Maine Hospice Council, Inc.

Promoting Excellence in End-of-Life Care

693 Western Avenue, Manchester
Post Office Box 2239, Augusta, ME 04338

(800) 438-5963
www.mainehospicecouncil.org

About the Council

Since 1984, the Maine Hospice Council has been creating innovative opportunities, fostering collaboration, and serving as a convener and educator for end-of-life issues.

Change in attitudes and practice behaviors has been slow in coming; however, the social and demographic imperative to continue is stronger than ever, as demonstrated by the increase in Maine's aging population.

Maine's Aging Population: residents age 65 and over will increase from 13.9% in 2000 to 21.4% in 2025. In addition, there will be a 40% increase in the number of people over age eighty-five by 2010.

Mageean, Deidre, et.al.,
"Wither Maine's Population?"
Maine Policy Review, Winter 2000.

The Maine Hospice Council has been, and remains, the only state-wide nonprofit agency in Maine dedicated solely to improving the quality of end-of-life care.

The MHC provides:

Advocacy for individuals, families, and healthcare providers.

Consultation to patients, families, healthcare professionals, workplaces, and academic institutions.

Technical Support regarding program development, fundraising, grant writing and other infrastructure concerns.

Education for consumers, healthcare professionals, volunteers, and other caregivers.

Representation at local, state, and national levels.

Resources developed by the Council as well as other local and national leaders.

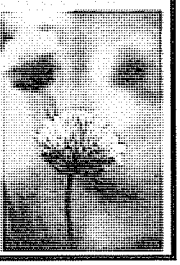
Collaboration and partnership development with local, state, and national organizations.

Research and data collection to benchmark progress.

Placement for undergraduate and graduate student interns.

Press Releases opinion pieces and professional journal submissions.

Public Speaking to increase awareness.



Programs and Partnerships

Maine Center for End of Life Care

The mission of the Center is to act as an incubator for change, promote innovation, and foster community-based collaboration.

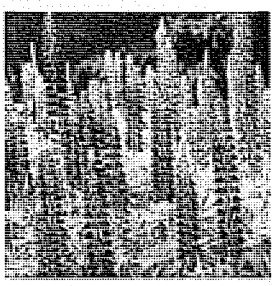
> "The goals outlined for the Center are instrumental in the expansion and improvement of hospice and palliative care in Maine." Dora A. Mills, MD, MPH, Director, Bureau of Health, State Health Officer.

Consumer Protection

The MHC, together with Maine's Office of the Attorney General, continue to address questions of importance to consumers:

- Will my pain be managed?
- Will my wishes be respected?
- Will I receive competent care?

Maine Pain Initiative



A multi-disciplinary group of healthcare professionals, consumers, and other interested persons committed to making pain relief a reality for all people in Maine.

Hospice/Veteran Partnership

A coalition of interested individuals from the Department of Veterans Affairs, Maine Veterans Homes, Maine Hospice Council and community hospice programs working together to ensure that quality end-of-life care is available for Maine's veterans and their families.

Maine Chapter ALS Association

A partnership to increase awareness and develop educational programs for patients, families, and healthcare providers dealing with neuro-degenerative diseases.

Maine Health Care Association

A partnership focusing on quality-of-life issues in Maine's long-term-care facilities.

Department of Corrections

MHC and the Department of Corrections are working collaboratively to improve the quality of end-of-life care within the Maine State Prison system.

> "There are many organizations willing to serve individuals who are in need . . . but only the Maine Hospice Council stepped up to the plate to work with one of the most disenfranchised group of individuals: offenders. June Koegel, President/CEO, Volunteers of America.

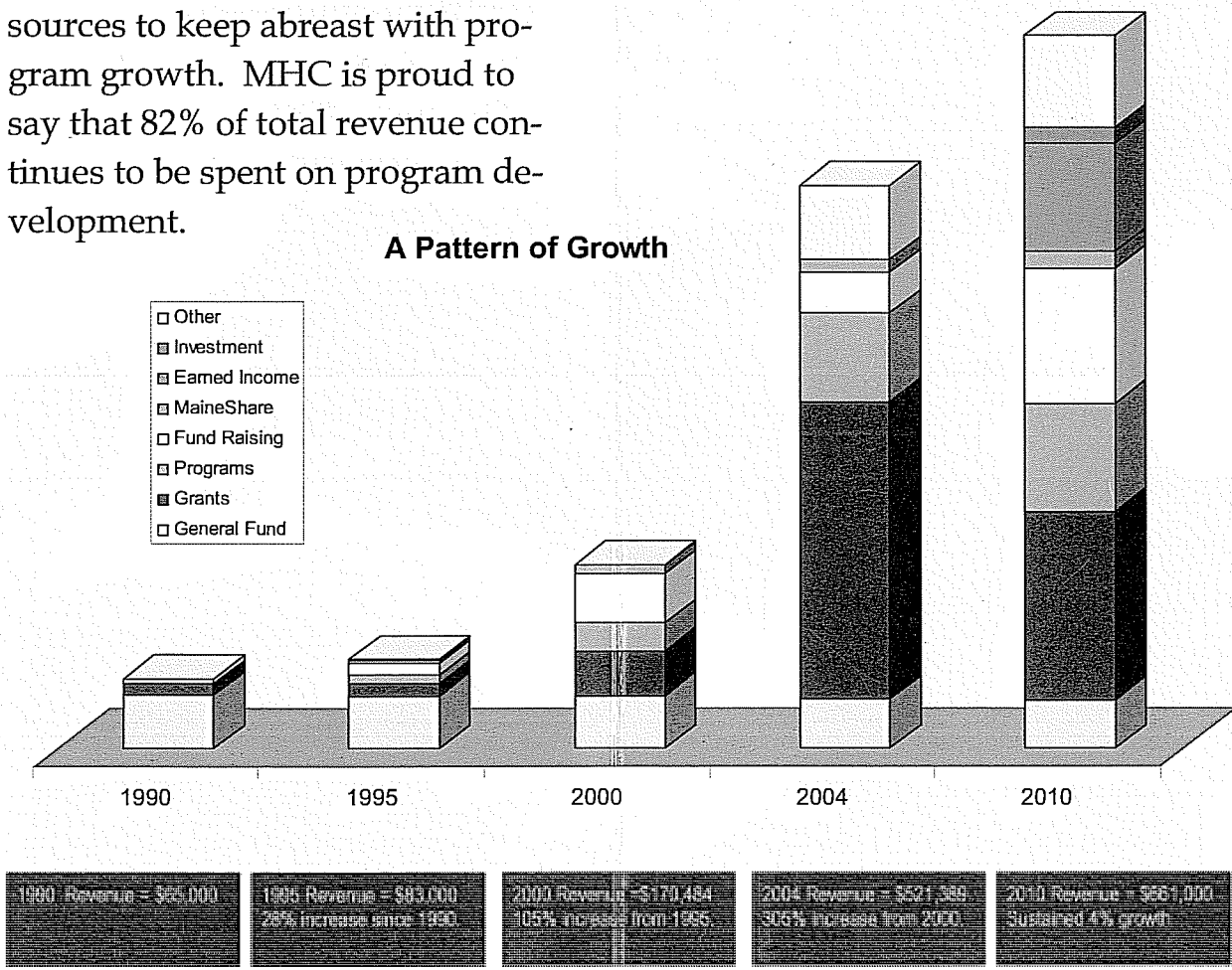
The Maine Hospice Council receives financial support from many sources, including grants, MaineShare (a workplace giving organization) membership dues, sponsorships, annual appeals, Maine State General Fund, memorial gifts, donations, estate planning, and private foundations.

Since 1990, the MHC has continued to expand its revenue sources to keep abreast with program growth. MHC is proud to say that 82% of total revenue continues to be spent on program development.

Ambitious programs, like the Maine Center for End of Life Care, require substantial funding. Your financial support is critical as the Maine Hospice Council continues this very important work.

You can make a difference!

A Pattern of Growth



Your Gift is Important!

Yes! I would like to support the work of the Maine Hospice Council. Please accept this gift in the amount of $_____

Name: _____

Address: _____

_____

Email: _____

❑ Check here to keep your donation anonymous.

Credit Card donations accepted by phone at 800-438-5963.

Mail this completed form
with your check to:
Maine Hospice Council, Inc.,
PO Box 2239,
Augusta, ME 04338-2239

Please also send me information about:

- ❑ Committee membership
- ❑ Educational events
- ❑ Estate planning
- ❑ Local Coalitions
- ❑ Volunteer opportunities

All gifts are tax-deductible and will be acknowledged with a personal thank you letter and tax receipt.

Hospice/Veterans Partnership of Maine

Working to Ensure Quality
Hospice and Palliative Care
For All Maine Veterans

Home Hospice Care

All enrolled veterans are entitled to home hospice care provided they meet hospice guidelines. These services are covered by Medicare and/or the VA. VA Hospice must be ordered by a VA provider. Hospice benefit guidelines require that the goal be palliative and not curative.

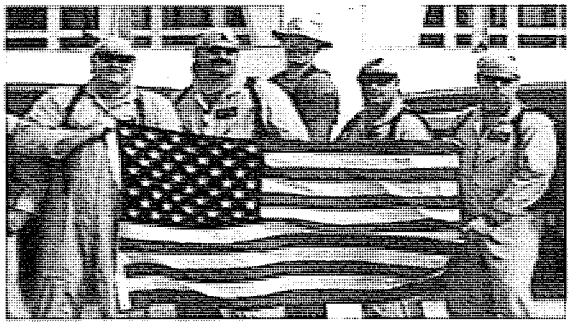
Hospice care includes:

- skilled nursing
- physical therapy
- social worker
- medications
- bereavement services
- aides
- occupational therapy
- Chaplain services
- medical equipment
- volunteers

Enrollment for veterans can be expedited in the case of a terminal diagnosis.

Hospice patients may also be eligible for the Home Maker Health Aide Program to assist with homemaking services, personal care and respite.

If you need to be enrolled (in order to receive hospice care), have questions regarding home hospice, or need a VA provider to receive hospice care, please contact the Community Health Nurse Coordinator at Togus VA Medical Center.



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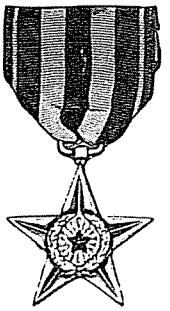
Maine Veterans' Homes
"Caring for those who served."

The Maine Veterans' Homes provide long-term care to veterans, their spouses, widowed spouses and Gold Star parents. MVH are not part of Togus or the Veterans Administration. Homes are located in Augusta, Bangor, Caribou, Machias, Scarborough, and South Paris.

Eligibility

To qualify for admission, the applicant must:



- be an honorably discharged veteran who served on active duty in the U.S. Armed Forces for at least 180 days;
- be a resident of Maine at the time of application, or have resided in Maine at the time of enlistment;
- be a spouse, widow or widower of an eligible veteran; or
- be a Gold Star parent of a veteran killed in the line of duty.

End-of-Life Care

The dedicated staff and volunteers at the Maine Veterans' Homes provide compassionate and supportive end-of-life care to our terminally-ill residents and their families. Pain and symptom control, psychological, social and spiritual concerns are addressed through an interdisciplinary approach. Community based hospice services will provide additional end-of-life services and resources for the resident and their family.

At Maine Veterans' Homes, we recognize and celebrate the individual and maintain their dignity in life and in the dying process.

Togus VA Medical Center

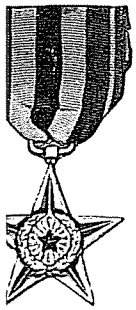
Togus VA Medical Center provides both inpatient and outpatient end-of-life services.

Inpatient services:

- hospice and palliative care
- respite care

Outpatient services:

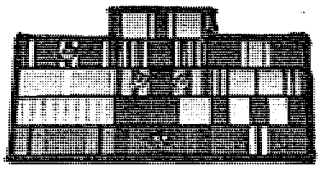
- hospice support calls to veterans and their families
- after-hours calls for veterans through local hospice agencies
- VA personnel may be available for home visitation on a case-by-case basis



Our goal is to "Honor veteran's preferences at the end of life" by providing the care they deserve in return for service to our country.

Maine Hospice Council

The Maine Hospice Council and Center for End-of-Life Care is the only statewide non-profit organization solely dedicated to improving end-of-life care for the many individuals and families in Maine who are facing terminal illnesses. We provide education, advocacy and research on end-of-life issues for both consumers and health care providers. The Council's programs address consumer protection, pain management, access to care, long-term care, bereavement, volunteer support, and many other issues.

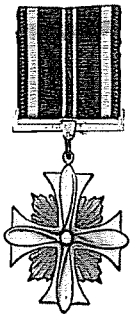


What is the Hospice Veteran Partnership?

HVP is a coalition of people from the Department of Veterans Affairs (VA), veterans homes, and community organizations working together to ensure that excellent end-of-life care is available for our nation's veterans and their families. The HVP of Maine is part of a national network.

Why were we formed?

The mission of the HVP is to establish an enduring network of hospice and VA professionals, veterans, volunteers and other interested organizations working together to provide quality end-of-life services. The HVP was formed to provide leadership, technical assistance, and program development recommendations in the following areas:



- Improving veterans' access to hospice and palliative care across practice settings, so they can receive care at the time and place of need.
- Strengthening relationships between state hospice organizations, USOs, VA organizations and veterans homes.
- Creating a comprehensive community engagement plan designed to reach veterans.

Who are our members?

Maine's HVP includes representatives from the Maine Hospice Council, the Maine Veterans' Homes, Togus VA Medical Center, Veterans Service Organizations, end-of-life coalitions, community hospice agencies, as well as other organizations and individuals interested in improving end-of-life care for veterans.

How can you get involved?

Contact the Maine Hospice Council at **(800) 438-5963.**

Contact Information

For information on enrollment, a VA provider, or home hospice:

Community Health Nurse Coordinator
(207) 623-8411 ext. 5264 or
(877) 421-8263 ext. 5264

For inpatient or outpatient services:

Togus VA Medical Center
Palliative Care Consult Team Coordinator
(207) 623-8411 ext. 5029

For information on the Maine Veterans' Homes:

Augusta	(888) 684-4664
Bangor	(888) 684-4665
Caribou	(888) 684-4667
Machias	(877) 866-4669
Scarborough	(888) 684-4666
South Paris	(888) 684-4668

For information on hospice services statewide:

Maine Hospice Council (800) 438-5963

Web Resources

Maine Hospice Council
www.mainehospicecouncil.org
Department of Veterans Affairs
www.va.gov
National Hospice and Palliative Care Organization
www.nhpco.org

 Funding for this brochure was provided in part by grants from the Maine Veterans' Homes and the Administration on Aging.

Consumer Protection and End of Life Care

Report from "A Listening Conference"

Our special thanks to:

Carol Donnell** and **Donna Muto

For sharing their compelling personal stories.

Along with

The cast of B.O.A.T.I.N.G.

Jill Bixby, Author

Carol Schoneberg, Producer

For their time and dedication to the presentation of their inspired play.

Consumer Protection And End-of-life Care

Report From "A Listening Conference"

Initial Report

Prepared by

Listening Conference Planning Committee

A partnership of

The Office of Maine's Attorney General

and

The Maine Hospice Council

This project has been made possible with generous funding from

American Cancer Society

Davis Family Foundation

Hospice Education Institute

Maine Health Access Foundation

Maine Hospice Council

Office of Maine's Attorney General

Rallying Points

Will My Pain Be Managed?

Consumer Story by **Donna Muto**

PANEL

June Dahl, PhD, Department of Pharmacology
University of Wisconsin Medical School

Diana Rae, RN, MSN
Penobscot Bay Medical Center

Steven L. D'Amato, RPh, BCOP, Clinical Pharmacy Specialist
Maine Center for Cancer Medicine and Blood Disorders

James Cameron, Assistant Attorney General
Maine Office of the Attorney General

Will My Wishes Be Honored?

Consumer Story by **Carol Donnell**

PANEL

Myra Christopher, President & CEO
Center for Practical Bioethics

Carol Schoneberg, BA, End-of-Life Educator and Volunteer Program Manager
Hospice of Southern Maine

Deborah Alpern, MSW, Palliative Care Social Worker
Midcoast Hospital

Laurel Coleman, MD
Geriatrics and Palliative Care

Will I Receive Competent Care?

Dramatized by the play **B.O.A.T.I.N.G.**

PANEL

Ben Rich, JD, PhD, Associate Professor of Bioethics
University of California Davis School of Medicine

Tom Keating, MD, Medical Oncologist
Maine Center for Cancer Medicine and Blood Disorders

Lauren Michalakes, MD, Medical Director
Hospice of Southern Maine

Jill Bixby, NP, MA, BSN, Palliative Care Coordinator
MaineGeneral Medical Center

Introduction

In 2003, Drew Edmonson, Attorney General of Oklahoma and President of the National Association of Attorneys General (NAAG), focused his presidential initiative on end-of-life care. Attorney General Edmonson realized that what individuals needed to insure a death free from pain, with adequate resources, in a setting of choice – was, in many cases, not what was happening in reality.

"Listening Conferences" were scheduled in three regions: Kansas City, San Diego, and Baltimore. Family members, health care professionals working in end-of-life care, Attorneys General and Assistant Attorneys General were invited to hear stories and relevant health care data. Poignant consumer stories led off each topic that addressed the following three questions:

Will my pain be managed?

Will my wishes be honored?

Will I receive competent care?

The intent was clearly not to point fingers or place blame, rather to increase awareness and engage State Offices of Attorneys General in these efforts.

The stories were provocative and challenged those in attendance to improve education, clinical practice, reimbursement, policy and regulation.

An Assistant Attorney General from Maine's Office of the Attorney General and Kandyce Powell, Executive Director of the Maine Hospice Council, returned from Baltimore with information and ideas to discuss with Attorney General Steven Rowe.

As a result, information was added to the Attorney General's website; the Attorney General designated a contact person for end-of-life issues; and plans began taking shape for a "listening conference" for Maine.

Through the generous financial support of several organizations and foundations, the diligence of the planning committee and the involvement of the Attorney General and his staff, a successful "Listening Conference" was held on September 28, 2004 at the Samoset Resort in Rockport, Maine. The stories of two courageous consumers and a compelling play written by Jill Bixby were presented to highlight the questions mentioned above.

The following pages contain highlights of the conferences as well as recommendations for next steps. We invite you, the reader, to join us as efforts continue to effect change and improve care for all people in Maine.

Kandyce Powell

Kandyce Powell, Executive Director,
Maine Hospice Council

Opening Remarks

The following are excerpts from Attorney General Steven Rowe's opening remarks.

The Office of the AG is proud to be a co-sponsor of this "Listening Conference" with the Maine Hospice Council. I want to thank Kandyce Powell and the Planning Committee for all the work they did to make this conference a success.

Dying is a fact of life. Just as sure as we were born, we will die. We all know loved ones who have died. Most of us, I expect, know loved ones who have died with pain. We know from statistics that many of us will experience pain associated with dying.

You may wonder why my office is involved with this issue. The answer is quite simple. One of the key missions of the Office of the Attorney General is to protect consumers, including health care consumers. And end-of-life care is the ultimate health care consumer protection issue.

At the end of the national listening conferences, a group of AGs met to discuss what we had learned. We found that the conferences confirmed what we had heard. When asked about their expectations at the end-of-life, most people expressed the same desires: to receive effective pain management, to be surrounded by family and friends and to avoid extraordinary medical intervention. We also learned some other things.

- We learned that end-of-life care in the United States is mediocre at best.
- We learned that most Americans know nothing about hospice and palliative care.
- We learned that 90% of Americans do not know that hospice is covered by Medicare. And that 75% do not know that hospice can be provided at home.
- We learned that almost all pain can be safely and effectively treated to ensure an individual's comfort, yet almost 50% of patients report unrelieved pain.
- We learned that although some of our state legislatures and professional licensing boards are beginning to adopt policies to encourage better pain management, to clarify the role of opioid analgesics and to address physicians' fears of being investigated for inappropriate prescribing, there is still a significant gap between policy and practice.
- We learned from certain experts (including physicians and nurses) that deficits exist in educational requirements in medical, nursing, social work and pharmacy schools for end-of-life health care. We also learned that statistical studies reflect a lack of education as a major factor contributing to substandard care near the end-of-life.
- We learned that there is work to do to educate people about the importance of having advance health care directives in place. And that there have been issues regarding

honoring these directives, even when they do exist.

I think it would be fair to say that the most important thing we learned is that there is a gulf between the vision that citizens have about end-of-life care and the harsh reality that too often confronts patients and caregivers at a time when they are most vulnerable.

Do these national findings reflect what is happening in Maine? I believe they do.

Over 80% of Mainers say they would prefer to die at home, yet only around 25% do. Also, half of dying patients in Maine report being in pain. Public awareness of hospice services and the benefits of such services are extremely low in our State.

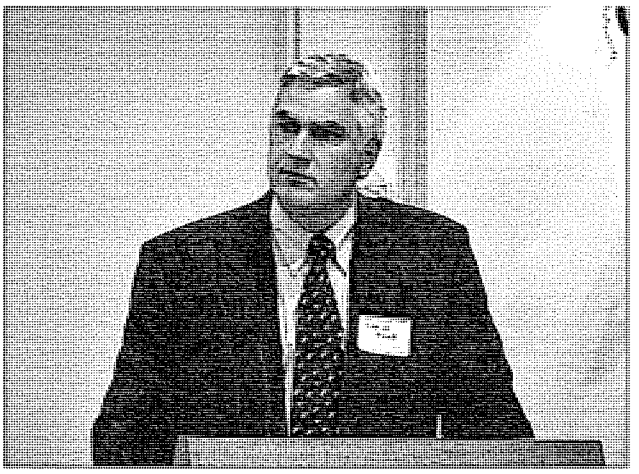
Although we have some seen a slight increase in Maine's Medicare hospice utilization rate over the past three years, we still have one of the lowest rates in the nation. The national rate is about 25%. Our state rate is about 14%. It may surprise you to know that hospice utilization rate is lowest in some urban areas where there are numerous health care facilities.

There have been improvements here in Maine. I certainly want to acknowledge that. A new End-of-Life Care law was enacted in Maine which increased the Medicaid hospice rates and mandated comprehensive hospice coverage in private insurance policies for all non-ERISA employers. It also provided for an annual budget appropriation to be divided among Maine's voluntary hospice programs.

Importantly, the new law also mandated creation of the Maine Center for End-of-life Care and required basic research on the current status of end-of-life care in Maine. The new law's main benefit – beyond extending hospice coverage – has been to expand public awareness about end-of-life care for policymakers and consumers.

To continue to expand public awareness and drawing on the experience of the national listening conferences, Kandyce Powell of the Maine Hospice Council and I thought it would be beneficial to have an end-of-life listening conference right here in Maine. We believed it necessary to better understand the barriers and opportunities to quality end-of-life health care in our State.

Attorney General, Steven Rowe



Donna's Story

My father had been living at home and had been in severe pain. He would say, "I don't mind dying, but I can't stand the pain." The helplessness and anxiety were felt by all of our family. We couldn't think clearly — it was very, very difficult. We needed help.

Father was taken to the hospital in the middle of the night and given medication to make him sleep. We went home and were told to return in the morning. When we returned early the next morning, the ER physician told the us that there was "nothing we can do for your dad, he has to go home."

He returned home and rallied for a few days but still had very bad headaches. During this time, our family physician visited and gave us the sense "that Dad had longer to live and it wasn't as bad as it was." We were able to get someone to come in during the day to assist with care, but Mom and I would be up every night because he'd be screaming in pain.

The following week, a social worker got hospice involved. After the hospice nurse talked to Dad, she went right to the phone, talked to the doctor and said that Dad needed medication. Things started to happen. The doctor prescribed a patch and the headaches were better, but still there. We could talk to him, and he could talk to us.

He had come home right after Thanksgiving and was home for five weeks before he died. The newspaper said he had died at home surrounded by his family, and it sounded wonderful. But it wasn't, it was horrible. One of the most difficult things is to watch someone you love suffer in pain, dying and feeling helpless. Hospice should have been involved earlier, but no one knew.

People do die in pain.

Will My Pain Be Managed?

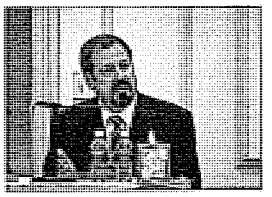
June Dahl, PhD

"We have to believe the reports patients give us. It is really unbelievable to me that people can be brought into an emergency room in desperate pain, yet only given something to provide temporary relief from pain. That any physician would say, 'There is nothing we can do for your dad, he has to go home.' Of course there are lots that can be done, primarily something in terms of appropriately managing pain. And for severe pain, the opioid analgesics are the appropriate drugs of choice — they can relieve any kind of pain known to man. There are barriers and myths to their usage, and it is up to all of us to overcome or to look for solutions to these."

Diana Rae, RN, MSN

"The reason we don't do well with pain management at the end-of-life is that we don't do well with pain in general. There are many myths that we have about pain. We used to think that pain was a benign annoyance. Science has shown us that this is not true, that it is stressful on the heart and lungs; it increases stress hormones; and it slows healing and depresses the immune response. There are enormous economic and quality of life consequences. We should listen to the patient. We shouldn't question the patient. We are far worse at approximating someone else's pain level than the patient, so we must believe them. Patients are discouraged from taking their medications appropriately, for fear from family, friends, doctors and even themselves that they may become addicted."

"We must teach the difference between addiction, tolerance and dependence."



Steve D'Amato, RPh, BCOP

"Pain should be looked at as the fifth vital sign and be monitored in all patients. It should be monitored on a routine basis and everyone's pain should be managed. One medication may work for you, but not for another person. Every dose is unique. The 'correct' dose is the dose that works. Barriers to quality pain management are access, education of medical establishments and patients and family, cost and communication."

James Cameron, Assistant Attorney General

"We should not allow the concerns for diversion or abuse of these drugs to become the emphasis of policy makers. Rather, it should be maximizing the appropriate use for these opioids."

From the facilitated discussion group

The discussion was wide ranging, but three main themes resonated throughout: awareness, communication, and accountability.

Awareness: There is a need for greater awareness of the problem of inadequate pain management in both the medical and lay communities. To this end, several ideas were introduced:

- Quality indicators for pain management could be integrated in health care policy;
- Public Service Announcements could be a valuable tool to increase public awareness;
- End-of-life and pain management goals could be part of the State health plan;
- An educational initiative addressing myths and misconceptions about pain was recommended.

Communication: Tools to improve communication could include:

- A hot line to address pain management issues for consumers and health care professionals;
- An interdisciplinary team approach to pain management;
- A statewide resource database;
- A single point-of-contact for consumers.

Accountability: There needs to be accountability for the under management of pain. Suggestions for the process of handling complaints could include the following:

- A state ethics committee that would review cases and provide recommendations;
- A system for reporting the under management of pain;
- Pain-specific continuing education as a licensure requirement for appropriate health care professionals;
- Patient representative or advocates available to patients and families.

Highlights

- Awareness
- National policy statement for prescribers
- Public service announcements
- Interdisciplinary team approach
- Continuing education requirement for license renewal
- End-of-life care included in state health plan
- Consumer line for reporting pain management issues
- State ethics committee
- Patient advocates
- Resource database of local resources
- Reimbursement issues
- Improved communication
- Single point of contact
- Universal access

Carol's Story

My parents moved to Maine so that we could help care for them in their last years. We knew what was needed and thought we did everything right.

Dad cared for mother as long as he was able, but eventually, she needed more care than he could provide, and she was placed in a nursing home. It was a very difficult decision. Dad received hospice care and died a peaceful, good death.

Several years later, we got the call we had been dreading, Mom's vital signs were not good. She rallied, but three days later, a night nurse called and said they were transporting her to the hospital. We said, "No, we have a POA". The nurse replied that we did not have a "do not hospitalize" order so the POA didn't matter and Mother was sent to the hospital.

At the emergency room she was subjected to invasive and painful tests and procedures. We could hear her screaming in pain. When the ER nurse said that we do not have to continue this, we asked what to do. He said to tell the ER doctor you want nothing more done. We did this immediately.

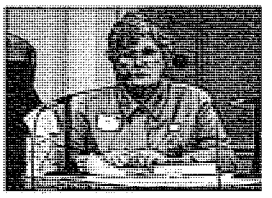
It was about four hours later when the doctor wanted to put her in ICU. I said, "She doesn't need intensive care, she's dying," and he agreed.

We left for about an hour. When we returned a nurse stopped me and said my mother had died about 10 minutes earlier.

Why did my mother have to die under such horrible circumstances? Who was responsible for her being taken to the hospital against our wishes? The nursing home, the doctor, the nurse, or did I fail somewhere along the line? The POA gave me 'the power to consent to giving, withholding, stopping any health care treatment, service or diagnostic procedure.' Why did it take an ER nurse to end the senseless pain and suffering?

Will My Wishes be Honored?

Myra Christopher, Center for Practical Bioethics



"People should have the right to be self-determining; to be autonomous; and to name others they trust to be their decision makers when they no longer have capacity. The vast majority of us will not have capacity at the time of our death. Any valid expression of a patient's prior wishes, whether verbal, written, or video taped should be honored."

Carol Schoneberg, BA

"Technology has a lot to offer and that can give rise to some very hard decisions. The same technologies that can support life and help our bodies heal, when that's what we want, can also be used when our bodies are no longer able to heal. This technology can add a lot of discomfort as well as pain and suffering. Someone needs to decide how much and how long these treatments are going to be used, and at what point being comfortable and free of pain should have priority over invasive tests and treatments that are aimed at the disease. Ideally, it should be the patient that guides these decisions, but when they can't speak, someone else must decide for them. When looking at advanced care planning you assess your current health status, your values and goals and what it means to you to live well at the end-of-life. It's about personal goals, not the goals of the health care provider. We may need advocates to get this message across."

Laurel Coleman, MD

"In certain populations it becomes difficult to elicit advanced directives. Patients suffering dementia or Alzheimer's disease are especially difficult cases. We can have great policy, great forms, and a great staff, but the conversation about patient wishes needs to happen years before, not at admission to a nursing home."

"We ask a lot of long-term care but give it relatively little in the way of resources."

Deb Alpern, MSW

"When a patient is ready for discharge from the hospital, we need to be aware of perhaps the greatest barrier of all to honoring patient's wishes: the imposing of our own views on patients and families. This is not about us, or what a health care provider would choose in the same situation."

"When we help one patient and one family to a decision that is right for them, then we have been successful."

From the facilitated discussion group

A number of issues were identified as barriers to honoring the wishes of a dying person: the lack of uniformity and limitations of advance directives documents; failure of patients to express their wishes while competent; lack of a central repository for advanced directives; and concern for liability by medical professionals when confronted with the conflicting wishes of family members. Additional barriers include: the lack of accountability for professionals who fail to honor wishes; the frequent turnover of providers; inadequate discussion regarding advance directives; and the lack of an interdisciplinary team approach to care.

A suggested action plan emerged:

Education

- Educate using a uniform and interdisciplinary team approach at all levels and in all venues.
- Advocate for educational opportunities for any individual who becomes a health care power of attorney.
- Change the current culture so that end-of-life issues become acceptable and easy to discuss.
- Encourage women's groups to include this issue as part of their agenda.
- Improve communication/discussion about the dying process, specifically discussions about honoring the individual's wishes.
- Educate consumers regarding the preparation of advance directives.
- Encourage end-of-life education in the school systems.
- Clarify the differences between a Do Not Resuscitate (DNR), Health Care Power of Attorney (HCPOA) and advance directives.

Policy

- Address liability for those who fail to honor the consumer wishes.
- Provide immunity for those who honor the legal wishes of the consumer.
- Develop uniform terminology and standards for advance directives.
- Encourage the National Association of Attorneys General to assist in developing and advocating for model legislation and national standards. This action is seen as necessary so that out-of-state advance directives are recognized.
- Provide protection for persons unable to express wishes; for example, persons with cognitive impairment.

Provider

- Recognize that continuity of care is interrupted, in part, due to staff turnover.
- Require a reliable system of communicating consumer's wishes and/or any changes in those wishes to all providers, especially, on-call staff.
- Improve communication among all disciplines.

Highlights

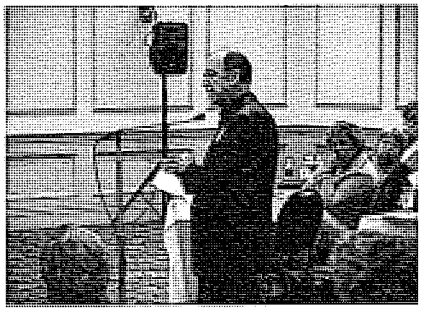
◊ Education
- K-12
- Seminaries
- Health care curricula
- Law Schools
- Print and broadcast media

◊ Standardization
- Protocols
- Tools
- Best practice models
- Training

◊ Consumer Issues
- Advance directives conversation
- Central registry
- Education
- Impact of diversity (gender, race, religion, age, economic status, etc.)

◊ Provider issues
- Staff shortages
- Education / Training
- Regulations / Licensure
- On-call issues

◊ Other Comments
- Promote integrated training
- Work with special needs populations
- Involve faith communities
- Engage families in discussions
- Insure portable, standardized advance directives
- Address accountability within the health care community for not honoring wishes



B.O.A.T.I.N.G.© (Before Offering Another Treatment, Identify New Goals) is a powerful, one-act play that provides insight into the benefits and burdens of treatment at the end of life:

Ramona is diagnosed with metastatic cancer and is treated with aggressive chemotherapy and procedures. Each new treatment option is dramatized by Ramona taking on a new piece of scuba gear until she ultimately is unable to move or find comfort. Her physician words, "There is nothing more we can do for you!" are repeated over and over again, demonstrating the many ways this phrase can be heard.

However, a whispered voice says, "There is plenty we can do for you." The care given Ramona will now reflect her goals. As the invasive treatments are discontinued and replaced with comfort care, Ramona is made more comfortable and allowed to die peacefully, on her own terms.

Using these metaphors, B.O.A.T.I.N.G.© is able to address this issue clearly and with greater impact than a didactic presentation could ever hope to do. This play speaks to everyone at a deeply personal level about a subject that has or will impact each of us.

The author, Jill Bixby, was inspired by a vivid dream. She had been wrestling with a way to educate physicians and other medical professionals on the importance of recognizing the point at which aggressive, curative treatment might no longer be consistent with the patient's goals. When is the right time to refer to palliative care and hospice—to determine what the patient really wants?

Will I receive competent care?

Ben Rich, JD, PhD

"The question, 'will I receive competent care' can be answered with another question -- 'what do you define as competent care?'. Competent care, in the medical community, is defined by what is usual and customary, and this definition has already been described as 'mediocre at best'. Is this the level of 'competent care' we want at the end-of-life? What happens if I don't get competent care? Will there be consequences, not just for the patient, but for the provider giving less than competent care? ***How do you break the bad news without using the 'D' word?*** The 'D' word has been replaced with the term 'multi-organ system failure'. How are we going to provide care which is consistent with the patient's goals and values if we have cultivated our ignorance of what they are, or acted as though our sublime indifference to them is competent medical care."

> *"End-of-life care has become one of the vast wastelands of informed consent."*

Lauren Michalakes, MD

"Maine was one of two states which received a failing grade from Last Acts with regards to the utilization of Medicare hospice benefit. We have wonderful hospice providers in Maine – some of the most skilled, most compassionate, most dedicated. But when the hospice model is complicated with issues of reimbursement and regulation, it changes from this wonderful community-driven, born-in-our-hearts type of entity, into something less than it should be."

Jill Bixby, NP, MA, BSN

"*'Will you receive competent care? It depends on who's on.'* As a result of a multi-million dollar law suit, California physicians are required to take continuing education on pain management and end-of-life care. The problem is cultural. In some countries, people look forward to death; in others, death is honored. In the US, we look at death as an option. The first step is to acknowledge and accept that a patient is dying. Once this is real to the caregiver and patient, steps can be taken to provide appropriate care."

Thomas Keating, MD

"The likelihood of someone receiving competent care is much better now than it was 10 years ago. It wasn't very long ago that shared decision making was not heard of. The general public is much more sophisticated, and physicians are realizing this. Mainstream medicine is finally getting the message. Reimbursement is a big key. Physicians want to do the right thing, and they will respond to what is valued in society. We need to value the time spent by a physician speaking with the patient about patient wishes and care options – time to develop a relationship which will be needed to answer the difficult questions."

From the facilitated discussion group

The group identified the following list of issues as concerns and barriers: self-advocacy, physician training, DEA concerns on prescribing, absence of interdisciplinary team approach, current licensing requirements, reimbursement levels, and Maine's low grades in the Last Acts State Ranking report.

Education: There is a lack of educational competencies for end-of-life health care professionals. The medical and nursing schools need core curricula regarding hospice and palliative care. Consumers need more information — often, they do not know what they do not know. Informed consumers drive social change.

- Continuing education could be tied to license renewal. For example, refer to laws in California.
- Medical and nursing school curricula need to include end-of-life care modules.
- Consumers need a process to obtain information on the competency of health care professionals.

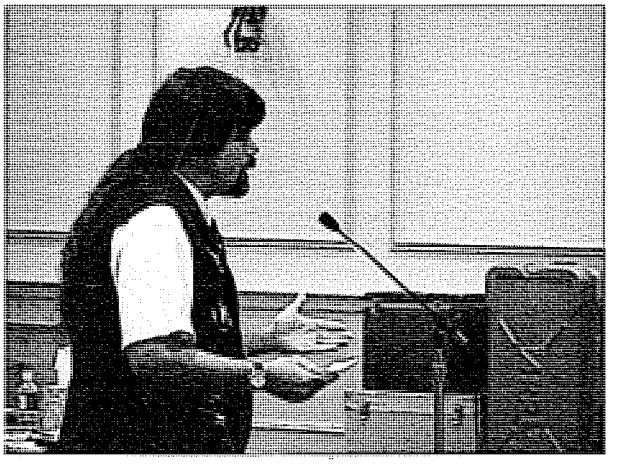
Policy and regulation: The climate surrounding the prescribing of opioids is difficult, at best. Physician prescribing practices have been under increased scrutiny because of the concern for opioid abuse. More and more prescribers have decided to drop their DEA licenses, or they simply shy away from prescribing these drugs for legitimate purposes. As recently as last October, the State of Maine adopted a monitoring system to track physicians' prescribing practices for Schedule II drugs. There needs to be a balance between providing appropriate pain management and addressing issues of diversion.

"What happens when you wage a war on drugs in the absence of a war on pain?"
Ben Rich

Highlights

- ◊ Increase . . .
  - understanding of the Medicare hospice benefit
  - education
  - hospice referrals
  - education regarding the dying process
- ◊ Address . . .
  - regulatory environment
  - licensure requirements
  - communication barriers
  - law enforcement issues
  - accountability issues
  - elements of Last Acts State Ranking Report
  - institutional barriers
- ◊ Develop competencies
- ◊ Utilize interdisciplinary tem approach
- ◊ Respect/honor patient wishes
- ◊ Empower consumers
- ◊ Educate third-party payers
- ◊ Promote ELNEC and EPEC training
- ◊ Involve print and broadcast media in outreach

Communication: This requires the coordination and cooperation of everyone involved. It is important to identify where communication breaks down. Communication breakdown creates problems and interferes with competent care. The need for honest, open communication is critical. An interdisciplinary team approach has been proven to be the most cost-effective resource in obtaining better outcome. However, it is not always the standard of care.



Summary

The purpose of this Listening Conference was straightforward — bring people together to discuss what seems to be working well in end-of-life care, identify existing gaps, and propose solutions.

Obviously, this is an ambitious effort and not easily achieved due to many factors. The value is in the process — increasing the dialogue about issues that impact our families, neighbors and community.

Working together is the only way this kind of social change will ever take place. Listed below are action items (strategies) that have occurred since the conference, followed by suggestions for the future.

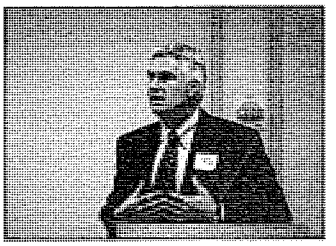
Once again, our gratitude to all who participated. This is your document.

Current Activities:

- Discipline specific focus groups (nurses, etc.)
- Physician Self-Study Packet (AACPI Grant project)
- EoL Certificate course (USM Continuing Education)
- Market Research 2005 (The Potholm Group)
- Maine Attorney General's Office contact regarding end-of-life care (Carmen Coulombe)

Suggested Activities:

- Institute state report card following the model from Last Acts
- Work with partners (faith communities, state organizations, medical organization, etc.) to assess state wide end-of-life services, identify gaps, and make recommendations to address future needs and changing demographics.
- Follow-up "Listening Conference" (2006?)

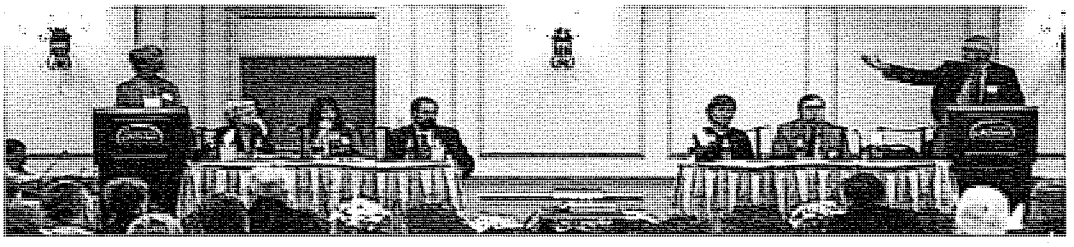


Attorney General Steven Rowe

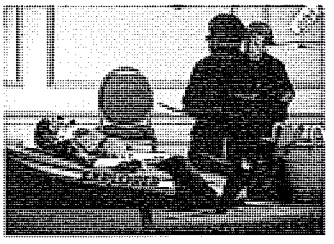
Kandyce Powell

Carol Donnell

Donna Muto



Left to Right: Kandyce Powell, June Dahl, Diana Rae, Steve D'Amato, Donna Muto, James Cameron, Steven Rowe



B.O.A.T.I.N.G.

Listening Conference Planning Committee

Co-chairs

Steven Rowe, Attorney General
Kandyce Powell, Maine Hospice Council

Members

Laurel Coleman, MD
Carmen Coulombe, Office of Maine's Attorney General
Steve D'Amato, Maine Center for Cancer Medicine
Donna DeBlois, Kno-Wal-Lin Homecare and Hospice
Christine Gianopoulos, Bureau of Medical Services
Lisa Kavanaugh
Izabel Lutostanska, MD
Jessica Maurer, Office of Maine's Attorney General
Deborah Nickerson, Maine Licensing & Certification
Sandra Parker, Maine Hospital Association
Kathe Pilibosian
Diana Rae, Pen-Bay Medical Center
Janice Reynolds, Midcoast Hospital
Cheryl Tucker, American Cancer Society
Romaine Turyn, Maine Alzheimer's Project

Event Coordinator

Alfred Hipkins, Maine Hospice Council

Facilitators

Anna Bragdon, Maine Medical Association
Azerlea Bryant
Greg Burns, The Jason Program
Carmen Coulombe, Office of Maine's Attorney General
Donna Deblois, Kno-Wal-Lin Homecare and Hospice
Janice Reynolds, RN, OCN, Midcoast Hospital

Maine Hospice Council, Inc.

Promoting Excellence in End of Life Center

The Maine Hospice Council exists to ensure the continued development of Hospice and Palliative Care in Maine. The Council provides education and technical assistance regarding end-of-care, as well as advocacy for terminally ill and bereaved persons regarding quality-of-life issues throughout the state.

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Cover art donated by Sarah Gray of Portland, Maine
www.sarahgray.com

Maine Hospice Council

Promoting Excellence in End-of-Life Care

2006 Annual Report

Maine Hospice Council, Inc.

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This project is supported in part by funds from the Administration on Aging.

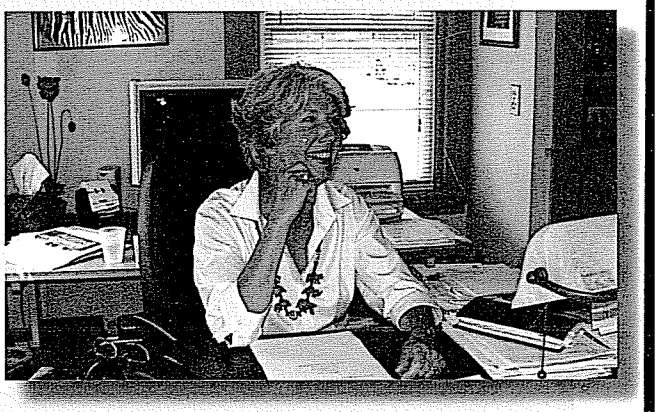
Maine Hospice Council, Inc.
2006 Annual Report

A Message from the Executive Director

Access — The Most Important Hospice Issue

Each year brings unique challenges for any organization, some years more challenging than others. The hope for any Executive Director is for staff and board members to rise to any challenge with thoughtfulness and respect, always keeping the mission of the organization in focus.

The past year has been one of partnership building, program development, event planning, organizational growth and travel. During the past nine months the Maine Hospice Council (MHC) has added two staff positions. In addition to Al Hipkins, Event Planner/Webmaster, and Donna Jacobs, Office Manager, we have added Patty Renaud, Development Director, and Lorie Rezendes, Administrative Assistant. Each staff member brings unique skills and, together, they add depth to the capacity of the organization.



Reprioritizing goals is an ongoing process, given the complex nature of end-of-life care, a rapidly changing health care system and limited financial resources. However, the priority for the coming year has been clear to many for some time. Access to hospice is one of the most important issues facing consumers today.

According to several studies, Hospice has been shown to be a cost effective approach to end-of-life care, producing quality outcomes and high family satisfaction. However, in Maine the Medicare Benefit remains underutilized. Recent data from CMS shows Maine ranking 48th in utilization of Medicare Hospice services.

Ideally, all individuals who desire Hospice and meet the admission criteria should be able to receive the services. Addressing this issue in a comprehensive way will help us to understand barriers to access as well as specific under served populations. Then, in concert with our many partners, recommendations could be made and changes instituted. For the next fiscal year, this will be the focus of program development and grant proposals for the MHC. Public and private partnerships will continue to be vital to this effort. Without the continued support and participation of many knowledgeable decision makers, changes are unlikely to occur.

It must also be said that there is a social imperative giving impetus to this effort: projected changes in age and disease demographics; escalating costs of health care; increased development of technology to prolong life; and decreased access to insurance coverage, to name but a few. In addition, there is some discussion that end-of-life care is emerging as a public health concern.

Remarkable changes in our health care system over the past 100 years have had a significant impact on our present system of care. Let's consider, for a moment, some characteristics of public health priorities:

- Incidence

- Burden of Suffering
- Major Impact
- Potential for Prevention

Death itself has a universal incidence. Every individual will experience some type of end-of-life event and, unfortunately, there is often a significant burden of suffering associated with dying. In regard to pain management alone, many people still die in pain. Research indicates that 40 – 60% of all people experience moderate to severe pain during the dying process. Caregivers also experience unanticipated life changes through the dying and bereavement process. Because of the projected demographic changes, the pool of caregivers will decrease within the next ten to fifteen years. Considering that the health care labor force is already stressed, this can only become more critical.

Individuals and families often suffer extreme financial consequences as a result of a terminal illness. There is loss of work time for care giving, loss of a job and insurance coverage and/or personal bankruptcy. Statistics show that catastrophic illness is a leading cause of personal bankruptcy in Maine. There are also implications for society. With new technology constantly being developed to extend life, the costs to the health care system will become even more staggering.

Within the past few years, end-of-life care has gained increased recognition as an issue that warrants more attention; however, it is also being constantly challenged. The potential for prevention is enormous, not to prevent dying, rather to decrease the burden of suffering. One step toward that goal is to increase access to end-of-life services. The task is daunting, but with political will and increased collaboration, I believe we can accomplish just about anything ☺

We look forward to your support in the coming year.

Kandyce Powell, Executive Director

Kandyce has over 25 years experience working with Hospice and end-of-life care. Since 1992, she has been the Executive Director of the Maine Hospice Council where she provides educational, technical and advocacy assistance for agencies, organizations, institutions, and individuals interested in improving the quality of life for the dying and bereaved.

She has been instrumental in developing partnerships to work on these issues and is a tireless advocate for the underserved. Several ongoing partnerships are: Maine Pain Initiative, Maine Hospice Council/Maine Office of the Attorney General, Hospice and Corrections and Hospice Veterans Partnership of Maine, which Kandyce presently chairs.

Kandyce is a frequent speaker in Maine and throughout the US on topics related to end-of-life care.

Professional Achievements:

- 1999 - Appointed Chair of the Bureau of Health's Palliative Care Workgroup
- 1999 - Co-authored the Robert Wood Johnson Community/State Partnership grant entitled, "Care at the End of Life: A Public/Private Partnership"
- 1999 - Joined the board of Maine's Comprehensive Cancer Plan
- 1999 - Received the Senior Legislative Advocacy Coalition Distinguished Service Award
- 2002 - Elected President of the American Alliance for Cancer Pain Initiatives
- 2002 - Appointed to the Community Advisory Committee of the Maine Health Access Foundation
- 2002 - Chaired the Steering Committee for the Hospice/VA Partnership in Maine
- 2003 - Rallying Points Consultant
- 2004 - Elected to the NHPCO Council of States Steering Committee
- 2004 - Chaired the Hospice/Veterans Partnership Advisory Council
- 2004 - Elected Secretary for the American Alliance of Cancer Pain Initiatives
- 2005 - Appointed to the National Advisory Committee for the Robert Wood Johnson Foundation NHPCO Caring Connections Program
- 2006 - Appointed Chair of the NHPCO National Veterans Affairs Advisory Council

Promoting Excellence in End-of-Life Care: 2006 and Beyond

Lisa Harvey-McPherson, President

Lisa is a nationally certified Home Care and Hospice Executive with over 20 years of nursing leadership experience in this specialty area. She has also served as President of both the Home Care Alliance of Maine, OMNE — Nursing Leaders of Maine and represented the New England Region on the board of directors of the National Association for Home Care.

Lisa is currently the Director of Health Policy and Continuing Care with Eastern Maine Healthcare, providing both legislative and policy expertise for healthcare and hospice related issues. Lisa was actively involved in the passage of Maine legislation creating the Medicaid Hospice Benefit, private insurance hospice mandates and the Maine Center for End-of-Life Care.

Amy Line, Vice President

Amy spent 20 years in the United States Navy. Her career required travel abroad and provided the opportunity to experience and appreciate many diverse cultures. In 1997, she retired from the service and settled in Maine.

Amy is a part-time adjunct at the University of Maine at Augusta teaching courses in the Mental Health and Human Service degree program. She is active in her community and is a member of the Litchfield Senior Advisory committee and a volunteer at the Litchfield Food Bank.

Her husband, Roger, is on active duty and is stationed at the Naval Air Station Brunswick.

Maine Center for End-of-Life Care

The Maine Center for End-of-Life Care was established as a program of the MHC by Public Law 439 (adopted 2001), to "act as an incubator for change, promote innovation, foster community-based collaboration, and serve as an informed convener and educator" toward improving end-of-life care in Maine.

The past year has seen significant growth and expansion of Center programming in community engagement, education, research and data collection, and advocacy.

Community Engagement: Engaging the broader community includes expanded outreach to consumers as well as organizations and individuals directly engaged in end-of-life care services. The Center has expanded outreach to consumers by providing more than 500 advanced care directives, referrals to local hospice programs, assistance with insurance and other health care questions, as well as educational workshops.

The Center continues to build on existing partnerships with many organizations throughout the state. All of its work is collaborative, and without the active engagement of so many of these partners we could not be as effective in improving end-of-life care for the people of Maine. Many of these partnerships are described in the individual reports on the following pages. A list of organizations committed to the continued development of the Center is published in the business plan: it includes: the ALS Association Northern New England Chapter, Togus VA Medical Center, Maine Veterans' Homes, and the Department of Corrections, Maine's Office of the Attorney General, and many others.

Professional and Public Education: Many of these partnerships help give shape to the expanded educational offerings of the Center. The University of Maine System is developing courses and expanding the curriculum around end-of-life care and geriatric mental health. A pilot USM Certificate Course, "End-of-Life Care: A Comprehensive Perspective," was so well received that it has become a regularly offered continuing education course. The Maine Pain Initiative has completed "A Physician Self-Study Packet: Pain Management at End of Life," which is available to

physicians statewide as well as serving as a model for other states.

As part of the recognition of National Hospice Month, the Center sponsored a very successful workshop, "Expanding Access to Hospice Care," led by Fay Burrs, RN, BSN, of NHPCO. Fay's presentation challenged the nearly 50 participants from diverse healthcare and academic settings to think more creatively about access and how they might take positive steps to increase access through their programs.

"Positioning Your Volunteer Program for the Future," offered volunteer hospice programs legal, organizational, and financial information. A new spring pain symposium, "Pain Management: A Human Right," was held at the University of Maine at Presque Isle in response to the expressed needs of caregivers in northern Maine. In addition, the year closed with the First Annual Education Conference held in conjunction with the 2006 MHC Annual Meeting.

Research and Data Collection: Research is an ongoing focus, beginning the year with a Membership Survey sent to partners, stakeholders and supporters. In addition, a long-term-care retrospective chart review was completed. We have also begun engaging diverse ethnic communities in discussions about access.

In the coming year, we will survey legislators to identify ways the Center can assist in serving their constituents. A project to assess Maine's end-of-life delivery system is also in the planning stages.

Advocacy: Legislative policy reform has been ongoing. Recent support includes:

- LD 1763: An Act to Ensure the Authority of "Do Not Resuscitate" Orders in Advance Health Care Directives, and
- LD 1842: An Act to Amend the Laws Governing Living Wills of Terminally Ill Persons.

Kandyce Powell, Executive Director, and MHC board members provided oral and/or written testimony at the State House on behalf of end-of-life care in Maine.

The work of the Center is on-going and offers many opportunities for program expansion. There is much to do to improve end-of-life care in Maine, and the Committee welcomes participation by individuals from all disciplines.

Amy Line, MSW, Chair

Barbara Clark, Secretary

Barbara is the Executive Director of Hospice of Hancock County. She has a background in nursing, a bachelor's degree from Boston University with a dual major in English and Psychology, and graduate level courses and workshop experience in human development, hospice and bereavement care.

Barbara became Director of Clinical Programs at Hospice of Hancock County in 1994, and was appointed Director in 1999. She serves as Board President of the Down East AIDS Network, and is a board member of the Beth Wright Cancer Resource Center and a member of the Palliative Care Team development committee at Maine Coast Memorial Hospital.

She is married to Bill Clark, mother of four, and has seven lively grandchildren.

Juliana L'Heureux, Treasurer

Julie, a Marylander from Baltimore, moved to Southern Maine several decades ago. She has an extensive background in nursing and is currently Executive Director of CHANS Home Health Care. She previously served six years as Director of Southern Maine Emergency Services and chaired the Critical Incidence Stress Debriefing Program for Southern Maine. She is also Current Past President of Rotary Club of Brunswick.

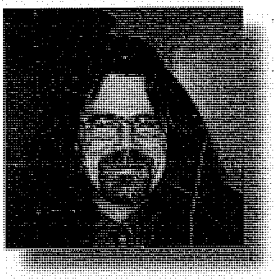
Starting in 1988, the Portland Press Herald has published her stories about Maine's Franco-American population in a column that appears every Thursday. She also writes for Le Forum, a newspaper for the Franco-American Centre at the University of Maine – Orono, and many other publications.

Greg Burns

Greg is Nursing Director of The Jason Program and has a long history of caring for seriously ill children and adults. After graduating with a B.S.N. in nursing from the University of Southern Maine, Greg worked on one of the medical-surgical wards at Maine Medical Center, where he developed an expertise in orthopedics. He transferred to the pediatric floor out of his love of children, where his duties ranged from direct patient care to teaching, communication, and leadership.

Greg was recently honored as a 2005 recipient of the ELNEC Pediatric Palliative Care Excellence Award.

Greg and his wife live in Windham with their two sons Joe and Logan. He is also a proud grandfather. His daughter Jenna, her husband and grandson Amuwes live in Princeton, Maine.



Rev. Suzanne F. Colburn

Suzanne is Priest-in-Charge of Christ Episcopal Church in Biddeford. Before returning to Maine, where she and her children lived for 20 years, Rev. Colburn worked at Emmanuel Church in Boston. The Rev. Colburn also was a chaplain at Sherrill House and specialized in palliative care, end-of-life issues and hospice. Rev. Colburn has two children. Son Robert and wife, Laurie, live in Damariscotta with their new baby. Daughter Sara lives and works in Boston.

Rev. Colburn is a graduate of Harvard Divinity School, Episcopal Divinity School and Bowdoin College.

Hospice/Veterans Partnership

The Maine Hospice Council continues to work with the Veterans Administration Medical Center at Togus and the Maine Veterans Homes to develop community-based Hospice programs to address the needs of our state's veteran population. Maine's Hospice/Veterans Partnership is a model that is being replicated in many other states.

This last year featured a series of regional community programs to bring further attention to veterans needs for quality end-of-life care. Many veterans, their families and friends, veteran service organizations and local community hospice providers participated in meetings held in around the state.

The evening events featured presenters from the VA, Maine Veterans Homes, the directors of the local hospice, and Kandyce Powell of MHC. Also included was a video "Wounded Warriors: Veterans Last Battle," featuring frank discussions about the unique experiences of veterans with end-of-life care.

Togus VAMC has just rolled out a new community hospice contract, modeled after the Medicare Hospice Benefit.

A new brochure about this program is planned for publication in the Summer of 2006. This brochure will include information for veterans and their families as well as local contact information for hospice programs, VA benefit enrollment, chaplain and social worker services, nursing home placement, and grief support.

In Spring 2006, Kandyce Powell was appointed to the National Veterans Affairs Advisory Council. Senator Susan Collins sent her congratulations: "I am so pleased that Kandyce Powell has been appointed to the National Hospice and Palliative Care's National Veterans' Affairs Advisory Council. For nearly twenty-five years, Kandyce has demonstrated her unwavering commitment to providing hospice care to our citizens. Her appointment to the National Veterans' Affairs Advisory Council is another example of that longstanding commitment, and her presence and dedication will be a substantial asset for our veterans."

Patrick Daly, MD
Bangor VA Clinic

Corrections Partnership

In 1999, the MHC Executive Director Kandyce Powell, met with Maine State Prison staff to provide information about hospice services. Interest in developing a hospice prison program was supported by Warden Jeff Merrill, who appointed a committee to develop the program. The composition of the Committee was a varied blend of staff and community volunteers from different disciplines who were committed to the goal of offering a range of services to the prison population.

Since then, the Committee has instituted a variety of hospice program components. These include staff training on issues of dying and death, training for medical staff on pain management, a bereavement support group for prisoners (now known as Healing After Loss Group) and a quarterly memorial service for prisoners. Recently, the Committee's psychiatrist member offered to develop and teach a curriculum on issues of personal loss. Her class raises the awareness of the range of losses an incarcerated offender may experience from the loss of his freedom and family connections to the death of a loved one.

With the Department's male infirmary housed at the prison, the Hospice Committee is committed to developing another important hospice program component that would allow selected and trained prisoners to participate in the support care of terminally ill prisoners. Over the next six months, the Committee will be working on a proposal for an end-of-life program component that meets DOC policy and procedures and American Correctional Association standards.

The partnership between the Maine State Prison and the Maine Hospice Council has brought elevated awareness of end-of-life issues to the prison. This partnership has enhanced services for prisoners and provided staff with greater knowledge of these issues.

Leida Dardis
Deputy Warden of Prisoner Services

Maine Pain Initiative

The Maine Pain Initiative produced two symposia this past year. In September, 2005, the 11th Annual Symposium, "Pain Management: A Human Right," was held at the Samoset Resort in Rockport. Over 200 participants gave the symposium rave reviews.

Jennifer Comeau

Jennifer is Founder and CEO of I-Amplitude, a business advisory firm dedicated to inspiring leaders to 'live full measure'©. Jen has spent more than two decades harnessing the rich capacities of people and systems inside corporations such as General Motors, and, and as a consultant to clients such NIST Manufacturing Extension Partnership, and 20th Century Fox.

Jen brings her proficiency in motivational speaking, leadership development, and interpersonal communication to both non- and for-profit organizations.

Jen is a published author and columnist. Her avocations include honoring lives as a Hospice volunteer and honoring the earth as a Wells Estuarine Research Reserve volunteer. With her husband and two dogs, she sails the rocky coastline of her home in Southern Maine.

Rebecca Colwell

Becky earned her BSN in nursing from USM and her MBA from Thomas College. She worked in the field of home health and hospice for 20 years, and currently serves as the Vice-President for HomeCare, Hospice, and Palliative Care for MaineGeneral Health and HealthReach Network. In 1988, Becky developed HealthReach Hospice, which was the first Medicare-Certified Hospice in the State of Maine.

Becky has served on numerous boards and councils, including the Home Care Alliance of Maine, Hospice Volunteers of Kennebec Valley, and the Maine Cancer Consortium. She is currently serving as Vice-Chair of the Dirigo Health Maine Quality Forum, and as a City Councilor for the City of Gardiner.

Richard Erb

Rick Erb is the President and Chief Executive Officer of the Maine Health Care Association, which represents over 200 long-term care providers.

Previously, he served as town manager in three Maine communities, including thirteen years with the Town of Kennebunk. Immediately prior to joining MHCA, Rick served as county administrator in Ithaca, New York.

He holds a bachelors degree from the University of Maine and a masters degree from Cornell University.

Rick lives in Brunswick with his wife, Shannon, and son, Garrett.

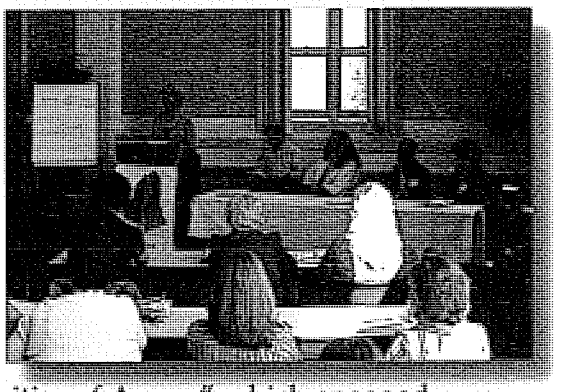
Peter Goth

Dr. Goth is Board Certified by the American Board of Emergency Medicine and has been practicing emergency medicine since 1973. Peter also served on the State of Maine Medical Direction and Practice Board (MDPB), and assisted with the development of state-wide EMS clinical protocols.

In 1984, he founded the Wilderness Medical Associates, a training and consulting organization that specializes in emergency medicine and wilderness rescue.

Peter lives on Springtide Farm with his wife, Wendy Pieh, and extended family, as well as 100 Cashmere goats, seven horses, six dogs, three donkeys, chickens, cats, and a variety of spouses-in-law on the Maine coast.

On April 11, the MPI produced its first Spring Symposium at the University of Maine at Presque Isle. Going to northern Maine answered one identified need for more educational opportunities in this region of Maine. Diana Rae, RN, C, MSN; Janice Reynolds, RN, C, OCN; and Peter Goth, MD presented general sessions to the 40 participants. This was followed by a panel presentation on "Disparities of Access" which engaged participants in discussions about regional disparities. A return to Presque Isle next spring is planned.



The 12th Annual MPI Symposium "No Pain Left Behind" will be held at the Holiday Inn By The Bay on Friday, September 29, 2006. This year's program will include presentations on many topics of pain management, including "Rural Substance Abuse Issues," "Unique Needs of Veterans," and the "Economics of Pain Management." A consumer panel on "Pain From the Patient's Point of View" is also being developed.

The American Alliance of Cancer Pain Initiatives awarded the Council a grant to develop a physician's self-study packet. The Maine Pain Initiative Committee started this project in the Summer of 2005, working collaboratively with the Muskie School of Public Service and the American Cancer Society. The activity was jointly sponsored by the Maine Medical Education Trust, the Maine Osteopathic Association, and the State of Maine Bureau of Medical Services. Funding for the project was provided by the AACPI, the American Cancer Society, the Administration on Aging, and the Maine Office of Substance Abuse.

One thousand copies of the packet will be made available to Maine physicians starting June 14, 2006. This project has garnered great interest from other state pain initiatives. The New Hampshire and Connecticut Pain Initiatives have already contacted the MPI expressing interest in replicating this project in their own states. Other states are likely to follow. The MPI is considering tailoring this packet for nurses.

Diana Rae, RN, C, MSN, Chair

Provider Advisory Committee

The PAC began the year with a discussion to determine the committee goals. The topic chosen was "relationships between hospices and long-term care facilities." The thoughtful process of assembling and prioritizing a problem list began with the goal of using it to create a work plan. Committee members are motivated and have chosen to meet monthly.

The project may offer an opportunity for some grant funding, as educational offerings will likely be the focus of strategic planning.

The PAC is an open committee and encourages hospice and palliative care providers to participate in this exciting work.

Arlene Wing, RN, MHSA, Chair

Development Committee

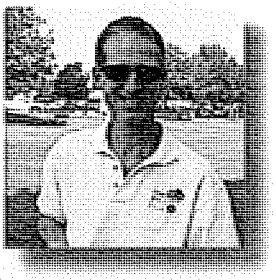
The Maine Hospice Council took a significant step in 2005 to expand development efforts in order to build sustainable funding for the Maine Center for End-of-Life Care. Patty Renaud joined our staff as Development/ Marketing Director in October. With the Development Committee, she introduced several strategies for engaging new constituencies which have demonstrated the potential we have to bring real change to people's lives.

Critical to this success has been the active participation of our volunteer Board members. Through an expanded Annual Appeal, the introduction of the *Stewardship Circle* recognizing donors of $100 or more, recruitment of new member organizations and individuals, the spring auction, increased grant funding and business support, this new initiative has greatly expanded our presence and base of support in the community.

As a result of these efforts, we have welcomed more than 250 new donors who support improving end-of-life care in Maine. As always, we are grateful for continuing relationships with hundreds of supporters who have sustained us through the years. And in a new outreach effort, we welcomed three new Associate Members: Eastern Maine HealthCare Palliative Care Department, MaineGeneral Health Palliative Care Program, and Maine Health Care Association. The engagement of all of these individuals and organizations will greatly enrich our efforts to improve end-of-life care for all the people of Maine.

Thomas Keating

Dr. Keating is a native of Maine, born in Portland and raised in South Portland. He graduated from Bowdoin College in 1974 with a degree in biochemistry, and attended Tufts University School of Medicine where he earned his MD degree in 1983. His post-graduate training was done at St. Elizabeth's Hospital in Boston, with an internal medicine residency and subsequently a fellowship in hematology-oncology. At the completion of his training, he returned to Maine, and joined the Maine Center for Cancer Medicine, opening an office in Brunswick. He helped develop the Medicare-certified hospice program at CHANS and has served as its medical director for the past fifteen years.



Tom currently lives in Brunswick with his wife and three children, and is an avid runner when time and conditions allow.

Shawn Lewin

A native of Presque Isle, Maine, Shawn graduated from Husson College in 1970 with a BS in Accounting. He received his Chartered Life Underwriter (CLU) designation in 1977, and became a Fellow of the Life Management Institute, with a specialization in Electronic Data Processing.

He worked extensively with Planned Giving, Charitable Gift Endowments, Life Insurance Gift Endowments, and Charitable Remainder Trusts.

He is a Volunteer for the Palliative Care Program of Eastern Maine Medical Center, supporting patients and families facing life-limiting illnesses, and has worked closely with the Coordinator of Palliative Care to develop their volunteer program.

Teresa M. Mayo

Dr. Mayo is currently the Director of Psychology at Riverview Psychiatric Center in Augusta where she has been for the past five years. Teresa received a BA in psychology and an M.Ed. in counseling from the University of Maine at Orono. She directed a college counseling center in Massachusetts and worked for the University of Maine at Augusta before obtaining her Doctorate at the University of Denver.

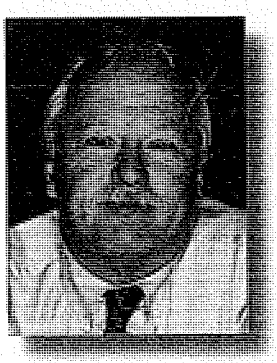
Dr. Mayo was employed by Hartford Hospital and the Institute of Living in Connecticut before returning home to Maine. A native of Thomaston, Teresa came home to help care for her brother Joe Mayo who lived with ALS.

William McKenna

Bill is a Paramedic and Director of Community Relations for Delta Ambulance in Waterville/Augusta. He has 22 years in emergency medical services, and has a background in Holistic Health. He is a member of the local emergency planning committee, Northern & Southern Kennebec Triads, Local Advisory Committee — Cohen Center; and serves as a Board member for Healthy Communities of the Capital Area and Big Brothers Big Sisters of Kennebec Valley.

Bill is also a member of the Augusta City Planning Board, Comprehensive Planning Committee, KV Chamber of Commerce, Kennebec Leadership Institute Advisory Committee, Mid Maine Chamber of Commerce, and a past president of the Rotary Club of Augusta.

He is also a photographer and avid motorcyclist.



We are now looking ahead to engaging many more individuals and organizations in our work to provide quality care at the end of life. We know that these efforts result in greater resources for consumers and hospice providers, expanded educational opportunities, results-oriented research, and advocacy that will bring more effective policies and a better environment for quality end-of-life care to flourish in Maine. Ultimately, individuals and families facing terminal illnesses will be able to access the care they so need at one of the most vulnerable times of their lives.

Shawn Lewin, Chair

It's About How You Live! Celebrate Mud Season in Maine

First Annual Auction Raised $17,000

Nearly 150 people gathered on March 29 for some Downeast "humah" and good clean fun at the end of the Maine winter and raised $17,000 for the Maine Center for End-of-Life Care. Gary Crocker, Maine humorist, volunteered as host and all who attended gave the evening very high marks. We are grateful for all who helped make the evening a success — Board members, volunteers, hospice programs, and the many new partnerships with sponsors, artists, craftspeople, businesses who donated items as well as individuals who could not attend but sent financial contributions.

Special thanks to our planning committee for their extraordinary efforts — Rita Melendy, Board member; Kay Johnson of Pine Tree Hospice; and Lisa Hawkins, Council volunteer. The auction gave many people previously on the fringe of our work a chance to support and participate in a fun and productive event.

Thanks to our auction sponsors: AARP Maine, Beacon Hospice, Maine Veterans Homes, Medical Supplies Inc., Viking Inc., Wine Institute, Doyle & Nelson, Patty Stowell PhD, Augusta Fuel Company, Brookings-Smith Funeral Homes, Charlie's Motor Mall, Down East Enterprises, Kennebec Journal/Waterville

Sentinel, WBACH Radio, and WERU Community Radio. Food and beverage costs were underwritten by CHANS Home Health and Hospice.

Teresa Mayo, Chair

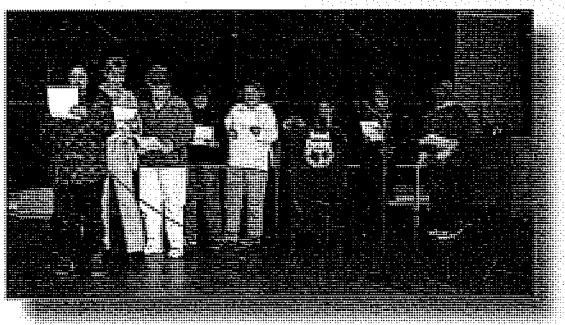
Maine Hospice Council Annual Retreat

The Council's Retreat was established as an ongoing reminder to care for the care givers. Everyone is invited, nurses, social workers, administrators, directors, volunteer coordinators and the wonderful volunteers. All are encouraged to take time to relax, to learn, to laugh, and to renew.

After a decade of retreats in the Rangeley area, the Committee chose to move to the Poland Spring Resort. Much of the format remained the same. One popular new event was the Trivia Contest, held on Friday evening. Clustered into teams, participants fought it out amid lots of laughs for a cash prize and bragging rights.

The 12th Annual Retreat will be held October 27-29, 2006, at the Poland Spring Resort. Lots of fun is planned (trivia, the talent show and raffles) along with a variety of workshops.

Dee Bickmore, Chair



Rita Melendy

Rita has worked many years as a certified medical assistant for an internist and also assisted several new doctors in getting their offices set up in Rockland. She owned a small business — Wine and Cheese Galley — then became active in Maine politics. She served as a State Representative in the Maine House for twelve years then served an additional six years working in the offices of the Clerk and Speaker.

Her last three years with the legislature were in the capacity of Administrative Assistant to Clerk/Clerk Emeritus Joe Mayo as he battled ALS (Lou Gehrig's) disease.

Rita worked for the Northern New England Chapter of ALSA as Coordinator of patient services for ALS patients in Maine. She currently serves on the Board of Visitors of the Maine State Prison. Rita is married, with two sons and a grandson.

Hon. Wendy Pieh

Wendy received her Master of Science in Organization Development from Pepperdine University School of Business. She is currently a consultant with Changes Consulting in Bremen Maine, and Manager of Springtide Farm.

From 1996 to 2000, she served as the Representative to House District 56 where she served on the Health and Human Services and Marine Resources committees and was Chair of the Agriculture, Conservation and Forestry Committee.

Wendy and her husband, Dr. Peter Goth, own and operate Springtide Farm in Bremen Maine, where they produce some of the finest Cashmere fiber in the United States.

Carol Schoenberg

Carol has been a hospice educator since 1992. She is currently serving as the Director of End-of-Life Care at the Hospice of Southern Maine, where she provides hospice education to staff, volunteers, healthcare providers, and the community.

Certified as an Advance Care Planning Facilitator Trainer through the Respecting Choices program at Gundersen-Lutheran Hospital in La Crosse, Wisconsin, she believes strongly that helping people talk about their choices for end-of-life care can make a huge difference in the way families experience the dying process.

Romaine Turyn

Romaine is a Research Associate at the Muskie School of Public Service, Institute for Health Policy at USM. She also serves as the Project Direct for the Maine Alzheimer's Project, a research and demonstration grant awarded to the Office of Elder Services at DHHS.

Prior to this she worked for the Majority Leader in the Maine Senate and for over 10 years as the Executive Director of the Maine Committee on Aging, a statewide organization mandated to advocate on behalf of older citizens before the Legislature and state and federal government.

Her master's degree was awarded in 1976 from the University of Maine. She lives in Readfield, Maine with her husband and they have two daughters, a junior in college and a junior in high school.

Dan Michaud Memorial Ride

Twenty years ago, friends of Dan Michaud first rode to increase awareness about the indiscriminate nature of cancer and to support organizations dedicated to improving care for terminally ill people, their families, friends, and caregivers. Dan R. Michaud of Topsham, Maine, was a dedicated husband, father of four children, avid cyclist, and only 32 years of age when he lost his long and painful battle with cancer.

Last August, 55 riders raised nearly $10,000 for the Maine Hospice Council and Hospice Volunteers: Center for Grief and Loss in Mid Coast Maine. This year is the 20th Anniversary of this event to be held on August, 26, 2006. It will be marked by a return of the original three riders who are challenging themselves and other riders with a $5,000 pledge goal. This challenge will be sent out to riders, supporters and sponsors.

Greg Burns, Chair

The Annual Blaine House Tea

To celebrate National Hospice Month, the Maine Hospice Council partnered with the Home Care Alliance to hold the Annual Blaine House Tea at the governor's mansion on November 9, 2005. The keynote speaker was Fay Burrs, RN, BSN, Director of Access and Diversity for the NHPCO. Fay is also the Interim Director of the Foundation for Hospices in Sub-Saharan Africa (FHSSA). She spoke on access to hospice as well as her work on expanding hospice in Africa. Her address was very well received, with many requests to invite her back to Maine. Fay was joined by several representatives of Maine's Congressional delegation.

Special Recognitions

Joe Mayo Award

The Maine Hospice Council created The Joe Mayo Award in 2001 to recognize the untiring efforts of The Honorable Joseph Mayo, Clerk Emeritus of the Maine House of Representatives, to improve end-of-life care for all Maine citizens.

There are some people who, because of their extraordinary personal commitment, deserve to receive individual recognition. Rita Melendy is one of those people. When Joe Mayo, Clerk Emeritus of the House of Representatives, was diagnosed with ALS, Rita accompanied him to work three days a week, assisting Joe, both personally and professionally so he could continue living life to the fullest. Rita and Joe started a support group at the State House for other individuals and family members living with ALS, which continues to this day. After Joe died Rita facilitated the support group on behalf of the Northern New England Chapter of ALS. She has been an incredible support for families who are living with the extraordinary burden that often comes with neurodegenerative diseases like ALS, often making home visits to assess needs and connect family members with appropriate resources.

Rita remains active with the ALS community, trying to increase awareness of the disease, as well as improve the quality of life for individuals who are affected.

Friend of the Maine Hospice Council

The Annual Friend of the Maine Hospice Council award is given to an individual or organization who has provided exceptional support to the Council, and to the growth and improvement of end-of-life care in Maine.

Partnerships remain critical as we attempt to increase access to quality end-of-life care for underserved populations.

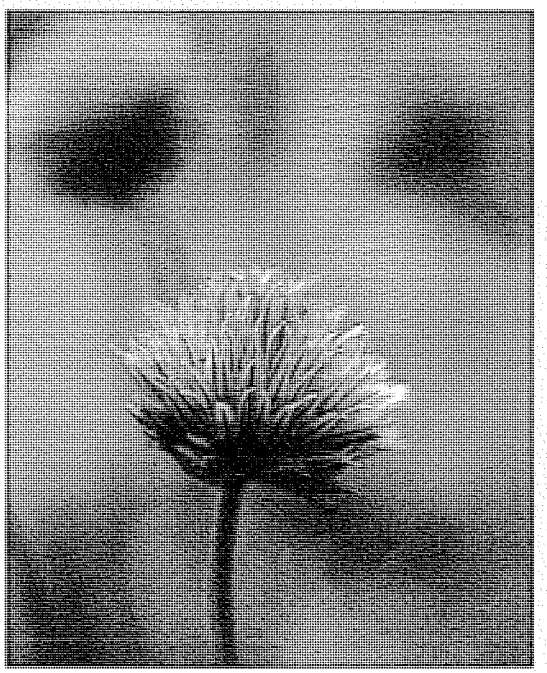
Every day 1,800 veterans die in the United States; however, only eight percent of them are enrolled in and receive care from Veterans Administration Medical Centers (VAMCs), like Togus. The needs are extraordinary, so much so that the VA Central Office in Washington has required VAMCs to develop stronger, more formal relationships with community-based Hospice programs.

(continued next page)

Arlene Wing

Arlene first became a member of the Maine Hospice Council Board of Directors beginning in 1990. She has served many years on the Council and has held various offices including President and Vice President. She chaired the Education Committee, Clinical Regulatory Committee, and currently chairs the Provider Advisory Committee. Under her leadership, the Clinical Regulatory Committee produced the White Paper on Hospice Inpatient Facilities and the Side-by-Side Comparison of the Medicaid and Medicare Hospice Insurance Benefits.

Arlene is a registered nurse who has always had a passion for working in the field of Hospice. She has over 15 years of healthcare management experience. She holds a Master's Degree in Health Services Administration, and has served as Vice President for Home Health and Hospice at Miles HealthCare in Damariscotta Maine for the past six years.



A Special Thank You . . .

. . . to the many volunteers who have served this past year. These dedicated individuals serve on committees, donate their time at the Council office, and volunteer for special events. Their time and energy contribute to the success of the Council. A few are listed here, and our appologies to those we may have missed.

Bob Bruce

Leanne Diehl

Dan Ellis

Bob Gross

Fred Hahn

Lisa Hawkins

Mary Lou Hofmann

Jason Howes

Ormond Irish

Jillian Jacobs

Kate Jacobs

Mary Kennedy

Ann Krebsbach

Tom Legare

The Martin Family

Priscilla Platt

Heidi Powell

Michelle Searcy

Heather Stambaugh

Kergan Thomann

DMMR rest stop volunteers

Merrymeeting Amateur Radio Association

Merrymeeting Wheelers Bicycle Club

Since 2002 the Maine Hospice Council, community-based hospice programs, Togus and Maine Veterans' Homes have been leaders in this partnership effort. Meeting regularly to collect data, develop need specific programming, improve communication, increase health professional education, and engage the community, much has been accomplished.

In recognition of the interest in and the commitment to this partnership, the MHC is honored to present both Togus VAMC and the Maine Veterans' Homes system with the "Friend of the Maine Hospice Council Award," in honor of their many dedicated professionals who have participated in these on-going efforts.

Welcome New Staff

This past year, we welcomed two new staff members – Patty Renaud, Development Director and Lorie Rezendes, Administrative Assistant. The Council family certainly has grown! A wonderful staff to accomplish an ambitious agenda.

Patty Renaud brings to the Council experience in non-profit development, communications, and membership building, most recently as Membership and Marketing Director for the Natural Resources Council of Maine. She has a positive energy, sense of humor, and love of the outdoors.

Lorie Rezendes has broad experience in customer service and office administration, and strong people skills. After her long-time employer closed the family business, she graduated from the Women, Work and Community retraining program. Following graduation, she was hired by Training and Development Corporation (TDC) in Bangor as the Administrative Supervisor/Purchasing Agent where she worked for several years. Lorie is a joy to have in the office.

Welcome New Member Organizations

Organizational members of the Maine Hospice Council and Maine Center for End-of-Life Care support the critical work to improve and promote excellence in end-of-life care throughout the state of Maine. New organizational members this past year include:

Maine Health Care Association
MaineGeneral Health Palliative Care Program
Eastern Maine HealthCare Palliative Care Department

Welcome *Stewardship Circle* Members

We are grateful for the leadership support provided by members of the new *Stewardship Circle*. With their gifts of $100 or more, these donors will help to establish a solid foundation for the Maine Center for End-of-Life Care to address the extraordinary needs of the future while supporting the Council's ongoing programs to meet today's challenges.

(This list represents gifts received through June 1, 2006. Please accept our appologies if we have omitted your name and call our office at 800-438-5963.)

William & Gail Ambrose
Burton R. Anderson
Marcia Appel
Debra & Thomas H. Arter
Leroy J. Barry
Sally S. Beaudette
Richard Berman
Richard Berne & Susan Schraft
Carl & Nancy Betterley
Michael Bither, MD
Patricia Bouton
Sr. M. Eunice Boyd
Hon. Joseph & Claire Brannigan
George & Deborah Brett
Marion Fuller Brown
Barbara Clark
Rev. Suzanne Colburn
Jennifer Comeau
Kathleen E. Deupree
Dianne Donovan
Avery E. Dunn
Richard A. Erb
Dr. Gina Faile & Dr. Janie Liliker
Steven M. Feinstein
Julian & Tatiana Fischer
Reine C. Fleck
Wesley Ford
Michael & Muriel Galgano
Gerald W. Gannett
J. Frank & Ruth Gerrity II
Robert & Edith Gingras
Peter Goth, MD, & Hon. Wendy Pieh
Dorothy & Rudy Graf
Maurice & Janet Granville
Thomas Guare
Marion & Francis Guthrie
Bonnie Handy, LCSW
Helene Harton & Roy Kasindorf
Lisa Harvey-McPherson
Peter S. Haskell
Malcom & Constance Henry
Melissa Hewey & Alan Chebuske
Rosalind S. Holt
Robert C. Howard
Albert & Lois Howlett
Donna Jacobs
Arthur Joost, Jr., MD
Jacqui & Jerry Kaufman
Thomas J. Keating, MD
Jaime Kline & James McCormick
Robert M. Ladd
Elizabeth A. Leach
George J. Leger
Shawn D. Lewin, CLU
Amy Line, MSW
William & Andrea Lott
Catherine M. Marden
Nancy H. Marshall
Teresa M. Mayo, PsyD
Dr. & Mrs. Robert McAfee
Eugene P. McCann, Esq.
Stanley G. McCurdy
William McKenna
Rita B. Melendy
Michael & Nancy Miller
Deborah N. & Frederick Molander, DMD
Linda & Eric Murphy
Murray Family Foundation
Ruth Naples
William U. Niss
Richard L. Page
Denise & John Palmer, Jr.
Janet T. & Arthur Perrin, Jr.
Charles & Julie Perry
Kandyce Powell
Alice W. Price
Patty Renaud
Arlene & Harry Robinson, Jr.
Victoria Rogers & Guy Senechal
Neil R. Rolde
Phyllis & William Rourke
Dr. Barbara Ann Ryan
Karen E. Saltus
Sal Scaglione & Dana Heacock
John Schinas
Julie & David Shackley, Jr.
Clare F. Shepley
Margaret L. Smith
Sharon T. Sullivan
Augustus Sylvester
Brooke P. Tenney
Romaine M. Turyn
Harold R. Van Siclen, Jr.
May L.Vaughan
Ruth R. Vietze
Matthew & Colleen Walker
Jane Walker Woodruff
Hartley D. Webster
Judith A. White
Rebecca M. Wyke

Program Members

Androscoggin Home Care & Hospice

Beacon Hospice, Inc.

CHANS Home Health & Hospice

Coastal Family Hospice Volunteers

Community Health & Counseling Services

Down East Hospice

Eastern Maine HealthCare Palliative Care Department

Hancock County Homecare Hospice

HealthReach Hospice and Volunteers of Kennebec Valley

Home Health and Hospice of St. Joseph

Hospice of Aroostook

Hospice of Eastern Maine

Hospice of Hancock County

Hospice of Southern Maine

Hospice of York

Hospice Volunteers: Center for Grief & Loss in Mid Coast Maine

Hospice Volunteers of Somerset County

Hospice Volunteers of Waldo County

Hospice Volunteers of Waterville Area

Kno-Wal-Lin Hospice

Maine Health Care Association

MaineGeneral Health Palliative Care Program

Miles Home Health and Hospice

New Hope Hospice, Inc.

Pine Tree Hospice

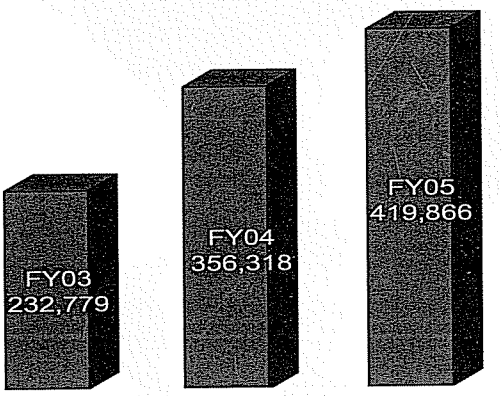
Vna Home Health Care

Waldo County Home Healthcare Services

Financial Review — Fiscal Year 2005

Year End Report

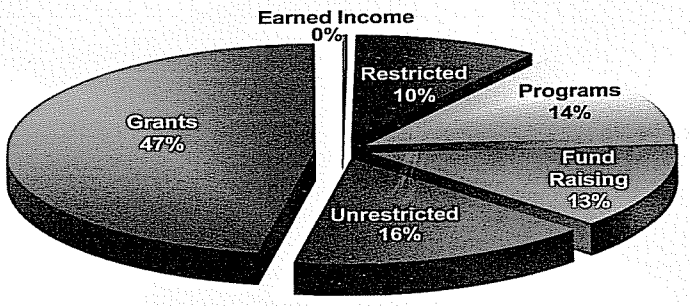
In Fiscal Year 2005, the Maine Hospice Council continued its remarkable growth trend demonstrated over the past several years. Since FY03, the Council's total income has increased from $232,779 to $419,866 — an increase of 180% During this period, the Council has been able to devote over 80% of all income to innovative program development.



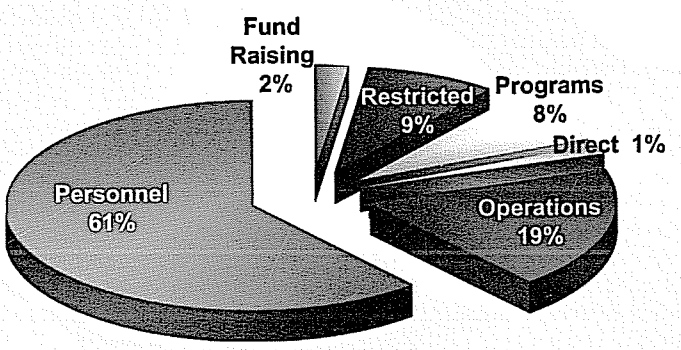
In the spring of 2006, a management audit review of the Council's FY05 finanancial statements was conducted. A copy of the complete "no findings" report is available at the Council office.

A final financial report for Fiscal Year 2005 will be presented at the July 2006 Council Board of Directors meeting. The numbers presented below represent actual activity through March with projections through the end of the Fiscal Year.

Earned Income	$1,000
Restricted	$40,453
Programs	$60,437
Fund Raising	$53,892
Unrestricted	$66,882
Grants	$197,202
Total Income	**$419,866**



Fund Raising	$9,409
Restricted	$35,347
Program	$32,606
Direct	$6,000
Operations	$76,999
Personnel	$250,595
Total Expense	**$410,956**



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