

**IMPROVING END-OF-LIFE CARE:
THE ROLE OF ATTORNEYS GENERAL**



best practices

2004 Report



National Association
of Attorneys General

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National Association
of Attorneys General

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**“ OUR CHALLENGE AS ATTORNEYS GENERAL
IS TO TURN THE VISION OF CONSUMERS
OF HEALTH CARE NEAR THE END OF LIFE
INTO A REALITY. “**

**Oklahoma Attorney General W.A. Drew Edmondson
Chair, NAAG End-of-Life Health Care Working Group, 2004**

INTRODUCTION

As chair of the National Association of Attorneys General 2004 End-of-Life Health Care Working Group, I have been privileged to work with Attorneys General from 13 states to establish our roles in improving health care to citizens who are near the end of their lives. Our progress toward that goal is reflected in this follow-up report on the activities and accomplishments achieved this past year on both the national and state levels.

Reflected here are the efforts and experiences of Attorneys General who have created a task force, sponsored a conference, published educational materials, posted information online, developed a continuing legal education program or otherwise committed their staff and resources to encourage a positive policy environment and bring together leaders in their states who can make quality end-of-life care a reality for their constituents.

My year as 2002-2003 NAAG president was devoted to working with Attorneys General on national issues regarding pain management policies, competent palliative care and acknowledgment and honoring of advance decision-making by terminally ill patients. This past year has seen success in the designation of an Assistant Attorney General or other staff in each state to continue to develop this role in representation of consumers of health care. To educate these individuals who have taken on the challenge of identifying specific barriers in their respective states, NAAG has provided a one-day training conference and monthly conference calls to support their chosen endeavors. Our working group of Attorneys General also met during NAAG's annual summer meeting to discuss best practices and outline plans for this project.

Lynne Ross, NAAG's executive director, has been assisted in this project by Dr. Wendy Pachter, chief counsel and director of the NAAG End-of-Life Health Care Project. Their leadership has allowed us to provide national input and to partner with health and legal professionals, including the Federation of State Medical Boards and the National Conference of State Legislatures.

The members of the Attorney General Working Group have proven invaluable in providing leadership in their respective offices. Moreover, this project would not have been possible without the continued support of individuals and organizations from the private sector. We have been fortunate to have an Advisory



W.A. Drew Edmondson
Oklahoma Attorney General

Committee composed of bioethicists, physicians, attorneys and educators who have been involved in improving end-of-life care for decades. This group, chaired by Myra Christopher, president and chief executive officer of the Center for Practical Bioethics, has pledged to continue to serve as a resource to Attorneys General who need assistance in addressing these issues. I am also grateful to the Center for Practical Bioethics, AARP and the National Hospice and Palliative Care Organization for their generous support of this project.

I am hopeful that the NAAG leadership and my colleagues will continue to embrace this cause which ultimately affects all of us, our families, friends, and most of all, the public that we are pledged to serve. Our success will ultimately rest on the shoulders of the dedicated staff in each Attorney General's office. Our assistants are the best and the brightest, the altruistic, the idealistic, the Don Quixotes with law degrees who believe they can change lives, because they have; who believe they can make better our communities, because they have. They are in Teddy Roosevelt's great "arena," knowing the great enthusiasms, the great devotions and spending themselves in worthy causes.

Oklahoma Attorney General W.A. Drew Edmondson
Chair, NAAG End-of-Life Health Care Working Group, 2004



END-OF-LIFE HEALTH CARE WORKING GROUP (2004)



ALABAMA
Attorney General
Troy King



MICHIGAN
Attorney General
Michael A. Cox



FLORIDA
Attorney General
Charlie Crist



NEW MEXICO
Attorney General
Patricia Madrid



GEORGIA
Attorney General
Thurbert E. Baker



OKLAHOMA
Attorney General
Drew Edmondson
Chair, End-of-Life Health Care Working Group



INDIANA
Attorney General
Steve Carter



OREGON
Attorney General
Hardy Myers



LOUISIANA
Attorney General
Charles C. Foti, Jr.



PENNSYLVANIA
Attorney General
Gerald J. Pappert



MAINE
Attorney General
G. Steven Rowe



RHODE ISLAND
Attorney General
Patrick C. Lynch



MARYLAND
Attorney General
J. Joseph Curran, Jr.



VERMONT
Attorney General
William H. Sorrell

“ SOME DOCTORS UNDERPRESCRIBE PAIN MEDICATION BECAUSE THEY FEAR PROSECUTION FROM LAW ENFORCEMENT. OTHERS MIGHT UNDERPRESCRIBE BECAUSE IN THE PAST THEY HAVE BEEN DUPED INTO PRESCRIBING MEDICATION WHICH ENDED UP SUPPORTING AN ADDICT'S HABIT. WE HAVE TO CREATE AN ENVIRONMENT WHERE DOCTORS ARE NOT AFRAID TO PRESCRIBE PAIN MEDICATION TO EASE THE SUFFERING OF THEIR PATIENTS AT THE END OF LIFE. ”

NAAG President and Vermont Attorney General William H. Sorrell

WORDS FROM OUR SPONSORS



As people age 50 and older engage in advance care planning, it is important to enhance their ability to discuss end-of-life options with their families, caregivers and health care providers. The National Association of Attorneys General End-of-Life Health Care Project provided a platform to address barriers and opportunities that will ultimately lead to improved conversations. We appreciated the opportunity to partner on this important project that furthers the mutual goals of AARP and the Attorneys General--making use of our power and responsibility to make life better for the people we represent. We look forward to more opportunities to work with Attorneys General to make real differences in the lives of people.

William Novelli, CEO



One of the fundamental tenets of the bioethics movement is that the professions must work together to resolve complex ethical issues in health care. The NAAG End-of-Life Health Care Project has done precisely this. It has brought together law enforcement agents, palliative care experts, policy makers, consumers and patient advocates to address the need to improve care of the seriously ill and dying, including better pain management, improved advance care planning and greater access to quality palliative care. The Center for Practical Bioethics (formerly Midwest Bioethics Center) has been pleased to support this important initiative and remains committed to working with Attorneys General across the country.

Myra J. Christopher, President and CEO

National Hospice and Palliative Care
Organization



We are happy to reiterate our support for the past accomplishments of the NAAG End-of-Life Health Care Project and look forward to being a part of its continuing efforts to improve care for all Americans. As the nation's oldest and largest end-of-life care organization, representing the interests of hospice and palliative care providers, professionals, volunteers, patients, caregivers and end-of-life care coalitions, we are pleased to be part of this process. While participating in the initial listening sessions sponsored by NAAG, and as I reflect on its continuing work, it becomes clear that patient and family wishes must be heard and honored in a variety of health care settings. The Attorneys General, through the End-of-Life Health Care Project and in their states, are playing a key role in raising the awareness of the necessity of informed patient choices that give credence to the full range of options that are available within the health care continuum.

J. Donald Schumacher, PsyD, President and CEO

PREFACE

It is my privilege, as chair of the Advisory Committee, to comment on behalf of my colleagues who have so generously served as advisors to the NAAG End-of-Life Health Care Project. Those of us who have worked in this field for many years were excited by the listening conferences hosted by Attorney General Drew Edmondson in 2002-03. The conferences challenged us with a new perspective (consumer protection) and rewarded us with new colleagues and valuable leadership.

The work done since then and reported herein has been just as exciting and perhaps even more important. Beyond merely reflecting the specific interest of a NAAG president, the End-of-Life Health Care Project now represents a shared concern of Attorneys General across the country. With the commitment of the NAAG board and the experience and wisdom of NAAG Executive Director Lynne Ross and dedicated staff, an enduring infrastructure has been established at the Association and in offices of Attorneys General across the United States.

This year fourteen Attorneys General formed an ongoing work group. Jack Schwartz, Annette Prince and Maureen Glynn, assistant attorneys general who have been deeply involved in the end-of-life movement, have been joined by peers from Maine to California and Washington to Florida to ensure that state law protects the rights of seriously ill people, emphasizing every citizen's right to have their pain managed, their advance directives honored and to receive quality palliative care.

Twenty-eight assistant attorneys general participated in a day-long educational seminar and a similar number have participated in regularly scheduled technical assistance calls. We hope one-hundred percent will benefit from an end-of-life continuing legal education program especially designed for Attorneys General and their staff, a project newsletter and other resources that have been distributed to them.

Already the results are impressive. Current NAAG President and Vermont Attorney General Bill Sorrell led an initiative to improve end-of-life care for Vermont seniors in the areas of pain management and decision-making. His initiative has already resulted in important legislative improvements, and additional draft legislation will be included in a report to be issued in early 2005. In Maine, Attorney General Steve Rowe and his staff partnered with the Maine Hospice Council to host their own listening conference patterned after those hosted by NAAG and to develop a plan of action specific to their state. In Missouri, Attorney General Jay Nixon's staff developed a resource package on advance care

planning for which they are finding it hard to keep up with the demand, and in Rhode Island, Attorney General Patrick Lynch's staff drafted rules and regulations to require end-of-life care continuing medical education credits for state physicians there. In this report, you will see many other examples of how this project has impacted the work of Attorneys General.

This project has received significant attention from health care professionals, patient advocates and policy makers. In 2005, Attorney General Drew Edmondson will receive the Nathan Davis Award for Government Service. Presented by the American Medical Association, this award is one of the most prestigious honors extended to elected officials and career government employees for outstanding endeavors that advance public health.

In May when Drew accepts this honor, he will without doubt accept it on behalf of all who have worked on this project, thereby shifting the focus away from himself. It is fitting that his good work is recognized in everyone who has served with him.

“BEHIND AN ABLE MAN THERE ARE ALWAYS OTHER ABLE MEN.”

- *Chinese Proverb*

Myra J. Christopher
Chair, NAAG End-of-Life Health Care Advisory Committee

END-OF-LIFE HEALTH CARE PROJECT ADVISORY COMMITTEE

MYRA J. CHRISTOPHER, CHAIR

President and CEO

- Center for Practical Bioethics

IRA BYOCK, MD

Director

- Palliative Medicine Dartmouth Hitchcock Medical Center

FRANKIE SUE DEL PAPA

Former Attorney General of Nevada

LINDA EDMONDSON, LCSW

Program Manager

- Oklahoma Alliance for Better Care of the Dying
- Co-Chair*
- Oklahoma Attorney General's Task Force to Improve End-of-Life Care

BETTY FERRELL, PhD, FAAN

Research Scientist

- City of Hope Medical Center

NEIL E. HARTIGAN

Chairman Emeritus

- World Trade Center Chicago

HUBERT H. HUMPHREY III

Senior Vice President

- Tunheim Partners

DAVID JORANSON

Director

- Pain and Policy Studies Group University of Wisconsin

RICHARD PAYNE, MD

Chief

- Duke Institute on Care at the End of Life Duke University Divinity School

CHARLES SABATINO

Assistant Director

- Commission on Law and Aging American Bar Association

J. DONALD SCHUMACHER, PsyD

President and CEO

- National Hospice & Palliative Care Organization

2004 ATTORNEY GENERAL END-OF-LIFE ACTIVITIES BY STATE

2004 END-OF-LIFE ACTIVITIES ¹	AL	IN	ME	MD	MA	MO	MT	NH	OK	OR	RI	VT
ATTORNEY GENERAL TASK FORCE									●		●	●
LISTENING CONFERENCE			●									
BROCHURE						●						
WEB PAGE			●	●		●	●		●	●		
END-OF-LIFE CLE			●	●					●	●		
SIMPLIFY OR OTHERWISE IMPROVE FORMS			●	●	●				●		●	●
INFORMATIONAL SESSIONS WITH THE PUBLIC	●			●	●	●		●	●			●
COOPERATIVE ACTIVITIES WITH COMMUNITY AND STATE COALITIONS		●	●	●	●	●	●				●	●
PROMOTING, DRAFTING, IMPLEMENTING LEGISLATION				●				●			●	●
WORKING WITH HEALTH CARE PROFESSIONALS TO IMPROVE END-OF-LIFE CARE				●		●			●		●	●
PARTICIPATING IN STATEWIDE END-OF-LIFE COMMISSIONS ²				●	●		●	●				
INVOLVEMENT IN IMPROVING PAIN ASSESSMENT/MANAGEMENT				●		●					●	●

¹ A few of the reports that follow are selective and may not describe activities listed here. Further information may be obtained by contacting the offices directly. Also, many offices have engaged in additional activities in previous years, as described in *Improving End-of-Life Care: The Role of Attorneys General, 2003*.

² Not all states have convened statewide end-of-life commissions, so a blank in this box does not denote lack of interest on the part of an Attorney General.

ATTORNEY GENERAL END-OF-LIFE REPORTS

ALABAMA

In 2004, Alabama Attorney General Troy King formed the Family Protection Unit to serve as a clearinghouse for crime and prevention issues that affect Alabama families. In September, Attorney General King convened a statewide seminar for law enforcement and social services workers to collaborate on ways to better address the problem of elder abuse and exploitation.



Troy King
Alabama Attorney General

Recognizing the importance of educating the public about the legal avenues available to protect Alabama's citizens, Attorney General King followed the statewide seminar for professionals with six regional seminars designed to give senior citizens information on ways they could protect themselves from fraud and abuse. One of the issues addressed at these seminars was the importance of advance planning for end of life health care. At each seminar, Assistant Attorney General Alice Maples gave a presentation on Legal Methods to Prevent Financial and Physical Abuse of the Elderly. This presentation included a detailed discussion of options for advance health care planning in Alabama and emphasized the importance of discussing with family members end of life issues that could arise in the future. Maples explained the purpose of advance health care directives, when the directives are applicable, what types of situations the directives address and the process for executing advance health care directives. She also discussed the availability of durable powers of attorney for health care decisions to address situations not included in an advance health care directive. Finally, she explained the process for appointment of a guardian. More than 1,500 senior citizens attended the seminars held in six different Alabama cities.

INDIANA

Indiana Attorney General Steve Carter has been pro-active in prosecuting elder abuse and ensuring that medical professionals in Indiana are held to the standards of practice required by state law. The office has developed a comprehensive policy to hold health facility administrators and other licensed providers accountable for failures in delivering quality health care, including the care provided to dying residents and patients. The Medical Licensing section of the office actively investigates complaints regarding all licensed medical professionals and

“ ONE OF THE KEY MISSIONS OF THE OFFICE OF THE ATTORNEY GENERAL IS TO PROTECT CONSUMERS, INCLUDING HEALTH CARE CONSUMERS. END OF LIFE CARE IS THE ULTIMATE HEALTH CARE CONSUMER PROTECTION ISSUE. WE MUST WORK TO ENSURE THAT CONSUMERS HAVE ACCESS TO COMPETENT CARE AND APPROPRIATE PAIN MANAGEMENT MEASURES, AND THE ABILITY TO APPROVE OR AVOID EXTRAORDINARY MEDICAL INTERVENTION AT THE END OF LIFE. “

Maine Attorney General G. Steven Rowe

has several nurses on staff to analyze complex medical cases.

The office has obtained more sanctions against long-term health care providers accused of abuse, neglect or fraud against patients since Attorney General Carter took office in 2001. There have been disciplinary sanctions against 59 long-term care administrators since 2001, compared to just one sanction obtained between 1998 and January 4, 2001.



Steve Carter
Indiana Attorney General

Further, the Attorney General's Medicaid Fraud Control Unit (MFCU) investigates allegations of abuse and/or neglect of patients in health care facilities that receive payments under the state Medicaid plan. The MFCU record includes:

- 885% increase in fraud and abuse referrals to licensing agencies and prosecutors for action; 124 referrals in the past year - up from just 14 in 2000;
- 28 criminal convictions by prosecutors for fraud as a result of referrals from the MFCU;
- 902% percent increase in the number of elder abuse and neglect complaints filed with MFCU since 2001.

Representatives of the office, Deputy Attorneys General Anne Flannelly and Jenna Stewart, attended the NAAG End-of-Life Conference in Chicago held in October 2004. Communications between the office and the Indiana Hospice and Palliative Care Organization (IHPCO) are ongoing and discussions have been held regarding cooperation between the office and IHPCO to disseminate information in an effort to further educate the public regarding end of life issues.

MAINE

In 2004, the Maine Office of the Attorney General took several steps to improve End-of-Life Care in Maine. First, we launched a web page designed to be a resource for Mainers looking for information on the issue. The web page focuses on hospice resources, pain management and Advance Health Care Directives. See: <http://www.maine.gov/ag/?id=254&r=elderissues&s=endoflife#advancedirective>

After determining that the model Maine Advance Health Care Directive available through most state agencies was not as clear as it could be, the office convened a committee to draft a new Advance Health Care Directive. We tested the new form during a Lunch and Learn held for our staff on Advance Health Care Directives. This program offered attorneys one hour of CLE. We found that very few individuals within our office had given the issue much thought. The session was well-received. After completing revisions from the feedback we received from our employees, we launched the form on our web page.

Finally, the Office of the Attorney General partnered with the Maine Hospice Council to host a Listening Conference in Maine on End-of-Life Issues. National and local panelists presented on three topics: Pain Management, Competent Care and Advance Directives. In the afternoon session, the 300 attendees broke into small facilitated discussion groups to identify barriers and solutions in each substantive area. The Listening Conference was a tremendous success as reported in the conference evaluations. Within the next few months, the Maine Hospice Council and Office of the Attorney General will publish a report outlining the ideas offered by the conference attendees. The conference offered attorney participants six hours of CLE credit.

MARYLAND

The Maryland Attorney General's Office has had a longstanding focus on systemic improvements in the delivery of end-of-life care. We try to influence the policy environment so that excellent care can flourish and, in fact, become routine - "we do things the right way around here." Although that goal can be achieved only if leaders in clinical medicine and nursing push for it and sustain it, we can help by giving sensible legal advice, offering frequent educational sessions and looking for law reform opportunities.



G. Steven Rowe
Maine Attorney General



J. Joseph Curran, Jr.
Maryland Attorney General

“ NAAG'S COMMITMENT TO FOSTERING QUALITY END-OF-LIFE CARE IS EXACTLY THE KIND OF WORK WE SHOULD BE DOING. AN ATTORNEY GENERAL CAN BE THE LINCHPIN FOR POSITIVE CHANGE IN HIS OR HER STATE. IN MY NEARLY TWO DECADES AS MARYLAND'S ATTORNEY GENERAL, ONE OF THE MOST SATISFYING ONGOING PROJECTS HAS BEEN OUR EDUCATIONAL AND LAW REFORM EFFORTS TO HONOR THE WISHES OF PATIENTS WITH LIFE-LIMITING ILLNESS AND TO SUPPORT THEIR FAMILIES AND HEALTH CARE PROFESSIONALS. “

Maryland Attorney General J. Joseph Curran, Jr.

In 2004, our main project involved promoting, and then implementing, legislation to improve communication about end-of-life preferences. Currently, when a patient with a serious illness or the patient's proxy (health care agent or surrogate) discusses a plan of care for the use of life-sustaining treatments, a health care provider's documentation of the outcome of this discussion is facility-specific, with high variability from site to site. Moreover, there is no established method for communicating information about a care plan when a patient moves from one facility to another.

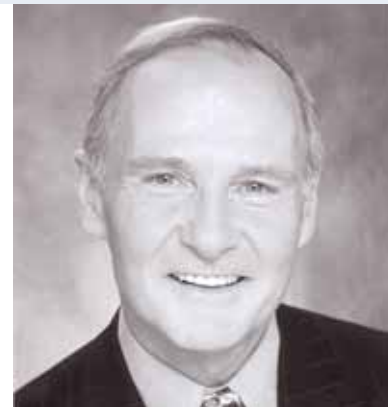
One response to this problem, a standardized physician's order form embodying decisions about the use of life-sustaining treatments, has had demonstrated success in other states. A bill to create such a physician's order form in Maryland was introduced in early 2004, with our support. Opposition to the concept, however, was sufficient to imperil the bill in committee. We helped to fashion a compromise. As enacted, the bill calls for the Attorney General's Office to develop a voluntary "Patient's Plan of Care" Form, which will be a synopsis of the main goals of care and any decisions about the use of life-sustaining treatments. If the patient is transferred from one facility to another, the form will go along and serve as a point of reference for further care planning.

We have been working to prepare a form that we hope will be widely accepted, in that it will be seen by health care providers and patients/proxies as useful. Our process for developing the form (and surrounding explanatory material) has been transparent and inclusive. Successive drafts of the form were posted for public comment. (Everything is available at this address: www.oag.state.md.us/health-pol/index.htm.) The draft form was vetted by the State Advisory Council on Quality Care at the End of Life. In addition, a diverse group of leaders from consumer rights, disability rights, governmental, health care, legal and religious organizations convened to critique the draft form.

The process of developing the form and conducting educational sessions about it in hospitals and nursing homes will continue well into 2005. Hence, we have no indicators about the ultimate success or failure of the effort. We are optimistic, however, that over time the "Patient's Plan of Care" Form will result in care delivery that is more attentive to the patient's wishes. In the interim, we are confident that our collaborative and open process has strengthened the belief among stakeholders that our office is a trustworthy ally in the effort to improve end-of-life care.

MASSACHUSETTS

Massachusetts Attorney General Tom Reilly's office collaborates with the Massachusetts End of Life Commission on end of life issues. The Commission has proposed legislation that would add the Attorney General to its core, statutory membership. The office is also working with the Commission to develop a survey to send for Massachusetts residents, age 35 and over, to better understand consumers' beliefs and knowledge about end of life issues. A representative of the Attorney General's Office serves on the survey advisory committee.



Tom Reilly
Massachusetts Attorney General

As part of our ongoing efforts to provide information to Massachusetts consumers about end of life issues, our office is reviewing the issue of whether to include model advance directives on our web site, and if so, which model to use. We have also begun meeting with the Commission and with the Central Massachusetts Partnership to Improve Care at the End of Life concerning the use of uniform Do Not Resuscitate Orders.

MISSOURI

The Missouri Attorney General's Office, along with the Missouri End of Life Coalition (MEOLC), launched its Life Choices consumer education initiative this year. The announcement of the initiative and presentation of the Life Choices publication were the products of a ten-month partnership between the Attorney General's Office (AGO) and the MEOLC, a grassroots organization comprised of health care professionals, patients, social workers and others who are working to improve end of life care. The office has distributed more than 15,000 Life Choices booklets to individuals and health care providers and dozens of CD-ROMS to hospitals. We also launched our End of Life web page, which is accessible from our AGO web site.



Jay Nixon
Missouri Attorney General

The Missouri AGO is also a participating member on the Missouri Advisory Council for Pain and Symptom Management (MACPASM), established by the Missouri legislature to create an annual report to various government officials. The content of the report may include issues and recommendations developed by the council regarding pain management, educational requirements for institutions providing health care education, information regarding the effectiveness and impact of various practices and a review of current policies regarding pain and symptom management. The Council is comprised of nineteen members including health care providers, policy makers and pain patients. Part of the mission of the council includes holding town hall meetings around the state to listen to patients, family members and health care providers tell their stories about barriers to pain, pain treatment and end of life care.

Members of our office spoke to several groups throughout the second half of the year on the topic of end of life care, including the Missouri Hospice and Palliative Care Association and palliative care doctors and nurses at Missouri Baptist Medical Center in St. Louis.

MONTANA

Attorney General Mike McGrath designated Thea Van Nice as his contact person on the End of Life/Palliative Care Initiatives. Van Nice attended the End-of-Life Health Care Seminar in Chicago in October 2004. Upon her return to Montana, meetings were held with directors of the Choices Bank in Missoula, Montana. The Choices Bank is the Internet repository for advance care directives (in Missoula only). Funding for the Bank is running out and Attorney General McGrath offered to host it on the Montana Department of Justice web site. It will become the repository for the entire state of Montana and will be accessible by all physicians, nursing homes, emergency rooms and emergency medical technicians. Information on the Choices Bank can be found at www.choicesbank.org.



Mike McGrath
Montana Attorney General

Recently, Van Nice represented Attorney General McGrath at the first Montana Palliative Care Summit, held in Helena, the state capital. Representatives from all over the state included doctors, nurses, social workers, the American Cancer

Society, legislators, hospital chaplains, hospice directors, AARP state directors, Montana Hospital Association staff and the director of Aging Services for the State of Montana. The Cancer Society is proposing legislation in the upcoming 2005 session which will create a Pain and Symptom Management Advisory Council. Montana currently does not have policy that explicitly addresses the needs of terminally patients, nor do we have a comprehensive pain management policy. The Attorney General's Office will support the creation of an advisory group to study the issue of pain and symptom management. The advisory group will create a statewide forum to consider ways to improve pain and symptom management in Montana.

NEW HAMPSHIRE

The Attorney General's Office is participating with a 30-member working group (the "Healthcare Decisions Coalition") to revise a number of New Hampshire statutes that deal with critical end-of-life issues. The draft legislation deals with living wills, do-not-resuscitate orders, health care directives and durable powers of attorney for health care decisions. The working group consists of physicians and nurses, legislators and public policy leaders, attorneys and law school faculty members, representatives of specific communities with unique perspectives on health care issues and a probate court judge. The working group is chaired by Shawn LaFrance, head of the Foundation for Healthy Communities in New Hampshire. The working group analyzed statutes from other states and considered provisions from the Uniform statutes in this area, in order to achieve consistency with developments in other jurisdictions, where possible. The draft legislation is in its final drafting stage and will be presented to the New Hampshire Legislature during this session for consideration. The working group will provide testimony on the draft legislation. In addition, if the legislation is enacted into law, the working group will prepare a commentary or publication, offering analysis for the lay reader and others of what is a complex and critical area of the law.

In addition, Attorney General Kelly Ayotte participated in a public forum at Dartmouth-Hitchcock Medical Center that addressed end-of-life issues. The session was designed as a listening session, to provide citizens with an opportunity to express their thoughts on these public policy issues.



Kelly Ayotte
New Hampshire Attorney General

OKLAHOMA

After launching NAAG's national palliative care initiative in 2002, Oklahoma Attorney General Drew Edmondson has taken a comprehensive approach to improving end-of-life health care in Oklahoma.

In April 2004, Attorney General Edmondson created a state task force made up of physicians, lawyers, nurses, social workers, chaplains, hospice leaders and state agency directors. The group's objective is to study barriers to quality end-of-life care within the state and generate recommendations to improve palliative care both through regulatory agencies for health care professions and legislation.

The task force recommendations are scheduled to be released in 2005. Upon making its final report, the task force is expected to request authorization to continue its work until at least April 2006, in an effort to further monitor progress and more extensively study health care issues affecting Oklahoma consumers.

Attorney General Edmondson also provides his staff with continuing legal education based on the NAAG end-of-life listening conferences. Assistant Attorneys General are advised on the issues of advance planning, pain management and competent health care. That message is carried to the public each April, as the Attorney General's Office partners with the governor to recognize Palliative Care Week by holding a ceremony in which both officials reaffirm their own advance health care directives.

There are also two units within the office that work directly to improve end-of-life health care in Oklahoma. Edmondson's Medicaid Fraud Control Unit advocates for effective pain management and competent care in long term care facilities. The Attorney General's General Counsel Section is often called upon to interpret the law and provide legal counsel for state licensing boards for physicians, nurses and pharmacists.

The efforts of Attorney General Edmondson and his staff have earned the office national recognition. On Oct. 1, 2004, Edmondson received the 2004 Public Policy Award from the National Hospice and Palliative Care Organization for his work to improve the care Americans receive at the end of life. Edmondson was also honored in May 2004 with the Vision to Action Award by the Center for Practical Bioethics in Kansas City.



W.A. Drew Edmondson
Oklahoma Attorney General

With the creation of the task force and the continual emphasis on education and accountability for those charged with providing palliative care, the Oklahoma Attorney General's Office is constantly working to improve the state of end-of-life health care in Oklahoma.

OREGON

Oregon Attorney General Hardy Myers thanks Oklahoma Attorney General Drew Edmondson for pursuing his NAAG Presidential Initiative on the Role of Attorneys General in End-of-Life Health Care Issues and thanks NAAG for the ongoing support of that effort through the NAAG End-of-Life Health Care Working Group.



Hardy Myers
Oregon Attorney General

As a direct result of the efforts of the NAAG End-of-Life Health Care Working Group, Attorney General Myers is offering an End of Life CLE program which will be made available to all Oregon Department of Justice employees during January and February 2005. In addition, during the coming year Attorney General Myers intends to facilitate communication among law enforcement organizations, regulatory agencies including Oregon's Pain Management Commission and health licensing boards, the Task Force to Improve the Care of Terminally-Ill Oregonians coordinated through the Center for Ethics in Health Care at Oregon Health and Science University (OHSU) and other interested parties to address appropriate pain management practices. Based upon communications with regulatory agency representatives and practitioners, Attorney General Myers believes his office can help negotiate the tensions between law enforcement/regulatory concerns about misuse or diversion of controlled substances used in pain management and the need for those with intractable pain to get proper treatment.

As to improving the likelihood that patient treatment wishes will be honored, Attorney General Myers has created web page space on the Attorney General's web site for information about end-of-life health care issues. The web site will provide information on end-of-life matters and provide links to the Oregon Department of Human Services web site, which already has direct links to Oregon's advance directive laws and forms as well as information about available resources. The Attorney General's web site will also provide a link to the OHSU

“ OREGON HAS A HISTORY OF ROBUST ACTIVITY ON END-OF-LIFE HEALTH CARE ISSUES THROUGH THE TASK FORCE TO IMPROVE THE CARE OF TERMINALLY-ILL OREGONIANS CONDUCTED UNDER THE AUSPICES OF THE CENTER FOR ETHICS IN HEALTH CARE AT OREGON HEALTH AND SCIENCE UNIVERSITY (OHSU). ATTORNEY GENERAL EDMONDSON'S INITIATIVE, HOWEVER, HAS HIGHLIGHTED THE FACT THAT ATTORNEY GENERAL OFFICES ARE SITUATED IN A UNIQUE POSITION AT THE INTERSECTION OF LAW AND POLICY AND THAT, THEREFORE, ATTORNEYS GENERAL CAN FACILITATE BROAD-BASED COMMUNICATION TO INCREASE AWARENESS ON END-OF-LIFE HEALTH CARE ISSUES. “

Oregon Attorney General Hardy Myers

web site, which provides detailed information about the Physician Orders for Life-Sustaining Treatment (POLST) program developed in Oregon. The POLST web site (<http://www.ohsu.edu/ethics/polst>) provides background information and forms to use for the POLST program designed to help health care providers honor the end-of-life treatment wishes of their patients through the use of an easily completed and easily recognized document setting out the medical treatment wishes of the patient in a physician order form that follows the patient through all care settings. This program facilitates conversations between patients and care providers and aids transfer and recognition of patient treatment wishes among health care providers and care settings.

RHODE ISLAND

Improving end of life care continues to be an important initiative for the Rhode Island Department of Attorney General. The Attorney General Task Force to Improve End of Life Care (“Task Force”) consists of approximately 60 members representing health care providers, academic medical programs, patient advocates, lawyers, religious/spiritual representatives and government. Since the last NAAG End-of-Life Care Health Care Report in 2003, the Task Force has continued with increasing awareness about hospice care, pain management and advance care planning. The Task Force receives no funding by the state of Rhode Island. Task Force members provide in kind contributions for the projects and apply for grants to provide funding for some projects, such as educational programs with nationally recognized experts.



Patrick C. Lynch
Rhode Island Attorney General

The Task Force worked with the Rhode Island Department of Health to prepare comprehensive regulations for the interpretation and implementation of the recently enacted Pain Assessment Act, which provided that pain shall be assessed in all health care settings. The regulations provide detailed guidance for assessing pain including, but not limited to, the use of a pain intensity tool, characteristics of pain, location of pain, duration of pain, onset of pain, the patient's goals and the alleviation of causative factors.

To help with educating physicians about pain, the Task Force worked with the

Rhode Island Medical Board to amend the rules and regulations related to continuing medical education for physicians to include end of life care, pain management, palliative care and hospice care as topical areas for required continuing medical education units.

Although end of life care is frequently considered an issue involving older people, end of life knows no age. Recognizing the importance of palliative care for children, the Attorney General drafted legislation and the General Assembly enacted legislation to provide children who are terminally ill and their families with palliative care services.

To help increase awareness of the importance of improving end of life care, the Task Force has sponsored numerous continuing education programs involving pain assessment and management and advance care planning. In addition to local experts, the Task Force has sponsored programming with regional and national experts such as Ira Byock, M.D. and L. Jean Dunegan, M.D., J.D.

Since July 1, 2004, the Patient's Bill of Rights has required hospitals, nursing homes and assisted living facilities to provide patients with information about hospice care. Until the Patient's Bill of Rights had been amended, patients were not entitled to information concerning hospice care as an alternative for the terminally ill.

The Task Force seeks to build networks between members. As a result of working with the Task Force, two significant groups have been formed. Rhode Island now has an Ocean State Ethics Network consisting of a hospital ethics committee, which meets quarterly to discuss varied issues involving end of life care as well as other ethical issues. This relationship has provided small community-based hospitals the access to academic medical centers who have a larger staff to assist with ethical issues. The other group that has formed as a result of networking through the Task Force is the Rhode Island Hospice Care Association. Until the Task Force began meeting, the individual hospices in Rhode Island had not met. Now, through the Rhode Island Hospice Care Association, the hospices are jointly planning educational programs to increase awareness about hospice services.

Upcoming Projects

Recognizing the importance of the medical director in nursing homes, the Task Force is undertaking the project of providing training for nursing home medical directors concerning hospice services and pain management so that the

medical directors will be able to train the physicians and nurses on staff in the nursing homes.

The Task Force is coordinating with a documentary filmmaker to prepare a video on the importance of advanced care planning. A rough cut of the film should be available by the beginning of 2005.

Rhode Island has made significant progress in laws, rules and policies concerning pain management. The next step is to review the Medical Board's policy concerning pain.

As long as people are needlessly suffering from pain, the Task Force to Improve End of Life Care will continue its efforts to improve end of life care.

VERMONT

During 2004, the Vermont Attorney General's Office engaged more than 80 people from a wide variety of backgrounds in an initiative to improve end of life care for Vermont seniors in the areas of pain and symptom management and decision-making. Committees promoted improvements in the 2004 legislature, which resulted in legislation requiring:

- studies by the Department of Health on improving pain management, creating a registry for advance directives and changing Vermont drivers' licenses and identity cards to indicate that the bearer has an advance directive;
- notice to residents in nursing homes of their rights to professional assessment of pain and pain management and to hospice services and hospice eligibility criteria; (Note: One hospice organization reports a 15% increase in the number of nursing home residents who access its services since the right became effective on July 1, 2004.)
- interim improvements in advance directives law such as making the statutory form optional rather than mandatory, combining and expanding various advance directives forms, clarifying that



William H. Sorrell
Vermont Attorney General

the most recently signed document controls if there is a conflict between various forms on advance directives and requiring health and residential care providers have systems in place to ensure that advance directives and do-not-resuscitate orders are readily available when services are to be provided and are followed by the provider.

As a result of the Initiative, the most popular form for advance directives in Vermont has been updated and is being reprinted, reflecting the improvements made in 2004 and anticipating legislation that will be introduced in 2005. Similarly, the Attorney General's Office, the Medical Society and the Vermont Bar Association are planning a pilot educational project of pairing retired physicians and attorneys working for the state seeking to fulfill their pro bono obligations to work for free with individuals or small groups to fully discuss and complete advance directives for health care.

The Initiative's committees continued to work on proposed legislation and other areas of improvement of end of life care throughout 2004. Their recommendations will be included in a report to be issued early in 2005 with draft legislation covering changes in the Hospital Bill of Rights on pain management, additional changes on advance directives, DNR orders and surrogacy.

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“ A SOUND PAIN POLICY BALANCES THE REDUCTION OR ELIMINATION OF PEOPLE'S SUFFERING WITH PREVENTING ABUSE OF PRESCRIPTION DRUGS. IT IS A DELICATE BALANCE, BUT ONE THAT IS NECESSARY. ATTORNEYS GENERAL ARE UNIQUELY QUALIFIED TO HELP THEIR CONSTITUENTS BY SUPPORTING PROPER PAIN MANAGEMENT WHILE WORKING WITH LAW ENFORCEMENT TO PREVENT ABUSE AND DIVERSION OF PAIN MEDICATION. ”

Rhode Island Attorney General Patrick Lynch

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“ THE TIME TO ACT ON THIS IS NOW. SPEAKING FROM THE PERSPECTIVE OF MY OWN GENERATION, THERE ARE FEW AMONG US WHO, WITHIN THE NEXT DECADE, WILL BE SPARED FROM HAVING TO ADVOCATE ON BEHALF OF OURSELVES, OUR PARENTS OR OUR LOVED ONES FOR THE RIGHT TO COMPETENT END-OF-LIFE CARE AND PAIN MANAGEMENT. THIS IS AN ISSUE THAT CANNOT BE IGNORED. ”

NAAG President and Vermont Attorney General William H. Sorrell