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ACCESS TO END OF LIFE CARE
IN MAINE:

AN ANNUAL REPORT PREPARED BY

THE MAINE HOSPICE COUNCIL

FOR

THE COMMITTEE ON HEALTH AND HUMAN SERVICES

DECEMBER, 2002

About This Report

During the 119th Legislative session, the Maine Consortium for Palliative Care and Hospice received a charge from the Committee on Health and Human Services to present an annual report which addresses issues of access and accountability, and to make recommendations to the Committee regarding legislation that could improve care at the end of life.

The Maine Hospice Council continues to generate this report for consumers, providers, and policy makers, documenting the State's progress and making recommendations for future steps to improved comprehensive end-of-life care.

The **Maine Hospice Council** exists to ensure the continued development of Hospice and Palliative Care in Maine.

The **Maine Consortium for Palliative Care and Hospice** envisions communities that are responsible for dynamic social policies and practices that support high quality end-of-life care.

Care at the End of Life: A Public/Private Partnership was a collaborative effort lead by the Maine Hospice Council and the Maine Consortium for Palliative Care and Hospice to address the barriers to quality end-of-life care in Maine.

It is our mission to create a socially responsive environment in the state of Maine for compassionate care at the end-of-life.

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Barriers to Access Quality End-of-Life Care

Many of the barriers listed have been addressed by activities and projects of the **Maine Hospice Council**, the **Community State Partnership** (CSP), and the **Maine Consortium for Palliative Care and Hospice**. The establishment of the **Maine Center for End of Life Care** as a committee of the Maine Hospice Council is a positive step toward continued assessment of barriers.

Education

- ⊖ Lack of licensure and continuing education requirements in hospice and palliative care for Maine's health care professionals continue to deter access to end-of-life care for patients and families around the state.
  - ✓ The University of New England has implemented an End-of-Life Care curriculum for second year medical students.
  - ✓ The Maine Medical Association is spearheading the AMA Educating Physicians on End-of-Life Care (EPEC) program. There are currently 12 EPEC trained physicians in Maine.
  - ✓ Nursing Schools throughout Maine participated in a curriculum audit to help determine the current status of end-of-life training provided to nursing students. (See the bullet on page 4 under 'Clinical Improvement' regarding nursing school curriculum.)
  - ✓ The Maine Department of Professional and Financial Regulations, Office of Licensing and Registration, undertook a study in 2001 of current professional entry-level and continuing education requirements related to end-of-life care for the following licensed professions: counselors, social workers, psychologists, allopathic medicine, osteopathic medicine, nursing, funeral directors, acupuncturists and naturopathy. The results of the study were presented to the Legislative Joint Standing Committee on Health and Human Services and will be used as a guide for the Education Committee of the Maine Hospice Council and Maine Center for End of Life Care.
- ⊖ Educational opportunities for the lay public concerning end-of-life care are inconsistent and not promoted by community, church, school, or business in any formal manner.
  - ✓ A project of the Maine Council of Churches for the Community State Partnership grant program resulted in a series of interfaith programs on end-of-life care and the development of a manual for creating Interfaith Programs and Dialogues.
  - ✓ The Maine Hospice Council sent two people to La Crosse, Wisconsin for certification training in Advance Care Planning.
  - ✓ Hospice programs and End of Life Coalitions throughout the state offer educational programs and community dialogues on end-of-life issues.
- ⊖ A lack of effective communication exists among the various stakeholders in end-of-life care (providers, health care institutions, legislators, consumers, insurers, regulators, and policy makers) with regard to the specialized information available to each group.
  - ✓ The Community/State Partnership has been effective in creating more dialogue. The effort will continue through the **Maine Center for End of Life Care.** The Maine Hospice Council has convened Strategic Planning Sessions to address the goals of the Center.
  - ✓ The Maine Hospice Council and other community hospice organizations are partnering with the Veterans Administration Health System at Togus.

- ⊖ Ever-changing federal and state rules and regulations regarding assessment, level of care, licensing, and reimbursement create difficulties in providing seamless health care delivery system in regards to end of life care.
    - ✓ Passage of Title 24-A, Sections 2759, 2847-J, and 4249, of the Part I Budget in 2002 implemented all elements of LD 802, including:
        - Mandated hospice benefit in private insurance policies.
        - Creation of the **Maine Center for End of Life Care.**
        - An assessment of Professional Education and Continuing Education requirements and opportunities.
        - Gathering of baseline data and development standardized assessment tools.
        - Medicaid reimbursement at Medicare rate plus 23%.
        - Funding for volunteer hospice programs.

Clinical Improvement

- ⊖ Lack of baseline data and a lack of standardized assessment tools for pain and symptom management.
    - ✓ The following projects have gathered and/or are continuing to gather much needed data:
        - Maine Hospice Council
        - Community State Partnership (Robert Wood Johnson Foundation) project work
        - Bureau of Health, State Cancer Plan
        - Maine State Prison project
        - Zero Acceptance of Pain (ZAP) Project
        - Educating Physicians on End-of-Life Care (EPEC)
        - End of Life Nursing Education Curriculum (ELNEC)
        - Maine Center for End of Life Care research projects
        - In-patient facility projects around the state.
    - ✓ The Maine Hospital Association has developed hospital-based teams and conducted educational sessions to advance end-of-life care. This project is a continuation of the MHA project work from the Community State Partnership grant, and is funded by a new grant from Robert Wood Johnson Foundation.
    - ✓ Hospitals are required by the JCAHO to develop pain management tools for all patients.
- ⊖ A medical culture that is biased against the prescribing of opioids adequate for effective pain management (fear of license revocation and/or litigation for excessive prescribing practices); social conditioning against "addiction;" and a lack of standardized assessment tools.
    - ✓ Boards of Licensure in Medicine and Osteopathy developed rules and regulations for the use of controlled substances in managing pain: Spring 1999.
- ⊖ Pain Relief Promotion Act and Oxycontin diversion issues have contributed to anxious practice behavior regarding effective pain management.
    - ✓ The *American Alliance of Cancer Pain Initiatives* and the *Maine Cancer Pain Initiative* are "committed to assuring their [opioid analgesics] availability for legitimate medical purposes as well as to preventing their diversion and abuse.
- ⊖ Limited curricula opportunities for palliative or end-of-life care and hospice in medical schools, or residency programs.
    - ✓ EPEC is educating physicians, but the program is still voluntary.
    - ✓ ELNEC is educating nurses.

  - ✓ University of New England has implemented palliative care and hospice curriculum for second year medical students.
- ⛔ There are no continuing education or licensure requirements for physicians or nurses with regard to palliative care and hospice.
- ⛔ Few nursing schools that offer training or clinical practicums on palliative care and hospice.
  - ✓ Maine Nursing Curriculum Audit and conference held in April 2001. Ten programs were reviewed.
    - ▪ Two programs (out of 10 respondents) have courses in palliative and hospice care: UMaine has listed one course but due to low enrollment, it has not been offered; Husson College has a hospice elective course which has been offered.
    - ▪ Seven programs participated in the HAPCEN program and four made curriculum adjustments as a result.
- ⛔ Managed care requirements often decrease patient contact with physicians, limiting the time necessary to address the complex issues surrounding chronic and terminal illness.
- ⛔ Lack of regional palliative care and pain management centers.
  - ✓ Several hospitals have developed/are developing palliative care teams.
- ⛔ Poorly understood and under-utilized interdisciplinary team approach to care.
- ⛔ No DRG code for palliative care.

<u>Economics</u>

- ⛔ Insurance companies are providing more expensive and less comprehensive coverage (premiums up, coverage down).
- ⛔ Reimbursement structures that favor procedures and testing over patient communication.
- ⛔ Fragmented reimbursement system.
- ⛔ No Medicaid palliative care or hospice benefit.
  - ✓ Passage of LD 1641 created a Medicaid Hospice benefit, and the 2002 Part I Budget bill (Title 24-A) fixed the rate at Medicare plus 23%.
- ⛔ No minimal benefit standard from insurers regarding palliative care and hospice.
  - ✓ Passage of Title 24-A, Sections 2759, 2847-J, and 4249, of the Part I Budget in 2002 states:
    - ▪ "All individual health policies, all group insurance policies and contracts, and all health maintenance organization individual and group health contracts must provide coverage for hospice care services to a person who is terminally ill."
    - ▪ "Hospice care services must be provided according to a written care delivery plan developed by a hospice care provider and the recipient of hospice care services. Coverage for hospice care services must be provided whether the services are provided in a home setting or an inpatient setting."
    - ▪ Defines hospice and palliative care.
- ⛔ Under Medicare, no reimbursement for hospice care until a determination of six months or less to live is given. Life expectancy for non-cancer diagnosis is difficult to determine and results in late referral to hospice for fear that patient will outlive six month prognosis.

- ✓ New legislation passed by the 120th Maine Legislature (Title 24-A) mandates that private insurance companies define a "person who is terminally ill" as a person who has a medical prognosis of a life expectancy of 12 months or less, provided the illness runs its normal course. This definition, however, does not apply to Medicare or Medicaid benefits.
- ✓ NHPCO is in the process of advocating for an increase in per diem Medicare Hospice reimbursement.
- ✓ NHPCO is also advocating for the a change in the 80/20 rule language.

- ⊖ Not all health-care organizations in Maine have made palliative and hospice care a priority.
  - ✓ Most health-care organizations have signed on the Maine Compact for Palliative Care and Hospice (attached at the end of this report) developed by the Maine Hospice Council and the Maine Consortium for Palliative Care and Hospice.
- ⊖ The number of home health agencies experiencing nursing shortages and significant financial stress is creating a serious problem to access.
- ⊖ No cost data available in Maine regarding the impact of untreated pain (workplace absence and decreased productivity, increased emergency room treatment and hospitalizations, alcohol and drug abuse).
- ⊖ Physicians refer patients to hospice very late (or too late) because they are concerned about being penalized if patients outlive the six month prognosis.
  - ✓ Title 24-A definition extends this period to 12-months but does not apply to Medicare or Medicaid.
- ⊖ Cost of medical care is one of the leading causes of personal bankruptcy in the U.S., and accounts for at least 10% of the personal bankruptcy filings in Maine. An un-named Chapter 13 Bankruptcy Trustee suggests that at least 30% of all personal bankruptcy filings include major medical expenses. This figure may be higher because injured or dying people will have reduced incomes.
- ⊖ Accelerating costs of pharmaceuticals.
  - ✓ Maine Legislation intended to cap prescription drug costs.
- ⊖ An unacceptable number of uninsured and under-insured people. Individuals with limited access to hospice care enter the treatment phase much later if at all, and are disproportionately impacted by the cost of care.

  > "Coverage among full-time workers is declining. Lack of health insurance is closely and increasingly correlated with low incomes. Between 1987 and 1996, the gap in health insurance coverage between low-wage and higher-wage workers widened: coverage for the lowest paid workers fell markedly, while coverage for the highest paid increased. In 1996, only 42.7% of workers earning less than $7 an hour were offered health insurance as compared to 93.4% of those earning over $15 per hour."
  > [Original Sources: A Profile of the Low-Income Uninsured. The Kaiser Commission on Medicaid and the Uninsured. August 1999. "More Offers, Fewer Takers for Employment-Based Health Insurance: 1987-1996," Health Affairs. Vol 16 No 6:145. November/December 1997.] [Quote from **Maine Center for Economic Policy**, *Within Reach*. Dec 1999. Web address: www.mecep.org/within/within.shtml]

  - ✓ Expanded Medicaid coverage for children and low-income families has improved coverage. However, coverage to full-time workers and poor elderly continues to decrease.

- Triangulated payment systems for hospice patients in long term care facilities create decreased utilization of hospice services and competition for reimbursement as well as raising red flags for fraud and abuse investigation.
- Transportation issues and lack of proximity to medical facilities pose special problems to rural Maine residents. This is especially relevant in Aroostock, Washington and Oxford Counties, each with only one Medicare Certified Hospice and each which has undergone dramatic cuts in staffing.

Community

- Dramatic family system changes have lead to a greater number of elderly patients living alone, "shut in", abandoned by their families, with reliance on social service agencies for transportation, meals, and other assistance.
- Poor awareness of hospice availability (according to a market survey conducted for the Maine Hospice Council in 1995, only about 50% of Maine citizens were aware that hospice services existed in Maine).
  - ✓ To improve hospice awareness, coalitions have been formed in several communities, Public Service Announcements have been made, and new brochures have been distributed statewide through Community State Partnership and MCPCH member organizations.
  - ✓ Public Service Announcements were developed and aired to create awareness of hospice.
- Poor understanding of grief and bereavement issues in the workplace, churches, and schools provide little support for those dealing with death and dying issues.
  - ✓ CSP projects are working to improve the level of understanding through interfaith dialogues, coalition building, public hearings, and support groups.
  - ✓ On-going workplace grief and bereavement study funded by the Gertrude G. Ford Foundation and coordinated by the Maine Hospice Council.
- No statistical data available to assess the impact on productivity of employees that also serve as primary caregivers in their homes.
  - ✓ The Workplace Grief and Bereavement Study is trying to ascertain the responsibility of the workplace regarding grief, bereavement, and death.
- Increasing elderly population (over age 65 population expected to quadruple in the next 20 years) with proportionate rise in chronic diseases will require more accessible community services.
  - ✓ Partnership with AARP regarding pain management and end-of-life issues.
- A culture that tends to be unfamiliar, uncomfortable, and resistant to discussing issues of death and dying.
- Lack of awareness and attention to issues of diversity as they impact end-of-life care.
  - ✓ Addressing issues of diversity through Maine Hospice Council Board and related activities.

Social Policy Recommendations

a. Develop a strategic plan for end-of-life care in Maine to include:
  1. Continuity of care across all practice settings;
  2. Minimal standards of care/standards of best practice;
  3. Development of regional/residential inpatient hospice and palliative care facilities with attention to regulation that supports this development. Projects currently underway:
     a. Lewiston,
     b. Southern Maine,
     c. Augusta,
     d. Damariscotta,
     e. Boothbay Harbor,
     f. Eddington,
     g. and Bangor;
  4. Support for appropriate data collection and research regarding hospice and palliative care – provisions in Title 24-A for data gathering and the Maine Center for End of Life Care a good beginning.

Further suggestions for improving care at the end-of-life

a. Promote systemic collaboration within the health care system to support a seamless health care delivery system.

b. Decrease bureaucracy and regulation in order for individuals to "die in place".

c. Continue to create collaborative, community based partnerships.

d. Provide support for the Maine Center for End of Life Care and other on-going projects to develop:
  1) the infrastructure necessary to support quality end-of-life care:
     - research,
     - advocacy,
     - education,
     - community;
  2) social policies which give impetus to hospice and palliative care in communities with the goal of improving care at the end of life;
  3) appropriate research on end-of-life care in Maine.

e. Develop and support a statewide ethics committee for end-of-life care.

f. Advocate for an increase in the Medicare Hospice per diem reimbursement rates.

Ongoing and Programs Regarding End of Life Issues in Maine

- Boards of Licensure in Medicine and Osteopathy
    - Developed rules and regulations for the use of controlled substances in managing pain: Spring 1999.
- Educating Physicians on End-of-Life Care (EPEC) – Maine Medical Association.
- End-of-Life and Nursing Education Curriculum (ELNEC) – Nursing schools in Maine.
- Hospice and Corrections: Development of a hospice program within the Maine State Corrections System.
- Inpatient Hospice Facility Programs being developed in Lewiston, Southern Maine, Augusta, Damariscotta, Boothbay Harbor, Eddington, and Bangor
- Listen to Me: Elder Ladies Seeking Input and Empowerment Regarding End-of-Life Care completed 1997 – Maine Hospice Council
- Loss and Grief Training
    - Center for Grieving Children
    - Hospice grief support groups.
- Maine Cancer Pain Initiative
    - National Cancer Pain Initiative meeting hosted in Portland, June 1998
    - Invited to participate in "Think Tank" to plan future of State Cancer Pain Initiatives
    - Zero Acceptance of Pain Protocol Implemented February 2000
    - Annual Cancer Pain Symposium.
- Maine Center for End of Life Care
    - Awarded to the Maine Hospice Council, Winter, 2001.
- Maine Consortium for Palliative Care and Hospice
- Market Research on End-of-Life Care -- 1998 – Maine Hospice Council
- Nursing Ethics Network Research on Ethics and Human Rights Concerns of Maine Registered Nurses 1998 – Maine Hospice Council
- Pediatric Palliative Care Program – Jason Program.
- Public Awareness Campaign on Hospice – 1998 – Maine Hospice Council
- Public Hearings on End-of-Life Care -- 1999
- Robert Wood Johnson Grant in Aroostook County for Northeast Maine Tele-medicine Network
- Ongoing survey of workplaces regarding hospice/palliative care benefits and services. Funding provided by the Gertrude Ford Foundation.

Maine Data

Demographic Profile	**1998**	**1999**	**% change (7)**
Total number of resident population (1)	1,242,051	1,227,928	-1.14%
65 years and older	173,419	174,833	0.82%
Personal income per capita (8)	$ 22,394	$ 23,499	4.93%
Median household income (3)	$ 27,200	$ 28,600	5.15%
Poverty rate (3a) (1996/1997)	135,000	124,000	-8.15%
Uninsured individuals (9)	182,000	160,000	-10.99%
% Uninsured individuals (94-95/96-97) (10)	12.8%	13.5%	5.47%
National Average (1996/1997) (10)	15.6%	16.1%	3.21%
Low Income	30.8%	31.8%	3.25%
Elderly	1.1%	1.0%	-9.09%
Elderly Low Income	3.6%	2.9%	-19.4%
Uninsured by Income - (Nationally)			
Less than $25,000	25.4%	23.2%	-2.2%
$25,000 to $50,000	18.1%	17.1%	-1.0%
$50,000 to $75,000	10.1%	10.2%	0.1%
$75,000 and up	8.1%	7.0%	-0.9%
Deaths occurring in state: (2)	**1996**	**1998**	**% change (7)**
Residents	11,337	12,070	6.5%
Nonresidents	345	267	-22.6%
By sex:			
Males	5,659	5,871	3.7%
Females	6,023	6,199	2.9%
By race:			
White/European American	11,657	11,965	2.6%
Hispanic/Latin American (5)			
Black/African American	17	25	47.1%
South Pacific/Asian American	3	21	600.0%
Native American (5)	58	32	-44.8%
Other	n/a	4	
Unknown	n/a	23	
By age:			
Infant deaths	65	86	32.3%
Deaths age 65+	9,340	9,714	4.0%

Hospice Survey Data (Survey of Medicaid and Volunteer providers) (11)
Percentages are based on those Hospice or Home Health Agencies responding to the survey.
50% indicate a decrease in hospice census.
60% indicate a decrease in length of stay.
30% describe situations where patients benefit runs out before service is complete.
90% provide services for which they are not reimbursed.
50% do not have a system to track pain or symptom management.
20% have standards in place for palliative care.

Places of death: (1)	**1998**	**1999**
Total Deaths	12,067	12,247
Maine hospital	4,741	4,948
Out of state hospital	204	233
On way to hospital	98	3
Skilled nursing care	0	0
Intermediate care	4,017	3,955
State penal institution	0	1
At home (most over age 65)	2,658	2,738
Other	349	369

Hospice Organizations (13)	**1999**	**2000**
Average daily census	14.12	15.15
Average length of stay	70.53	67.96
Deaths (cancer) (14)	60.00	56.50
Deaths (non-cancer) (14)	33.00	19.00
Deaths (total)	86.57	84.25
Number of patients	115.83	127.54

What Maine Wants? Outcome Survey Results
A survey of Maine residents – community members, students, healthcare professionals, and family caregivers -- asked for desired outcomes for end-of-life care in Maine in six specific issue areas. For complete results, visit out website. The most desired outcomes in each issue area are listed here. [16]
A. Dying persons and their families: Increase the control that people have over the treatments that they receive at the end of life.
B. Providers: Increase the professional training of all providers in the area of death and dying.
C. Relationships between dying persons, loved ones, and providers: Increase the ability of patients, families, and physicians to communicate openly and trustingly in health care at the end of life.
D. Institutions/Organizations: Expand the number of Hospice-type options for people at the end of life.
E. Economics: Increase the adequacy of insurance coverage so people have the supports they need to care for their loved ones at the end of life.
F. Community: Increase the conscious level of the public around end of life issues through community dialogues and other programs.

Leading Causes of Death (1) Data totals from Hospitals, Nursing Homes, and At Home	**1998**	**1999**	**% change (7)**
Other Ischemic heart disease	1,199	1,488	10.8%
Acute Myocardial infarction	940	914	-1.4%
Cancer of respiratory system	862	846	-0.9%
Cancer of digestive organs and peritoneum	676	712	2.6%
Cerebral hemorrhage	118	867	76.0%
Cerebral thrombosis	40	732	89.6%
Pneumonia	416	168	-42.5%

Leading Causes of Death (1) Data from Hospitals	**1998**	**1999**	**% change (7)**
Acute Myocardial infarction	566	558	-0.7%
Other Ischemic heart disease	491	582	8.5%
Cancer of respiratory system	348	328	-3.0%
Cancer of digestive organs and peritoneum	235	258	4.7%
Cerebral hemorrhage	100	364	56.9%
Cerebral thrombosis	20	335	88.7%
Pneumonia	181	83	-37.1%

Leading Causes of Death (1) Data from Nursing Homes	**1998**	**1999**	**% change (7)**
Other Ischemic heart disease	405	513	11.8%
Cerebral hemorrhage	14	410	93.4%
Cerebral thrombosis	16	266	88.7%
Cancer of respiratory system	230	192	-9.0%
Acute Myocardial infarction	169	175	1.7%
Cancer of digestive organs and peritoneum	186	163	-6.6%
Pneumonia	224	78	-48.3%

Leading Causes of Death (1) Data from At Home	**1998**	**1999**	**% change (7)**
Other Ischemic heart disease	303	393	12.9%
Acute Myocardial infarction	940	914	-1.4%
Cancer of respiratory system	862	846	-0.9%
Cancer of digestive organs and peritoneum	676	712	2.6%
Cerebral hemorrhage	118	867	76.0%
Cerebral thrombosis	40	732	89.6%
Pneumonia	416	168	-42.5%

Hospice Gospel [15]

The following are results from a market survey conducted for the Maine Hospice Council by Command Research. This survey of 400 Maine adults shows a great deal of support for Hospice. The statistical margin of error for a study of this type is plus or minus .049 at the 95th level of confidence.

This first section is a synopsis of the survey findings. On the next page are results of a 'Free Association' question where survey participants were asked "What do you associate with Hospice?"

- At the present time, 54% of those surveyed say that the current performance of Hospice is excellent (29%) or good (25%). 11% rate it as fair and only 1 % as poor. 34% say they are unable to rate it at this time.
- Moreover, spokespeople for the organization are highly regarded. 65% of those surveyed find a spokesperson for Hospice to be believable, including 28% who find such a person "very believable," 18% do not find them believable, 17% are not sure.
- Underlying these good general perceptions, however, lies some ambiguity. Only 15% say they are very familiar with the organization. 41% are somewhat familiar and no fewer than 44% of those surveyed are unfamiliar with the organization.
- When asked to free associate with the organization, fully 22% say "Nothing, not sure."
- 27% say the organization helps comfort dying people, 16% say it helps dying people and their family, 7% say it enables people to die at home and 4% say it enables people to die with dignity.
- The soft data (see section on soft data) shows a good deal of specific, positive knowledge of the organization.
- There would seem to be a huge potential "market" for the Hospice services. 63% of those surveyed said they would be likely to call on Hospice if they thought they were about to die due to a terminal illness. Only 11% said they would not and 26% were unsure.
- This number climbed to 70% when respondents were told that the costs associated with Hospice activities were basically covered by existing programs.
- 61% of those surveyed did not have a living will or some other set of directions for their family.
- For future outreach efforts, the following groups were most unfamiliar with Hospice:
  - 58% of unregistered voters
  - Over 40% of all political party members
  - 40% of all religious groups
  - 55% of those in the Bangor DMA
  - 48% of those in the Presque Isle DMA
  - Over 40% in every county except Cumberland (34%)
  - 40% of all income groups below $50,000 (34%)
  - Over 40% of all ethnic groups except Francos (37%)
  - 53% of those with a grade school education
  - 52% of those with a high school education (compared with 36% of those with a college education)
  - 52% of males, compared with 35-36% for women

What Do You Associate With Hospice? [15]

"Choice"

"The need for help at the end"

"Comfort"

"Being together at the end but needing help"

"Kind and caring people"

"Angels of mercy"

"Those who help when the end is near for people terminally ill"

"Not sure. are they the people who help you die?"

"Not clear why, but I think of 'super nurses' when I think of them, they seem so calm and careful and able to handle things"

"In the nursing homes as part of the service"

"People who are there for comfort during the dying process "

"Helping the sick" (2)

"The end of their life"

"To counsel patients" (6)

"Elderly care is what comes to mind" (5)

"Giving them peace"

"Dying and death is what I think of" (6)

"It is a form of a hospital" (2)

"Dying with zero dignity"

"Pastoral care, religious support and prolonging life"

"Support from others"

"Aids patients" (2)

"I think of a nursing home"

"It lacks personal attention and compassion"

"It deals with health issues"

"Like a business coming to a home-not comforting"

"Go between hospital and home"

"I think of compassion"

"A nurse"

"Helping the disabled"

"Home care for anyone"

"Hospice volunteers attend deaths and console relatives"

"They hurry the natural process along"

"They come to the aid of the dying person "

"Hospice helped our family cope with the death of my dad -- I will always be grateful to them"

"They are a group of trained volunteers who offer support and comfort to those who are most in need"

"I don't know too much about them but they seem to have a following"

"Hospice helped my brother and me deal with moms death"

"I will always be appreciative to them" (Hospice)

"They provide hospital beds to your house"

"They were at the hospital with us when my dad died, very comforting to us all"

"God knows we need something -- I think this subject is not one I care to discuss with a stranger"

"They really are wonderful people"

"Who can help with a very painful situation"

"They can work with the doctors and assist when the doctors are too busy"

"They are volunteers who help because of their training to those who are most vulnerable"

"Those people are angels of mercy"

"Hospice is a wonderful organization, they were with us when my mother died, I will always be thankful"

"I have a friend who volunteers with them, and they do remarkable work"

"Hospice comforted my 91 year old aunt -- she died at home at peace"

"I think there is a need for hospice -- they can remain calm during times of crisis"

"Hospice helps with dying"

"Do they support the Hemlock Society?"

Data Sets Footnotes:

(1) Office of Data, Research and Vital Statistics
(2) Data collected from salaries covered by unemployment insurance
(3) US Census Statistical Abstract of the United States, Section 14, page 14.
(3a) US Census Statistical Abstract of the United States, Section 14, page 31: based on federal poverty rate
(4) 2 year period 1994 - 1995 11.2%
(5) Native American and Hispanic categories are ethnicities, not races
(6) Data currently being compiled. Please check our website for updates
(7) % change is provided for information not to indicate trend.
(8) www.bea.doc.gov/bea/regional/articles/
(9) US Census Bureau: Health Insurance Historical Table 4.
(10) Current Population Reports: US Dept. of Commerce, Economics and Statistics Administration
(11) Survey conducted by the Palliative Care Workgroup of the Maine Consortium for Comprehensive Cancer Control, 1999.
(12) US Dept. of Census
(13) Maine Hospice Council Annual Census Survey of volunteer and Medicare certified programs. Not all programs reported.
(14) Only Medicare certified programs keep track of cause of death.
(15) Compiled by Command Research, 155 Hildreth Rd., S. Harpswell, ME 04079 (207) 729-0649 for the Maine Hospice Council.
(16) Survey originally conducted by the Coalition for Dialogue on Death and Dying, in (1996-1998) in affiliation with the Hospice Volunteers in Midcoast Maine. The survey was distributed state-wide as part of the State-Wide Dialogue on Death and Dying project of the RWJF funded Community State Partnership project (1999-2001).

Care at the End of Life: A Public / Private Partnership

(Grant work completed in 2002 – Final report available from MHC office.)

Executive Summary

In January 1999, the Maine Consortium for Palliative Care and Hospice (MCPCH) received a three-year grant of $450,000 from Robert Wood Johnson for a project entitled, "Care at the End-of-Life: A Public / Private Partnership". The Consortium was one of four implementation grants to receive funding under a new program encouraging state and community groups to reshape public policy affecting end-of-life care.

The Maine Consortium includes agencies, groups and individuals from throughout the state. The group believes Maine residents have begun to identify end-of-life issues unique to the state's culture, but that progress needs to be made in a number of key areas such as access, education, economics, clinical improvement and grassroots education. The goal is for death to be treated as more than a medical event by infusing the philosophy of hospice care into all end-of-life care.

The Maine Hospice Council will administer the program. The leadership team will be comprised of Kandyce Powell, MSN, RN; Larry Harcourt, M.D.; and Michael Murphy, Ph.D., and carried out by the 14 grant partners listed below:

Anthem Blue Cross and Blue Shield
Bingham Program
Coalition for Dialogue on Death and Dying
E.S. Muskie School of Public Service
Home Care Alliance
Maine Council of Churches
Maine Health Care Association
Maine Hospice Council
Maine Hospital Association
Maine Medical Assessment Foundation
Maine Medical Association
Maine Osteopathic Association
Organization of Maine Nurse Executives
University of New England

Each partner has carved out a piece of this project which is compatible with its mission, compatible with the mission of MCPCH, and realistic within the context of this proposal. Several of the partners have agreed to collaborate on objectives in order to more comprehensively address a specific barrier. With the understanding that, in order for change to occur, responsibility for that change needs to be shared. Following is a brief description of each partner's goals and objectives.

Anthem Blue Cross and Blue Shield

Goal: Develop a "model" Hospice benefit that is interdisciplinary, community centered, and evidenced based.

Objectives: 1) Collaborate with other partners in assessing current reimbursement practices for Hospice and palliative care. 2) Challenge the state's other managed care organizations to participate in the project. 3) Evaluate adequacy of reimbursement. 4) Collect qualitative data from nurse case managers regarding strengths/weaknesses of present system. 5) Extrapolate relevant financial/utilization statistics from existing database. 6) Identify any changes necessary in public policy re reimbursement and make recommendations for change.

Coalition for Dialogue on Death and Dying

Goal: Engage the local community to assume responsibility towards end-of-life care by replicating existing coalition model in five regions of the state.
Objectives: 1) Understand each of the areas diverse cultures of dying and bereavement. 2) Identify and assess the current system of care. 3) Evaluate end-of-life care delivery system by end of year two. 4) Adopt an action plan addressing end-of-life care systems change in each area. 5) Increase knowledge about end-of-life issues and resources available.

E.S. Muskie School of Public Service

Goal: Perform ad hoc policy analyses regarding Medicare/Medicaid policy and other reimbursement for Hospice.
Objectives: 1) Analyze relationships between managed care organizations and Hospice. 2) Analyze relationships between Long Term Care and Hospice.

Home Care Alliance

Goal: Work collaboratively with other grant partners to shape public policy.

Maine Council of Churches

Goal: To engage the local faith communities to assume responsibility for improving end-of-life care.
Objectives: 1) Establish 18 multi-faith congregational dialogues over a three-year period. 2) Develop an anthology/manual. 3) Prepare report for congregations in Maine.

Maine Health Care Association

Goal: Develop baseline data in long-term care settings.
Objective: 1) Design an assessment tool. 2) Collect information on LTC residents who are transferred to acute care facilities to die, the existence of pain management protocols in the LTC facilities, and the percent of patients with advance directives.

Maine Hospice Council

Goal: Increase awareness and education regarding Hospice and Palliative Care in Maine.
Objectives: 1) Develop a central repository for information regarding end-of-life care working in collaboration with the Maine Hospital Association. 2) Develop and publish a statewide resource directory in collaboration with the Coalition for Dialogue on Death and Dying and Council of Churches. 3) Design and implement a Hospice and Palliative Care curriculum for medical students at the University of New England in collaboration with UNE and the Maine Osteopathic Association. 4) Produce interim reports to the legislature. 5) Engage, print, and broadcast media in the partnership effort. 6) Schedule public hearings on end-of-life care throughout the state. 7) Increase Medicare Hospice referrals from 6% to 10% over a three-year period in collaboration with the Home Care Alliance and other appropriate organizations.

Maine Hospital Association

Goal: Examine the role of healthcare institutions regarding end-of-life care.
Objectives: 1) Provide information and education on advanced care planning, pain and symptom management resources for spiritual and emotional support. 2) Host conference for hospital and affiliated staff in year one with a follow-up conference in year two. 3) Initiate palliative care compact with member institutions.

Maine Medical Assessment Foundation

Goal: Collect epidemiological data on pain and symptom management across several practice settings in two communities in Maine.

Objectives: 1) Design a program for data collection. 2) Identify two communities in Maine willing to participate (one has been identified). 3) Seek outside funding for implementation of program. 4) Establish benchmarks related to end-of-life which may be established and tracked over time.

Maine Medical Association

Goal: To provide more physician education regarding end-of-life care.

Objective: 1) Send five to ten physicians to train with the AMA's EPEC project. 2) Establish forums to implement the EPEC Program statewide.

Maine Osteopathic Association

Goal: To provide more physician education regarding end-of-life care.

Objectives: 1) Work collaboratively with UNE to develop curriculum for medical students.

OMNE

Goal: Work collaboratively with other grant partners to shape public policy.

University of New England

Goal: Design, implement, and evaluate a curriculum, for medical students regarding end-of-life care.

Maine Consortium for Palliative Care and Hospice

History

There have been various individual and organizational efforts to increase awareness about end-of-life care in Maine since 1978. Since 1984, the Maine Hospice Council has provided leadership in this area with an emphasis on collaboration as a means to effect more lasting change. The mission of the Council has been to ensure the continued development of Hospice and Palliative Care in Maine.

In December 1997 in response to an overwhelming concern to improve end-of-life care in the State of Maine, the Maine Hospice Council partnered with other organizations to create the Consortium for Palliative Care and Hospice. Its mission is to create a socially responsive environment in the State of Maine for compassionate care at the end of life. It has served as the catalyst and consensus body for identifying, assessing, and discussing the culture, issues, programs, and potentially needed changes regarding death, dying and bereavement in the State.

The Consortium committed itself to several goals which are ongoing and sustainable. For the purpose of the Robert Wood Johnson Foundation Grant, the Consortium focused on five categories: education, clinical improvement, community dialogue, access, and economics. There were seven major goals set for the three-year project:

1. Identify the attitudes and perceptions of care at the end of life through community dialogues and focus groups as well as in various faith-based arenas.
2. Implement a Hospice rotation for medical students at the University of New England.
3. Address pain and symptom management through a collection of baseline data and community benchmarking.
4. Assess Hospice Medicare/Medicaid utilization as well as the impact of the Balanced Budget Act on the health care delivery system in Maine and analyze relationships between managed care organizations and Hospice.
5. Develop a more comprehensive patient satisfaction survey which addresses issues of palliative care.
6. Develop and pilot an "ideal" benefits package for cost-effective, quality care at the end of life.
7. Produce reports for consumers, providers and policymakers which will show progress toward improving care at the end of life.

MCPCH Vision and Mission Statement

Vision: We envision communities that are responsible for dynamic social policies and practices that support high quality end of life care.

Mission: Create a socially responsive environment in the state of Maine for compassionate care at the end of life.

Goals:

1. Identify the cultures of dying and bereavement in the state of Maine.
2. Increase awareness and understanding of Hospice and Palliative Care in Maine through education at the provider, consumer, legislative and individual level.
3. Awaken communities to the need for re-defining traditional roles and responsibilities in end of life care.

   For example: The term 'communities' is used broadly to encompass the health care community, social institutions, individuals and their families, private organizations, the workplace, etc.

   Address external and internal factors affecting end-of-life care.

For example: Cultural attitudes, reimbursement structures, policies and regulations, and other barriers to effective end of life care

4. Provide guidelines that improve end-of-life care.

   For example: Integrative guidelines, which address the continuum of Care and incorporate a Patient Bill of Rights and Responsibilities

5. Ensure accountability within the public and private sectors for access to end of life care.

   For example: Benchmarking

6. Develop and implement a statewide Compact on Hospice and Palliative care, which will address our uniquely human essence – the physical, spiritual, intellectual and emotional dimensions, which constitute the whole person.

   For example: Patient Bill of Rights and Responsibilities, Collaborative Compact

Promote legislative and regulatory changes that will improve end-of-life care.

7. Empower individuals and families to take an active role in their end-of-life care including appropriate advance planning measures.
8. Evaluate the economic changes that will need to take place to improve end-of-life care. Monitor and collaborate with other regional and national projects designed to study and improve end-of-life care.

   For example: Last Acts, Project on Death in America, and Foundation for Accountability.

Maine Consortium for Palliative Care and Hospice Membership

Abby Alexander, Portland
Henry H. (Toby) Atkins II, Bangor
Thom Blackstone, Presque Isle, Grant Memorial United Methodist Church
Stuart Bratesman, University of Southern Maine
Bonita Breault, Bar Mills
Myra Broadway, Augusta, Board of Nursing
Franklin Brooks, Portland, National Association of Social Workers
Joseph Bruno, Raymond, Maine House of Representatives
Gail Clinton, South Portland
Laurel Coleman, Augusta
Rebecca Colwell, Waterville, Healthreach Network
Kevin W. Concannon, Augusta, Department of Human Services
Virginia Delorimier, Augusta, Board of Nursing
Marguerite DeWitt, Rockport
George Joe Dreher, Family Practice Center
Janet L Durgin, Presque Isle, Hospice of Aroostook
Virginia Feleppa, Togus, Togus VA Medical Center
Jim Fernald, Mt. Desert, Maine Funeral Director's Association
Christine Gianopoulos, Augusta, Department of Human Services
John H. Grotton, Augusta, Board of Pharmacy
Megan Hannan, Brunswick, American Cancer Society
Larry J. Harcourt, Portland, Maine Council of Churches
Lisa Harvey-McPherson, Bangor, Ross Care EMHC
Nancy Herk-Bott, Brunswick, Bath-Brunswick Area Respite
Maureen Higgins, Scarborough, Maine Medical Center - Scarborough
Alfred L. Hipkins, Brunswick, MCPCH/CSP/MHC
Anne L. Hunter, Scarborough, Maine Center for Cancer Medicine
Greg Jamison, Holden, Maine Pharmacy Association
Martha Jordan, Augusta, National Association of Social Workers
Thomas J. Keating, Brunswick
Robert Keller, Manchester, Maine Medical Assessment Foundation
Patricia Kenney, Portland, Techmed IV
Marge L. Kilkelly, Wiscasset, Maine Senate
Juliana L'Heureux, Brunswick, CHANS Home Health Care
Lorraine Lachapelle
Dick Legere, Wells, Maine Board of Pharmacy
Randall Manning, Augusta, Board of Licensure in Medicine
Jan Martens-Staples, Portland

Kellie P. Miller, Manchester, Maine Osteopathic Association
Dora Anne Mills, Augusta, Dept of Human Services, Bureau of Health
Betty Lou Mitchell, Etna
Pam Morrill, Manchester, Maine Medical Association
Michael J. Murphy, Brunswick, Coalition for Dialogue on Death and Dying
Leslie H. Nicoll, Portland, E. S. Muskie School of Public Service, University of Southern Maine
Darby Northway, University of New England
Sylvia Drake Paige, Windham
Judy Paradis, Frenchville
Richard Polkinghorn, Falmouth
Kandyce Powell, Augusta, Maine Hospice Council
Vicki Purgavie, Augusta, Home Care Alliance
Michael W. Quint, Portland
Daniel Rissi, Blue Hill, Blue Hill Memorial Hospital
Kate Roberts, Portland, National Association of Social Workers
Gwen Rogers
Linda C Russell, Portland, Petrudcelli & Martin
Paul Saucier, Portland, E. S. Muskie School of Public Service, University of Southern Maine
Jim Schneid, Augusta
Ellen Jane Schneiter, Manchester, Maine Medical Assessment Foundation
Sheila Seekins, Washington
Joseph Semmes, South Portland
David Simmons, Calais, St. Croix Medical Group
Edie Smith, Hallowell, Maine Citizens Against the Dangers of Physician-Assisted Suicide
Gordon Smith, Manchester, Maine Medical Association
Lendall Smith, South Portland, Anthem Blue Cross and Blue Sheild
Ann E. Sossong, Old Town, Maine Bioethics Network
Sue Strout, Augusta, Board of Osteopathic Exam / Regulation
Kathleen Stuchiner, Augusta, Maine Hospital Association
Brooke Tenney, Scarborough, Maine Hospice Council
Meridith L. Tipton, S. Portland, Anthem Blue Cross and Blue Shield
Tom Tracy, Lewiston, Bates College
Cheryl Tucker, Brunswick, American Cancer Society
Paula Valente, Augusta, Maine Health Care Association
Jacob Watson, Portland
Elihu York, Brunswick, Physician, retired

THE MAINE COMPACT FOR PALLIATIVE CARE AND HOSPICE

SPONSORED BY
THE MAINE CONSORTIUM FOR PALLIATIVE CARE AND HOSPICE

AND
THE MAINE HOSPICE COUNCIL

PURPOSE To address the comprehensive management of the physical, psychological, social, spiritual and existential needs of people at the end of life.

WHEREAS The philosophy of Palliative Care and Hospice affirms life and regards dying as a natural process that is a profoundly personal experience for individuals and their families; and

WHEREAS The goal of Palliative Care and Hospice is to achieve the best possible quality of life through relief of pain and suffering while remaining sensitive to personal, cultural and religious values, and beliefs and practices; and

WHEREAS Palliative Care and Hospice guide patients and families as they make the transition through the changing goals of care and help the dying patient who wishes to address issues of life completion and life closure; and

WHEREAS Palliative Care and Hospice rely on the formulation of responsible policies and regulations by institutions and by local, state and Federal governments; and

WHEREAS Palliative Care and Hospice involve advanced care planning, including advance directives through ongoing dialogue among providers, patients and families; and

WHEREAS Palliative Care and Hospice recognize and address the economic costs of care-giving including the loss of income and non-reimbursable expenses; and

WHEREAS Palliative Care and Hospice will ensure accountability within the public and private sectors for access to end of life care; and

WHEREAS Palliative Care and Hospice increase awareness and understanding about end of life care through education of individuals, health care professionals, legislators, insurers and others.

BE IT RESOLVED that we, the undersigned, shall commit our efforts and encourage others to create a socially responsive environment in the State of Maine for compassionate care at the end of life.

Maine Consortium for Palliative Care and Hospice

Honesty. Dignity. Comfort

Organizations Represented on the Compact

American Cancer Society
Anthem Blue Cross and Blue Shield
Bates College
Bath-Brunswick Area Respite
Blue Hill Memorial Hospital
Board of Licensure in Medicine
Board of Nursing
Board of Osteopathic Exam / Regulation
Board of Pharmacy
CHANS Home Health Care
Coalition for Dialogue on Death and Dying
Department of Human Services
Department of Human Services, Bureau of Health
E.S. Muskie School of Public Service, USM
Family Practice Center
Grant Memorial United Methodist Church
HealthReach Network
Home Care Alliance
Hospice of Aroostook
Maine Bioethics Network
Maine Board of Pharmacy
Maine Center for Cancer Medicine
Maine Citizens Against the Dangers of Physician-Assisted Suicide
Maine Council of Churches
Maine Funeral Director's Association
Maine Health Care Association
Maine Hospice Council
Maine Hospital Association
Maine House of Representatives
Maine Medical Assessment Foundation
Maine Medical Association
Maine Medical Center
Maine Osteopathic Association
Maine Pharmacy Association
Maine Senate
MCPCH
National Association of Social Workers
Petrudcelli & Martin
Ross Care EMHC
St. Croix Medical Group
Techmed IV
Togus VA Medical Center
University of New England
University of Southern Maine

Individuals

Abby Alexander, Portland
Henry H. (Toby) Atkins II, Bangor
Thom Blackstone, Presque Isle
Stuart Bratesman,
Bonita Breault, Bar Mills
Myra Broadway, Augusta
Franklin Brooks, Portland
Joseph Bruno, Raymond
Gail Clinton, South Portland
Laurel Coleman, Augusta
Rebecca Colwell, Waterville
Kevin W. Concannon, Augusta
Virginia Delorimier, Augusta
Marguerite DeWitt, Rockport
George Joe Dreher,
Janet L Durgin, Presque Isle
Virginia Feleppa, Togus
Jim Fernald, Mt. Desert
Christine Gianopoulos, Augusta
John H. Grotton, Augusta
Megan Hannan, Brunswick
Larry J. Harcourt, Portland
Lisa Harvey-McPherson, Bangor
Nancy Herk-Bott, Brunswick
Maureen Higgins, Scarborough
Alfred L. Hipkins, Brunswick
Anne L. Hunter, Scarborough
Greg Jamison, Holden
Martha Jordan, Augusta
Thomas J. Keating, Brunswick
Robert Keller, Manchester
Patricia Kenney, Portland
Marge L. Kilkelly, Wiscasset
Juliana L'Heureux, Brunswick
Lorraine Lachapelle,
Dick Legere, Wells
Randall Manning, Augusta
Jan Martens-Staples, Portland
Kellie P. Miller, Manchester
Dora Anne Mills, Augusta
Betty Lou Mitchell, Etna
Pam Morrill, Manchester
Michael J. Murphy, Brunswick
Leslie H. Nicoll, Portland
Darby Northway,
Sylvia Drake Paige, Windham
Judy Paradis, Frenchville
Richard Polkinghorn, Falmouth
Kandyce Powell, Augusta
Vicki Purgavie, Augusta
Michael W. Quint, Portland
Daniel Rissi, Blue Hill
Kate Roberts, Portland
Gwen Rogers,
Linda C Russell, Portland
Paul Saucier, Portland
Jim Schneid, Augusta
Ellen Jane Schneiter, Manchester
Sheila Seekins, Washington
Joseph Semmes, South Portland
David Simmons, Calais
Edie Smith, Hallowell
Gordon Smith, Manchester
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Ann E. Sossong, Old Town
Sue Strout, Augusta
Kathleen Stuchiner, Augusta
Brooke Tenney, Scarborough
Meridith L. Tipton, S. Portland
Tom Tracy, Lewiston
Cheryl Tucker, Brunswick
Paula Valente, Augusta
Jacob Watson, Portland
Elihu York, Brunswick

The Maine Center for End of Life Care

> *"The Maine Hospice Council and the Maine Center for End-of-Life Care exist to ensure the continued development of Hospice and Palliative Care in Maine. The Council and Center provide education and technical assistance regarding end-of-life care, as well as advocacy for terminally ill and bereaved persons regarding quality-of-life issues throughout the State."*

Strategic Plan: Modeled on the strategic plan developed for the Maine Hospice Council.

Report to Maine Legislature on January 15, 2003 on the progress of the Center.

Committees of the Maine Hospice Council and the Maine Center for End of Life Care:

- Advocacy
- Clinical/Regulatory
- Community Engagement
- Education
- Finance
- Maine Cancer Pain Initiative
- Marketing
- Policies and Procedures
- Provider Advisory
- Research and Data Collection

Barriers to End-of-Life Care: Perspectives from the State of Maine

Providing quality end-of-life care to terminally ill patients, their loved ones and families, requires that we have an understanding of what they need and want, and what barriers exist that are preventing quality care from being achieved. To identify issues of concern to Maine citizens around end-of-life care and to solicit their opinions on what strategies would be appropriate to address these issues, a series of seven public forums were held throughout the state to give citizens an opportunity to share their thoughts, feelings, concerns and opinions about end-of-life care.[†] Participants included health professionals, patients and family members, and others involved in end-of-life care. The leadership team of the Community-State Partnerships project, plus a local member of the healthcare community in which the forum was held, compromised the panel for these meetings. Participants were encouraged to openly share their thoughts, feelings, concerns and opinions in a non-judgmental and non-confrontational environment.

Findings

There were nine dominant themes that emerged from the meetings:

- People have a great fear of dying alone, isolated and lonely, away from loved ones, friends and family.
- For many, the notion of a "good death" is a myth.
- The health care system is a giant red-tape bureaucracy that is intimidating and must be managed. It is also expensive.
- Pain is an inevitable part of the dying process.
- There is a conspiracy of silence around death and dying, both conceptually and practically.
- People are often not able to obtain what they need, whether it be medication, services or a health care provider, or respite care.
- There is a desperate need for education, both for health care providers and the general public.
- The pain of survivors is real and long lasting.
- People have a great need to tell their stories.

Conclusions

People were able to articulate their frustrations with the health care system and the dying process, but were less able to suggest strategies to ameliorate the problems. There was a general consensus that we all own this problem: it is not something that will be fixed by policy or the heath care providers. Even though the system issues are seen as enormous problems, many people felt that even small changes in the system would generate big rewards. For example, earlier referrals of a dying patient to hospice would allow more time for the hospice team to be effective and for the dying person's family to come to terms with the situation. Having pain medications available in a timely fashion (many people described waiting 12-24 hours for medication) would help to manage the patient's pain and ease the suffering of the family. Increasing the number of volunteer and staff in hospice programs would provide a level of support and respite care that is currently perceived as limited.

[†] These hearings were conducted as part of the Robert Wood Johnson Foundation funded Community State Partnership. For the complete report on these public hearings and other relevant data and information regarding end-of-life care, please visit the Maine Hospice Council website: www.MaineHospiceCouncil.org