

# State Initiatives

## *in* End-of-Life Care

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Focus: Pediatric Issues — Part I

### Paying for Care Needed by Children with Life-Limiting Conditions



Susie Fitzhugh

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*The end-of-life needs of children can be met through manageable changes in policy and practice. Fourteen-year-old Luke—pictured above with his sister, Ali; his care coordinator, Mary DeMers (Hospice of Kitsap County); and his mother, Cathy Chadwick (far right)—suffers from a severe heart condition and pulmonary hypertension. He is served by the Pediatric Palliative Care Consulting Service at Seattle Children’s Hospital. There, he and his family benefit from the service’s innovations in reimbursement, medical decisionmaking, and case management. As a result, Luke’s care coordinator has diagnosed pneumonia early, prevented unnecessary emergency room trips, and found resources for Luke and his family. After a lifetime of often frustrating and fragmented medical care, Luke and his parents now feel supported.*

## Children Are Not “Little Adults”

About 50,000 children die every year in the United States. Half of them die suddenly and unexpectedly, usually from injuries; the rest die expected deaths because of life-limiting conditions. Though the annual number of children who die seems small when compared to the 2.2 million adults who die each year, the impact of a child’s death is more far-reaching for families and society. Depression, dysfunction, lost work, and broken relationships commonly result, say experts.



Susie Fitzhugh

*Children may live with life-limiting conditions for hours, months, or years. In such cases, palliative care can relieve discomfort, improve quality of life, and support families, but most American children do not receive it. Reorganizing services and changing reimbursement policy can broaden the availability and quality of care for dying children.*

While we have made substantial progress in providing a policy climate that encourages good end-of-life care for adults, we have done shockingly little for children. In a recent study, Joanne Wolfe, MD, MPH, Dana-Farber Cancer Institute and Children’s Hospital Boston, found that 89 percent of children who died of cancer suffered significantly from at least one symptom—pain, shortness of breath, fatigue—during their last month of life. The depth of their emotional and spiritual distress, and that of their families, has not been documented.

Like adults, children too often die in ICUs, hooked up to machines that cause them discomfort and prevent them from talking, given unnecessary nutrients that cause bloating and nausea, stuck in an environment where their loved ones cannot hold them, where visitors may be limited, and where they and their families aren’t helped to deal with the most emotionally traumatic event in their lives.

Yet much could be done. “In many ways it’s a manageable problem because the numbers are small,” says Wolfe. “Pediatric end-of-life care is a place where funding and resources can make a huge difference: We can fix this problem.”

### Children’s End-of-Life Needs Are Complex

Seriously ill children live all across America—from inner cities to remote rural areas. Because most medical providers see so few dying children, they have a hard time developing expertise in pediatric end-of-life care. And experience in treating sick and dying adults does not always translate into good treatment for children. Other circumstances particular to children further complicate the picture:

- Children suffer from a broad range of sometimes rare conditions whose course of development is unpredictable.
- Their illnesses often have long treatment trajectories (up to 20 years), and the illness may be very different—and require varying treatment and medical equipment—at different ages.
- Children, unlike adults, are still developing physically, mentally, and emotionally; they need to work toward developmental milestones in spite of their illness.

**“Pediatric end-of-life care is a place where funding and resources can make a huge difference: We can fix this problem.”**

Joanne Wolfe, MD, MPH, Dana-Farber Cancer Institute and Children’s Hospital Boston

## Current Reimbursement Policies Don't Serve Anyone's Needs

- The grief of parents, siblings, providers, and the community when a child loses the opportunity to experience life is different from the grief of losing an adult and tends to have more far-reaching and potentially destructive impacts on all concerned.
- Parents and medical professionals may resist moving to palliative care if the family is not ready to give up cure-oriented treatment, because palliative care is often misunderstood as an alternative, rather than a complement, to treatment.

We know a lot about good end-of-life care for children: Several existing programs offer children good pain and symptom management; they attend to the child's social and spiritual needs; support the family throughout the entire illness; help identify ways to pay for services, medications, and equipment; and make it possible for children to get curative treatment when that is appropriate. But programs like these have to contend with long-standing barriers to providing good end-of-life care for children: inadequate reimbursement mechanisms, legal restrictions, misconceptions about drug use, inadequate training of health care professionals, and fragmentation of care, for example.

This brief will examine how traditional reimbursement policies complicate care from the outset and how pioneers are overcoming these barriers. Issue 16 of this series will take up the ethical, legal, and educational problems related to pediatric palliative care. ■

“Palliative care” refers to a set of practices that minimizes suffering and improves quality of life. For a child with a life-limiting condition, ideally such care is individualized, family-centered, and coordinated, says the American Academy of Pediatrics (AAP). It may include working with the child to assess her level of pain and other physical discomfort and then alleviating it, providing spiritual support for a family in distress, facilitating therapeutic work with a social worker or psychologist to help the child identify and achieve life goals, and ensuring bereavement counseling for the family and friends of the child.

Hospices are often the most experienced palliative care providers, yet sick children don't necessarily have access to hospices. Some state Medicaid programs don't cover hospice care at all. In states that do, few adult hospices will care for children: They lack expertise in meeting children's unique needs and find children too expensive

to care for, given reimbursement restrictions in Medicaid and many private insurance plans. “We do more expensive interventions for children that are still under the rubric of palliative care,” explains Sarah Friebert, MD, director, Regional Pediatric Palliative Care Service, Children's Hospital Medical Center of Akron. “They're much more likely to have tube or IV feedings, transfusions, and so-called ‘aggressive therapy’ right up until the end. This care allows these children to keep playing and going to school. But it also costs more, which shouldn't exclude children from receiving the full complement of hospice services even while this aggressive treatment is going on.”

The AAP states that palliative care should be provided to all children not expected to survive childhood. Changing the Medicaid and private insurance regulations that create barriers to palliative care is an essential first step toward this goal.

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Susie Fitzhugh

*“We have to teach people a new language of hope.... We have to appreciate that even while the hope of cure doesn't fade for a family, there can be other hopes.”*

Gerri Haynes, RN, project manager for the Pediatric Palliative Care Project and former program manager of the Pediatric Palliative Care Consulting Service, both at Seattle Children's Hospital and Regional Medical Center

## Current Reimbursement Policies

### Don't Serve Anyone's Needs

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### Children Need Simultaneous Curative and Palliative Care

Experts argue that palliative care for children should start at the moment of diagnosis, which for children may be many months or up to 20 years before death. If children get simultaneous curative and palliative care, they and their families will be better supported, and they will be able to establish good relationships with the team that will become increasingly important in providing care as death approaches. Since children form attachments to care team members, it can be cruel to replace a trusted caregiver with someone new when they have little energy to put into forming attachments and are at their most vulnerable.

Unfortunately, the reimbursement structure of Medicaid and private insurers generally keeps children from experiencing the benefits of palliative care throughout their illness by allowing hospice care only in the last months of life and by forcing families to choose between hospice or nursing care.

### The Six-Month Prognosis

Under Medicaid regulations, patients aren't eligible for hospice care unless they are expected to die within six months (patients are eligible for an extension if they survive six months and a doctor is willing to say that they are likely to die within another six months). This requirement creates a barrier for children who have unpredictable conditions and could benefit from hospice care for years, not months.

In addition, withholding ideal care until parents and providers say that a child will die within months ensures that children and their families will have many unmet needs. "For parents to see themselves as good parents,

they have to exhaust all treatment possibilities," says Joanne Hilden, MD, chair, Department of Pediatric Hematology/Oncology, the Children's Hospital at the Cleveland Clinic. "This need to leave no stone unturned is parents' hard-wired reality. We have to stop calling it 'unrealistic expectations' and instead work with this loving instinct. Since reimbursement rules require patients to receive either curative or hospice treatment, the decision to switch from one to the other tends to be put off for as long as possible, at the expense of the child's well-being."

### Forced Choice Between Hospice or Nursing Care

Children who are eligible for home nursing services under state Medicaid waivers for medically fragile children aren't also eligible for the hospice benefit, even though the two types of care don't overlap. This choice is difficult for parents of very ill children who need expert nursing to keep their children at home and who know that their children could also benefit from the constellation of services offered by hospice.

**"We need to integrate palliative care principles earlier into the continuum of care, so that children receive this care from diagnosis forward. But because this care often consists of talking, not doing procedures, it can't be billed for adequately and is almost never reimbursed."**

Sarah Friebert, MD, director, Regional Pediatric Palliative Care Service, Children's Hospital Medical Center of Akron

### Reimbursed Communication and Psychosocial Support Are Crucial

The communication so crucial in managing children with life-threatening conditions is generally not paid for by Medicaid, and private insurers tend to follow suit. "Physicians are well reimbursed for interventions involving scalpels or needles," says Hilden, "but not for the time spent talking with the parents of a dying child to help them make decisions."

Parents and children need to talk to physicians and others in order to understand the future and make decisions about care. Leaving parents and patients in the dark about what will happen causes unnecessary trauma. Because these conversations happen often, tend to be long, and take place without the patient being present, this communication doesn't meet Medicaid's requirements for reimbursement and the provider will not be compensated fairly for those hours.

Communication needs to be paid for in several contexts: medical conferences (on the phone and with parents alone and with the child); psychosocial support for sick children, their siblings, and other children who feel the impact of this illness and death; care team communication; and bereavement support. Billing codes for such communication are poorly understood by physicians, and even when used correctly are very poorly reimbursed. Experts call for the establishment of codes for patient evaluation and management as well as codes for palliative, hospice, and bereavement care. They also ask that payment be enforced for telephone consultation and care oversight responsibilities. In addition, everyone on interdisciplinary teams should be reimbursed, say experts. Currently, team members who provide psychosocial and spiritual support are reimbursed poorly if at all.

### How Innovative Programs Address Reimbursement Limitations

Despite these reimbursement barriers, some institutions fund good pediatric end-of-life care through extensive private fund-raising and the support of a well-established adult hospice. If they have home health licenses, some hospices are able to provide palliative care to children from the time of diagnosis, usually operating at a deficit since the services of pastoral and child life workers are not reimbursed. The Hospice of the Florida Suncoast, the Hospice and Palliative Care Center in Buffalo, and the San Diego Hospice are examples of such programs. But smaller institutions cannot afford it.

Other programs, like Seattle's Pediatric Palliative Care Project, establish agreements with state and private payers and use philanthropic funds for administrative time to manage the relationships that allow good palliative care to happen. When the project came to the end of its Promoting Excellence in End-of-Life Care grant, its home institution, Seattle Children's Hospital and Regional Medical Center, began covering the administrative time so that the program could continue as a consulting service of the hospital.

Children's Hospice International has developed demonstration projects to offer palliative care to children even if they are expected to live longer than six months and are still receiving curative treatment. CHI has received federal appropriations for Programs for All-Inclusive Care for Children and Their Families® (PACCs) with bipartisan support led by Sen. Robert Bennett (R-Utah) and Rep. James P. Moran (D-Virginia) and receives technical assistance from the Centers for Medicare and Medicaid Services. The PACCs in Florida and Utah are ready to begin providing services, while others—in Kentucky, New York, Virginia, and Colorado—are developing infrastructures. The PACCs link interested state Medicaid agencies with providers and use existing Medicaid waivers.

While those in the field are happy to see any children getting the care they need, they point to the sustainability problems of relying on charity and continually negotiating payment arrangements to make good care possible. They call for structural change to remove barriers to care. ■

## A New Language of Hope

### Seattle Children's Hospital Weaves Communication, Reimbursement, and Case Management Innovations

After years of constantly fighting to get information, treatment, drugs, and equipment paid for, "It was so good to finally be asked, 'What do you need?'" says Kent Chadwick, whose son, Luke, is enrolled in Seattle's innovative program for children with life-limiting conditions, the Pediatric Palliative Care Consulting Service of Children's Hospital and Regional Medical Center. Kent and his wife, Cathy, were initially stunned by the service's new approach, in which they and Luke were seen as the focal point of care rather than as a source of demands and needs.

Fourteen-year-old Luke's health is currently stable, though fragile. He has suffered from a serious heart condition and secondary pulmonary hypertension since before he was adopted at the age of two. Pulmonary hypertension is a disorder in which the blood vessels of the lungs become increasingly narrow, stressing the heart as it works to force blood through the lungs. Kent and Cathy Chadwick knew Luke was sick when they adopted him in Taiwan, but when American doctors told them that he wouldn't live long, they were shocked. "Here he is—our first child—and they're telling us he's going to die, and that there's nothing we can do," recalls Cathy. Cathy and Kent were soon researching Luke's conditions, finding

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### Two New *State Initiatives* Audio Programs Available Now

The Pediatric Palliative Care Consulting Service at Seattle Children's Hospital receives more extensive feature coverage in *State Initiatives'* newest audio release: *Heart to Heart: Improving Care for the Dying through Public Policy: Part III—Children*. The taped program includes interviews with patients, families, providers, and payers, as well as several national experts.

*Heart to Heart: Part II—Policy Heroes* profiles three "policy champions" who are offering exceptional leadership on end-of-life issues.

To order any of the three audio tapes currently available in the series, call **1 (800) 989-9455** or visit **www.partnershipforcaring.org** (Click on "Store Products," then "Order Form," and then *Heart-to-Heart* under "Audio.")

**A New Language of Hope:**

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a doctor willing to treat him, enduring medical crises, and joining a group of other families who also live with pulmonary hypertension. Twelve years later, Luke is a funny, sensitive, and loving teen with profound medical needs and the normal volatility of adolescence. Luke and his family struggle to live ordinary lives in the face of difficult circumstances; the service helps them achieve some of their hopes for life.



William Stickney

*“State Medicaid agencies need to be assured flexibility within regulations. Our flexibility has allowed us to help children and be aware of costs. If we didn’t provide care for children through this project, they would likely be hospitalized, which is usually more expensive than in-home care through home health or hospice.”*

Phyllis R. Coolen, director of Medical Operations, Division of Medical Management, Medical Assistance Administration, Washington State

“The idea that cure is the only form that success can take in medicine is engrained in our society,” says Gerri Haynes, RN, who managed the program during its demonstration phase. “But cure is not possible for some children. Success is the best possible process through which the child comes to resolution, so the family feels cared for and the caregivers feel successful.

“We have to teach people a new language of hope, beginning with the question ‘What is your highest hope for this child?’ We have to appreciate that even while the hope of cure doesn’t fade for a family, there can be other hopes—that he doesn’t experience pain, that they’ll be able to snuggle with him, that their other children will be able to be cared for, for example.” This new language of hope is created by innovations in case management, communication, and reimbursement for children with potentially life-limiting conditions in Children’s catchment area (Washington, Alaska, Montana, and Idaho).

Luke’s palliative care coordinator, Mary DeMers, RN, Hospice of Kitsap County, works in consultation with a whole team of medical and insurance professionals. She has helped the family get counseling, has facilitated counseling for Luke himself when he was feeling afraid and angry about the threat of death, has found local volunteers who can offer respite care to the family and who can give Luke some one-on-one attention, has arrested pneumonia in its early stages, and has saved the family from unnecessary trips to the emergency room. She works with an insurance case manager to be sure that Luke and his family get what they need in order to have a high quality of life and care.

Luke is currently able to go to school and do many of the things any teenager needs to do. Like most boys his age, he has a lot of questions about girls—they intrigue him, to say the least. He is an avid fan of Seattle’s sports teams. This past summer, he got to be a counselor at a day camp for special needs children. He uses a wheelchair, but when he feels strong enough he walks; his parents have to remind him that he can’t run. Luke wears a small pump that infuses a drug into his body every minute to expand the blood vessels in his lungs.

**Working within Existing Policy to Pay for Coordinated Care**

In its demonstration phase, the Pediatric Palliative Care Project established agreements with Regence BlueShield, Premera Blue Cross, and the Department of Social and Health Services (DSHS) for Washington to provide flexible reimbursement for the care of children who are not expected to survive childhood. Regence BlueShield used a benefits management clause (included in most member contracts) to exchange covered services for services that might not be part of a member’s contract, but meet his needs. DSHS used a reimbursement code that was “empty”—not designated for other services—to reimburse providers for services to children who need palliative care but have a life expectancy of more than six months and may be receiving curative treatment.

These agreements were forged through discussions with payers, policymakers, and clinicians who wanted to help children and who were willing to think outside the box—but within existing policy—to make the project work and to find out how such care can be financially feasible.

William Stickney



“A child with a life-limiting condition lives under a shadow,” says Ross Hays, MD, medical director of the consulting service, explaining the driving force behind it. “The anticipated end of her life informs her whole experience, her whole life. How can we make that experience better? How can we support her?” This desire to help improve children’s experiences at the end of life drove all the participants—providers and payers alike—to make the system work. By getting agreements with private insurance plans and Medicaid to pay for many needed services, the service makes a higher standard of care possible.

While the number of patients served by the consulting service is relatively small, and cost-savings data is still being analyzed, officials from DSHS believe that they saved an average of \$3,000 per month per child in the demonstration program because the children used emergency rooms and hospitalization less often.

### The Decisionmaking Tool: A Blueprint for Communication and Action

The decisionmaking tool (DMT) is a form that provides a blueprint for treatment decisionmaking and goal setting and ensures that child and family preferences are at the center of care. Central to the form are quad-

rants that document answers to four key questions: What are the child’s diagnoses and symptoms? What are the patient’s and family’s preferences for treatment and decisionmaking? What are the physical, social, and spiritual components of the child’s daily life? What activities give value and meaning to the patient? The form is initially discussed and filled out at a care planning session among the entire team providing care for the child (including the family, the care coordinator, the insurance case manager, the medical professionals involved with the case, and anyone else the family wants to be present). The DMT allows the team to identify problems, define steps toward solutions, and assign tasks to specific team members.

Because the DMT makes visible the process leading to decisions about care, it helps insurance case managers, who can better justify expenditures if they understand how they fit into the coordinated plan for care. The child’s care coordinator regularly updates the DMT, and everyone involved with care (including the family) has a current copy. For parents who have lived with a very sick child for his whole lifetime, filling out the form can be healing. (For more on the DMT or the consulting service, visit [www.cshcn.org/palliativecare](http://www.cshcn.org/palliativecare).)

*A care planning conference will involve the child’s parents, care coordinator, primary physicians, specialists, sometimes the insurance case manager, and anyone else the family wants to be present. Coordinated care and team communication ensure that the child’s needs—and those of the family—are articulated and met. The patient’s and family’s goals and preferences are recorded on a decision-making tool, along with a list of tasks and responsible parties.*

### Helping Amber: Memories of a Care Coordinator

Amber reached the end of her life while she was in the program. The 14-year-old was enrolled in the program for nearly five months before her death from leukemia. She had had a bone marrow transplant, lived through the extremely strict diet and lifestyle requirements of a patient who has had a transplant, had a remission of her disease, and then a relapse. Amber’s care coordinator, Catherine Nunneley, RN, MN, from Providence Hospice of Seattle, was increasingly active in her care, establishing relationships with Amber, her family, and her classmates.

“I’m glad I got to know them before we knew that she was going to die soon,” says Nunneley. “I was able to gain their trust. Then, when it was clear that Amber wouldn’t be cured, I could help her and her family make that transition. Patients who have had transplants live on very limited diets and their parents are terrified of infections. Patients and families who have been vigilant for years can’t just suddenly put all that aside; they need help and support. I brought some chocolate chip cookies into the hospital one day and said, ‘You know, that diet that you’ve been on doesn’t seem to be

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helping you, and I know you love cookies. It's OK for you to eat whatever seems good to you." This allowed them all to start letting go of aggressive curative treatment.

Minors vary in the extent to which they want to be involved in discussions of their care. Because of the DMT process, the team knew that Amber did not want to discuss possible treatments or the limits of medical interventions, but she did want to be informed. Nunneley made sure that she and Amber's parents discussed Amber's illness with her in the room but without demanding that she participate. Amber was able to talk about it on her terms, when she was ready. Five days before she died, Nunneley says, Amber had a surge of energy: "She was bopping around the house, wearing cool little sunglasses, and looking good." Amber told Nunneley that she was getting ready for her trip, using a metaphor that sometimes occurs to teens who are preparing to die.

After Amber's death, Catherine visited her classmates and the medical professionals involved with her care and described Amber's last day—what she said, that she was comfortable, that she felt loved and cared for at the end. Nunneley sees this as an important part of her job. The people who loved and cared for Amber wanted—and needed—to know that she died as well as possible. ■

The Institute of Medicine recently released a report titled *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. For more information, visit [www.nap.edu/catalog/10390.html](http://www.nap.edu/catalog/10390.html).

## Selected Resources

### Policy Barriers

**"End-of-Life Care: Special Issues in Pediatric Oncology,"** Hilden, Himmelstein, Freyer et al. From *Improving Palliative Care for Cancer*, ed. Foley and Gelband, National Cancer Policy Board, National Research Council, 2001. Available online at [www.nap.edu](http://www.nap.edu).

***A Call for Change: Recommendations to Improve the Care of Children with Life-Threatening and Life-Limiting Conditions, Children's International Project on Palliative/Hospice Services (ChIPPS)***. Available through the National Hospice and Palliative Care Organization.

**"New End-of-Life Benefits Models in Blue Cross & Blue Shield Plans,"** ed. Jeanne Sheils Twohig, Last Acts Financing Committee, 2001. Available online at [www.promotingexcellence.org](http://www.promotingexcellence.org).

***Heart-to-Heart: Improving Care for the Dying through Public Policy: Part III—Children. State Initiatives in End-of-Life Care***, 2002. (See page 5 of this brief for more information.)

### Standards

**"Palliative Care for Children: A Statement by the American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care,"** *Pediatrics*, vol. 106, no. 2, August 2000. Available online at [www.aap.org/policy/re0007.html](http://www.aap.org/policy/re0007.html).

**"Pediatric Chronic Pain: A Position Statement from the American Pain Society,"** American Pain Society, Glenview, IL, 2001. Available online at [www.ampainsoc.org/advocacy/pediatric.htm](http://www.ampainsoc.org/advocacy/pediatric.htm).

### Cases and Practices

**"Symptoms and Suffering at the End of Life in Children with Cancer,"** Wolfe, Grier, Klar et al. *NEJM*, vol. 342, no. 5, February 3, 2000.

***Hospice Care for Children*, 2nd ed.**, Armstrong-Dailey and Zarbock, eds., Oxford University Press, 2001.

***The Compendium of Pediatric Palliative Care***, Children's International Project on Palliative/Hospice Services (ChIPPS). Available through the National Hospice and Palliative Care Organization.

## State Initiatives in End-of-Life Care

### Information about the Series

"Pediatric Issues—Part I: Paying for Care Needed by Children with Life-Limiting Conditions" is the fifteenth in a series of briefs profiling promising new policies and practices in end-of-life care.

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### To Order Audio Programs

To order Parts I, II or III of the new *State Initiatives* audio programs, *Heart-to-Heart: Improving Care for the Dying through Public Policy*, visit [www.partnershipforcaring.org](http://www.partnershipforcaring.org) or call **1 (800) 989-9455**.



## Last acts.

A national coalition to improve care and caring at the end of life

*Last Acts* is a coalition of more than 850 national and local organizations dedicated to improving end-of-life care. For more information about the *Last Acts* campaign, contact

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