

The Evolution of Hospice Care: Expanding Access with the Concurrent Care for Children Provision

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Their son had metastatic cancer. His life expectancy was less than 6 months, and he was suffering with worsening pain and shortness of breath due to his disease. As his condition progressed, he needed frequent medical assessments for adjustments of the medications used to manage his symptoms, but the trips to the clinic were difficult for him and his family to manage as they lived some distance away from the hospital. Admission to the hospital also went against their goal of keeping their family together at home. However, when presented with the option of hospice to minimize his suffering and help him to maintain as high a quality of life as possible with close monitoring and care, the family was unwilling to give up the option of seeking treatments that might provide a cure.

The development of hospice care in the United States is relatively young and still evolving. Dame Cicely Saunders, who created the first modern hospice in a London suburb, first brought the idea of specialized care for the dying to the U.S. in 1963.¹ Almost a decade later, the first U.S. hospice was founded in 1974, and in the late 1970s, a task force of the U.S. Departments of Health, Education, and Welfare determined that the hospice movement should receive federal support as it provided “more humane care for Americans dying of terminal illness while possibly reducing costs.”¹ Since the creation of the Medicare hospice benefit in 1982, coverage for hospice care has expanded and is now provided under Medicare, Medicaid, and most private insurance plans and managed care organizations.²

The hospice model allows for a holistic approach model of care provided by an interdisciplinary team.² This team includes, at a minimum, a hospice nurse, social worker, chaplain, physician, and volunteers. The team members make regular visits and are available 24 hours a day, seven days a week to: manage the patient’s pain and symptoms; assist with the emotional, psychosocial, and spiritual aspects of dying; provide medications and medical supplies and equipment; and provide bereavement care and counseling to surviving family. Palliative care also has the goal of maximizing quality of life for patients with serious illnesses.³ It is provided by an interdisciplinary medical team at any stage of illness to provide an extra layer of support.

For children with life-limiting or life-threatening conditions, palliative care can be initiated at the time of diagnosis to provide symptom management, address psychosocial and spiritual needs, and assist with goals of care.⁴ However, eligibility for hospice services, and the expansion of services that it offers, historically has had two requirements whether the patient is an adult or a child. The first was that the patient had a life expectancy of no more than six months; the second was that all life-prolonging, curative, or disease-directed care be discontinued.⁵ Families in such hard situations were faced with the very difficult decision of whether to discontinue therapies such as chemotherapy, radiation therapy, dialysis, and medications such as antiretroviral and transplant rejection therapies. Private duty nursing services, necessary for the safe care of many medically complex and technology-dependent children, would also have to be discontinued with the transition to hospice care.⁶⁻⁸

Forcing parents to make these nearly impossible decisions was alleviated with the passage of the Patient Protection and Affordable care Act (ACA) of 2010.^{9,10} Included within section 2302 of this large piece of legislation is the concurrent care of children requirement (CCCR). This provision was written in response to the growing voice of those who provide end-of-life care asserting that hospice eligibility requirements were preventing many patients, in particular children, from receiving adequate care at the end of their lives. It makes an allowance for terminally ill patients under the age of 21 who are enrolled in Medicaid or Children's Health Insurance Programs (CHIP) to receive both curative and hospice care thereby expanding access to the benefits of hospice care for children.⁵ This legislation more aligns with basic principles of palliative medicine which recognize an individual person's goals may include both pursuing life-prolonging disease-directed treatments while at the same time focusing on the best quality of life with thoughtful attention to emotional, social and spiritual aspects of care.

Enactment of the CCCR has occurred gradually. Almost 3 years after its passage, only 31 states had put the legislation into action with Delaware beginning implementation in 2011.¹⁰ While no economic, political, or legal factors have been shown to affect states' implementation, several clinical challenges have been identified.^{8,10} These challenges include: knowledge of end-of-life care for this population; practitioner concerns about adopting a palliative care model of care with focus on comfort; coordination of care between hospice providers and other caregivers; reimbursement for services and durable medical equipment that could not be provided under the hospice per diem reimbursement model; and insurance coverage.

There is a pervasive belief in our society that children should not die. Because of this and common misconceptions, pediatric hospice referrals in particular have been viewed negatively – that there has been a failure or that the family or medical team has given up hope.¹¹ The goal of palliative and hospice care is not to take away hope, but to provide care to ensure a good life no matter how long that life may be. With the passage of the CCCR, an important step toward removing barriers to pediatric referrals for expert care to relieve psychosocial, spiritual as well as physical suffering has been taken.

“When I first ran for the Senate in 2010, I sat down with a group of Delaware physicians to get their thoughts on America's health care system. They all told me the most important health care problem that they wanted elected leaders to fix was the lack of clarity around patients' preferences for care in the event of serious illness or injury. Every doctor could think back to a case in which a patient faced a terminal illness and did not have long to live – yet each performed operations or interventions that the doctor didn't think the patient would have wanted and that often came at an enormous emotional cost for the patient's family.

“These conversations, in addition to countless others I've had with Delawareans up and down the state, showed me that we must do more to encourage patients and doctors to have these difficult, but critically important conversations. That's why I introduced the bipartisan Medicare Choices Empowerment and Protection Act to help encourage these conversations by establishing a financial incentive for Medicare beneficiaries to create electronic advance directives, legal documents that allow patients to clarify their end-

of-life preferences. I believe this bill is complementary to what's already happening in Delaware through the implementation of the Delaware Medical Orders for Scope of Treatment, or DMOST. I commend the state legislature for taking this important step and look forward to partnering with state and local leaders to transform how we approach end-of-life care issues.

“None of us should have to spend the final months of our lives worrying about looming health care bills or complicated procedures, or navigating a complex maze of legal and medical decisions. We should be able to spend this time on our own terms: in comfort, in dignity, in the company of family and faith. The Medicare Choices Empowerment and Protection Act is a key step in that direction, and I will continue building on the strong support this bill has from both parties and a broad coalition of palliative care experts and religious organizations to see it over the finish line.”

- Senator Chris Coons

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Bipartisan legislation is first of its kind to receive support from the National Right to Life Committee

WASHINGTON – U.S. Senators Chris Coons (D-Del.) and Bill Cassidy, M.D. (R-La.) and U.S. Representatives Diane Black (R-Tenn.), Mike Thompson (D-Calif.), Chris Collins (R-N.Y.), and Peter Welch (D-Vt.) today introduced legislation to encourage Medicare beneficiaries to create electronic advance directives, legal documents that allow patients to clearly articulate their preferences for their medical care should they suffer from a debilitating illness or condition. The Medicare Choices Empowerment and Protection Act would offer a small, one-time financial incentive to encourage Medicare beneficiaries to provide clear legal guidance to their medical providers and family members should they become incapable of speaking for themselves. With recent attention on the announcement from the Centers for Medicare and Medicaid Services to pay physicians for advance care planning, this legislation would incentivize Medicare beneficiaries themselves to create and register a certified and secure advance directive online. In addition, the bill would provide beneficiaries with access to a website with model advance directives representing a range of options.

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