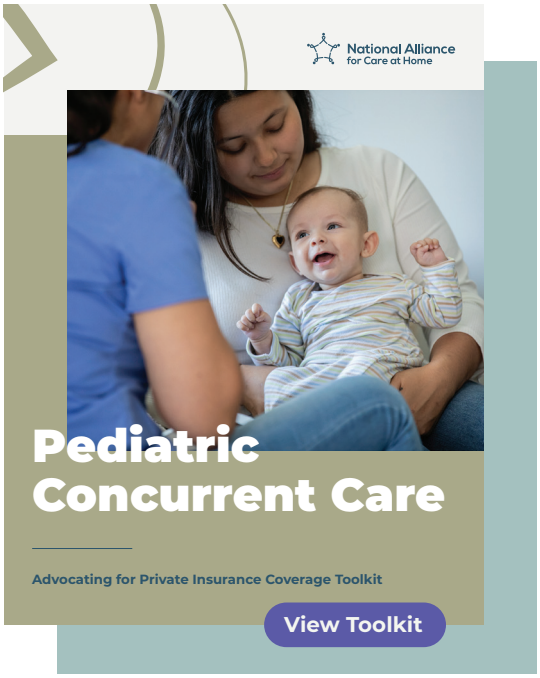
- The patient's and family's goals.
- The current disease-directed treatment plan.
- Expected treatment benefit and burden.
- Symptom management responsibilities.
- Red flags for reassessment.
- Any changes in status.

RECOMMENDED COMMUNICATION TOOLS

- Shared care summaries.
- Medication reconciliation forms.
- Care conference notes.
- Treatment responsibility grids.
- Escalation plans.
- Respite plans.
- Provider communication templates.
- HIPAA compliant email or texting.

Payment

Concurrent care can reduce avoidable hospital admissions, improve symptom management in the home setting, and facilitate smoother and more efficient care transitions. By highlighting these outcomes, hospice programs can more effectively engage private insurers and Medicaid agencies in discussions about coverage and reimbursement. Concurrent care is not only clinically appropriate, but also a cost-conscious approach that aligns with quality care objectives for children with medical complexity. There should be clear distinctions between hospice-covered services and those considered concurrent care/ non-hospice carve-outs (see the case example tables).



Commercial insurers often still require a family to choose between hospice care and disease-directed therapies. In those situations, it can be particularly important to involve the hospice medical director in discussions with the insurance company's medical director, or another designated clinical equivalent, through a peer-to-peer discussion to explore case-by-case scenarios.

Billing and Compliance

Concurrent care must be implemented in compliance with hospice Conditions of Participation, state and federal law, payer-specific concurrent care rules, authorization requirements, and organizational billing policy. One condition of participation that is not required is the forgoing of life prolonging or curative treatment. The child must still meet the 6-month prognostic timeline based upon the normal course of illness like the adult hospice standard with consideration for renewal of hospice services in the clinical context of pediatric prognostic uncertainty. The hospice bills for hospice-covered services included in the plan of care, while non-hospice physicians, hospitals, therapists, and other providers may separately bill Medicaid or the managed care payer for approved disease-directed treatments. Careful documentation and coordination are essential to prevent duplicate billing and claim denials.

Administrative Billing Tip: A good point to consider when making a determination for coverage of a medication, service, treatment under the hospice benefit is to consider the goal and purpose as well as who is prescribing, ordering, and supplying it. A practical approach is for hospices to order what they are covering and for the non-hospice provider to continue to order what they are billing to Medicaid or the revenue source. Hospices should bill only for services included in the hospice plan of care while non-hospice physicians, hospitals, therapists, and other providers submit claims independently for disease-directed treatments. Proper coordination of benefits, documentation, and claim review are critical to avoid denials, audits, and duplicate billing. Hospices should follow state Medicaid policy, managed care contract requirements, and CMS guidance regarding claim submission, coordination of benefits, and covered services. Pediatric hospice care teams must be prepared to explain the premise of concurrent care to insurers – many of whom are not familiar with the benefit.

CASE EXAMPLE: ETHAN

Ethan is a 2-year-old little boy who loves cars and dinosaurs. He was diagnosed with a progressive neurodegenerative disorder with a terminal prognosis. His parents elected the Medicaid pediatric hospice concurrent care benefit, allowing Ethan to receive hospice services while continuing disease-directed treatments. The hospice provides routine home care services such as nursing visits, symptom management, caregiver education, social work support, and medical equipment related to comfort care. At the same time, Ethan continues neurologic consultations, seizure management with escalating anticonvulsant therapy, therapy services, and medically necessary hospitalizations. Under concurrent care rules, hospice enrollment does not require families to discontinue curative or disease-directed treatments.

Case Billing Takeaway - From a billing perspective, the hospice bills for services included in the hospice plan of care, typically under the hospice per diem payment methodology, while non-hospice providers bill Medicaid or the managed care organization separately for approved disease-directed services. Clear documentation and communication between providers is essential to prevent duplicate billing and ensure proper reimbursement. The hospice maintains records demonstrating which services are covered under the hospice benefit and which are billed separately under the concurrent care provision. Anticonvulsants and specialty medications ordered by the non-hospice physician are billed separately from those covered under the hospice benefit.

Table. Case Example (Ethan) Billing Approach

Service Provided	Provider	Billing Entity	Billing Consideration
Routine nursing visit, symptom assessment, caregiver education	Hospice RN	Hospice Benefit	Included in hospice per diem; billed by hospice.
Social work, chaplain, bereavement support	Hospice	Hospice Benefit	Covered under hospice plan of care.
Hospital bed, suction machine	Hospice	Hospice Benefit	Equipment related to comfort and symptom management.
Pediatric neurology office visit	Neurologist	Medicaid/ Managed Care Plan	Disease-directed treatment; billed separately from hospice.
Seizure medication management	Neurologist/ Physician	Medicaid/ Managed Care Plan	Concurrent care allows continued treatment billed separate from hospice benefit.
Physical, occupational, or speech therapy	Therapy Provider	Medicaid/ Managed Care Plan	Billable separately when authorized by payer and ordered by subspecialist, not hospice.
Inpatient hospitalization for acute seizure management	Hospital	Medicaid/ Managed Care Plan	Hospital bills separately from the hospice benefit; hospice coordinates care; RN may make visits in hospital for continuity.
Specialized adaptive wheelchair	DME Supplier	Medicaid/ Managed Care Plan	Billable separately when authorized by payer and ordered by subspecialist, not hospice.

CASE EXAMPLE: DAMARUS

Damarus is a 7-year-old child with severe hypoxic-ischemic encephalopathy (HIE) resulting from a perinatal brain injury. Damarus has profound neurological impairment, is ventilator-dependent via tracheostomy, receives nutrition through a gastrostomy tube, and experiences recurrent respiratory infections and seizures. Her condition meets hospice eligibility criteria due to progressive complications and a limited life expectancy.

Damarus' family elects the Medicaid pediatric hospice concurrent care benefit, allowing her to receive hospice services while continuing life-sustaining and disease-directed therapies. The hospice team provides routine nursing visits, symptom management, psychosocial support, spiritual care, caregiver education, and comfort-focused medications and equipment. At the same time, Damarus continues pulmonology, neurology, and complex care clinic follow-up, ventilator management, private-duty shift nursing, enteral nutrition support, and hospitalizations when medically necessary. Under concurrent care provisions, enrollment in hospice does not require discontinuation of ventilator support or other ongoing treatments intended to maintain health and function.

Case Billing Takeaway - The primary billing challenge is ensuring that hospice-covered services and ongoing disease-directed services are clearly distinguished and appropriately documented. From a billing perspective, concurrent care for children with HIE and ventilator dependence requires careful delineation between hospice-covered services and disease-modifying or life-sustaining treatments. The hospice bills for services that are included in the hospice plan of care and covered under the hospice per diem, while non-hospice providers bill Medicaid or the managed care organization separately for authorized ventilator management, specialty care, private-duty nursing, and other ongoing treatments. Clear documentation is essential because durable medical equipment, supplies, and nursing services may have different billing pathways depending on whether they are related primarily to comfort care or ongoing disease management. Coordination among hospice, specialty providers, home care agencies, and payers helps prevent duplicate billing and ensures appropriate reimbursement.

Table. Case Example (Damarus) Billing Approach

Service Provided	Provider	Billing Entity	Billing Consideration
Routine hospice nursing visits, symptom assessment, caregiver education	Hospice RN	Hospice Benefit	Included in hospice per diem; billed by hospice
Social work, chaplain, bereavement support	Hospice	Hospice Benefit	Covered under hospice plan of care
Comfort medications for symptom management (e.g., dyspnea, secretions, pain)	Hospice	Hospice Benefit	Included in hospice benefit when related to comfort care
Pulmonology clinic visits and ventilator management	Pediatric Pulmonologist	Medicaid/Managed Care Plan	Life-sustaining treatment continues under concurrent care
Neurology visits and seizure management	Neurologist	Medicaid/Managed Care Plan	Disease-directed treatment billed separately
Home ventilator and ventilator supplies	DME Supplier	Medicaid/Managed Care Plan	Often billed separately from hospice benefit due to ongoing life-sustaining function; payer-specific rules apply
Enteral formula and feeding supplies	DME Supplier/ Home Infusion Provider	Medicaid/Managed Care Plan	Typically related to ongoing medical management
Private-duty (shift) nursing services	Home Health Agency	Medicaid/Managed Care Plan	May continue under concurrent care if approved by payer
Inpatient hospitalization for pneumonia or respiratory decompensation	Hospital	Medicaid/Managed Care Plan	Hospital bills directly; hospice coordinates care
Complex care or multidisciplinary specialty clinic visits	Specialty Care Team	Medicaid/Managed Care Plan	Continued disease management under concurrent care provisions

CASE EXAMPLE: SOPHIA

Sophia is a 12-year-old who loves music and volleyball. Sophia has relapsed, refractory Acute Myeloid Leukemia (AML). Her disease has not responded to initial lines of treatment and she is not a candidate for transplant or CAR-T therapy. Her oncology team has certified a terminal prognosis, and her family elects the Medicaid pediatric hospice concurrent care benefit. While enrolled in hospice, Sophia continues to receive disease-directed treatments intended to control symptoms and potentially prolong life. She receives continued chemotherapy aimed at a goal of cure and frequent platelet and blood transfusions. Concurrent care allows Sophia and her family to benefit from hospice services, including pain and symptom management, nursing visits, psychosocial support, chaplain services, and bereavement counseling, without forfeiting ongoing cancer-directed treatment.

From a billing perspective, the hospice bills for services included in the hospice plan of care and related to symptom management and end-of-life support, while oncology providers, infusion centers, radiation oncology departments, hospitals, and blood banks bill Medicaid or the managed care organization separately for approved disease-directed treatments. Careful coordination is essential because chemotherapy and radiation therapy for the purpose of treatment (rather than palliation) are typically not included in the hospice per diem under pediatric concurrent care and may continue to be reimbursed through the child's medical benefit. Although, palliative radiation for the purpose of pain would likely be covered through the hospice benefit. Documentation should clearly identify which services are hospice-covered and which are separately reimbursable to avoid duplicate billing, coverage disputes, or claim denials.

Table. Case Example (Sophia) Billing Approach

Service Provided	Provider	Billing Entity	Billing Consideration
Routine hospice nursing visits, pain and symptom management	Hospice RN	Hospice Benefit	Included in hospice per diem; billed by hospice
Social work, chaplain, and bereavement services	Hospice	Hospice Benefit	Covered hospice services
Medications related to symptom control (pain, nausea, anxiety)	Hospice	Hospice Benefit	Included under hospice plan of care

Service Provided	Provider	Billing Entity	Billing Consideration
Radiation therapy for leukemia-treatment	Radiation Oncology Provider	Medicaid/ Managed Care Plan	Disease-directed treatment allowed under concurrent care
Chemotherapy administration and monitoring	Oncology Provider/Infusion Center	Medicaid/ Managed Care Plan	Separately billable cancer treatment
Red blood cell transfusions	Hospital or Infusion Center	Medicaid/ Managed Care Plan	Billed separately as medically necessary treatment
Platelet transfusions	Hospital or Infusion Center	Medicaid/ Managed Care Plan	Billed separately as medically necessary treatment
Oncology clinic visits	Pediatric Oncologist	Medicaid/ Managed Care Plan	Professional services billed outside hospice benefit
Inpatient hospitalization for complications of AML	Hospital	Medicaid/ Managed Care Plan	Hospital bills payer directly; hospice coordinates care
Medical equipment related to comfort and symptom management	Hospice	Hospice Benefit	Covered under hospice services when included in plan of care

Case Billing Takeaway - For pediatric patients with relapsed, refractory AML, hospices should bill only for hospice-covered services included in the plan of care, while oncology-related treatments such as chemotherapy and radiation therapy to treat the disease itself and specialist visits are generally billed separately by the treating providers. Ongoing communication between the hospice, oncology team, hospital, and payer is critical to ensure accurate reimbursement and compliance with concurrent care requirements.

BILLING PRINCIPLES

- Verify coverage before or at admission when possible.
- Identify which services are hospice-covered and which are non-hospice and separately billed.
- Document payer-related decisions clearly.
- Educate the patient/family about possible financial responsibility.

AUDITS

Because pediatric concurrent care involves the coordination of hospice services with ongoing disease-directed treatments, hospices should anticipate heightened scrutiny related to documentation, billing accuracy, and care coordination. Internal audits should periodically review patient records to ensure that hospice-covered services are clearly distinguished from non-hospice services billed separately by non-hospice providers. Documentation should demonstrate eligibility for hospice, election of concurrent care when applicable, hospice and non-hospice care planning, coordination with other non-hospice providers, and medical necessity for hospice and non-hospice services provided.

Hospice programs should establish processes to identify, track, and complete payer-specific concurrent care coordination and documentation requirements as part of routine operations and audit readiness activities. In addition to meeting clinical, regulatory, and billing standards, hospices must ensure compliance with payer-mandated care management activities that may be necessary for continued authorization and reimbursement of hospice services. Requirements vary by payer. For example, some state programs require completion and submission of a Concurrent Care Program Coordination Form on a monthly basis to document ongoing eligibility and care coordination activities. State Medicaid programs, managed care organizations, and commercial insurers may also require recurring authorizations, case management reviews, updated care plans, or documentation demonstrating communication among hospice providers, specialists, and primary care teams.

Organizations should develop a standardized process to monitor payer-specific requirements throughout the patient's enrollment. This process should include identifying the patient's payer at admission, documenting all required forms and authorization timelines, assigning responsibility for completion and submission of recurring documentation, verifying that authorizations remain active, and maintaining records of care coordination activities. Incorporating payer-specific requirements into hospice workflows and quality assurance reviews can help prevent claim denials, reimbursement delays, and interruptions in service while supporting effective coordination among all providers involved in the child's care. A payer requirements matrix or tracking tool that lists payer-specific forms, submission frequencies, responsible staff, and due dates may be particularly useful for compliance monitoring and audit preparedness.



Audit reviews should also evaluate claims for potential duplicate billing, appropriate allocation of medication costs, durable medical equipment, physician certification and recertification requirements, and evidence of communication among providers involved in the child's care. Findings should

be incorporated into the organization's quality assessment and performance improvement (QAPI) activities, with corrective action plans implemented when needed. Routine auditing supports regulatory compliance, promotes accurate reimbursement, and helps ensure that children and families receive the full benefits of both hospice and disease-directed care under the concurrent care model.

Table. Pediatric Concurrent Care Audit Checklist

Audit Focus Area	Key Review Elements
Eligibility Documentation	Hospice election, physician certification, patient under age 21, payer eligibility
Care Coordination	Evidence of communication with specialists, hospitals, and primary providers
Plan of Care	Documentation of hospice goals and concurrent disease-directed treatments
Billing Compliance	Clear distinction between hospice-covered and non-hospice services
Duplicate Billing Prevention	Verification that hospice and other providers are not billing for the same service
Medication Review	Appropriate assignment of medications to hospice versus disease-directed treatment. A general consideration is that if the hospice would have provided the medication/treatment absent the concurrent care provision (supportive care or symptom management), then the medication remains the responsibility of the hospice to provide and pay for it.
DME Review	Documentation supporting whether equipment is hospice-covered or separately billed
IDG Documentation	Evidence of interdisciplinary hospice team review and ongoing care planning
QAPI Monitoring	Tracking of pediatric concurrent care outcomes, denials, and compliance trends

COMPLIANCE SAFEGUARDS

- A payer reference sheet.
- An authorization workflow.
- Chart audits for concurrent care cases.
- A review pathway for unusual, high-cost, or high-risk services.
- Close collaboration with specialty providers.

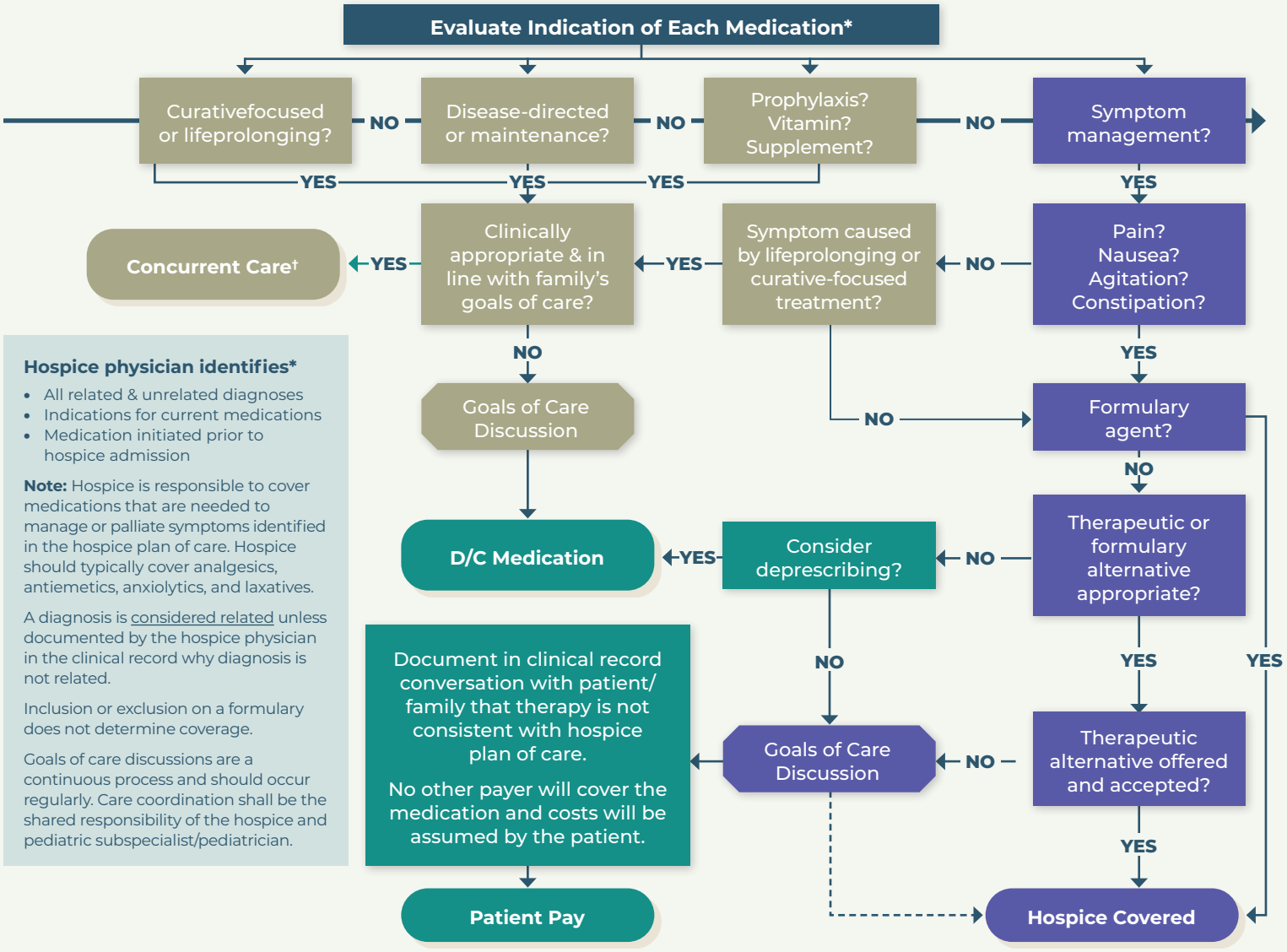
Special Clinical Situations

MEDICATIONS

Medications should be reviewed at time of hospice enrollment. The creation of a medication coverage chart can be a helpful approach to show who prescribes, who authorizes, who dispenses, and who pays.

Determination of Hospice Medication Coverage in CHILDREN

Always take into consideration patient-specific factors when making these decisions.



Hospice physician identifies*

- All related & unrelated diagnoses
- Indications for current medications
- Medication initiated prior to hospice admission

Note: Hospice is responsible to cover medications that are needed to manage or palliate symptoms identified in the hospice plan of care. Hospice should typically cover analgesics, antiemetics, anxiolytics, and laxatives.

A diagnosis is considered related unless documented by the hospice physician in the clinical record why diagnosis is not related.

Inclusion or exclusion on a formulary does not determine coverage.

Goals of care discussions are a continuous process and should occur regularly. Care coordination shall be the shared responsibility of the hospice and pediatric subspecialist/pediatrician.

Section 2302 of the Affordable Care Act, titled Concurrent Care for Children†

Seriously ill children who are <21 years of age and have a 6-month prognosis are entitled to receive hospice benefit in addition to all necessary disease-directed therapies with the goal of providing access to comprehensive care to live as long and as well as possible. Medicaid shall continue to be responsible to pay for disease-directed therapies in addition to the hospice benefit providing comfort-directed therapies.

Medicaid shall reimburse appropriate Medicaid-enrolled providers directly through the usual and customary Medicaid billing procedures. A hospice provider shall not be responsible for life-prolonging treatment, medications prescribed by non-hospice providers/subspecialists, or any aspect of the patient's medical care plan that is focused on treating, modifying, or curing a medical condition (even if that medical condition is also the hospice-qualifying diagnosis). Life-prolonging services and hospice services shall be billed and reimbursed separately, meaning the child can receive services concurrently.

EQUIPMENT

Durable medical equipment should be paid and authorized by the provider that orders it for the child. Custom Durable Medical Equipment (DME) such as specialized wheelchairs, adaptive devices, suction machines, respiratory support equipment, and feeding equipment should be continued for children enrolling in hospice. When DME has been prescribed and supplied by existing non-hospice specialty clinicians (e.g., pulmonary, gastroenterology, rehabilitation services, etc.) before hospice enrollment, those providers generally remain responsible for ongoing orders and modifications, and billing typically remains unchanged. Hospice care teams should document continued medical necessity and engage with existing vendors to ensure continued delivery after hospice enrollment. If equipment remains medically necessary for the child's underlying condition, responsibility and billing for that item may continue through the existing provider and payer arrangement. Families should never experience a loss or delay of essential equipment because of confusion regarding coverage or concurrent care.

HOSPITALIZATION

Hospitalization coverage depends on the purpose of the stay and location of the hospitalization. Children receiving concurrent care should not be automatically discharged from hospice when admitted to the hospital. Concurrent care is not just a home-based concept; it can also be used to improve transitions during inpatient symptom crises. Hospice care team should proactively determine a plan for where and when General Inpatient Care (GIP) will be provided and how and when to coordinate both admission and discharge home. Depending on hospital arrangements and agreements, ongoing visits by the hospice nurse may provide continuity and allow concurrent care to be provided during hospitalization, maintaining compliance with hospice status. Treatment-directed hospitalizations may be billed through the non-hospice specialist/subspecialist responsible for the patient's care during hospitalization. Familiarity with the Certificate of Need (CON) is important for determining approaches to hospitalization.



SHIFT NURSING

Concurrent care often requires multiple sources of nursing care. Coordination between hospice and shift nursing is essential. This helps programs avoid conflict when multiple nursing service lines might overlap. This is especially important for children with medical complexity who may have tracheostomies, ventilators, and/or significant technology dependence.

RESPITE

Respite resources for pediatric families should be identified and include local or state options for respite care, sibling support, and emergency backup. Families caring for children who are medically fragile often need more than symptom management; they need practical support that helps them keep caring safely at home.

Staff Competency and Hospice Quality

All staff involved in providing hospice care to pediatric patients and their families should receive specific pediatric orientation and training on hospice philosophy, concurrent care principles, end of life care, shared decision-making, communication skills, care coordination, documentation requirements, payer basics, symptom escalation, and ethical issues related to treatment burden and transitions.

Hospice organizations should establish clear pathways to pediatric competency that may include formal education and continuing professional development, mentorship from experienced pediatric clinicians, case consultation, participation in pediatric-focused learning collaboratives, and partnerships with tertiary pediatric hospitals, specialty palliative care programs, and other pediatric centers of excellence.

Ideally, members of the hospice team possess pediatric training, experience, and, when available, relevant pediatric certifications. Ongoing competency assessment and access to pediatric clinical expertise can help ensure the delivery of high-quality care for children and families receiving concurrent care.

COMPETENCY EXPECTATIONS

- Explain concurrent care in plain language.
- Identify appropriate referral situations.
- Differentiate hospice-covered and non-covered services.
- Document clearly.
- Escalate concerns appropriately.

QUALITY IMPROVEMENT AND PROCESS MONITORING

Suggested Metrics

- Number of pediatric referrals and pediatric admissions.
- Referral-to-admission time.
- Median and mean length of stay for pediatric hospice patients
  - Some hospices track and compare the LOS of pediatric hospice patients that have access to the concurrent care for children provision vs those that do not have access to the concurrent care for children provision.
- Percentage of cases with completed care plans.
- Documentation completeness.
- Number of care conferences held.
- Symptom burden outcomes.
- Caregiver satisfaction.
- Hospitalization and ED use.
- Payer denials or authorization delays.
- Number of cases requiring medical director review.

Ongoing System Improvement Reflections

- Was concurrent care clearly identified?
- Was informed consent documented?
- Were goals of care documented?
- Were responsible providers clearly identified?
- Was communication with outside providers documented?
- Was payer authorization verified?
- Was the treatment burden reviewed over time?

Case-Specific Process Reflections

- Were goals clearly documented and revisited?
- Were communication and role responsibilities clear?
- Did the plan remain aligned with patient goals?
- Were any treatment burdens identified early and addressed appropriately?
- Did staff and teammates feel unified and supported in caring for the child?

Quick-Start Implementation Checklist for Hospices

Note: The templates in this toolkit are provided for informational purposes only and are intended as a guide. Please review applicable federal and state regulations and requirements to ensure compliance.

A hospice program does not need to build the entire toolkit at once. The fastest implementation strategy is to begin with four elements: a clear policy statement, a referral and intake pathway, a shared care plan template, and a billing / coverage workflow. Once those are in place, the program can add after-hours triage tools, provider communication templates, and family-facing education materials. Programs should also assign one person or ideally a team of hospice colleagues to own concurrent care implementation so that the process does not become fragmented across departments.

Task	Responsible Party	Due	Completed
Identify an internal concurrent care lead and develop a clear policy statement	Administrator		☐
Review state Medicaid and payer policies	Billing / Compliance		☐
Create a pediatric concurrent care referral pathway	Clinical leadership		☐
Develop a provider responsibility matrix	Medical director / IDT		☐
Build a shared care plan template	RN / Quality team		☐
Create an after-hours pediatric triage guide	Clinical leadership		☐
Train hospice staff on pediatric hospice and the concurrent care provision basics	Administrator / Education lead		☐
Create billing guidance for meds and DME	Billing / Authorization		☐
Establish monthly touch-base meetings with palliative and specialty teams	Clinical leadership		☐

Task	Responsible Party	Due	Completed
Develop family-facing explanation materials	Social work / Education team		☐
Create templates for Certification of Terminal Illness (CTI), ER action plan, contact list, and billing agreement	Quality / Clinical documentation		☐
Identify local respite, child life, music therapy, and bereavement resources	Social work / Community liaison		☐
Implement quality monitoring metrics	Quality Team		☐

Practical Hospice Templates

This toolkit includes practical, editable templates that hospice staff, hospitals, and families can modify for use.

Hospice Care Screening Checklist

Patient Name: _____

Date: _____

Completed By: _____

CLINICAL SCREENING

- ☐ Serious or life-limiting illness
- ☐ Hospice-level needs identified
- ☐ Ongoing treatment under consideration
- ☐ Patient/family open to hospice support
- ☐ Prognosis of 6 months or less* should the disease run its natural course *(*note that some states allow for a 1 year prognosis for access to the hospice benefit for children).*

GOALS AND READINESS

- ☐ Goals of care discussed
- ☐ Patient/family understands hospice care
- ☐ Patient/family wants hospice care in addition to selected treatment
- ☐ Family/caregiver understanding assessed

OPERATIONAL SCREENING

- ☐ Payer verified
- ☐ Authorization needed? ○ **Yes** ○ **No**
- ☐ Treating clinicians identified
- ☐ Communication pathway established
- ☐ Medical director review needed? ○ **Yes** ○ **No**

DISPOSITION

- ☐ Determine that the child has access to concurrent care under the hospice benefit
- ☐ Admit to hospice
- ☐ Hold for further review
- ☐ Refer to palliative care / other service
- ☐ Not appropriate at this time

Pediatric Certification of Terminal Illness (CTI) Template

This form provides one example of a Certification of Terminal Illness (CTI). A recommended best practice is to build upon the hospice's existing adult CTI to promote consistency, streamline workflows, and maintain staff familiarity. The adult CTI may then be adapted for pediatric populations, including consideration of developmental status, family dynamics, and sibling needs, provided the resulting CTI remains consistent with applicable federal, state, and local regulatory requirements.

PEDIATRIC CERTIFICATION OF TERMINAL ILLNESS

Child's Name: _____

DOB: _____

Medical Record #: _____

Primary Diagnosis: _____

Secondary Diagnoses: _____

Date of Certification: _____

CERTIFICATION STATEMENT

Life expectancy without the services provided under concurrent care is six months or less, if the illness runs its normal course. This child's condition is appropriate for hospice services. The child's clinical course includes functional decline, escalating symptom burden, increased dependence on medical technology/support, or increasing caregiver burden. The child may continue selected disease-directed treatment under a concurrent care plan if clinically appropriate and allowable under payer policy.

FUNCTIONAL / CLINICAL EVIDENCE SUPPORTING ELIGIBILITY

- _____
- _____
- _____
- _____

PERFORMANCE STATUS (IF APPLICABLE)

Lansky Play-Performance Score: _____

PHYSICIAN ATTESTATION

I certify that this child meets hospice eligibility criteria and that concurrent care is clinically appropriate based on current goals of care and care plan.

Physician Name: _____

Physician Signature: _____

Date: _____

Hospice Care Plan Template

This form provides one example of a care planning template. However, hospices may choose to develop or adapt their own template to align with existing electronic medical record workflows and documentation processes. Regardless of format, hospices should ensure that care plans meet all applicable regulatory requirements and the standards of their accrediting organization.

Patient Name: _____

DOB: _____

Date Initiated: _____

1. PATIENT GOALS

- _____
- _____
- _____
- _____
- _____

2. HOSPICE SERVICES TO BE PROVIDED

- ☐ Nursing
- ☐ Social work
- ☐ Spiritual care
- ☐ Aide services
- ☐ Child Life Specialist
- ☐ Volunteer support
- ☐ Bereavement planning
- ☐ Other: _____

3. CONTINUING TREATMENTS

Treatment: _____

_____

Purpose: _____

_____

Responsible Clinician: _____

_____

Expected Benefit: _____

_____

Expected Burden/Risk: _____

_____

4. SYMPTOM MANAGEMENT PLAN

Primary symptoms: _____

_____

Current interventions: _____

_____

Medication responsibilities: _____

_____

Escalation triggers: _____

_____

5. COMMUNICATION PLAN

Hospice contact: _____

External provider contact: _____

Family contact: _____

After-hours instructions: _____

_____

_____

_____

6. REASSESSMENT PLAN

Next review date: _____

Review triggers: _____

_____

_____

Planned hospice and non-hospice review date: _____

Hospice Care Interdisciplinary Huddle - Topical Template

This form provides one example of an interdisciplinary, topic-based approach to Hospice Interdisciplinary Group (IDG) meetings. IDG discussions typically focus on the current plan of care, significant events and interventions since the previous meeting, anticipated needs over the coming two weeks, whether the plan of care continues to meet patient and family needs, and ongoing hospice eligibility. For pediatric patients, hospices may also incorporate child-specific considerations, such as developmental status and milestones, siblings, educational needs, and family dynamics. Hospices may adapt this framework to align with their workflow, documentation practices, and regulatory requirements.

Patient: _____

Review Date: _____

- Current goals reviewed
- Benefit of continuing treatment reviewed
- Treatment burden or side effects reviewed
- Symptom burden reviewed
- Family/caregiver understanding assessed
- Payer/authorization status reviewed
- Communication with external providers documented
- Plan remains appropriate or updated

Family Care Conference - Topical Template

- Patient goals and values
- Current symptom burden
- Review of ongoing treatment
- Benefit vs. burden discussion
- Family concerns and questions
- Communication and responsibilities
- Plan for reassessment

Coordination Considerations Template

Hospice Care Patient Name: _____

DOB: _____

Date: _____

Hospice services, disease-directed treatment, medications, equipment, and specialty services may be billed differently depending on payer policy, prior authorization, and the care plan.

SERVICES COVERED BY HOSPICE MAY INCLUDE

- Hospice nursing visits:
- Hospice social work:
- Hospice spiritual care:
- Hospice aide services:
- Certain medications and supplies as determined by the hospice benefit:

NON-HOSPICE ORDERED SERVICES MAY INCLUDE

- Specialty clinic services:
- Disease-directed treatment visits:
- Certain medications or infusions:
- Durable medical equipment not covered by hospice:
- Anticipated hospital or outpatient procedures:

CARE COORDINATION

Coverage decisions that may require review or prior authorization include:

- The points of contact for submitting prior authorizations include:

Coverage Determination Guide Template

STEP 1: Identify the service being requested and determine availability (access to concurrent care).

Service: _____

STEP 2: Determine whether the service is:

- Hospice-covered
- Separately billed
- Not covered

Whether a service is related or unrelated to the terminal illness also factors into the determination decision.

STEP 3: Determine whether prior authorization is needed.

Authorization Required: ○ **Yes** ○ **No**

STEP 4: Identify who is responsible for:

Ordering: _____

Authorizing: _____

Documenting medical necessity: _____

Billing / submission: _____

STEP 5: If coverage is unclear, escalate to:

- Hospice administrator
- Billing lead
- Payer contact
- Medical director/ or designee

STEP 6: Document the final decision and communicate it to the family and care team. Family should be made aware of their right to clarify/dispute coverage determinations made by the hospice agency.

Referring Clinician Frequently Asked Questions (FAQs)

What is pediatric concurrent care?

Section 2302 of the Affordable Care Act (ACA) amended Sections 1905(o)(1) and 2110(a)(23) of the Social Security Act to allow eligible children to receive hospice services while continuing disease-directed, curative, or life-prolonging treatments. Under this provision, a child's voluntary election of hospice care does not require the child or family to forgo coverage for medically necessary treatments related to the child's underlying condition. Often referred to as concurrent care, this provision took effect on March 23, 2010, and applies to children enrolled in Medicaid or the Children's Health Insurance Program (CHIP). Rather than creating a new hospice benefit, Section 2302 established a coverage and payment framework that allows hospice services and disease-directed treatments to be provided simultaneously for eligible children.

Are palliative care, hospice care, and concurrent care all the same thing?

No. Palliative care is a specialized approach to care focused on improving quality of life through symptom management, communication, decision support, and psychosocial support. It can be provided at any age, at any stage of illness, and alongside curative treatment. Hospice is the benefit and model of care that provides hospice and non-hospice support focused on comfort, quality of life, symptom management, and family support for individuals with a terminal illness (prognosis six months or less). Concurrent care is a coverage and payment provision that allows eligible children to receive hospice services while continuing disease-directed, curative, or life-prolonging treatments. Concurrent care is not a separate hospice benefit. Rather, it is a provision that enables eligible children to access the hospice benefit without having to forgo ongoing treatment related to their underlying condition.

Term	Description
Palliative care	A clinical service and philosophy of care focused on quality of life and symptom management at any stage of illness.
Hospice	A benefit and model of interdisciplinary care for patients with a terminal illness (typically a 6 month or less life prognosis).
Concurrent care	A provision that allows eligible children to receive hospice and disease-directed treatment simultaneously.

How can I learn more about concurrent care?

Implementation of concurrent care requires state Medicaid programs to allow eligible children to receive hospice services while continuing disease-directed treatments. Although states may differ in their operational policies, billing processes, and provider guidance, all states must comply with the

federal Concurrent Care for Children requirement. For the most current information, providers should consult their state Medicaid agency, Children's Health Insurance Program (CHIP), or Department of Health website. Resources from pediatric palliative care organizations and state hospice associations may also provide practical guidance on implementation, billing, and care coordination. A useful resource for reviewing and comparing state-specific concurrent care policies is the University of Tennessee Knoxville Pediatric End-of-Life Care Research Program's State Concurrent Care website, which provides state-by-state information and links to relevant regulations and guidance.

Why does concurrent care matter?

Children with serious illness and life-limiting conditions often benefit from ongoing disease-directed treatment even as they develop increasing symptom burden, caregiver burden, and hospice-level care needs. When available, concurrent care allows teams to support comfort, coordination, and home-based care without disrupting those disease-modifying interventions. Concurrent care:

- Enables safe discharge home and helps children remain at home when possible
- Improves symptom management
- Supports family psychosocial needs
- Preserves continuity with specialty teams

When should I consider concurrent care?

Consider concurrent care when:

- the child meets hospice eligibility criteria,
- the family wants support from hospice but is not ready to stop all treatment,
- and payer rules permit concurrent coverage.

Who does what when a child is enrolled on concurrent care?

- Hospice provides end-of-life care, manages symptoms, psychosocial care, spiritual care, caregiver support, and coordination.
- Specialists continue to manage specialty interventions such as devices, lines, and/or treatment protocols if those remain active.
- Pediatricians help with continuity, family communication, and overall guidance.

What are key actions?

- Clarify current goals of care
- Identify which treatment(s) continue and why
- Define who owns each order
- Confirm coverage and authorization
- Document the concurrent care plan
- Update the plan after any major clinical change

What language could I use to introduce the concept of concurrent care to a family?

- "Hospice can support comfort and caregiving while some treatments continue."
- "I can review how the concurrent care benefit may allow for additional support for your child and family. We can review what hospice will do, what we cover, and what can continue with your existing providers."

Sample Communication with Families

Plain-Language Explanation

"Concurrent care is a benefit that lets many children get hospice services while they also continue receiving treatments meant to cure the illness or help them live longer. Hospice helps with comfort, symptoms, caregiving support, and care coordination. The team will also work with other clinicians to make sure treatment still fits your goals."

Key Messages for Families

- Hospice is focused on comfort, quality of life, and support.
- Hospice will coordinate with other clinicians whenever possible.
- We will work with you, your child, and your other health care providers to be sure we are all working to meet your goals of care the best we can.

Suggested Language

- What matters most to you right now?
- What are you hoping hospice will offer/support?
- What treatments are most helping your child?
- We can revisit this plan any time your goals change.



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