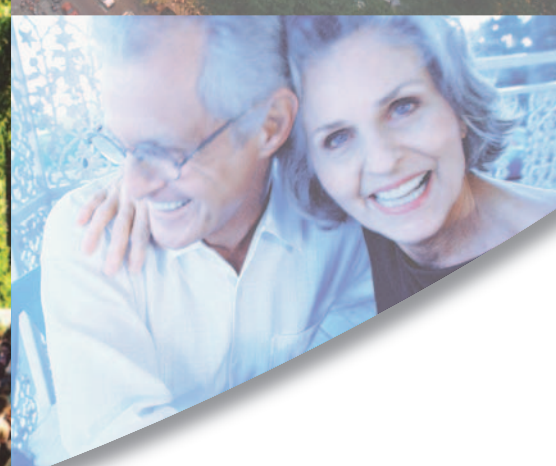


Section II: Connecticut Cancer Plan 2009 – 2013

B. The Continuum of Cancer Control

5. Palliative and Hospice Care

The Power of Unity.



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Bridgeport Hospital
Visiting Nurse
Union Baptist Church, Hartford
Yale Cancer Center
St Vincent's Medical Center
CT VNA Hospice/Masonicare
Regional Hospice of Western CT, Inc.
Family Member of Cancer Patient
CT Assn. for Home Care and Hospice
Stamford Hospital
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Visiting Nurse and Hospice Care of Southwest CT
Connecticut Pain Initiative
Greenwich Hospital Home Hospice
CT Coalition to Improve End of Life Care

5. PALLIATIVE AND HOSPICE CARE

Helping people with cancer live well at every stage of their illness is the primary purpose of palliative care. The Health Resources and Services Administration has defined palliative care as patient- and family-centered care that optimizes quality of life by active anticipation, prevention, and treatment of suffering. It emphasizes the use of an interdisciplinary team approach throughout the continuum of illness, placing critical importance on building respectful and trusting relationships. Moreover, the provision of palliative care is not dependent upon prognosis and can be used alongside curative or life-prolonging treatments. Palliative care addresses physical, intellectual, emotional, social, and spiritual needs for patients of all ages and their loved ones, facilitating patient autonomy, access to information, and choice.¹

Hospice services offer a combination of palliative and supportive care services for people in the final stages of illness and their families, when curative treatments are no longer sought. In addition to direct care, services provided may also include respite care, bereavement support, and financial planning. Hospice care may be received in the home or in residential inpatient settings such as hospitals, nursing homes, or hospice homes. Hospice care has a long history involving many partners in Connecticut. The first inpatient hospice program in the United States was established in New Haven in 1971 and the first freestanding inpatient hospice opened in Branford in 1980. This inaugurated the national hospice movement.

Why this goal is important...

- 1. Availability and Accessibility of Care:** Adequate services are still not readily available in many health care settings. For example, only 14 of 26 mid and large sized Connecticut hospitals had a palliative care program in 2007.⁽¹⁾ In 2007, only 28% of Medicare patients dying in Connecticut were on the hospice benefit,⁽²⁾ and only 27.7 % of deaths in 2006 occurred at home.
 - Patients in Connecticut are referred to palliative and hospice services too close to time of death, thus denying them and their families the opportunity to receive optimal care and support.
 - Although Connecticut adopted a Medicaid hospice benefit in 2008, there are still gaps in coverage for pain and palliative care services.
 - Poor and medically underserved populations may have limited access to culturally appropriate palliative and hospice care services.
 - 2. Coordinated Care:** Surveys indicate that Connecticut residents would like:
 - Better coordination of care and dialogue with providers about death and dying.
 - Prompt referrals to hospice and palliative care.
 - Counseling to dying patients, and more access to spiritual care.⁽³⁾
 - 3. Palliative and Hospice Care Workforce:** Although numbers are increasing, in Feb. 2009 there were only 27 physicians and 163 nurses certified in palliative and hospice care.^(4,5)
- (1) Center to Advance Palliative Care. America's Care of Serious Illness: A State by State Report Card on Access to Palliative Care in Our Nation's Hospitals. 2008.
- (2) The Dartmouth Atlas of Health Care. <http://www.dartmouthatlas.org/>.
- (3) Connecticut Department of Health Death Registry. Unpublished analysis of 2006 Place of Death Data.
- (4) American Academy of Hospice & Palliative Care Medicine. Certification Overview. <http://www.association-office.com/ABHPM/etools/publicdir/Search.cfm>.
- (5) National Board for Certification of Hospice & Palliative Care Nurses. <http://www.nbchpn.org>.

Goal: *To ensure that high quality palliative and hospice care services are available and accessible to all Connecticut residents.*

For purposes of this Plan, palliative care is available at every step of the cancer experience, whereas hospice care is offered when the life expectancy is six months or less. Few people are fully prepared to make the hard choices that are needed at the end of life. Palliative and hospice care can ease the pain and provide invaluable support for making informed end of life decisions.

In 2008, the Connecticut State Department of Health provided funds to the Connecticut Coalition to Improve End-of-Life Care to conduct an online educational needs assessment of providers who care for patients and their families at end-of-life, including nurses, physicians, social workers, pharmacists, chaplains, administrators, funeral directors, and nursing assistants. The survey was available online through April, 2009 and data are currently being analyzed by demographic characteristics, years of experience, and work setting. Results will be used to develop a long term Plan to meet the education needs of providers in Connecticut to ensure high quality palliative and hospice services for all Connecticut residents.

1. Availability and Accessibility of Care

Many patients do not receive adequate palliative and hospice care services, even when these services are available.^{2, 3, 4} This is the result of several factors. First, the kind, quality, and amount of palliative and hospice care received varies with the setting in which terminally ill patients reside (at home, long-term care facilities, assisted-living facilities, hospitals, or prisons). Second, health care professionals are often inadequately trained in palliative or end-of-life care. Third, there are often financial barriers. Medicare, Medicaid, and some insurance plans cover hospice care, whereas palliative care is often covered

indirectly, if at all. Finally cultural backgrounds, religious beliefs, and socioeconomic status can affect both the use and delivery of palliative and hospice care.

In 2007, the average length of stay for Medicare Hospice beneficiaries nationally was 72 days.⁵ That year, the average length of stay in Connecticut was 45 days, ranking Connecticut last among all the states. Among just the New England states, the median length of stay for 2007 was 56 days; almost 25% more than the 45-days seen in Connecticut (NH:51, VT:58, RI:61, ME:67, MA:68). A focus on increasing the average length of stay will help insure that more patients at end-of-life, and their families, receive the supportive services intended by this Medicare benefit.

2. Coordinated Care

A coordinated interdisciplinary team affords the best chance at providing optimal palliative care to persons who need pain or symptom relief or end-of-life services. The palliative care team includes a variety of health professionals, such as the doctor or care team leader; the nurse, who gives direct care to the patient and assists with managing pain and other side effects of cancer or its treatment; the social worker who helps with financial issues, family support and discharge from the hospital to home or hospice care; a spiritual advisor who counsels the patient and family members on religious and spiritual matters; a dietitian who advises on nutritional needs; a pharmacist who coordinates access to and management of medications; a physical therapist who helps maintain mobility as long as possible; and a grief and bereavement coordinator who provides both counseling and assistance with memorial services planning.⁶

3. Palliative and Hospice Care Workforce

Increasing the number of professionals who have training or certification in palliative and hospice care can directly affect how people learn about available services, how they access services, and the timing and amount of care they receive. To create a culturally diverse workforce that understands the importance of palliative and hospice care, training opportunities for health care professionals are endorsed by the Palliative and Hospice Care Committee. The trainings might include college courses, certification preparation programs, continuing education conferences, and on line learning.⁷ The development of certification programs varies by professional groups. To date, both physicians and nurses have made significant more progress than other groups. There are accrediting bodies established for both and others are in various stages of development, including social work and administrators.

Note to Reader: Measures, Targets, and Data sources may be found in the Section III B Implementation section: Tracking Plan Progress. All targets in the objectives are 2013 targets.

Palliative and Hospice Care Objectives

OBJECTIVE 1. *Increase the number of health care professionals who specialize in or are certified in palliative and hospice care.*

- *Increase from 27 to 30 the number of certified physicians.*
- *Increase from 163 to 250 the number of certified nurses.*
- *Increase from 0 to 6 the number of nursing administrators.*

Strategies:

1. Use the results of the 2009 CT Palliative and Hospice Care Needs Assessment Survey to:
 - a. Identify organizations that offer palliative or hospice care education programs.
 - b. Collaborate across organizations and agencies to develop standards in end-of-life education.
2. Include palliative and hospice care curricula in programs at medical, nursing, counseling and pastoral care schools.
3. Partner with member organizations to provide palliative and hospice care continuing education programs for physicians, nurses, social workers, hospital chaplains, community clergy, and lay volunteers through Connecticut health care systems, professional organizations, and community groups.
4. Provide links to palliative and hospice care information and resources for health professionals on the Connecticut Cancer Partnership web site.
5. Partner with member organizations to provide educational opportunities within health care systems, colleges and organizations for physicians and nurses to become certified in hospice and/or palliative care.

OBJECTIVE 2. Increase the number of health care settings offering palliative and hospice care services.

- Increase from 14 to 20 the number of hospitals offering palliative care services.
- Increase the number of Home Care Providers with Hospice Licensure.

Strategies:

1. Advocate for coverage for palliative and hospice services through all health insurance programs.
2. Disseminate information on best practices for palliative and hospice care in health care facilities.
3. Provide links to education programs about integrating palliative care into clinical services on the Connecticut Cancer Partnership web site.
4. Promote integration of palliative care into clinical services offered in hospitals, home care agencies and long-term care facilities.
5. Obtain baseline data for Nursing Homes and Home Care Providers (survey or student project).

OBJECTIVE 3. Increase the number of people served by palliative and hospice care initiatives, including current pediatric, prison, and Veterans' initiatives, that address targeted and/or medically underserved population groups.

Strategies:

1. Identify and initiate quality improvements for pediatric palliative and hospice care.
2. Promote collaboration between the Connecticut Prison Hospice Initiative and the Connecticut Department of Correction's Hospice and Palliative Care Program to train correctional staff and inmate hospice volunteers.
3. Identify and initiate end-of-life quality improvements for the care of Connecticut's Veterans.
4. Advocate for expanded initiatives to address palliative and hospice care needs of uninsured, racial/ ethnic minorities, people with mental health conditions, developmental disabilities, and addictions.

OBJECTIVE 4. Increase the proportion of patients receiving effective pain management.

Strategies:

1. Work with partners and Data, Surveillance, and Evaluation to initiate collection and analysis Connecticut data (see Data Sources above) to obtain baselines, identify disparities that might be targeted with interventions, and determine future targets.
2. Promote educational programs in colleges, health care facilities and communities about best-practices in pain management targeting health care professional audiences (physicians, nurses, administrators, social workers, pharmacists, substance abuse counselors).
3. Promote opportunities and incentives for physicians and nurses to become certified in pain management by their respective boards (ABMS, AAPM).⁸
4. Promote updating/revision of patient care policies and programs at Connecticut health care facilities as needed to reflect best practices in pain management.
5. Advocate for revision/improvement of state regulations and policies to conform to the Pain & Policy Study Group's (PPSG) *Central Principle of Balance* and to achieve a grade of "A" on their Report Card.⁹

OBJECTIVE 5. Increase the percentage of Connecticut residents who receive hospice care in a timely manner and at home.

- Increase from 28% to 35% the percentage of Medicare patients in Connecticut who are on hospice benefit at time of death.
- Increase from 27.7% to 35% the percentage of persons receiving hospice care at home at time of death.
- Increase from 45 days to 56 days as the average length of stay on Medicare hospice benefit prior to death.

Strategies:

1. Promote educational opportunities for the public to learn about the benefits and availability of palliative and hospice care and the benefits of creating a living will.
2. Working through church leaders, senior citizen groups and local public health officials, institute culturally competent outreach, education, and partnership efforts within diverse communities to reach minority, immigrant, and English as a Second Language (ESL) population groups.
3. Improve quality of care and provider expertise per Objectives 1 and 2 above.