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

NATIONAL ASSOCIATION OF ATTORNEYS GENERAL



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# IMPROVING END-OF-LIFE

## CARE:

THE ROLE OF ATTORNEYS GENERAL



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

**W.A. DREW EDMONDSON  
PRESIDENT, NATIONAL ASSOCIATION  
OF ATTORNEYS GENERAL, 2002-2003**

# TABLE OF CONTENTS

## SECTION ONE: INTRODUCTION

The Vision Versus Reality . . . . .	2
Preface. . . . .	4
Acknowledgements . . . . .	6
Overview of End-of-Life Care in the United States. . . . .	9
The Role of Attorneys General. . . . .	15

## SECTION TWO: PROTECTING CONSUMERS

Consumer Stories . . . . .	23
Will My Pain be Managed? . . . . .	27
Will My Wishes be Known and Honored?. . . . .	35
Will I Receive Competent Care?. . . . .	47

## SECTION THREE: ATTORNEYS GENERAL PROMISING PRACTICES . . . . . 53

## SECTION FOUR: RESOURCES

National End-of-Life Care Organizations. . . . .	73
Related National Organizations and Web Sites. . . . .	76
National Experts in End-of-Life Care . . . . .	77
State-by-State Coalitions. . . . .	81
2002-2003 Listening Conference Attendance List . . . . .	89

CD . . . . . Back cover of report  
Information contained on the CD titled, "Court Decisions on the Legal Aspects of Withholding/Withdrawing Medical Treatment," was compiled by Patrick Kelly, professor emeritus and former dean of the University of Missouri-Kansas City School of Law. Kelly is also a former board member of Midwest Bioethics Center. The CD was provided courtesy of Midwest Bioethics Center, which reserves copyright.

**SECTION 1: INTRODUCTION**

# THE VISION VERSUS REALITY

**BY: Oklahoma Attorney General W.A. Drew Edmondson**

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W.A. Drew Edmondson

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As President of the National Association of Attorneys General (NAAG), 2002-2003, it is my privilege to select a presidential initiative for consideration by Attorneys General during my term of office. When asked about our expectations for end-of-life care, most of us share the same vision: to be free of pain; to be at home surrounded by family and friends; and to have our wishes known and honored. Despite these expectations, we continue to hear stories recounted by family members of patients who endure needless pain and frustration when legal or medical professionals discount their wishes. Advocates for improvement of end-of-life care have been aware of this reality every day, in every state, for decades.

The cornerstone of my initiative centered on three regional listening conferences to provide an opportunity for Attorneys General to hear compelling stories recounted by the mothers, sisters, children and spouses who were thwarted in efforts to fulfill the wishes of loved ones.

We challenged national experts to testify before assembled panels of Attorneys General and to address the three questions repeatedly raised by consumers: “Will my pain be managed?” “Will my wishes be known and honored?” and “Will I receive competent care?”

These clinicians and health care advocates reported that 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 of controlled substances. We also heard that there is still a significant gap between policy and practice.

More than 50 attendees from Attorney General offices across the country listened and learned about the barriers that persist, despite legislation in every state, to provide advance care directives, health care proxies and powers of attorney.

We listened to physicians and nurses who cited deficits in educational requirements in medical, nursing, social work and pharmacy schools for end-of-life health care. As consumers, we expect these professionals to be trained in pain management and be informed regarding health care choices, such as hospice. To the contrary, statistical studies reflect a lack of education as a major factor contributing to substandard care near the end of life.

The emerging role of Attorneys General in the protection of these consumers of health care is a challenge and a call to partner with clinicians and advocates to eliminate legal and policy barriers to safeguarding the rights of patients and families.

My initiative, to examine our role as Attorneys General in improvement of care near the end of life, originated when I first listened and learned of this discord between the expectations and experiences of terminally ill patients. Invitations to attend national health care conferences were extended to me, not because of my political office, but because of the leadership role of my wife, Linda Edmondson. Linda worked as a hospital social worker for many years and then in a leadership role as director of the Oklahoma Association for Health Care Ethics and administrator of the Robert Wood Johnson grant to the Oklahoma Alliance for Better Care of the Dying.

It was at one of these conferences that I heard Myra Christopher, president and chief executive officer of the Midwest Bioethics Center, cite the statistic that 80 percent of us express the wish to die at home, surrounded by family and friends, free of pain and without unwanted medical intervention to prolong our suffering. Myra continued to explain that 80 percent of consumers actually die in pain, in hospitals or nursing homes, receiving unwanted extraordinary medical intervention. This presentation triggered my personal exploration as to what I could do to remove the legal barriers that contribute to this tragic statistical gap.

As the highest law officers in our respective states, we are charged with representing our constituents, regardless of economic, social or political status, in matters affecting the public interest. This charge includes protection of the dying. Our role as Attorneys General in protection of the reasonable expectations of consumers of end-of-life care offers an opportunity to address and assist in resolution of this conflict between the law as written and the law in action.

This past year, listening to Attorneys General, consumers and health care advocates who have been passionately committed to this issue for decades, I have been reminded of a statement by President John F. Kennedy at a news conference. One of the female correspondents asked, “Mr. President, what have you done for the ladies of this country?” He replied, “Well, I am certain it has not been enough.” Whatever we have done to improve health care for patients near the end of life in our states, from Maine to California, these conferences have made us acutely aware that it certainly has not been enough. Acting through my assistant attorneys general as advisors, interpreters and advocates, I am privileged to serve the people of the state of Oklahoma as a vital force in the creation of a legal environment that promotes therapeutic jurisprudence in regard to this critical issue that ultimately affects all of us.

As President of NAAG, I can imagine no finer legacy for a public servant than to reduce human suffering in our states. As my term as President of NAAG comes to an end, I look forward to the beginning of a commitment by the National Association of Attorneys General to the protection and representation of these most vulnerable consumers in our respective states.

# PREFACE

BY: Myra Christopher

When Oklahoma Attorney General Drew Edmondson assumed office as President of the National Association of Attorneys General (NAAG), 2002-2003, he announced that he would devote his presidential initiative to the role of Attorneys General in the protection of consumers of health care near the end of life. Despite caution from advisors that he consider a more popular political issue in an election year, he remained resolute. As a long time advocate for improved end-of-life care, it has been my great privilege to participate in Attorney General Edmondson's commitment of NAAG to this critical issue.



Myra Christopher

To place this important initiative in perspective, certain events are relevant. In the November 1995 issue of the *Journal of the American Medical Association*, the Study to Understand Prognoses and Preferences Regarding Treatment, *SUPPORT*, was published. At a cost of \$28 million, this study, conducted in five of the most highly respected medical institutions in the United States, yielded alarming and irrefutable results. The researchers reported that, prior to death, participants in the study were isolated in hospital intensive care units for extended periods, averaging 10 days. Many were unconscious, hooked up to machines, until the moment of death. The wishes of those who had executed advance directives were often ignored with the costs of unwanted medical treatment, resulting in financial devastation to their families. Of those who were conscious at the time of death, more than half were in severe to acute pain.

In a *USA Today* article, "Breaking the Silence on Death," Doug Levy reported that researchers in the *SUPPORT* study observed "doctors are so oriented toward keeping people alive, they are reluctant to shift toward keeping patients comfortable as they die." He concluded that the study cast a pall over any claim that improvements in the health care system would occur.

Fortunately, reformers in the end-of-life movement were less pessimistic. Those who had started hospices in the 1970s viewed *SUPPORT* as an opportunity to re-energize efforts to improve care of the seriously ill and dying, regardless of where they received health care. A new robust phase of the national movement emerged focusing on the necessity of training doctors and nurses in pain management and palliative care, establishing clinical standards for end-of-life care, ensuring the readiness of institutions, reforming health policy and engaging the public.

Significantly, even before *SUPPORT*, this challenge captured the attention of Attorneys General. Former Nevada Attorney General Frankie Sue Del Papa convened a state end-of-life commission. In Maryland, Attorney General Joe Curran empowered Assistant Attorney General Jack Schwartz to assume a role in these issues. With their encouragement, following the publication of *SUPPORT*, a panel on end-of-life issues was convened at an annual NAAG meeting. Following that presentation, some Attorneys General, including Attorney General Edmondson, joined with end-of-life care coalitions in their respective states to support this national movement.

As I have worked with Drew this past year, I have been reminded of another leader who was not always guided by what was popular or deterred from his vision of public service by political caution. In describing his job as President of the United States, Abraham Lincoln said, “What I want is to get done what the people desire to have done, and the question for me is how to find that out exactly.”

I believe that readers will recognize in this report on Attorney General Edmondson’s “listening” conferences a marvelous mechanism for finding out exactly what the people want done. It provides tangible evidence of participatory democracy at its best as a result of his vision, courage and leadership. I am confident that it will be a valuable resource for Attorneys General and their staff for years to come.

My only regret is that the written word cannot capture the excitement and electricity generated at his conferences. As I speculate on the impact of this initiative on Attorneys General across our country and their role in improving end-of-life care, my belief in the truth of Andrew Jackson’s statement is confirmed, “One man with courage makes a majority.”

Myra Christopher, President and CEO  
Midwest Bioethics Center  
Kansas City, Missouri

May 2003

# ACKNOWLEDGEMENTS

BY: Oklahoma Attorney General W.A. Drew Edmondson

It was easy for me to announce this initiative, but without the people who carried it forward, this report on the lessons learned in the listening conferences in Kansas, California and Maryland would not have been possible.

On behalf of all of the Attorneys General and staff who attended the conferences, I want to express my heartfelt appreciation to the “consumers” who shared their personal encounters with end-of-life issues: Bishop Marvin Donaldson, Chris Cruzan White, Clark Lamoreux, Edith O’Neil-Page and Peggy Paddyaker.

Special acknowledgment is due to Maryland Attorney General J. Joseph Curran, Jr., and Assistant Attorney General Jack Schwartz. The long term commitment of Attorney General Curran to end-of-life issues serves as inspiration for our emerging role as Attorneys General. Their invaluable contributions to this initiative have provided us with an excellent model in taking on this challenge in our respective states.

I also want to thank the organizations that partnered with the National Association of Attorneys General (NAAG). In addition to the direction provided by NAAG, the success of the conferences is also due to generous support from the Last Acts Campaign, funded by the Robert Wood Johnson Foundation, the Midwest Bioethics Center, The Robert Wood Johnson Foundation National Grant Program, Promoting Excellence in End-of-Life Care and AARP.

Particularly, I want to express my appreciation to the following people behind the organizations: Karen Orloff Kaplan, president and chief executive officer of Partnership for Caring and national program director for Last Acts; Victoria Weisfeld, The Robert Wood Johnson Foundation; Myra Christopher, president and chief executive officer of Midwest Bioethics Center; Dr. Ira Byock, director, The Robert Wood Johnson Foundation National Grant Program, Promoting Excellence in End-of-Life Care; and Cheryl Matheis, AARP.

In addition, special thanks to the other clinicians, attorneys and health care advocates who participated in the conferences including: Connecticut Attorney General Richard Blumenthal, former Nevada Attorney General Frankie Sue Del Papa, former Maine Attorney General James E. Tierney, Rhode Island Assistant Attorney General Maureen Glynn, Bill Colby, J.D., Lavera Crawley, M.D., Betty Ferrell, R.N.,PhD, Patricia Good, Gema Hernandez, PhD, David Joranson MSSW, Susan Goldwater Levine, Richard Payne, M.D., Charles Sabatino, J.D., Don Schumacher, Psy.D, Joan Teno, M.D., Susan Tolle, M.D., and Robert Williamson.

Conference receptions and luncheons were hosted by Karen Orloff Kaplan, Last Acts; Myra Christopher, Midwest Bioethics Center; Burnele V. Powell, dean of the School of Law, University of Missouri-Kansas City; Stephen R. McAllister, dean and professor of law, University of Kansas School of Law; Judy Citko, California Coalition for Compassionate Care; Dr. Frank Ferris, San Diego Hospice and Palliative Care; Dean Karen Rothenberg, University of Maryland School of Law; and Lynne Ross, executive director, National Association of Attorneys General.



W.A. Drew Edmondson

I wish to also acknowledge the invaluable assistance of Oklahoma Assistant Attorney General Annette Prince, who has been my primary staff resource during this year of exploration and work. In preparing for and implementing these conferences, Annette and I have also been aided by Oklahoma Attorney General staff members, First Assistant Tom Gruber, Director of Communications Charlie Price and Executive Secretary Suzy Thrash.

Special thanks are expressed for the outstanding leadership provided by Lynne Ross, executive director of NAAG. She was assisted in “the work behind the idea” by Debbie Manson, executive assistant, Angelita Plemmer, communications director, and Manja Kargbo, communications assistant. NAAG will also host a web page for Attorneys General that will be devoted to updates on end-of-life issues and best practices by Attorneys General.

To all of the organizations and individuals who contributed, thank you for the privilege and challenge that you have presented and intrusted to us to help turn this vision into reality.

Oklahoma Attorney General W.A. Drew Edmondson



**“ATTORNEYS GENERAL HOLD THE KEY TO UNLOCK  
DISCOURSE ON BEHALF OF THEIR CONSTITUENTS  
BETWEEN POLICY DECISION MAKERS AND THE  
NETWORK OF STATE COALITIONS WORKING TO  
IMPROVE HEALTH CARE NEAR THE END OF LIFE”**

**MYRA CHRISTOPHER  
PRESIDENT AND CEO  
MIDWEST BIOETHICS CENTER  
KANSAS CITY, MISSOURI**

# OVERVIEW OF END-OF-LIFE CARE IN THE UNITED STATES

BY: Ira Byock, Myra Christopher and Karen Orloff Kaplan

A virtual tsunami wave of caregiving needs is racing toward us. It will test us in many ways. The 78 million baby boomers are aging. Caring for the most ill, infirm and advanced elderly among us is the central social and moral challenge confronting that generation.<sup>1</sup> Attorneys General are on the front lines of consumer protection and, as such, have vital contributions to make to solving many of the dilemmas facing us.

Among these dilemmas, people die in this country in appalling ways. A number of groundbreaking reports confirm serious deficiencies in the way America cares for dying people and their families. The 1995 *SUPPORT Study*<sup>2</sup>; the 1997 Institute of Medicine Report, *Approaching Death: Improving Care at the End of Life*,<sup>3</sup> and the 1999 Brown University study, *Prevalence and Treatment of Pain in US Nursing Homes*,<sup>4</sup> detail significant shortcomings in care for those nearing the end of life and shocking gaps in care for our most vulnerable members of society.

These and other studies provide a substantial body of scientific data that describe barriers to care and gaps in knowledge. Together, their rigorous data document that “far too many people needlessly suffered physically, psychologically, spiritually and socially at the end of life. Their preferences regarding care were too frequently ignored and their families often left in emotional despair and financial ruin.”<sup>5</sup>

- Opinion polls reveal that most Americans would prefer to die at home, free from pain and with their loved ones. Yet they often die alone in hospitals or nursing homes, in pain and attached to life support machines they may not want.<sup>6</sup>
- Experts and the public generally agree that the best care near the end of life treats the whole person – mind, body and spirit. Yet the primary funding mechanisms for end-of-life care – Medicare and Medicaid – are not designed to provide comprehensive care, known as palliative care.
- Despite the general agreement of medical experts that at least 90 to 95 percent of all serious pain can be safely and effectively treated, at least half of the people diagnosed with serious illness report unrelieved pain and other distressing symptoms.
- Physicians, pharmacists and front-line health care workers lack sufficient understanding of hospice and other models of interdisciplinary palliative care.
- Too few clinicians and health care institutions are aware of indicators for quality of care for the dying, and know how to assess pain or understand options for pain management and other aspects of palliative care.



Ira Byock, M.D., of the Robert Wood Johnson Foundation, details significant shortcomings and shocking gaps in end-of-life care



Myra Christopher, of Midwest Bioethics Center, discusses dilemmas in end-of-life care



Karen Orloff Kaplan, M.P.H., Sch.D., of Partnership for Caring and Last Acts, urges Attorneys General to consider reform efforts

- Too few members of the public, the medical community and policy leaders know about a patient's rights under the law regarding pain management.
- The public has little understanding of how to express their treatment preferences in advance so that if they are unable to communicate with health care providers, their wishes will nevertheless be known. Loved ones do not understand their responsibilities as health care proxies and advocates.
- Doctors, nurses and counselors from various backgrounds may have only a superficial knowledge of the beliefs and practices common in a particular ethnic or cultural group. The unique needs, wishes and views of these patients near the end of life are not consistently obtained and respected.
- Communication and documentation about a patient's care preferences are often lost in transfer between the hospital and the nursing home.
- Too many families are disrupted and resources are depleted when a loved one becomes seriously ill.

- Despite several studies that recognize the importance of spirituality in the care of dying people, their pastoral and spiritual needs are largely unmet.

The Institute of Medicine report concludes, “Too many people suffer needlessly at the end of life both from errors of omission and errors of commission. Legal, organizational and economic obstacles conspire to obstruct reliably excellent care at the end of life. The education and training of physicians and other health care professionals fail to provide them with the attitudes, knowledge and skills required to care well for the dying patients. And our current knowledge and understanding are insufficient to guide and support the consistent practice of evidence-based medicine at the end of life.”

The report *Means to a Better End: A Report on Dying in America Today*<sup>7</sup> reinforces the urgency of the problem. “The need for serious efforts to figure out how to best care for dying people and their loved ones is becoming more urgent every day. A large aging population, increases in the incidence of chronic disease, and the reduced availability of paid and unpaid caregivers, among other factors, must soon focus more attention on ways to improve the care we offer individuals nearing the end of their lives.”

### **Promising Practices**

Although the health care system in America is clearly in crisis, a number of innovative demonstration projects, partnerships and collaborations are making substantial progress in our ability to engage consumers, tackle policy issues, create useful training tools for health care professionals and improve the way institutions – even those involved in the most challenging clinical situations – care for dying patients.<sup>8,9</sup>

These initiatives almost always involve interdisciplinary collaboration among providers and other key stakeholders. The most successful of these include clinicians, allied health care professionals and their institutions, as well as policymakers, educators, government stakeholders, community leaders from diverse cultural and ethnic backgrounds, faith leaders, caregivers and other natural allies. These partners are working diligently to overcome competition and dissension in order to jointly identify common obstacles, create comprehensive strategies and carry out mutually agreed-upon clinical reforms, educational initiatives and policy changes. These partnerships and collaborations create a whole that is greater than the sum of its parts. Their collaborative approach has produced human and social capital and a collective capacity to respond to important health issues. A list of local, state and national partnerships, programs and experts is included in this report.

### **Recommendations**

In order to maintain momentum and establish lasting programs of care, an even stronger and wider network of engaged policy champions, health care professionals and consumers is essential. To make real headway, successful reform strategies will need to focus on the “izing” of excellent care: institutionalizing and routinizing such care throughout systems. State Attorneys General are in an outstanding position to spearhead or support the following recommendations.

## **Recommended Actions for Public Policymakers**

We urge policy leaders to recognize that end-of-life care is just as important an issue in health care as is birth. Policy leaders can become full partners in creating a policy environment in which quality end-of-life care thrives. They can focus reform by collecting the stories and views of everyday citizens to learn about their values, concerns and attitudes about this last chapter of life. They can create, update and interpret laws and regulations so that all are consumer friendly. Wide consensus among end-of-life reformers has resulted in the following list of recommendations for action for public policymakers<sup>10</sup>:

### **General recommendations**

1. Make care near the end of life a special priority in aging policy.
2. Support public/private initiatives to meet the needs of family caregivers.
3. Encourage policies to enhance consumers' knowledge of the options for quality care near the end of life.

### **Decisionmaking**

4. Promulgate policies that encourage advance care planning and out-of-hospital Do Not Resuscitate programs.
5. Ensure that in the absence of advance directives, family surrogacy is recognized and used in the best interests of dying people.

### **Professional Capacity**

6. Set state targets for the numbers of doctors and nurses with palliative care training needed to care for the state's critically ill and dying patients, and work with state-funded educational institutions to achieve them.
7. Encourage requirements for continuing medical and nursing education about end-of-life care.

### **Service Delivery**

8. Establish good pain management policies that tackle the problem of under treatment of pain.
9. Encourage coordination of health services programs.
10. Require that hospitals and nursing homes establish palliative care services.
11. Reassess the rules and regulations that apply to nursing homes and allow greater flexibility in caring for dying residents.
12. Support the provision of hospice services in government-run institutions – prisons, jails, mental health hospitals and so on.

13. Change the Medicare hospice eligibility criteria to allow Medicare beneficiaries to qualify for the hospice benefit by diagnosis, rather than an estimate of a six-month prognosis of terminal illness.

### **Research and Financing**

14. Support large-scale demonstrations of promising models of coordinated end-of-life care that are likely to show both better quality of life for patients and families. Then, act to revise coverage.

### **Actions for Health Care Leaders**

Health care leaders can work to establish multidisciplinary palliative care services in hospitals – particularly in intensive care units – and nursing homes for seriously ill patients who have symptoms that are difficult to handle or painful treatments, or who are likely to die. They can include hospice or palliative care service rotations in physician, nurse, social work and pharmacy training. They can support practicing physicians who seek training in palliative care and encourage the capacity of end-of-life teams to be culturally competent.

### **Actions for Consumers**

The public clearly wants competent, compassionate and respectful care for themselves and their loved ones. In addition to actions by public policymakers and health care leaders, many of today’s end-of-life reformers are also calling for consumers to embrace personal advocacy and public activism. They advise consumers to learn what constitutes good end-of-life care and join others who are trying to make positive changes. Ask employers to have policies in place to help seriously ill employees, those caring for a seriously ill family member and those who are bereaved. Encourage spiritual leaders to help congregations explore the spiritual aspects of illness and death. Complete an advance directive and learn practical ways to help friends and family who are grieving.

### **Conclusion**

The fact of human finitude has given rise to voluminous literature, musical masterpieces, hauntingly beautiful poetry and stunning scientific creativity, writes a colleague. “To face our dying and death or that of another is nothing less than an act of faith. We have to open ourselves to contingency, the unknown, and the unknowable. The challenge for reformers is to clear the path of obstacles so we can focus on the profundity of dying.”<sup>11</sup>

Meeting this challenge will demand a degree of social and political commitment rivaling that required to prevail in the world wars of the 20<sup>th</sup> century.<sup>12</sup> Now as then, American heroes are needed to galvanize national attention and show us the way. This time around, it is not arms that we must raise, but standards of care and public expectations. Our tools will not be weapons, but our voices, our health care dollars, our letters, our petitions and our votes. Now, as then, our efforts will be fueled by our love of country and for one another. Defeat is unthinkable.



Representing Attorney General offices from across the country, assistant attorneys general gather information on state best practices

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<sup>1</sup> I Byock *Need: Role Models for Living, Caring and Dying Well*, speech, April 2001.

<sup>2</sup> SUPPORT Principal Investigators, "The SUPPORT Study," *Journal of the American Medical Association*, 1995.

<sup>3</sup> M Field and C Cassel, *Approaching Death: Improving Care at the End of Life*, Institutes of Medicine, (Washington: National Academy Press, 1997.

<sup>4</sup> J Teno, *Prevalence and Treatment of Pain in US Nursing Homes*, Brown University, 1999.

<sup>5</sup> M Metzger and K Kaplan, *Transforming Death in America*, Last Acts, January 2001.

<sup>6</sup> J Peres and K Kaplan, *Means to a Better End: A Report on Dying in America Today*, Last Acts, November 2002.

<sup>7</sup> *Means to a Better End*, *Ibid*.

<sup>8</sup> M Christopher, E Blacksher, C Collins, *Lightning Rods of Reform*, Midwest Bioethics Center, 2002.

<sup>9</sup> I Byock, J Twohig, *Promoting Excellence in End-of-Life Care*, University of Montana Practical Ethics Center, 2001.

<sup>10</sup> *Means to a Better End*, *Ibid*.

<sup>11</sup> *On the Road of Reform: Advocacy and Activism in End-of-Life Care*, E Blacksher, M Christopher. Quote from Pam Dobies, widow of the late Bill Bartholeme, M.D., an early advocate for pediatric palliative care.

<sup>12</sup> I Byock, *Ibid*.

# THE ROLE OF ATTORNEYS GENERAL

BY: Maryland Attorney General J. Joseph Curran, Jr. and  
Maryland Assistant Attorney General Jack Schwartz



J. Joseph Curran, Jr.

Much of this report discusses why an Attorney General ought to become involved in end-of-life issues. This chapter focuses on what an Attorney General might do after deciding to become a force in the effort to bring improved care to dying patients. The touchstones of Attorney General involvement, in our experience, are these:

- Commitment to promoting excellent care at life's end. The truth is, most Attorneys General can go through their terms of office without really engaging the issue of end-of-life care. Unlike many aspects of the office, it is not a given that an Attorney General do this. If an Attorney General decides to make this an integral aspect of his or her work, it is because the Attorney General genuinely sees the importance of helping to make quality care at the end of life a reality for all. Consequently, the work of an Attorney General's office should be consciously based on, and consistently reflect, a belief in certain fundamental precepts of palliative care, which have been formulated by Last Acts and widely accepted in the field: that the goals, preferences and choices of individual patients should be respected; that care should comprehensively address the needs of the dying patient, especially in responding to pain and other distressing symptoms; that interdisciplinary resources should be available to meet the patient's needs; that the concerns of family caregivers should be addressed; and that best practices must be supported in a systematic way, including the responsible attention of policymakers.
- Visibility. The Attorney General ought to be seen as an ally of consumers who want their voices heard and of those caring for patients near the end of life. The visible engagement of the Attorney General and his or her staff will itself help change the atmosphere for the better. Visibility can be achieved in a variety of ways, including participation in public events and professional conferences, the convening of public meetings, the writing of newspaper columns and the dedication of a portion of the Attorney General's web site. It is also most helpful to designate a senior staff member as a single point of contact, for lawyers within the office as well as members of the public, on end-of-life issues.

- Openness to new information and ideas. Who really knows the policy-related problems with end-of-life care in your state? Most likely, it is a coalition of health care professionals, patient advocates, religious leaders, elder law attorneys and others working on a variety of steps to improve care. Join the coalition, or at least send a liaison to many of its meetings. Invite your state's leaders in end-of-life care to meet with you to share their concerns. Ask what you can do to help. Join Last Acts, the leading national coalition for improvement in end-of-life care, so that you can better understand how your state's situation compares to trends elsewhere.



Jack Schwartz

- Moderation. Keep the right perspective on how legal and policy issues can affect end-of-life care. Our role is, first, to avoid mistakes, to recognize that the wrong regulatory and enforcement steps can make things much worse for patients and their caregivers. Second, if we pay attention, we can do some things that are a little helpful for those in the bed and at the bedside. Dramatic changes for the better, however, cannot be summoned by an Attorney General, but instead, require systemic changes that go well beyond any issues of legal interpretation or enforcement. Advocates must also be educated not to expect an Attorney General to exceed the bounds of the office. They may not initially understand that an Attorney General must respect the policy domains of others and, especially in tough economic times, cannot obtain extra state resources for end-of-life care.
- Specific actions. An Attorney General should try to achieve results by identifying (with the help of local advocates) a number of discrete tasks that the Attorney General's Office can most usefully carry out. Exactly what these



Attorneys General hear testimony from consumers and other health care experts on how they can become more involved in the effort to improve end-of-life care

might be will vary from state to state. But it is far better to grasp, and be able to assess the effect of, a handful of accomplishments than to pursue an ever-receding horizon of overly ambitious, sweeping goals. In the balance of this chapter, we identify some examples of actions that an Attorney General might consider, organized by reference to many of the customary roles of an Attorney General's Office.

### Interpretation and Explanation of Current Law

No one doubts that adults have a legal right to design an overall framework for end-of-life care that best reflects their values and beliefs. Yet, this right is grounded in a sometimes uncertain mix of constitutional, common law, statutory and regulatory considerations. An Attorney General can serve as an authoritative interpreter of the relevant law.

**Example:** Issue an opinion or advice letter about some particular clinical issue that has been brought to your attention (for example, the entry of “do not resuscitate” orders) to clarify that common law rights exist in parallel with statutory decision-making mechanisms. Post the letter on your web site; send e-mail notice of it to interested groups.

**Example:** To help consumers understand how they can go about advance care planning, distribute a plain-language explanation of the process and include specific information about designating a proxy or declaring one's treatment preferences. Unless the choice is absolutely foreclosed by statute, issue an opinion or advice letter making clear that a consumer who wants to write an advance directive is not limited to any particular form.

**Example:** New developments in the law can cause uncertainty and confusion, potentially to the detriment of patients. Be proactive in giving advice. For instance, clarify for providers that the new federal rules on the privacy of health information do not impair a legally authorized proxy from obtaining the information needed to make end-of-life care decisions for the patient.

**Example:** Send your designated staff member to speak at hospitals, nursing homes, county medical societies and other venues about the legal framework for health care decisionmaking. Develop a concise PowerPoint presentation for this purpose, and write an article for your medical licensing board's newsletter. Focus on topics that worry clinicians most (for example, what to do when the patient is incapacitated and has no advance directive). Reassure clinicians that practicing to the standard of care will keep them out of liability trouble. If clinicians are confused or worried about potential criminal liability under an assisted suicide prohibition, reassure them that these criminal laws have nothing to do with the practice of good palliative care.

**Example:** As you issue interpretive guidance about health care decisionmaking, compile the information on your web site as an ongoing resource for consumers, clinicians and the private bar. On the Maryland Attorney General's site, for instance, those interested can access five formal opinions and 16 letters of advice about end-of-life legal issues.



Conference participants discuss pain management studies

### Advice to Agency Clients

Good lawyers do more than give clients technically sound legal advice. As Rule of Professional Conduct 2.1 puts it, “a lawyer may refer not only to law but to other considerations such as moral, economic, social and political factors, that may be relevant to the client’s situation.” This is all the more true for an Attorney General, whose role as representative of the state itself implies that advice to client agencies ought to be broad-gauged, so that those with policy-making responsibility can understand both the extent of their legal discretion or constraints and the potential impact on those affected by the decision.

**Example:** The agency that licenses and inspects nursing homes can significantly affect the quality of end-of-life care for nursing home residents. The regulations that the agency enforces ought to be applied with sensitivity to the special circumstances of dying patients. For instance, the Attorney General can advise that a regulation calling for certain minimal nutritional levels, which makes great sense applied to the nursing home population in general, need not be construed to mandate the use of feeding tubes in dying patients for whom such intrusive efforts achieve no benefit.

**Example:** The nursing home licensing agency can also be advised that a facility’s knowing disregard of a resident’s advance directive is a significant violation of the resident’s rights and grounds for a deficiency. One or two cases of this kind, vigorously pursued by the Attorney General’s Office on behalf of the agency, can result in a generally increased level of attentiveness to advance directives in nursing homes.



Maryland Attorney General J. Joseph Curran, Jr. cites the importance of legislative advocacy



Assistant Attorneys General Sandy Lynskey (l), of Ohio, and Maureen Glynn (r), of Rhode Island, discuss state initiatives

**Example:** The Attorney General can encourage the state’s licensing and disciplinary boards for physicians and other health professionals to review their policies and investigatory standards, to avoid any unintended chilling effect on the use of narcotics to respond to the pain of dying patients.

**Example:** The Attorney General can work with the state’s medical licensing board to consider the possibility of disciplinary actions against physicians for severely deficient pain management, akin to a recent action by the California Attorney General on behalf of that state’s medical board.

**Example:** Although no one can reasonably expect the Attorney General to shape Medicaid policy, where, for instance, the Medicaid program requires managed care contractors to provide hospice services, the Attorney General can urge the Medicaid program to ensure that these services are being provided in a timely way.

### Criminal Law Enforcement

Whether in the Attorney General's own enforcement of criminal laws or in the Attorney General's counseling of other law enforcement agencies, the Attorney General should actively promote the concept of balance: that legitimate law enforcement goals should be pursued without adversely affecting the provision of quality end-of-life care.

**Example:** Systems for monitoring narcotic prescriptions should be assessed, not only for their ability to flag potentially crooked doctors, but also for the burdens that they might impose on legitimate prescribers, to the ultimate detriment of their patients. In advocating for such a system, an Attorney General should be explicit about both needs.

**Example:** The Attorney General, working with local clinical experts, could establish an informal and private screening mechanism for cases that the police, a prosecutor or a medical examiner think might be a homicide by means of a deliberately excessive dose of narcotics. It is facile, and often incorrect, to suspect wrongdoing based solely on the level of morphine or similar drug in a patient's bloodstream after death, and a high-profile investigation can have a destructively chilling effect on physicians generally. An Attorney General could ensure an expert review of the facts before matters are made public.

### Legislative Advocacy

If an Attorney General is active in these various areas related to end-of-life care, most likely, some potential legislative reforms will come to his or her attention. Because the Attorney General is an active and respected advocate for legislative change in areas of particular concern (for instance, consumer protection and elder abuse), Attorney General advocacy for legislative reform affecting end-of-life care may carry particular weight.

**Example:** If legislation is thought to be needed to ensure that a physician's order for end-of-life care can be honored in any care setting where the patient



Jack Schwartz highlights legal successes of the Maryland Attorney General's Office



Lynne Ross, of NAAG, and Karen Orloff Kaplan, of Partnership for Caring and Last Acts, discuss the conference agenda

may be, the Attorney General could help draft the appropriate legislation and advocate for it in the legislature.

**Example:** Most states would benefit by having an ongoing advisory body to monitor trends in end-of-life care and recommend changes in law and practice. The Attorney General could take the lead in pushing for enactment of a bill creating this kind of advisory body.

**Example:** Elder law attorneys and others may have useful suggestions for amendments to existing health care decisions statutes, to reduce unnecessary procedural burdens and make the advance care process more user-friendly. The Attorney General could play a key role in considering this kind of legislative reform.

### **Conclusion**

Attorneys General do their most satisfying work when they protect the citizens of their states against direct harm. Whether we speak of the victims of criminal violence, or those who lose their hard-earned money to scam artists, or those of our elderly who suffer abuse and neglect, we seek ways to protect our people.

This vision of those whom we work hardest to protect should include those facing death. We owe it to them, and to ourselves, to do all that we can to honor and safeguard them. Helping to reduce human suffering in the last chapter of life would be an unsurpassed legacy for any Attorney General.



**“AS PUBLIC OFFICIALS, WE CAN FORM ALLIANCES AND  
TAKE THESE CONCERNS TO THE PUBLIC AND ADVOCATE  
FOR LEGISLATIVE AND POLICY CHANGES TO REDUCE  
HUMAN SUFFERING IN OUR STATES”**

**JACK SCHWARTZ  
MARYLAND ASSISTANT ATTORNEY GENERAL**

## SECTION 2: PROTECTING CONSUMERS

# CONSUMER STORIES

**Chris Cruzan White**, of Centerville, Mo., is the older sister of Nancy Cruzan, whose pivotal right-to-die case found its way to the United States Supreme Court in the 1980s. Today, White is the executive director of the Cruzan Foundation, which was established by her family to provide information and assistance to others who are confronted with medical treatment decisionmaking and other end-of-life issues.

In January 1983, the Cruzan family received a call that Nancy Cruzan had been in a car accident. Nancy was found dead at the scene. Emergency personnel were able to get her heart started and get her lungs working, however, medical professionals later determined that she had gone without breathing for at least 12 to 14 minutes and possibly longer.

Just after her accident, some health care providers told Cruzan family members to “wait and see” and “do everything you can to get her to respond.” However, the family waited years before realizing that they had to take the initiative and ask for things like a diagnosis and prognosis. The family spent years trying to do the thing that would bring about a response from Nancy, not realizing she had lost that ability. Three weeks after Nancy’s accident while she was still in ICU, doctors informed the family that it would be necessary to surgically implant a feeding tube. The consent forms were signed and the surgery was done.

Nancy’s condition stabilized and she was eventually admitted to the Missouri Rehabilitation Center (MRC) in Mt. Vernon in October 1983. A few months later, at the suggestion of some of Nancy’s physicians, a guardianship hearing was scheduled. Nancy’s parents were named as her guardians and conservators.

As the years went by without any real improvement, the family finally began to accept the reality that Nancy’s condition was not going to change. Nancy was in a persistent vegetative state.

After researching the condition, family members learned that other families with loved ones in the persistent vegetative states had chosen to go through their state courts to ask to have treatment stopped on behalf of their loved ones. The ultimate question facing the Cruzan family: What would Nancy want, given that she was in this persistent vegetative state? The answer to that question was obvious to all who knew and loved “Nan.” She would not want to simply exist being totally dependent on others for her care.

Family members asked the judge who had granted the guardianship if Nancy could be brought home and treatment stopped – so neither the hospital nor the courts would have to be involved. However, the judge said no, warning Nancy’s parents that they could face murder charges if they brought Nancy home and



Chris Cruzan White shares the painful details of her family’s legal battle

stopped the feedings without going through the courts. The judge suggested that the family request permission from the Missouri Courts to have her treatment stopped.

In May 1987, nearly four-and-one-half years after Nancy's accident, the family found attorney Bill Colby who agreed to represent the family pro bono.

On May 28, 1987, the Cruzan family hand-delivered a letter to MRC, formally requesting the removal of the feeding tube. Several weeks later, the family received a letter stating that only with a court order, in which the state of Missouri was a named party, could they consider complying with the family's request. The legal aspects of the case proved complex and challenging, and the case slowly moved through the Missouri courts, to the United States Supreme Court, and then back to the Missouri courts.

The family continued their legal battle over the years, motivated by their love for Nancy and the knowledge that her current existence was contrary to everything they knew and loved about her.

Finally, on December 14, 1990, the Missouri Probate Court allowed for the removal of the feeding tube, after finding clear and convincing evidence that Nancy would not want treatment to continue.

Later that afternoon, after doctors removed the tube, Nancy's father wrote, "During the late fall and winter of 1986 realizing that Nancy was not going to recover and knowing that she would not wish to continue in her present condition I made a commitment to her to allow her to die with some dignity." The final journey ended after 1,295 days.

**Edith O'Neil-Page** is a registered nurse and the Administrator of Home Health Services at Centinella Hospital and Medical Center in Los Angeles, Calif. Prior to serving as the administrator, she was the director of cancer programs at Dominican Hospital and Medical Center in Santa Cruz, Calif. Edith is the co-author of *Nurse's Knowledge of Opioid Analgesic Drugs and Psychological Dependence*.

More than 20 years ago, she began working as an oncology nurse. Her experiences included bedside care, home care and hospice. She also worked for inpatient and outpatient departments of major medical centers, smaller community hospitals and cancer centers. She opened three cancer centers, managed inpatient units, cancer resource centers, and developed and participated in cancer support groups. Through those experiences, she saw firsthand the incredible needs of patients and families, particularly for pain management and, in varying degrees, the supportive care necessary at the end of life.

As a nurse, Edith recalled one patient, – a 17-year-old man with metastatic testicular cancer, in so much pain that nothing could help him. While working with home care, Edith cited many instances of jumping through hoops, stretching rules, begging and pleading with someone to increase medication, fill a prescription or just change what was being given in order to give patients something that would help manage pain.

Finding pharmacies that carry the appropriate medications and were open on weekends and holidays was frustrating, time consuming and exhausting.

However, these professional experiences became even more personal when Edith was diagnosed with breast cancer four years ago. She kept a log of her experiences as a patient and how she has survived nine surgeries. Starting in November 1998, Edith underwent her first operation for breast cancer, followed by a mastectomy the next day, and



Health care professional Edith O'Neil-Page describes her experiences as a cancer patient

a third operation the next day. Her log recounts the exhaustion of surgery, the emotional and psychological stresses of a cancer diagnosis, nausea, vomiting and wracking physical pain. Her personal experiences as a patient illustrate the harsh realities of managing pain.

Addressing Attorneys General during the San Diego End-of-Life Listening Conference, Edith said: “As an inpatient after surgery, I found a lack of understanding from medical and nursing staff. Pain medication was metered out with the regularity that would make the changing of the Palace Guard look

haphazard. Pain doesn't come on that way. Sometimes it's there and sometimes it's not and you don't predict it.”

Using a local pharmacy, Edith recalled they often did not have what she needed. Consequently, the waiting began. The pharmacy refused to fill a prescription and allow her husband to pick it up when it finally was filled. When called, the pharmacy told her that she was using too much of the medication and that she was becoming an addict.

“I'm a nurse, an oncology nurse,” Edith told Attorneys General. “But in addition to that, I'm a consumer, and with all of my years of education and experience and connection to the medical world, I found my personal comfort and pain management to be elusive --- fighting my way through a maze.”

Although she is in recovery, Edith said her experiences clearly illustrate the need for better prepared clinicians, better support and most of all, better designed delivery systems.

“Everyone here will face death some time, some sooner than others,” Edith said. “We must ensure that all of us have a say so, not only in how we live, but also in how we die.”

**Peggy Paddyaker** is an Investigative Analyst in the Consumer Protection Unit of the Oklahoma Attorney General's Office. Prior to working in the Consumer Protection Unit, she served as a paralegal in the Criminal Appeals Unit. She is the Attorney General designee for the Oklahoma Indian Affairs Commission and serves on the Senior Companion Program Advisory Council at Sunbeam Family Services.

At the age of 25, Peggy's son, Johnny, tested positive for HIV. He died from complications of the AIDS virus when he was 36 years old. About 18 months before he died, he became ill with what he thought was a flu-like virus. By Christmas, he did not feel well enough to be with the family. When his condition worsened, she took him to the Ft. Sill Indian Hospital. Johnny could barely walk. After they hydrated him, they turned him away. They told him that they could not care for individuals with AIDS. They also told him that if he needed care in the future, he would have to go to the University Hospital Emergency Room --- formerly a state hospital.

She took her son home. The virus was taking its toll. Johnny could no longer work. Although Peggy worked during the day, she would visit him at lunchtime and check on him later after work. One day, during a visit, her son said, “Mom, I’m going to die and you might as well get used to it.” Shortly after that, she took him to the emergency room at University Hospital. Doctors hydrated him and sent him home, after making an appointment for him to see a doctor the following week. Her son had no insurance and doctors failed to suggest hospice or applying for Medicaid.

Johnny’s first medications were prescribed by the University Hospital doctor, and an appointment was scheduled with the infectious disease specialist. However, her son had to wait three months for that appointment. He never made it.

Again, he had to go to the University Hospital emergency room, where he was admitted and stayed overnight, over the objections of the emergency room doctor. The next day, he was discharged to a nursing home for individuals with AIDS.

He had no memory of going to the hospital, of being discharged from the hospital or of going to the nursing home. Again, no health care professionals suggested any alternative to the nursing home. Her son remained in the nursing home for about one year. Although he had gained weight and was strong enough to walk again by summer, he could not return home. There was no one to help provide the full-time care he needed. Nursing home staff knew that he wanted to go home, but provided no information about hospice care. Medicaid coverage in Oklahoma did not include hospice care.

Finally, in mid-winter, her son was taken to the hospital for the last time. He had obtained Medicaid coverage and was in the hospital less than a week. Peggy’s son died 36 hours after she was told that he was not going to live. The doctors agreed to discharge him and send him home after Peggy requested that he be allowed to return home. However, he died before he could be discharged. He died before she had the opportunity to tell him he could finally go home.

Peggy, a Comanche Indian, requested and received special permission from a tribal elder to speak her son’s name during her testimony. It is a Comanche tradition not to speak the name of the deceased person in public out of respect for the family.



Peggy Paddyaker educates participants about the importance of hospice care for dying patients

# WILL MY PAIN BE MANAGED?

BY: David Joranson and Richard Payne



David Joranson, MSSW

Unrelenting pain cripples the ability of humans to function at the most basic levels. It corrodes the capacity to think, work or simply enjoy human relationships. Over the past 50 years, great strides have been made in understanding and treating pain. Scientific breakthroughs include new drugs; new formulations of existing drugs; new combination therapies; and new methods of administration.

Today, medical experts say that about 95 percent of all pain can be effectively relieved. Yet, there is a large body of evidence that documents the undertreatment of pain throughout America's health care system. The most glaring example is in the nation's nursing homes, where, according to a 1999 Brown University study, more than 40 percent of elderly residents are in moderate to excruciating pain daily—two to six months after they first report it.<sup>1</sup> The findings are sobering, given that nearly half of all people who live into their 80s spend some time in a nursing home, and that 40 percent of all Americans are projected to die in nursing homes by the year 2020.

There are many effective treatments for pain, but opioid analgesics are often essential for the relief of pain in the 50 million Americans who suffer from chronic pain associated with cancer, HIV/AIDS and other serious diseases. While classified by the federal government as a controlled substance because of their potential for abuse, opioids (also known as narcotic drugs) can be used safely to treat moderate to severe pain in most patients without fear of addiction or mental impairment. But, public beliefs, provider practices and state policies are slow to adapt to modern research findings.

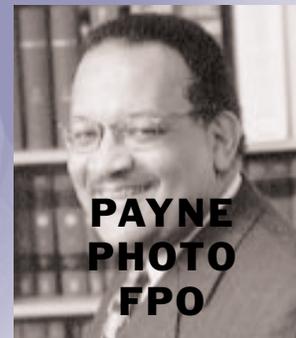
Patients still fear addiction, physicians dread regulatory scrutiny for prescribing them and many state policies still impede their appropriate use.

Access to pain relief is a consumer protection, and state public policy,

issue, and Attorneys General can exert a wide scope of influence to ensure that their states' residents can get it, when needed. This article takes a closer look at the barriers to opioid use, with particular focus on state laws, guidelines and regulations – an arena where Attorneys General have direct control. It recommends specific actions Attorneys General can take to improve public policy, physician practice and consumer awareness to ensure access to effective and appropriate pain relief.

## Barriers to Pain Management

Barriers to the effective and appropriate use of opioid analgesics can be placed into three broad categories:



Richard Payne, M.D.

patients' beliefs; physician and institutional practices; and public policies, which can be one factor that influences institutional practices. Patient race and ethnicity are also found to influence how pain is treated, as is discussed later in this chapter.

### **Patients' Beliefs**

Patients' fear of addiction is a deeply-rooted misperception that causes many to reject opioids for pain relief. Until recently, both physician practice and public policy were guided by the incorrect assumption that addiction is defined by physical dependence and tolerance for a certain drug; opioid use will cause both symptoms. But opioid use in and of itself will not cause the psychological dependence that marks addiction, defined by the World Health Organization as "a behavioral pattern characterized by craving for the drug and an overwhelming preoccupation with obtaining it."<sup>ii</sup> Research confirms that the vast majority of people who use opiates for pain management do not become addicted. "The problem of addiction doesn't reside within a medicine, it resides within the person," says Russell Portenoy, M.D., chairman of the Department of Pain Medicine and Palliative Care at Beth Israel Medical Center in New York.

### **Physician and Institutional Practices**

A number of factors explain why health care providers often under prescribe opioids to treat pain. Lack of education is one. Studies suggest that many physicians have only limited knowledge of opioid pharmacy and too little training and experience with pain assessment. The scarcity of medical school training around pain management is striking. In school year 1999-2000, only one in 125 medical schools accredited by the American Medical Association offered pain management as a separate course; most folded a few lectures into other required courses, according to Last Acts, a national coalition that promotes better end-of-life care.<sup>iii</sup>

Liability concerns are another factor that overlap with lack of education and unclear public policies. Some physicians, particularly those inexperienced in prescribing narcotics, fear criminal prosecution because they believe that the dose of opioids needed to relieve excruciating pain would depress the respiratory system and unintentionally hasten death, an outcome known as the "double effect." Pain experts note that this is another medical myth about opioid use that needs to be dispelled.

Only recently has pain treatment become an expected part of medical practice. During the past 10 years, medical standards and practice guidelines to evaluate and treat pain have begun to emerge. In 1999, the Joint Commission on Accreditation of Healthcare Organizations required that hospitals, hospices and other health care facilities add pain to the four vital signs that providers regularly check for in their patients (along with temperature, pulse, respiration and blood pressure). Guidelines were also issued by the Agency for Healthcare Research and Quality, the American Pain Society, and the American Society of Anesthesiologists; all acknowledge that opioids are an essential drug to treat serious pain. Physicians and patients can now find these standards on the Internet.<sup>iv</sup>

According to numerous studies, physicians also avoid prescribing opioids because of a prevailing fear that they will be scrutinized by state medical boards and narcotics regulators. For instance, in a recent survey of 1,400 New York physicians conducted by the state's Department of Health, about 30 to 40 percent said that fear of regulators has influenced their prescribing practices. Attorneys General, as the states' chief prosecutors and advisors to governors, legislatures, medical licensing and pharmacy boards and executive agencies (including those that regulate nursing homes), can do much to calm these fears.



Payne, of the Memorial Sloan Kettering Cancer Center, cites research indicating racial disparities in pain management

### Public Policies

The availability, prescribing and dispensing of opioids that are essential for pain relief is governed by international treaties and federal and state laws. The main purpose of these policies is to prevent diversion and abuse of drugs. But international and federal laws also note that opioids are essential for managing serious pain and call on governments to make sure that opioids are available for appropriate medical use.<sup>v</sup> For instance, the Federal Controlled Substances Act, passed by Congress in 1970, states that, “Many of the controlled substances in the [CSA] are necessary to maintain public health.” Pain policy experts note that the ideal regulation of opioids

is one that takes a balanced approach – preventing the abuse of narcotics while not interfering with medical practice and patients’ access to adequate amounts of opiates to control pain.

### Restrictive State Policies

In the United States, medical practice is regulated by the states. It is governed by controlled substances, medical practice and pharmacy practice laws, regulations and guidelines.

Over the past decade, driven by cancer control advocates and other pain relief supporters, the number of state pain-specific laws, regulations and guidelines has grown dramatically. But analysts find that, on the whole, state policies are still less balanced than federal and international law. Flawed state policies include “lack of legal recognition of the medical value of opioids, limitations on prescribing and dispensing, exclusion of substance abusers with pain from prescriptions for medications, and ...terminology that confuses physical dependence with addiction,” according to a report published by the University of Wisconsin Pain and Policy Studies Group.<sup>vi</sup> These impediments spring from states that have not updated their policies, and from some states that, with the intent of improving pain management, have unintentionally restricted opioid use through flawed or unclear new policies.

Another state pain policy trend that experts believe is well-intentioned but potentially harmful is the growth of intractable pain treatment acts (IPTAs). These laws grant physicians immunity from medical board discipline for aggressively treating intractable pain. But experts point to a number of drawbacks. For instance, “the language used in some IPTAs implies that opioids are a last resort, and that use of opioids is not considered part of ordinary medical practice. The use of the term ‘intractable’ implies pain that is not treatable, even though chronic pain is treatable,” according to the Pain and Policy Studies Group.<sup>vii</sup>

In addition, experts note that some IPTAs exclude pain patients who are substance abusers and may erect other barriers, such as requiring providers always to consult with another physician.

## Reversing a Chilling Effect

In 1998, the Federation of State Medical Boards (FSMB) went a long way towards modernizing medical board policies on opioid use by issuing “Model Guidelines for the Use of Controlled Substances for the Treatment of Pain.” (State medical boards are responsible for licensing physicians and regulating their conduct.) The guidelines contain clear language recognizing the legitimate role of opioids in relieving pain. They also address providers’ concerns about being disciplined. “Physicians should not fear disciplinary action from the Board or other state regulatory or enforcement agency for prescribing, dispensing, or administering controlled substances, including opioid analgesics, for a legitimate medical purpose and in the usual course of professional practice,” the guidelines state.<sup>viii</sup>

According to FSMB, medical boards in 43 states have some type of policy regarding pain management; 21 of them have adopted policies that are identical or similar to the model guidelines.<sup>ix</sup>

In the past several years, increasing reports of the abuse of opioid pain medications have led to concerns of a chilling effect on progress made by states and providers in making opioids available for legitimate use. To address this concern, in October 2001, the DEA (which monitors and regulates the use of legal controlled substances) and a number of national health care organizations endorsed a joint statement, titled, *Promoting Pain Relief and Preventing Abuse of Pain Medications: A Critical Balancing Act*. According to the statement, “Preventing drug abuse is an important societal goal, but there is consensus, by law enforcement agencies, health care practitioners, and patient advocates alike, that it should not hinder patients’ ability to receive the care they need and deserve.” The statement marks the first time the DEA has collaborated with these groups to support better pain management.<sup>x</sup>

## Racial Disparities

Disparities in pain treatment based on race and ethnicity are found throughout the research literature on pain management. The health care system has done an especially poor job of managing pain, particularly at the end of life, for several vulnerable populations. Studies have revealed that African-Americans and Hispanics are less likely than whites to receive effective pain treatment in emergency rooms, during hospital stays, and in outpatient clinics and nursing homes. For instance, in one study, Hispanics admitted to the ER with long bone fractures were more than twice as likely as whites with identical conditions to receive no analgesic to manage pain. In another study, white ER patients were more likely than blacks to receive analgesics (74% vs. 57%), despite similar complaints of pain recorded in their medical records.<sup>xi</sup>

In studies of cancer patients in outpatient and nursing home settings, it has been documented that African-Americans and Latinos are at three-fold or greater risk for their pain to be under-treated than are other patients.<sup>xii</sup> Furthermore, recent studies have shown that pharmacies in poor and minority communities in New York City and Detroit are much less likely to carry morphine and other DEA schedule II opioids than are pharmacies in white, affluent areas of these cities.<sup>xiii</sup>

For example, one particular study showed that nearly 75 percent of pharmacies in non-minority, affluent areas of New York City stocked strong opioid drugs, whereas less than 25 percent of retail pharmacies in poor and minority areas stocked similar drugs, even when pharmacy theft rates and other crime statistics were similar.<sup>xiv</sup> Although the causes of these disparities are unclear, pharmacists and other clinicians often cite the low demand for opioid prescriptions in poor and minority areas, and concerns that they may be scrutinized by regulators and law enforcement officials because they work in areas that are perceived or actual sites of high illicit drug use.

The causes of this differential treatment have not been documented. According to some experts, they may in part be due to racial prejudice among health care providers and language and cultural barriers that keep patients from communicating their level of distress to providers. As a recent Institute of Medicine report notes, in encounters where clinicians face time pressures to evaluate and make decisions about complex problems, such as assessing a patient's level of pain, many providers resort to stereotyping, often on an unconscious level.<sup>xv</sup> The extent to which these factors cause the racial disparities in pain management needs to be evaluated.

## Recommendations

A major gap still exists between the science of pain management and state policies, provider practices and public knowledge. And, in cases where state policies have been improved, oftentimes, the medical community and the public have not been apprised. Attorneys General can do much to improve state pain policies and to communicate these new policies to providers, the public, state regulators and the legal system. The following recommendations for action should be useful.

1. Create a multidisciplinary task force to first study the barriers to pain management in state laws, regulations and guidelines. Among the policies to be reviewed are: the state controlled substances act; pharmacy regulations regarding opioid dispensing; state medical board policies; hospice, hospital and nursing home inspection and certification criteria; and managed care pain relief policies.
2. Evaluate these policies according to criteria based on the concept of balance. The Pain and Policy Studies Group offers the following as measures that enhance pain policies;<sup>xvi</sup>
  - controlled substances are recognized as necessary for the public health;
  - pain management is recognized as part of general medical practice;
  - medical use of opioids is recognized as legitimate professional practice;
  - pain management is encouraged;
  - providers' concerns about regulatory scrutiny are eased;
  - prescription amount alone is stated as insufficient to determine prescribing legitimacy; and
  - physical dependence or analgesic tolerance is not confused with addiction.

...and measures that impede pain policies:

- opioids are implied to be a last resort;
- the belief that opioids hasten death is perpetuated;

- medical decisions are restricted; and
  - practitioners are subject to burdensome prescription requirements.
3. Create a regulatory climate that is supportive of pain-relief efforts. As chief counsels to state drug-control agencies, make sure that state narcotic, medical and pharmacy investigators know about current pain management practices and have ample cause to conduct investigations of physicians suspected of over-prescribing opioids with an awareness of how those investigations are perceived by other physicians. Convey to hospital, hospice and nursing home regulators that pain management is a priority.
  4. Meet with state medical licensing boards and medical associations to voice support for effective pain management. Encourage them to adopt the FSMB model guidelines.
  5. Encourage state health officials to offer the public information about pain and symptom management, and where to go for help.
  6. Have medical expertise available within the Attorney General's Office or by consulting arrangements, to guide policy review, communication and investigations into physician over prescribing.
  7. Evaluate the possible discriminatory effects of regulatory enforcement of drug laws in minority communities, particularly as they relate to lack of drug availability at the community retail pharmacy level.

### Conclusion

While affecting the life quality of millions of Americans, pain management is an issue that, until recently, has existed with little public notice or concern. Attorneys General are in a strategic position to ensure that residents of their state receive medical care that offers effective pain relief. The tools are now available. Health care providers need to learn them and feel safe in prescribing the dosage of narcotics necessary to relieve patients' pain. As states'

chief legal officers who advise governors, legislatures, and executive agencies, Attorneys General can improve state policies, physician practices and public knowledge regarding effective pain relief. As one state assistant attorney general described his motivation to pursue this goal, "When you ask yourself, 'What have I accomplished in my term?' You can say, 'I helped reduce the amount of human suffering in my state.'"



Consumers discuss limited legal and medical options for the dying

## Resources

- The Pain and Policy Studies Group (PPSG) at the University of Wisconsin is a research organization specializing in state, federal and international policies that promote effective pain relief. PPSG reports and studies are available at <http://www.medsch.wisc.edu/painpolicy/>.
- The Federation of State Medical Boards' Model Guidelines for the Use of Controlled Substances for the Treatment of Pain contains clear language recognizing the legitimate role of opioids in relieving pain and addressing physicians' fear of regulatory scrutiny. More than 20 state medical boards have adopted the policies that are identical or similar to these guidelines. They are available at [www.fsmb.org](http://www.fsmb.org).
- The American Pain Foundation has published Pain Action Guide. The guide is designed to dispel myths about pain-medication addiction; help patients through conversations with their health care providers; and describe what kind of pain care they should expect. A copy of the guide can be ordered online at [www.painfoundation.org](http://www.painfoundation.org).
- The Joint Commission on Accreditation of Healthcare Organization's pain-management standards, effective January 1, 2001, as basis for accreditation, mandate that hospitals treat pain as a "fifth vital sign," along with temperature, pulse respiration, and blood pressure. These standards can be viewed online at [www.jcaho.org/search/frm.html](http://www.jcaho.org/search/frm.html).
- Researchers at Brown University have developed a step-by-step Pain-Relief Manual to help health care facilities gauge how well they provide pain management. The manual is posted at [www.chcr.brown.edu/commstate/homepagewithframes.htm](http://www.chcr.brown.edu/commstate/homepagewithframes.htm).
- The Initiative to Improve Palliative Care in African-Americans, a recently formed research and policy initiative, has many resources addressing disparities in pain management and palliative care as they relate to African-Americans and other communities of color. This information is available at [www.iipca.org](http://www.iipca.org).

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Kansas Attorney General Phill Kline questions experts



Patricia Good, of the U.S. Drug Enforcement Administration, describes federal drug policies

# WILL MY WISHES BE KNOWN AND HONORED? POLICY AND PRACTICE PERSPECTIVES

BY: Charles P. Sabatino



Charles P. Sabatino, J.D.

Health care advance directives have become the central legal tool in virtually every state as a way to make one's health care wishes known and assure they are honored. However, whether they really achieve that goal is still an open question. This article provides an overview of key features of the legal landscape of end-of-life decision making generally, and advance directives specifically, and suggests some specific opportunities for action to improve and clarify public policy uniquely suited for Attorneys General.

A good starting point in understanding this landscape is a realization that law and regulation are but one slice of the universe of variables that affect the experience of dying in America. As illustrated in the pie chart below, other key variables include institutional innovation, the role of financing systems, professional and public education and professional standards and guidelines. And all these operate in a larger framework that is defined by family, workplace, community life and spirituality. Thus, the isolation of law and regulation as a focus of analysis requires a sense of humility in going forward, lest we overstate the influence of law in the lived experience of the dying. At the same time, although it is but one piece, it is a very powerful variable in the big picture.

State statutory law addressing surrogate and the use and recognition of advance directives stands out as the predominant feature of law and regulation. These laws include advance directive statutes, default surrogate statutes, out-of-hospital do-not-resuscitate order provisions, organ donation laws and guardianship laws. The focus of this overview is on advance directive laws (liv-

## FACTORS INFLUENCING END-OF-LIFE CARE



ing wills and durable powers of attorney for health care) and on default surrogate laws, which establish decision-making authority in cases where advance directives do not exist.

### Non-Exclusivity of Statutes

Though predominant, these statutes are by no means

the exclusive legal authority defining our decision-making rights and responsibilities. Statutory law fits within a conventional hierarchy of legal authority, illustrated below, with federal and state constitutions at the top of the pyramid, under which stand statutes and regulations (I will skip treaties for purposes of this discussion), and then common law (i.e. principles established through case adjudication).

But that is not the whole pyramid. The law also turns to professional standards and guidelines as a benchmark for behavior where the formal rules of law are silent or unclear, and then to custom and practice where formally prescribed standards or guidelines are lacking. Thus, starting with constitutional law, each level below fills in some or all the interstitial spaces of the authority above. Higher levels of authority can preempt those below, if conflicting; or in the case of statute, legislators may explicitly decide to preempt the common law or other authorities below. But, normally, the relationship is complementary.

The hierarchy of legal authority is important in the law of end-of-life decisionmaking because it is all too often forgotten. A desire for caution and solid footing is quite understandable with respect to end-of-life decisions, but it frequently leads health care providers, institutional counsel, lawyers in general and the public to embrace a common myth that the only valid advance directive is a statutory one. To the contrary, most advance directive statutes were enacted to provide one bright-line pathway, but not the exclusive one, that individuals can use to express their wishes and to strengthen the likelihood that their wishes will be followed. The “carrot” for providers is statutory immunity for following the patient’s wishes.

In most states, this non-exclusivity is expressly stated in the law in language such as the following:

Nothing in this act shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In such respect the provisions of this act are cumulative. Kan. Stat. Ann. §65-28,108(d)

Such a provision, as in the Kansas provision above, is intended to make clear that the statute does not preempt other expressions of one’s wishes that may also be “valid” – that is, worthy of compliance – based upon the broader scope of legal authority found in common law or constitutional law principles and in accepted standards of medical practice.

Even a cursory review of legal history reveals that the right to consent to or refuse almost any medical intervention carries long-standing legal recognition in both the common law<sup>1</sup> and constitutional law<sup>2</sup>. The reality is that any authentic and relevant expression of one’s wishes and values deserves respect. Statutory advance directives deserve special status only to the extent that they may offer one highly recognizable way of facilitating advance planning for a richly diverse public.

## **SOURCES OF LAW & INTERPRETATION OF LAW**



The statutory bonus of provider immunity may be less important today than it was 25 years ago, since the desire for such protection arose in a relatively new medical era faced with a clash between technologically-controlled dying and emerging assertions of personal autonomy and dignity. Interestingly, when it comes to other medical interventions, from brain surgery to flu shots, medical providers receive no promise of statutory immunity, nor do they demand one. Their protection comes from complying with generally accepted medical standards. Why is immunity needed in order to respect a patient's wish to stop treatment? As we pass through the first decade of the 21st century, the now well-established recognition of patient choice and direction in the practice of medicine may further vitiate the importance of immunity provisions.

### Default Surrogate Laws

The law governing decisionmaking *in the absence of an advance directive* deserves priority in any review of the legal landscape, if for no other reason than the fact that most adult Americans do not have an advance directive<sup>3</sup>. Most decisions relating to end-of-life care for persons lacking decisional capacity are made without the guidance or authority of a health care advance directive. Who makes the decisions in these cases?

One answer is provided by laws that may be referred to as default surrogate consent or family consent laws. These exist in some 36 states and the District of Columbia, although they vary significantly in breadth and depth<sup>4</sup>. All create a list of permissible surrogates, usually in next-of-kin order of priority, with some extending as far as any living relative, no matter how distant in degree.

About a dozen include “close friend” or its equivalent in the list of permissible surrogates<sup>5</sup>. Arizona additionally includes “patient’s domestic partner,” as an authorized surrogate for some health decisions, although the definition of close friend may be broad enough to encompass domestic partner in other states.<sup>6</sup>

These laws differ, in part, according to the kind of statutory context in which they emerged.

- a. Some were included in *informed consent* statutes enacted in the 1960s and 1970s. These laws provided for family consent to treatment primarily as a way to ensure *access* to care. They are usually silent on the issue of refusals of treatment, so their applicability to refusals of life support may be unclear.
- b. Some *living will* statutes include family consent authority, but these statutes are typically limited to patients in *terminal conditions* or in permanent unconsciousness and to decisions about life-sustaining treatment. Their application to the full range of health care decisions is sometimes unclear.
- c. Some are *decision-specific* laws, such as New York’s narrow family consent provision that deals *only* with do-not-resuscitate orders<sup>7</sup>. A few other states have enacted family consent provisions specific to medical research consent.
- d. Finally, several states – some 22 plus the District of Columbia – have included family/surrogate consent within *comprehensive* state health-decisions statutes. These tend to be the most comprehensive in the kinds of decisions covered.<sup>8</sup>

In states without default surrogate laws, long-standing custom and practice tends to look quite similar to the legislatively sanctioned practices in the states with default surrogate laws. For whether a statute exists or not, health care providers quite naturally like to rely on close family as the spokesperson and responsible party for patients lacking capacity. Yet, the customary reliance on family is increasingly strained by the power of medical science to control the timing and experience of death. Thus, default surrogate laws offer the potential for better clarity in knowing who the authorized decisionmakers are and greater security in relying on their decisions.

Most of the default surrogate laws prescribe some method of handling disagreements among multiple surrogates of the same priority. For example, what happens if the authorized surrogates are adult children, and the children disagree over a particular health care decision? Approaches vary. Some states require consensus among the reasonably available co-equal surrogates, and if consensus cannot be reached, judicial resolution is necessary. Some allow the majority view to prevail, although this may work far less in practice than in theory, since health care providers are often reluctant to proceed with a decision in the face of contentious children. Other statutes are unclear about conflicts, merely permitting providers to rely on the consent of any member of the priority class. Delaware and Maryland provide for referral of such disputes in institutions to a patient care advisory committee or its equivalent. They also give a measure of protection to physicians relying on the recommendation of such committees.<sup>9</sup>

Most states have not addressed what to do if none of the listed surrogates are available. The default in that case is a guardianship proceeding. A few states have taken tentative steps toward prescribing non-judicial means for making decisions for these persons, sometimes referred to as “unbefriended” patients.<sup>10</sup>

### **Advance Directive Laws**

The first health care advance directive law – a living will act – was passed by California in 1976.<sup>11</sup> Since then, every state has enacted one or more health care advance directive statutes. Most have at least two statutes, one establishing a “living will” type directive; the other establishing a proxy or durable power of attorney for health care. The spread of advance directive legislation did not lead to uniformity of the law. Indeed, formalities and other requirements vary to such an extent that no single comprehensive advance directive form can possibly meet the statutory requirements in every state. One group – Aging with Dignity, Inc. – sought to create a truly national advance directive form in 1998, called *Five Wishes*, and could meet the statutory requirements, by their own estimation, in only 35 states. This Balkanization is a problem, at least to the extent that it confuses the public and deters them from advance planning, and to the extent that it leads providers and the public to embrace the myth that the only valid advance directive is a statutory one.

During the 1990s, states began moving toward simplification by combining these laws into comprehensive advance directive acts. By mid-2000, about 18 states had comprehensive or combined advance directive statutes<sup>12</sup> which, at a minimum, cover living wills and proxies in the same law. The most comprehensive ones also recognize the authority of default surrogate decisionmakers in the absence of an advance directive.

The primary model for a flexible combined advance directive and default surrogate law is the *Uniform Health-Care Decisions Act*.<sup>13</sup> The Uniform Act was promulgated as a national model by the National Conference of Commissioners on Uniform State Laws in 1993, and given recognition by the American Bar Association in 1994. The Act establishes very simple rules for recognizing almost any kind of written or oral statement as an advance directive, although the states that have adopted the *Uniform Act* have commonly added to the Act’s baseline require-



Attorney Bill Colby reads book excerpts describing Cruzan family legal battle

ments.<sup>14</sup> The Act includes a comprehensive sample form with options for instructions, appointment of an agent, organ donation and the naming of a primary physician. In addition, the Act covers surrogate or family/friend decisionmaking for persons who do not have an advance directive.

Despite the variability in advance directive law detail, there is a now accepted consensus that they are the primary legal tool for making sure one's health care wishes are known and honored. But every good policy idea deserves to be tested, and over the last 25 years, many researchers have delved into the question of whether advance

directives really work – that is, do they really have an impact on the way decisions are made and carried out? While a thorough review of the literature is not intended here, it can fairly be said that the cumulative research on advance directives reveals a dark and discouraging side. In short, the medical/social science literature suggests the following conclusions:

1. Most people never complete an advance directive;
2. When they do, the directives are boilerplate forms that do not provide much guidance;
3. Individuals often do not understand the forms they complete;
4. When individuals name an agent or proxy, they seldom explain their wishes to the agent;
5. Even if a directive has been completed, health care providers usually don't know about it;
6. Even if providers know a directive exists, it is not in the medical record when and where it is needed; and
7. Even if the directive is in the record, it is not consulted.<sup>15</sup>

On the positive side, we can at least say that there appears little evidence of intentional abuse of advance directives for the purpose of causing premature termination of treatment or otherwise misrepresenting a patient's wishes. Yet, overall, the picture is very discouraging and requires a sober reassessment of advance directive policy.

The starting point of such a reassessment is a more realistic understanding of what advance directives can and cannot do.

## What Advance Directives CANNOT Do

An advance directive:

... Cannot provide cookbook directions for end-of-life care, as a last will and testament can give instructions on how to distribute one's property. Most advance directives express very general sentiments about not wanting life support if it only prolongs the dying process or if the treatment is extraordinary or heroic. These kinds of stock instructions are not especially informative.

... Cannot change the fact that dying is complicated. Even though there is definitely a point each of us may reach in which the quality of our existence is worse than dying, that point is different and unique for each person. Moreover, our values and priorities may change as our circumstances change. There is truth to the old saw, "The world looks different horizontally than vertically." Defining the "No More" point is difficult to do ahead of time, unless one happens to have an extraordinary crystal ball.

... Cannot eliminate one's personal ambivalence. Most people have some level of ambivalence for themselves, and for loved ones, when faced with trade-offs between length of life versus quality of life. Advance directive forms presume decisiveness, not ambivalence.

... Cannot be a substitute for discussion about the individual's goals of treatment and goals of living in the face of serious illness. Completing a legal form may give one the impression of completing an important task, yet in reality may merely provide a way of avoiding the essence of the task – communicating with one's doctor and loved ones.

... Cannot control health care providers. With the power or status of their positions and inertia of the institutional routine, providers still have an upper hand. They may also invoke a conscience objection if they cannot resolve or circumvent a disagreement. Again, the underlying communication process stands out as the key to good decisionmaking.

## What Advance Directives CAN Do

Advance directives, used realistically, can help accomplish at least three vital goals.

Advance directives:

... CAN be an important part of the process of advance planning, but the emphasis must be on the ongoing process of discovering and communicating one's values and priorities as circumstances change.

... CAN be an effective tool to prompt individuals to stop and think and discuss key questions.



Charles Sabatino, of the ABA Commission on Legal Problems of the Elderly, highlights policy roles of Attorneys General

... CAN empower and give direction if the written product truly reflects the patient's voice and not merely a boilerplate sentiment in a standard form.

In short, the starting point of a more effective advance planning policy is the realization that advance directives are not worth the paper they are written on. Rather, they are worth only the thought and discussion they are based on. The latter value can be high indeed.

Much of the statutory simplification that has occurred in the past decade has been motivated, in part, by this kind of policy reassessment. The clearest example is the Uniform Act itself, which places far greater emphasis on flexibility and simplicity

than virtually any state advance directive law presently in existence. As state policy makers struggle with these policy challenges, the role of Attorneys General in the process is too often overlooked. Yet, Attorneys General play a key advisory role in the law and wield tremendous influence. The six areas of action and opportunity recommended below are uniquely suited for Attorneys General.

## Opportunities and Actions for Attorneys General

### 1. Simplify and De-emphasize Mandatory Forms or Language in Advance Directive Laws.

This can be accomplished through the use of advisory opinions to remove misperceptions or other barriers to simplicity and flexibility. Several kinds of questions lend themselves to Attorney General review, for example:

- This overview already touched upon one question that could effectively be addressed—the myth that the only *valid* advance directive is a statutory one. Clarification can be provided to professionals and the public that the statute is non-exclusive and that other advance directives, even oral directions, may be “valid” in the sense of being legally worthy of compliance. The goal of enhancing communication with respect to health care decisions will favor the recognition of instructions expressed in any way, as long as their authenticity and content is clear.
- Another common question about statutory forms occurs in those states where the law provides that the advance directive must be “substantially in the following form” set forth in the statute. About a dozen states have this or similar language in their advance directive laws. The notion of substantial compliance arises with great regularity in many areas of law, but it lacks any authoritative construction with respect to advance directives. The uncertainty leads many providers to adopt a restrictive view that substantial compliance requires verbatim use of the statutory form. An authoritative interpretation of the statute as a

whole may lead to a more flexible construction based on the typical core requirements of merely having an identifiable writing with signature, date and proper witnessing.

- The notion of “terminal condition” serves as a common trigger for the implementation of living wills, yet its definition is surprisingly variable from state to state and almost universally lacking in clinical clarity.<sup>16</sup> Again, as is understandable in the face of uncertainty, the tendency is to resort to overly restrictive interpretations that may ultimately undermine the known wishes of the patient.

Where statutory language is truly deficient and cannot be salvaged by interpretation, then the Attorney General stands in an ideal position to recommend needed changes to the state legislature.

## **2. Support/Enhance the Role of the Proxy.**

All states recognize some version of a durable power of attorney for health care that enables an individual to appoint a proxy (or agent, surrogate, representative, etc.) to make health care decisions in the event the individual loses decisional capacity. In the real world of decisionmaking, the use of a proxy offers many advantages over purely instructional (living will) directives. The proxy can be authorized to make virtually all health care decisions; the choice of proxy is in the control of the patient and successor proxies can be named; and a proxy has the advantage of being able to ascertain and weigh all the relevant variables and options at a time a decision needs to be made. Yet, policy and practice often fail to support the role of the proxy.

Opportunities for Attorney General action include the following:

- Develop proxy supports, such as a “job description” and guidebook. Few people have any clear notion of the responsibilities, rights and expectations of a health care proxy. It is not a role we routinely experience, so there is a tremendous need for authoritative guidance.<sup>17</sup> Attorneys General have the visibility, authority and ability to bring the key resources together to accomplish this kind of task.
- Where state law is unclear, clarify that the authority of the proxy has priority over an instructional directive (i.e., living will) unless the patient has specified otherwise in the advance directive. Likewise, if unclear, clarify the authority of the proxy over that of a guardian, unless the presiding court specifically orders otherwise.
- Promote by opinion, training or statutory change the standard of decision-making by proxies recommended in the Uniform Health Care Decisions Act: Surrogate shall make a health-care decision in accordance with the patient’s individual instructions, if any, and other wishes to the extent known to the surrogate. Otherwise, the surrogate shall make the decision in accordance with the surrogate’s determination of the patient’s best interest. In determining the patient’s best interest, the surrogate shall consider the patient’s personal values to the extent known to the surrogate. UHCDA, Sec. 5A

### **3. Clarify Proxy/Surrogate Authority in Medical Research Settings.**

In the development of advance directive law, medical research has been largely an invisible, unaddressed issue. In most states, the extent to which a proxy or surrogate has authority to give consent to participation in medical research on behalf of a patient is unclear. One of the populations most affected by this uncertainty are persons suffering from Alzheimer’s disease and for whom new treatments are vitally dependent on the conduct of research. Attorneys General have the ability to speak to this issue in a constructive way. One example is Maryland, where the Attorney General undertook a policy study of Alzheimer’s disease care, examining a wide range of issues, including research consent under the state’s advance directive law. The chapters of the policy report were posted on the Attorney General’s web page.<sup>18</sup>

The report clarified that “Health care” as defined in the law, includes “participation in research that, considering the risks and benefits of participation, presents a reasonable prospect of direct medical benefit to an individual.”<sup>19</sup> Thus, so long as research can fairly be characterized as holding out the prospect of direct medical benefit to participants, the authority to consent is presumptively within the scope of authority of a health care proxy or surrogate.

The report goes on to recommend the study of efforts to spell out in greater detail consent authority. The report cites the example of an advance directive used by the Clinical Center at the National Institutes of Health, which provides the following four alternative instructions:

- If I lose the ability to make my own decisions, I do not want to participate in any medical research.
- If I lose the ability to make my own decisions, I am willing to participate in medical research that might help me.
- If I lose the ability to make my own decisions, I am willing to participate in medical research that won’t help me medically, but might help others as long as it involves no more than minimal risk of harm to me.
- If I lose the ability to make my own decisions, I am willing to participate in medical research that will not help me medically, but might help others, even if it involves greater than minimal risk of harm to me.<sup>20</sup>

The advance directive also encourages the individual to “indicate any specific values, goals, or limitations that you would like to guide your participation in medical research.” The proactive role of the Attorney General in this example helps push forward the discussion of policy and practice in a positive way.

### **4. Ensure Portability of Advance Directives Across State Lines.**

Many advance directive statutes explicitly recognize the validity of advance directives executed in other states. Even without express recognition, the doctrine of comity arguably supports such recognition. But, as in the case of non-statutory advance directives, the lack of specific authority affirming such a conclusion, or ambiguity in the authority itself, engenders considerable doubt and confusion among medical providers, advisors and the public. Not surprisingly, a common question among older persons who attend programs on health care advance planning is whether a directive executed under the law of one state is “valid” in another state. In such a highly mobile society, the question affects many people. An advisory opinion or other guidance issued by the Attorney General on this question can help dispel doubt and could encourage greater acceptance of advance directives across state lines.



Georgia Attorney General Thurbert Baker reviews policy questions

### **5. Recognize Default Surrogates**

As discussed earlier, default surrogate laws vary considerably in content, form and clarity, and in some states simply do not exist. Where state law is unclear, encourage reasonable recognition of default surrogacy, or recommend options for statutory reform.

### **6. Support Advance Planning Knowledge Skills Across All Systems: In the Community, In the Medical Profession and In the Government.**

Recall the pie chart at the beginning of this article, which highlights law and regulation as a slice of a much larger constellation of factors that together determine the experience of end-of-life care. The people and institutions affected by law and regulation are all stakeholders who play an integral role in all the other slices of the pie—medical institutions, private and public financing systems, the health and legal professions, representatives of family, workplace and the faith community and the general public. The state Attorney General stands in a uniquely influential and credible position to bring these stakeholders together to examine and remedy needs in multiple dimensions of end-of-life care.

## Conclusion

These opportunities for action arise from the essential nature of the Office of Attorney General as legal advisor to the state and as a foremost authority in interpreting and enforcing the law of the land affecting us all from birth to death. By examining and acting upon important legal and policy issues relating to life near the time of death, Attorneys General will reap tangible benefits for the public and for all the stakeholders in the care system. Making the process of end-of-life decisionmaking truly patient-friendly and family-friendly benefits everyone. Practically and politically, it offers a win-win opportunity for all.



Attorney General staff members discuss legal barriers to health care

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<sup>1</sup> See National Center for State Courts, *Guideline for State Court Decision Making in Authorizing or Withholding Life-Sustaining Medical Treatment* (1991).

<sup>2</sup> See *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 110 S.Ct. 2841, 111 L.Ed.2d 224 (1990).

<sup>3</sup> See Steven H. Miles *et al.*, "Advance End-of-life Treatment Planning. A Research Review, 156 *Arch Intern Med* 1062 (May 27, 1996); United States General Accounting Office, *Patient Self-Determination Act: Providers Offer Information on Advance Directives but Effectiveness Uncertain*, HEHS-95-135 (1995); Dallas M. High, "Advance Directives and the Elderly: A Study of Intervention Strategies to Increase Use," 33 *Gerontologist* 342 (1993).

<sup>4</sup> A summary chart of these laws, updated annually by the ABA Commission on Law and Aging, is available on the internet at <http://www.abanet.org/aging/update.html>.

<sup>5</sup> *Id.*, specifically Arizona, Colorado, Delaware, Florida, Hawaii, Illinois, Maine, Maryland, Missouri, New Mexico, North Dakota, Oregon, and West Virginia.

<sup>6</sup> For example, Florida law defines "Close personal friend" as "any person 18 years of age or older who has exhibited special care and concern for the patient, and who presents an affidavit to the health care facility or to the attending or treating physician stating that he or she is a friend of the patient; is willing and able to become involved in the patient's health care; and has maintained such regular contact with the patient so as to be familiar with the patient's activities, health, and religious or moral beliefs." Fla. Stat Ann. §765.101(c) (West 2001).

<sup>7</sup> N.Y. Pub. Health Law §2965 (McKinney 1999)

<sup>8</sup> See note 4, *supra*.

<sup>9</sup> Del. Code Ann. tit. 16, §2507(b)(8) ; Md. Health-Gen. Code Ann., §5-605(b)(1).

<sup>10</sup> Cite Gillick article on unbefriended patients.

<sup>11</sup> See California Natural Death Act, Cal. Health & Safety Code §§ 7185-7195 (West 1991).

- <sup>12</sup> AL, AZ, CA, CT, DE, FL, HI, KY, ME, MD, MN, MS, NJ, NM, OK, OR, VA, WV. A complete summary chart of state health care power of attorney and combined advance directive laws, updated annually by the ABA Commission on Law and Aging, is available on the Internet at <http://www.abanet.org/aging/update.html> .
- <sup>13</sup> See <http://www.law.upenn.edu/bll/ulc/fnact99/1990s/uhcda93.htm>. For a descriptive review of the Uniform Act, see Charles P. Sabatino, "The New Uniform Health-Care Decisions Act: Paving a Health Care Decisions Superhighway?" 53 *Maryland Law Review* 101 (1994).
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- <sup>15</sup> See e.g., Edward J. Larson and Thomas A. Eaton, "The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act," 32 *Wake Forest Law Review* 249 (1997); Joan Teno *et al.*, "Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention," 45 *Journal of the American Geriatrics Society* 500 (1997); Diane E. Hoffmann *et al.*, "The Dangers of Directives or the False Security of Forms," 24 *J. of Law, Medicine & Ethics* 5 (1996); Stephen H. Miles, *et al.*, "Advance End-of-Life Planning. A Research Review," 156 *Arch. of Internal Med.* 1062 (1996); R. Sean Morrison *et al.*, "The Inaccessibility of Advance Directives on Transfer From Ambulatory to Acute Care Settings 274 *JAMA* 478 (1995); David Orentlicher, "The Illusion of Patient Choice in End-of-Life Decisions, 267 *JAMA* 2101 (1992).
- <sup>16</sup> Joanne Lynn *et al.*, "Defining the 'Terminally Ill:' Insights from Support," 35 *Duquesne L. Rev.* 311 (1966).
- <sup>17</sup> Some examples of job descriptions for proxies already exist and could provide a model. See e.g., ABA Commission on Law and Aging, *The Lawyer's Tool Kit for Health Care Advance Planning* (2000), particularly Tool #9 – "Guide for Health Care Proxies."
- <sup>18</sup> See <http://www.oag.state.md.us/Healthpol/index.htm> .
- <sup>19</sup> Maryland Attorney General, Health Policy Division, Policy Study of Alzheimer's Disease Care, Chapter 2: Health Care Decisions – Patient Capacity and Proxy Decision Making, p. 11 (Discussion Draft 2001), accessible at: <http://www.oag.state.md.us/Healthpol/alzchap2.pdf> .
- <sup>20</sup> *Id.*, at Chapter 4: Advance Planning: Health Care Choices and Research Participation, p. 11-12 (Discussion Draft 2001), accessible at: <http://www.oag.state.md.us/Healthpol/alzchap4.pdf>.

# WILL I RECEIVE COMPETENT CARE? IMPROVING CARE AT THE END OF LIFE

BY: Betty Ferrell



Betty Ferrell

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The question, “Will I Receive Competent Care?” is a reasonable question voiced by consumers, as they should well expect competent, compassionate care at life’s end. Unfortunately, significant data suggests that the likelihood of consumers receiving competent care at the end of life is very poor.<sup>1,2</sup> One of the key barriers to receiving competent care is the availability of professionals who are competent in both their knowledge and skill in caring for patients and families at life’s end. One thing is certain: Professionals cannot practice what they do not know. Therefore, if ever we are to improve end-of-life care, it will occur because we have been able to educate professionals to become competent in this area.<sup>3,4</sup>

The Institute of Medicine (1997) defined palliative care as that care which “seeks to prevent, relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure... Palliative care in its broad sense is not restricted to those who are dying or enrolled in hospice programs. It attends closely to the emotional, spiritual and practical needs and goals of patients and those close to them”.<sup>1</sup> This definition reminds us that palliative care is applicable across all diseases and populations, is multidisciplinary and holistic care and should be implemented early in the course of serious life-threatening illness. The education of professionals may not be the direct domain of practice by the Attorney General, yet involvement and support in raising the expectations of professional education can do much to raise the bar on quality care.

Supported by a grant from the Robert Wood Johnson Foundation, I, and my colleagues at the City of Hope National Medical Center, have conducted a series of studies to document the current status of nursing education in end-of-life care.<sup>5,7</sup> One of the key studies reported on the review of 50 leading textbooks in schools of nursing.<sup>8</sup> This review was conducted to evaluate the amount of information within these leading texts as an indicator of professional education in end-of-life care. The results of that study that reviewed 45,638 pages across these 50 texts indicated that only two percent of the content had any relationship whatsoever to any end-of-life topic. Only 1.4 percent of the chapters in this text review were focused on an end-of-life related topic.<sup>8</sup> These numbers are actually generous, as we credited any information that could possibly be

useful to nurses caring for patients at the end of life. As we were conducting this study, our colleagues at the University of California, San Francisco, conducted a similar analysis of 50 leading medical textbooks. Their results were almost identical to ours.<sup>9</sup>

An additional study we conducted reported on the frequency of occurrence in end-of-life care of dilemmas by more than 2,300 practicing nurses.<sup>6</sup> Nurses face daily dilemmas with advanced directives, preserving patient choice, uncertainty about the patient's prognosis and an erroneous fear of causing death by giving pain medication. Other common dilemmas

involve discontinuing life-sustaining treatment, withdrawing or withholding nutrition or hydration, the influence of managed care and lack of continuity. Other barriers included the knowledge or attitudes of professionals, patients and family caregivers. An interesting finding from this process was to recognize that those topics that often receive the most publicity, such as assisted suicide or euthanasia, are relatively uncommon. Yet, it is the day-to-day difficulties that are encountered in our nation's clinical settings that create the greatest barriers to quality care.

Our studies conducted with practicing nurses often revealed that most nurses indicate that their basic nursing education was highly inadequate in preparing them for areas such as pain management, end-of-life care, symptom management, grief/bereavement or communication with patients and families. Each of these findings has challenged us to ask if we are truly providing end-of-life care or if we are providing only what has been described as "brink-of-death" care.

A landmark contribution to this dialogue has been the 1997 report from the Institute of Medicine (IOM) on improving care at the end of life.<sup>1</sup> The report is a broad statement about the many reforms needed in end-of-life care. Throughout the document, the importance of professional preparation to provide this care is paramount. Subsequently, the IOM issued reports specific to end-of-life care in cancer<sup>(10)</sup> and in pediatric care<sup>(11)</sup>.

One of the major contributions to advancing nursing knowledge has been the End of Life Nursing Education Consortium (ELNEC), supported by the Robert Wood Johnson Foundation (<http://www.aacn.nche.edu/el nec>). This project is a comprehensive national effort to improve end-of-life care by nurses. It is conducted jointly by the American Association of Colleges of Nursing and the City of Hope Medical Center. The ELNEC curriculum consists of nine modules. The content areas include nursing care at the end of life, pain, symptom management, ethical/legal issues, cultural considerations, communication, grief/loss/bereavement, achieving quality of life at the end of life and care at the time of death. This curriculum is intended to provide nurses with knowledge in physical aspects of care, such as pain and symptom management, but also to provide a very broad foundation for psychosocial aspects of care. Eight national conferences have been supported through this grant, of which the highest priority has been the integration into the nation's undergraduate nursing programs. More than 550 nursing programs have been trained to implement the ELNEC content, which represents one out of every three nursing programs in the nation.



Betty Ferrell, of the City of Hope National Medical Center, shares her expertise in palliative nursing care



Delaware Attorney General Jane Brady comments on provisions for pain management

Additionally, three courses have been conducted for continuing education providers, such as clinical educators in hospitals or home care agencies, and five regional courses were sponsored through the Robert Wood Johnson funded Last Acts Project. These regional courses attracted a broad clinical audience of educators with a high representation by hospice and palliative care programs. The ELNEC project will continue to reach these audiences.

Additionally, in 2003, we will launch a national pediatric ELNEC course to address the needs of children and their families at the end of life. We also have received support from the

National Cancer Institute for a Graduate Education version of ELNEC, which will integrate end-of-life content into essentially all graduate nursing programs in the nation. We also hope to receive support for a project focused on oncology nurses, as we are aware of extreme deficits in end-of-life care within the nation's cancer care settings. Attorneys General are encouraged to visit the ELNEC website (<http://www.aacn.nche.edu/elnec>), which includes a state-by-state listing of ELNEC trainers. Attorneys General can contact these ELNEC trainers in their own states to foster collaboration.

In addition to these continuing education activities, there is a very significant opportunity for promoting improved care through professional practice by the regulation of health care professionals. Boards of pharmacy, nursing and medicine have generally provided little direction or regulation to ensure competent care. Some model states have contributed significantly to advancing pain relief however, there is considerable untapped potential for the promotion of improved care through these state agencies.

Legislating professional education can best be described as a two-edged sword. While many schools of medicine do not support mandates regarding their curriculum, our general experience has been that legislation of professional education is successful. The same is true in the realm of continuing education for practicing physicians. In California, legislation has been enacted that mandates pain education in all state medical school curricula and, more recently in 2002, a requirement of 12 hours of CME in pain or end-of-life care for re-licensure. While somewhat controversial, these efforts are working. Ensuring professional education will take bold action on the part of regulatory and professional agencies. While these mandates present many barriers and encounter opposition, failure to act aggressively will only mean that our nation continues to receive inadequate care at the end of life.

A common question in any dialogue regarding improved end-of-life care is "What will it cost?" Certainly, reform in end-of-life care will incur costs. Yet, a critical question is what is it costing us now to fail to provide good end-of-life care?<sup>12,13</sup> Failure to provide pain management or symptom control is serious. Patient and family disruption from end-of-life care, lost work time and the sequelae of unresolved problems, in both patients and families, is costing our nation a considerable sum. Our aging population and the prevalence of chronic and life-threatening disease means that we have tremendous opportunities to not only improve the quality of care, but to provide the most cost efficient care.

In 1998, Dr. Susan Tolle, a physician and leader in improved end-of-life care in the state of Oregon, acknowledged that the amount of dollars spent on advertising for and against the intensely debated assisted suicide legislation of Oregon was enough to fund access to hospice care for every dying person in Oregon for the next three years. Dr. Tolle challenged us that if so much money can be found to fight debates regarding moral views, it seems that as a society we should fund high level end-of-life care.

As each of us return to our communities and work settings, I would issue a challenge that a minimum of resources be devoted to continued “fact finding” or descriptive projects. We clearly have abundant documentation to tell us that end-of-life care is poorly managed. We should focus our resources on demonstration projects, educational endeavors, research and efforts that will begin to change the practice of care. In the words of Mother Teresa, “Too many words...let them just see what we do”.

The Attorneys General of the United States have tremendous power and influence over many aspects of improved end-of-life care. The opportunities presented in this forum have the ability to do more to improve care than many activities conducted over the past decade by many professional organizations. The palliative care community, in partnership with the Attorneys General, can be a powerful force to create the kind of care system that each of us would want at the end of our lives or for our families at life’s end.

Betty Ferrell, RN, Ph.D., has been in oncology nursing for 25 years and has focused her clinical expertise and research in pain management, quality of life and end-of-life care. She is also a research scientist at the City of Hope National Medical Center.



Vermont Attorney General Bill Sorrell cites importance of public education

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<sup>1</sup> Field, M.J., & Cassel, C.K. (Eds.). (1997). *Approaching death: Improving care at the end-of-life* (Report of the Institute of Medicine Task Force). Washington, D.C.: National Academy Press.

<sup>2</sup> SUPPORT Study Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatment. *JAMA*, 274(20), 1591-1598.

<sup>3</sup> Ferrell, B.R., Virani, R., Grant, M. (1999). Strengthening nursing education to improve end-of-life care. *Nursing Outlook*, 47(6), 252-256.

<sup>4</sup> McCahill L, Ferrell BR, Virani R. (2001). “Improving cancer care at the end of life.” *The Lancet Oncology*, 2(February 2001): 103-108.

<sup>5</sup> Ferrell BR, Borneman T (2002). “Community Implementation of Home Care Palliative Care Education.” *Cancer Practice*, 10(1): 20-27.

<sup>6</sup> Ferrell BR, Virani R, Grant M, Coyne P, Uman G. (2000). “Beyond the Supreme Court Decision: Nursing Perspectives on End-of-Life Care.” *Oncology Nursing Forum*, 27(3): 445-455.

- <sup>7</sup> Ferrell BR, Grant M, Virani R. (1999). "Strengthening nursing education to improve end-of-life care." *Nursing Outlook*, 47(6): 252-256.
- <sup>8</sup> Ferrell BR, Virani R, Grant M. (1999). "Analysis of end-of-life content in nursing textbooks." *Oncology Nursing Forum*, 26(5): 869-876.
- <sup>9</sup> Rabow MW, Hardie GE, FairJM, McPhee SJ. End-of-life care content in 50 textbooks from multiple specialties. *JAMA.*( 2000); 283(6): 771-778.
- <sup>10</sup> Kathleen M. Foley & Hellen Gelband, (Eds.). (2001). *Improving Palliative Care for Cancer*, Institute of Medicine. Washington, D.C.: National Academy Press.
- <sup>11</sup> Marilyn J. Field & Richard E. Behrman, (Eds.). (2002). *Improving Palliative and end-of-life care for children and their families*, Institute of Medicine. National Academy Press Washington, D.C.
- <sup>12</sup> Lynn, J., Schuster, J.L., & Kabcenell, A. (2000). *Improving care for the end-of-life: A sourcebook for health care managers and clinicians*. New York, NY: Oxford University Press.
- <sup>13</sup> Lynn, J. & Harold, J. (1999). *Handbook for mortals: guidance for people facing serious illness*. New York, NY: Oxford University Press.



J. Donald Schumacher (l), of the National Hospice and Palliative Care Organization, responds to a concern raised by consumer, Peggy Paddyaker (r), regarding information on hospice care



**“THE OFFICE OF ATTORNEY GENERAL IS A UNIQUELY  
POWERFUL AND CREDIBLE POSITION TO BRING ALL  
STAKEHOLDERS, COMMUNITY, MEDICAL, AND  
GOVERNMENTAL, TOGETHER IN SUPPORT OF  
ADVANCE PLANNING FOR END OF LIFE HEALTH CARE.”**

**CHARLES P. SABATINO, J.D.  
ASSISTANT DIRECTOR  
ABA COMMISSION ON LEGAL PROBLEMS OF THE ELDERLY**

# ATTORNEYS GENERAL PROMISING PRACTICES

The role of state Attorneys General in the improvement of end-of-life care has become more critical than ever as the gap widens between the laws as written and the harsh reality that too often confronts patients and caregivers. As the chief legal officers in their respective jurisdictions, Attorneys General are charged with the representation of all people in matters affecting the public interest. Acting as interpreters or advocates, they are a vital force in the creation of a legal environment that promotes therapeutic jurisprudence as an instrument to provide better care of the dying.

Here is a brief sampling of some of the “promising practices” that Attorneys General throughout the nation have adopted in order to ensure the provision of effective pain management, honoring of advance decisionmaking and competence in the education and regulation of health care professionals.

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Terry Goddard

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## ARIZONA

### Outreach and Education

The Arizona Attorney General’s focus on end-of-life issues has been and continues to be in the area of public awareness, education and community programs relating to advance directives. These directives empower consumers to make their wishes known and have those wishes honored, to have their pain managed and to receive competent care at the end of their lives.

The Attorney General’s Office reviewed the law governing health and financial powers of attorney and created the Life Care Planning Documents. The documents are printed in booklet form and allow consumers to prepare for themselves a Durable Health Care Power of Attorney; a Living Will; a Pre-Hospital Medical Directive (DNR); a Durable Mental Health Care Power of Attorney; and a Durable General Power of Attorney so that consumers can plan their own health and financial futures. The documents are in an easy-to-read format, with instructions on how to create legally valid forms.

In addition to creating these forms, the office also provided the documents to the citizens of Arizona. The Arizona Republic Newspaper printed 130,000 copies as a public service, all of which have been distributed to Arizonans.

The office continues to distribute copies in response to individual requests, as well as through community outreach and education seminars. This year, the office held 16 seminars on Life Care Planning, presented by the office's Elder Affairs Program. These presentations are in PowerPoint format and describe the purpose of each form and how each form may be utilized. There are many more presentations planned in the weeks and months ahead. Additionally, the documents are available on the Attorney General's web site at [www.ag.state.az.us](http://www.ag.state.az.us), where consumers can download them from home, at senior centers, at libraries and anywhere else Internet access is available. The seminars have been presented to Arizonans around the state and continue to be extremely popular and well attended.

There are no current legislative initiatives or Attorney General opinions in this area, although the office is reviewing the current law as to some of the directives, and may seek legislative changes in the future, if required after further study.

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Richard Blumenthal

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### CONNECTICUT

Attorney General Richard Blumenthal has been a tireless advocate for informing Connecticut consumers about the importance of Physician-Assisted Living (PAL) in Connecticut.

The PAL initiative is a joint effort between the Office of the Attorney General, the Hospice Institute for Education Training and Research (the Institute), the Connecticut Bar Association and is supported by the clergy and other leaders demonstrating the kind of broad power elicited by this concept. The *Journal of the Connecticut State Medical Society* published and thereby helped launch this initiative in winter 1997. By spring 1998, the National Association of Home Care and Hospice (NAHCH), through its founder and president, Val Halamandaris, agreed

to take the initiative to the 50 states.

The PAL initiative allows individuals to express a preference for hospice care, before the onslaught of pain and depression, through a document similar to the living will and power of attorney for health care instruments. PAL includes a document entitled, Notice for Desire of Hospice Care, as well as a consumer brochure that explains the need for end-of-life planning.

Attorney General Blumenthal, along with the Institute's researchers, know that families of terminally ill patients are better prepared to meet the days ahead following the loss of a loved one if they and their loved ones are enabled to have hospice care. Through interviews conducted by the Institute with hospice families during the last six years, there is now evidence that there are fewer days lost from school and work, fewer emergency room visits and less depression with hospice care.

PAL is an instrument designed to help the medical professional communicate with their patients about their needs. PAL provides a message of hope that is durable and does not respect time. The PAL concept creates a means for each patient, through collaboration with their physician, to view the broadest array of care options.

Connecticut gave the nation its first hospice, and with PAL, Connecticut became the first state to adopt the best way to assure the family of a terminally ill patient a death with dignity and compassion.



Mark Bennett

## HAWAII

The Kokua Mau (Hawaiian for Continuous Care) project is a statewide campaign backed by a 260-member coalition of agencies, health care providers and community groups. The organization’s vision statement sums up its operating philosophy and definition of a “good death:” To build a web of support so that the people of Hawaii can die in the place of their choice; free of pain and suffering; and in accordance with their values, traditions and beliefs.

### Background, Funding and Leadership

The project was born out of a 1998 Blue Ribbon Panel on Living and Dying with Dignity, convened by Hawaii’s governor, which found: insufficient access to Hawaii’s rich and varied spiritual and cultural resources; limited public and professional awareness about good end-of-life care; limited use of advance directives; limited use of hospice; inadequate pain control; and institutional, policy, and regulatory barriers to a good death. Funding was received from a variety of different foundations to establish the coalition and support its activities.

The leadership of Kokua Mau was initially comprised of four organizations:

- **Hawaii Executive Office on Aging (EOA)** provided staffing, served as a policy research and analysis resource, and developed and provided training on end-of-life resources for the aging network.
- **Hawaiian Islands Hospice Organization (HIHO)** acted as an umbrella organization for all seven hospice organizations, overseeing public outreach activities.
- **The Center on Aging, University of Hawaii (UH-COA)** developed and provided training to faith communities through The Complete Life Course. UH-COA is currently developing programs for multi-ethnic caregivers and nursing homes.
- **St. Francis International Center for Healthcare Ethics** is part of a major health care system that worked on pilot courses for health care students and professionals and sponsored “pain as a fifth vital sign” program for long-term care facility staff.

Kokua Mau’s leadership has now expanded. And, although St. Francis is no longer directly involved, the Department of Geriatrics, the University of Hawaii, Kaiser Permanente-Hawaii, and the Hawaii Medical Services Association (Hawaii’s Blue Cross Blue Shield) are active participants.

### Will my pain be managed?

The Controlled Substance Act 165 of 2002 eliminates duplicate prescriptions for physicians when prescribing controlled substances for pain. This legislation was passed in a unique collaborative effort between the Cancer Pain Initiative and Hawaii’s Drug Enforcement Agency.

## **Public Awareness/Education**

Efforts to raise awareness about end-of-life issues were spearheaded by HIHO. Speakers were provided with curriculum materials and hand-outs regarding planning ahead, talking about preferences with others, controlling pain and acknowledging/respecting cultural differences. Presentations were made in a variety of settings, including long-term care facilities to families, caregiver conferences and meetings, senior centers, legal aid forums, regular meetings of retirees, clubs, military units and companies.

Based on Hawaii's Uniform Health Care Decisions Act (UHCDA), the one-page form was developed and widely distributed, along with materials designed to "start the conversation." The form was made available to all hospitals, health care and long-term care facilities, physicians' offices, the Department of Motor Vehicles, State ID offices and senior centers. The form was also distributed by the Long Term Care Ombudsman Program and the four Area Agencies on Aging.

A web site was created with an inventory of services that can assist people at the end of their lives. Both national and local resources were listed, recognizing the mobility of residents and family members. Downloadable advance directives also are available, and videos, curricula and resource kits can be ordered through [www.kokuamau.org](http://www.kokuamau.org). Additionally, the Executive Office on Aging's website has an end-of-life section and links to other sites: [www2.state.hi.us/eoa/](http://www2.state.hi.us/eoa/).

Also developed and distributed were press releases, radio and television public service announcements, including an eight-and-one-half minute video designed to facilitate discussions on end-of-life issues. Topics covered pain management, the discussion of preferences and making sure wishes were honored. The State Unit on Aging provides all of these materials for free.

## **Programs**

In a program coordinated by St. Francis International Center of Healthcare Ethics, health care workers were trained at 12 long-term care facilities in pain management and began tracking "Pain as a Fifth Vital Sign" in 2000. The Center also coordinated the LTC Facility Pain Protocols, which established pain protocols with nursing homes to enable them to assess, track and manage pain. The program is now coordinated by UH-COA. Through the Hawaii Cancer Pain Initiative, staff provided training sessions and developed programs designed to improve the identification and management of cancer pain. This initiative is part of a national program. More information is available at <http://www.aacpi.org/index.htm>.

Palliative care guidelines are currently under development for use in facilities.

## **Will my wishes be known and honored?**

The Uniform Health Care Decisions Act, modified Act 169 of 1999, combined into one statute the stipulations of the living will and durable power of attorney for health care; provided for surrogate decision making in the case of the "friendless" patient; mandated safeguards for patients; and established penalties for non-compliant healthcare providers.

The Advance Health Care Directive Act of 1999 required the Department of Motor Vehicles and the State Civil Identification Branch to ask all applicants to indicate whether they had an advance directive (along with willingness to be an organ donor) on drivers' licenses and state identification cards. In March 2003, 26 percent of all those renewing licenses indicated they had an advance directive.

A critical opinion related to this area is the matter of the *Guardianship of Shirley Sargent Crabtree, an Incapacitated Person. Family Court of the State of Hawaii, FC-G No. 86-0031 (1990)*. This opinion indicates the possible decision for future incapacitated person cases. This is prior to the enactment of the UHCDA in Hawaii, but could serve as a guideline in cases where a surrogate decisionmaker is yet to be appointed. This was the first case where the guardian was able to remove feeding tubes without a written declaration of the incapacitated person's intentions. Despite the wishes of a child, other family members and interested persons were allowed to testify and confirm the incapacitated person's wishes to not be kept alive through feeding tubes.

### **Programs**

Recognizing the important role of professional and paraprofessional workers affiliated with Area Agencies on Aging and their service-provider networks, training was provided out of the EOA. Members of the aging network were familiarized with the educational and resource materials developed for the public and encouraged to share them with clients, co-workers and agency board members. From this work, "End-of-life Care: An Aging Network Issues. An Advocacy Guide and Resource Kit," was created for national distribution.

Based on trainings with the aging network, additional groups in the community have received training, concentrating on starting the conversation, documenting wishes, managing pain, accessing hospice and understanding reimbursement. Training was also provided in Arizona, New Mexico, Washington and Utah. (Representatives from the Arizona Attorney General's Office presented at the Arizona training sessions.) End-of-life resource lists were also added to directories for seniors, women, health programs and professional education.

The Complete Life Course Curriculum was created by the University of Hawaii's Center on Aging to support faith communities to expand outreach to dying and bereaved members. Materials are available via the Kokua Mau website or from the State Unit on Aging.

An additional program includes a document bank. Working with Hawaii Medical Service Association (Blue Cross Blue Shield of Hawaii), a document bank was developed to give doctors and facilities statewide access to advance directives. The project is in the process of expanding nationally. For more information visit [www.myhealthdirective.com](http://www.myhealthdirective.com).

### **Will I receive competent care?**

The Hospice Reimbursement Act of 1999 provided for: reimbursement for room and board in hospice units; reimbursement for hospice referral visits, even if the referral does not result in admission; and the Department of Health licensing of hospice service agencies.

Another important factor in ensuring competent care is establishing appropriate curricula, by facilitating changes to medical and nursing school curricula, incorporating end-of-life and palliative care into existing programs and creating appropriate courses for public health and social work students. ELNEC and EPEC, end-of-life education programs for practicing nurses and doctors, also were offered.



G. Steven Rowe

## MAINE

### Legislation

Maine law has a comprehensive statute that provides citizens with the opportunity to express their wishes regarding the type of care they want to receive, once they no longer have the capacity to make decisions. Uniform Health-Care Decisions Act, 18-A M.R.S.A. §§ 5-801 to 5-817. A health care directive executed pursuant to this Act is not limited to end-of-life care decisions and can include pain management or other medical care decisions. A format for the health care directive is provided in the statute to facilitate the process. In the absence of a written health care directive, this statute also permits surrogates to carry out the wishes of the individual (expressed while competent) regarding end-of-life care.

### Programs

Late last year, representatives from the Office of the Attorney General, the Department of Human Services and the Bureau of Elder and Adult Services, undertook plans to form a group to review deaths and cases of serious bodily injury associated with suspected abuse and neglect of elderly and vulnerable adults. These cases could include referrals that relate to the failure to provide reasonable and appropriate end-of-life care. The group is called the Maine Elder Death Analysis Review Team (MEDART).

The purpose of the group will be to review deaths and cases of serious bodily injury related to, or caused by, abuse and neglect in order to identify whether the systems that have the purpose or responsibility to assist or protect victims were sufficient for the particular circumstances, or whether such systems require adjustment or improvement. The group will, hopefully, act as a catalyst for system changes that will improve the response to victims and prevent similar outcomes in the future.

The MEDART has received a small, one-year grant from the Victims of Crime Act program of the U.S. Department of Justice to cover administrative costs for the group. Maine is one of four pilot sites in the United States to host this innovative program.

The team is currently at the stage of putting together the working group that will participate in the case studies. In doing so, they have secured representation from the following agencies: the Office of the Attorney General, the Bureau of Elder and Adult Services, Licensing and Certification, the Maine State Police, Office of the Chief Medical Examiner, the Long Term Care Ombudsman Program, and the Maine Chiefs, Sheriffs and Prosecutors Associations.

In April 2003, legislation was introduced, L.D. 1211, to recognize the team, define its composition, duties and powers, and resolve issues surrounding confidentiality and access to records. The proposed legislation has not yet been acted upon by the legislature. Although not an office initiative, the assistant attorneys general assigned to the Board of Osteopathic Licensure and the Board of Medical Licensure assisted these clients in drafting regulations regarding appropriate pain management. A primary purpose of these regulations was to encourage practitioners to properly treat pain without fear that they would be reported for over prescribing or hastening the patient's death. These regulations can be found at 02-373 or 02-283 C.M.R. Chapter 11.

<http://www.state.me.us/sos/cec/rcn/apa/02/chaps02.htm>.

Assistant attorneys general assigned to the medical boards also assist the boards in reviewing complaints regarding the appropriateness of the end-of-life care to assure that competent care is rendered.

Additionally, the office has a strong policy of trying to make sure that patients have access to appropriate, affordable medications. Furthermore, the office has worked closely with the legislature and client agencies on several issues that would impact palliative care.

### **Litigation**

In the past few years, the Maine Department of Human Services has attempted to initiate a program, (Maine Rx), that would reduce the costs of necessary medication to persons not eligible for the MaineCare, (Medicaid), or other public or private health care programs. This program could help eligible persons pay for necessary pain medication. A drug manufacturer filed litigation to block this program. This office represents the Department of Human Services and the Office of the Attorney General in this litigation and has supported the department in its efforts to have the state's Rx program approved by the U.S. Department of Health and Human Services. *Pharmaceutical Research & Manufacturers of America v. Kevin Concannon, Commissioner, Maine Department of Human Services*, 249 F.3d 66 (2001).

The office's Healthcare Crimes Unit also actively investigates providers of MaineCare who abuse or neglect patients and can initiate prosecutions when warranted. A recent case included an end-of-life care issue. At the conclusion of the investigation, a referral to the medical examiner's office and the licensing board was made.

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J. Joseph Curran, Jr.

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### **MARYLAND**

The Office of Attorney General has worked in a number of ways to address legal issues related to end-of-life care.

#### **Pain Management**

In the area of pain and other symptom management, the Attorney General has worked to clarify legal issues for professionals and the public. The office, via letter, has notified health professionals and the public that nursing homes have a regulatory obligation to provide medically appropriate pain management for terminally ill residents. The office also has notified health professionals, via letter, that Maryland's Assisted Suicide Act does not apply to medically appropriate measures to relieve pain and other symptoms, and guidelines can be identified to avoid misconstruing proper efforts to manage symptoms as assisted suicide. As part of this effort, the office has participated with physician educators in developing a web-based training program for medical residents, including a statement from the Attorney General's Office reassuring physicians about the use of opioids for appropriate symptom relief.

Recognizing the importance of creating a supportive environment for pain management practices, the office has arranged for an expert in pain management to train nursing home surveyors --- to encourage oversight of nursing home pain management practices. The office also has joined the medical licensing board in providing materials, including video, that inform physicians about state pain policy. Other successes include a partnership with palliative care physicians to create a hotline for general practice and other physicians who would need quick,

expert advice on pain management. In addition, the office has supported the creation of a state advisory group to make recommendations on improved pain management, with an employee from the Attorney General's Office serving as a member.

### **Respecting individual wishes**

The Attorney General's Office has been very active in ensuring that health care professionals and the public understand the complex legal issues at stake in identifying and carrying out the wishes of an individual. The office issued two formal opinions analyzing decisionmaking under the general durable power of attorney statute, the former living will law, and constitutional and common law, both before and after the landmark Cruzan case.

The office also advised, via letter, regarding the implementation of a nursing home resident's decision to decline attempted CPR. Other advisories include clarifying the distinction between a patient's decisionmaking through the informed consent doctrine and a patient's use of an oral advance directive, as well as the circumstances under which a living will is binding on a surrogate.

### **Working to create a supportive environment for individual planning**

The office has been actively drafting legislation, analyzing legislation and defending current laws that protect the rights of individuals. The office participated in drafting and enacting the Health Care Decisions Act of 1993. The office also was involved in assessing the impact of all proposed legislation in this area (e.g., failed bill last session that would have required Medicaid applicants to give special attention to completing advance directives). Other legislative activities include drafting and enacting legislation to create a permanent advisory council on end-of-life care (The Attorney General's Office serves as a member of this and two earlier, temporary advisory groups.); working on legislation authorizing recognition of an EMS "do not resuscitate" order in all care settings; and rewriting the EMS "do not resuscitate" order to make it easier to use.

The office has aggressively represented the state survey agency in imposing sanctions on nursing homes for intentional noncompliance with instruction in an advance directive. In addition, the office filed an amicus brief in support of deferential standard --- when a health care agent's decision is challenged by a family member who was not selected by the patient as an agent.

### **Promoting an effective system of care**

In promoting an effective system of care, the office has addressed the application and implementation of current law with respect to resuscitation orders, and provisions for "medically ineffective treatment." The office has issued: a formal opinion discussing the application of the Health Care Decisions Act to "do not resuscitate" orders; a formal opinion discussing how the law on "medically ineffective treatment" applies to feeding tubes; a formal opinion discussing care responsibilities for a terminally ill child in the public school system whose parents have authorized a "do not resuscitate" order; seven letters on various issues related to "do not resuscitate" orders; and three letters about the application of the "medically ineffective treatment" provision of the Health Care Decisions Act to various situations.

### **Working to create a supportive environment for quality care**

Working with the hospice network to bring training on end-of-life care to hospitals across the state has been invaluable to reaching out to health care professionals and to the public. Providing information through approximately 30 talks annually to various professional and lay groups on end-of-life care also has increased awareness and

sensitivity to this critical topic. The office responds to five to 10 calls per week from health care professionals asking questions about end-of-life decisionmaking. In addition, approximately 10-15 calls are fielded each week from citizens asking questions about advance care planning. Optional advance directive forms and instructions are available on the web site, in addition to a number of educational materials and legal interpretations in response to phone, e-mail, and postal requests. (The web site links directly to the “Five Wishes” document and has been part of a pilot project on the use of Five Wishes in the workplace.) The office prepares and makes widely available a number of educational materials, including summaries of the law, PowerPoint presentations and decision algorithms for physicians. The office provides training for judges on end-of-life issues; participates in a statewide ethics committee network; and actively participates in the Last Acts coalition.

Currently, the office is working with researchers to develop data on end-of-life decision making by public guardians. The office also is developing data on the impact of the state survey process on the use of feeding tubes in nursing homes. Additionally, staff members are conducting a study on state law and policy affecting people with Alzheimer’s disease and their caregivers.



Patricia A. Madrid

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### NEW MEXICO

In October 2002, the New Mexico Health Policy Commission (HPC) completed a report on end-of-life health care issues in the state. The report, compiled at the request of the New Mexico state legislature through Senate Memorial 22, was the result of a myriad of professionals working together, including two attorneys from the New Mexico Office of the Attorney General.

The final report was the result of a study of pain management in the state that included a survey of citizens receiving prescription medications, a site survey of the opinions, beliefs and knowledge of health professionals throughout the state and a task force asked to consider the issues and make recommendations to the legislature.

Although the report produced a number of key findings, there were several critical areas of concern that emerged – the need for more education about pain and pain management, for both patients and health professionals; significant limited knowledge about the etiology of pain; the actual risks and benefits of opioids in the treatment of pain and effective pain management, in general, by health professionals; lack of attention given to pain management in the curricula of the professionals school; no competency requirements for pain management that are required for licensure; fear among health care providers that they make themselves vulnerable to discipline and/or legal action when they prescribe opioids and other narcotics for pain; and the need for the creation of a State Advisory Council on Pain Management, which would be responsible for instituting statewide education efforts for both providers and patients.

The full set of recommendations also includes other issues, such as a patient bill of rights and establishing, in statute, the right of all New Mexicans to receive appropriate treatment for pain. The report provided citizens and the legislature with “insightful and useful” information and recommendations that can be used to develop effective pain management public policy for the state.



Jim Petro

**OHIO**

Building upon the office’s previous “Senior Protection Initiative,” in May 2003, Attorney General Jim Petro created the Child and Elder Protection Section of the Ohio Attorney General’s Office in an effort to expand protections for Ohio’s most vulnerable citizens. The new section, composed of presently existing units from the Corrections Litigation, Crime Victims and Consumer Protection sections of the Attorney General’s Office, along with programs currently housed in the Ohio Bureau of Criminal Identification and Investigation (BCI), will assist local prosecutors in investigating and trying elder abuse cases, as well as Internet and computer crimes against the elderly. More specifically, this new section will actively support local prosecutors with extradition situations and fugitive searches, pretrial and trial assistance, and complex financial investigation and asset recovery. Financial investigations and asset recovery are vitally important in cases of crimes against the elderly as those resources may be needed to care for the crime victim in his or her final years and/or to preserve assets for distribution to heirs.

The Ohio Attorney General’s Office also maintains a toll-free “Senior Hotline” to assist senior citizens in making consumer-related complaints and reporting fraudulent practices that target the elderly. The office also participates in a program that matches volunteer lawyers from the office with low-income senior citizens or individuals facing end-of-life issues who are in need of legal services in the area of preparation of wills, durable powers of attorney for health care and general powers of attorney.



W.A. Drew Edmondson

**OKLAHOMA**

**2002-2003 NAAG Presidential Initiative**

When expectations of competent health care for advanced illness are thwarted by a failure to provide adequate treatment of pain or reluctance to honor advance directives, terminally ill patients are the “ultimate” consumers seeking protection at a most vulnerable time. To address this growing concern, NAAG President and Oklahoma Attorney General Drew Edmondson launched his presidential initiative to address the vital role of Attorneys General in improving health care near the end of life.

The increasing involvement of Attorneys General in bridging the gap between the consumer’s vision and the harsh reality was the cornerstone of a series of three regional conferences held to examine the nature and extent of responsibilities of state Attorneys General through consumer protection activities, Medicaid fraud investigations, representation of agencies regulating nursing home administrators, physicians, social workers and nurses, as well as issuance of relevant opinions to interested lawmakers.

During these listening conferences, Attorneys General and their key staff heard testimony and questioned national experts on pain management, health care decision-making, facility regulation, professional education and standards. The testimony and other findings from these conferences are compiled in this report to serve as an information and resource guide for other Attorneys General, law enforcement, social workers and health care professionals. Additional information on end-of-life issues will be available to Attorneys General and the public on NAAG’s web site at [www.naag.org](http://www.naag.org).

## State Initiatives

In addition to increasing awareness of this critical legal area on a national level, the Office of Attorney General has worked to raise awareness on a state level. Attorney General Edmondson has assigned an assistant attorney general to liaison with the state coalition on end-of-life care for the past four years. This individual has represented the office in working with the Oklahoma Association on Health Care Ethics, the Robert Wood Johnson Foundation funded Alliance for Better Care of the Dying, in addition to making presentations to state agencies related to health care, and to the public on end-of-life care. As a result of this work, the current governor and immediate past governor endorsed Palliative Care Week in Oklahoma, and stood side-by-side with Attorney General Edmondson to inform Oklahomans of the importance of advance health care directives.

Attorney General Edmondson has advocated legislation to simplify the Advance Directive form in Oklahoma. And, this summer, Attorney General Edmondson will publish an article on the role of Attorneys General in improving end-of-life care in the law review of the Oklahoma City University School of Law.

The office continues its enforcement efforts. Recently, the office's Medicaid Fraud Control Unit prosecuted a nurse for felony caretaker abuse and misdemeanor verbal abuse by a caretaker. The nurse worked the evening shift at a nursing home. One of the patients complained about treatment from the nurse several times. The person holding power of attorney for the patient placed a video camera and monitor in the patient's room and advised the nursing home administrator of his action. The administrator, likewise, notified the staff of the camera recording events in the patient's room. Amazingly, the nurse continued to treat the patient in an abusive manner. In addition, an investigation revealed that the nurse had failed to administer the pain medication Darvocet on several occasions during her shifts. The doctor's order for Darvocet instructed that it be given every six hours for pain management. On the video, the patient is heard saying to the nurse and two aides that she feels she is "breaking in two." The nurse claimed that she didn't know what the patient meant by that. It was obvious from the six hours of video that the patient was in pain throughout the evening. The nurse waived a preliminary hearing and entered a guilty plea on July 11, 2002. She received a five-year deferred sentence. A condition of her probation is to refrain from employment as a caretaker for the elderly. On October 8, 2002, the chief of the office's Medicaid Fraud Unit received a letter from the Oklahoma Board of Nursing advising that the nurse's license was suspended.

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Hardy Myers

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## OREGON

The Oregon Attorney General's Office has served in a consulting and advisory role with respect to state agencies in the human services and health-related licensing board arenas. Those state agencies are partners with a number of organizations that are actively engaged in increasing public awareness and education on end-of-life health care issues, and they are also involved in developing standards for emerging issues related to end-of-life health care.

### **Will my pain be managed?**

Oregon has established, by statute, a Pain Management Commission within the Department of Human Services. Oregon Revised Statutes 409.500 - .570 call for the commission to develop a pain management education program curriculum, in coordination with health professional regulatory boards and other health profession-

als. The statute then phases in requirements for physician assistants, nurses, psychologists, chiropractors, naturopaths and physicians to participate in the pain management education program.

As part of its medical practices act, Oregon also has statutory provisions related to the administration of controlled substances for intractable pain. These statutory provisions, ORS 677.470 - .485 (Administration of Controlled Substances for Intractable Pain), attempt to address more specifically the acceptable uses of controlled substances for the palliative treatment of pain. In addition, Oregon has in place statutory provisions related to the medical use of marijuana for treatment of debilitating medical conditions. The Oregon Medical Marijuana Act, ORS 475.300 - .346, sets out a comprehensive registration program through which individuals diagnosed by an attending physician to be suffering from a debilitating medical condition, can obtain access to marijuana for treatment of the medical condition through a registry program maintained by the Oregon Department of Human Services.

The office makes an effort to educate health care professionals and the public about current state laws on end-of-life health care issues. The statutory provisions noted above impose pain management educational requirements on Oregon health care professionals. In addition, Oregon's Department of Human Services provides Internet website information to all Oregon citizens, with a particular emphasis on senior citizens. The website itself provides significant information and contains links to other organizations and sources of information.

State agency personnel participate in the Task Force to Improve the Care of Terminally-Ill Oregonians. The Task Force is coordinated through the Center for Ethics in Health Care at Oregon Health and Science University. The mission of the Task Force is to share information, experience and understanding of available resources for the care of terminally-ill Oregonians and assist in the development and coordination of services where needed. The Center for Ethics in Health Care also provides a website with links to other sources of information and available resources.

#### **Will my wishes be known and honored?**

Oregon's Death With Dignity Act is currently the subject of litigation pending in the 9th Circuit Court of Appeals. The case, *Oregon v. Ashcroft*, 9th Cir. Case No. 02-35587, was argued May 7, 2003. That case addresses whether the United States Attorney General has authority to determine whether the use of medications, listed as controlled substances under the Controlled Substances Act to end an individual's life under Oregon's law, is prohibited because it does not serve any legitimate medical purpose.

Oregon has enacted a comprehensive advance directive statute entitled, Oregon Health Care Decisions Act, ORS 127.505 - .660. These statutory provisions address the requirements for individuals to establish health care instructions or a power of attorney for health care decisions. The statutes include model forms for individuals to use. Oregon is also unique in having in place statutory provisions addressed to physician-assisted suicide. The Oregon Death With Dignity Act, ORS 127.800 -.897, provides a comprehensive program for individuals suffering from terminal illness to obtain, through consultation with medical professionals, prescriptions of medication to end his or her life.

The Department of Human Services website provides access to information about Oregon's advanced directive law and provides a direct link to the statutory provisions, including the forms necessary to execute such an advance directive, as well as links to information about available resources. It also provides direct access to information and resources about Oregon's Death With Dignity Act. The Center for Ethics in Health Care website also provides infor-

mation and resources about Oregon’s advanced directive law, and Oregon’s Death With Dignity Act. In addition, the Center for Ethics in Health Care website provides access to The Final Months of Life: A Guide to Oregon Resources.

**Will I receive competent care?**

In addition to the specific legislation cited in the section above, Oregon, like all other states, has comprehensive regulatory statutes governing health-related professionals. These regulated professions include: physicians, nurses, psychologists, clinical social workers, dentists, optometrists, chiropractors, naturopaths, pharmacists and physical therapists. Oregon’s Department of Justice provides legal representation to these state agencies when they engage in regulatory enforcement actions.

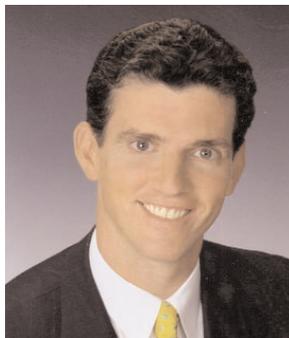
Significantly, the Oregon Board of Medical Examiners recently investigated and took formal disciplinary action against a licensee for under prescribing pain medication. And, as noted above, the pain management education program curriculum being developed by the Oregon Pain Management Commission will also impose additional pain management training requirements on physicians, nurses, psychologists, chiropractors, naturopaths and physician assistants in Oregon.

Oregon also has substantial regulatory authority and enforcement programs related to nursing home facilities, Medicaid fraud matters and other consumer protection activities. The Office also provides legal representation in these areas.

State agency personnel are actively involved in the Task Force to Improve the Care of Terminally-Ill Oregonians. State agencies involved in that task force include the following: the Oregon Board of Medical Examiners; the Oregon Board of Pharmacy; the Oregon Department of Human Services; and the Oregon State Board of Nursing.

The Office anticipates attempting to organize an Oregon conference modeled on the NAAG listening conferences during this coming year to enhance communication and further understanding of these issues in our state.

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Patrick C. Lynch

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**RHODE ISLAND**

The Rhode Island Department of Attorney General has pursued end-of-life care initiatives concerning pain assessment and management, honoring end-of-life wishes and increasing awareness about hospice. The Department of Attorney General participates in health care quality assurance initiatives; however, those programs are not directly operated through the Department of Attorney General.

The Department of Attorney General’s End of Life initiative began with a three-part conference series that reviewed the status of end-of-life care in the state. This analysis led to a 2001 report entitled, “Dying With Dignity: The Rhode Island End of Life Conference Series Report,” which summarized the recommendations of 18 speakers to improve end-of-life care. Through the End of Life Conference Series,

the Department learned that many aspects of end-of-life care in Rhode Island were handled well, although the report recommended several areas where end-of-life care could be improved.

To implement the recommendations of the End of Life Conference Series, an entity would need to be created to review the recommendations, to determine the feasibility of implementing the recommendations, and to imple-

ment the recommendations. After considering both public and private entities to fulfill those responsibilities, the Attorney General concluded, that as the chief legal officer for the state, he was in the unique position to bring both the medical and the legal community to the table to discuss improving end-of-life care. Thus, the Attorney General Task Force to Improve End of Life Care (“Task Force”) was formed in May 2001.

The Task Force consists of approximately 60 members, representing health care providers such as physicians, hospitals, nurses, nursing homes, hospices, academic medical programs, such as Brown Medical School, University of Rhode Island College of Pharmacy, Rhode Island College School of Nursing; advocacy groups, such as the AARP, CCJ and the Alliance for Better Long Term Care; the legal community, such as representatives from the Rhode Island Bar Association, hospital and advocate attorneys; religious/spiritual representatives, such as the Interfaith Ministries and the Rhode Island Council of Churches; and governmental entities, such as the Rhode Island Department of Health, Rhode Island Department of Elderly Affairs and the Rhode Island Department of Attorney General. The Task Force was divided into two steering committees --- the Clinical Steering Committee, which reviews recommendations concerning pain assessment and management, and the Medical-Legal Steering Committee, which reviews the advanced directive recommendations of the end-of-life conference.

### **Will my pain be managed?**

The Clinical Steering Committee reviewed the recommendations concerning pain assessment and management and concluded that a two-pronged approach, legislative and educational, would best implement the recommendation. The Clinical Steering Committee drafted the Pain Assessment Act, which was introduced in the General Assembly at the request of the Attorney General. It was enacted in June 2002. The Pain Assessment Act requires all licensed health care providers and health care facilities to assess pain on a regular basis and record findings in the patients’ medical records. In addition, the Pain Assessment Act makes pain assessment on a regular basis a patient’s right.

With the assistance of the Clinical Steering Committee, the Rhode Island Department of Health is in the process of promulgating Rules and Regulations Related to Pain Assessment. The scope of the proposed Rules and Regulations concerning the Pain Assessment Act is very broad and requires the following elements of pain assessment: assessing pain intensity, location of pain, duration, onset and characteristics of pain, and the patient’s goals and alleviation of causative factors. In addition, the proposed regulations require that a physical examination shall be conducted and noted in the record. The proposed regulations provide for both in-patient and outpatient treatment. We expect the proposed Rules and Regulation Related to Pain Assessment to be final by the end of June 2003.

In the course of reviewing the recommendations concerning pain, the Clinical Steering Committee reviewed state laws concerning pain management or pain assessment. Although Rhode Island has an Intractable Pain Act, the Act did not recognize the present state of who is licensed to prescribe pain medications. The Intractable Pain Act only pertained to physicians and did not consider the role of physician assistants and nurse practitioners as licensed prescribers of pain medication. The Clinical Steering Committee drafted an amendment to the Intractable Pain Act, which extended its protections to prescribed controlled substances. The revisions to the Intractable Pain Act became law in July 2002.

Recognizing that pain at the end of life is a great fear of patients, the Clinical Steering Committee drafted annual resolutions to create Pain Awareness Week, which the House of Representatives approved for 2001 and 2002 and is pending for 2003. The Pain Awareness Week Resolutions provide for a media opportunity to increase awareness

about pain assessment and management for health care providers and patients. The Task Force and its members provide educational programs concerning pain assessment or management for health care providers. The programs cover a broad range of topics, for example: the role of law enforcement in pain management; proper documentation for pain management programs; the medical-legal-ethical aspects of pain assessment and management; alternative complementary pain treatment; and explaining the Pain Assessment Act.

To help health care providers assess and manage pain, the Clinical Steering Committee prepared a Pain Relief Guide. It may be accessed at [www.riag.state.ri.us](http://www.riag.state.ri.us). The Pain Relief Guide is undergoing revisions to update it.

In 2003, the Hospice Steering Committee was formed to address the short length of stay in hospice. The Hospice Steering Committee prepared legislation to increase awareness about hospice by creating the opportunity for patients to receive information about hospice in the Patient's Bill of Rights. The legislation was introduced at the request of the Attorney General and has passed both the House and Senate. Also, the Hospice Steering Committee drafted a Hospice Awareness Week Resolution, which passed the House and Senate, and has been transmitted to the governor. The Hospice Steering Committee is preparing activities for Hospice Awareness Week, October 19-23, 2003, to educate the public and health care providers about hospice.

#### **Will my wishes be known and honored?**

The Attorney General Task Force to Improve End of Life Care formed the Medical-Legal Steering Committee, which consists of physicians, attorneys, social workers, nurses, religious/spiritual representatives and patient advocates. One of the recommendations from the End of Life Conference Series was to encourage more people to execute Durable Power of Attorney for Health Care forms by changing the Durable Power of Attorney for Health Care forms to be easier to execute and more meaningful to physicians. Hospitals frequently did not honor them because they were improperly witnessed or did not have two qualified witnesses. The Attorney General requested that the legislature revise the Durable Power of Attorney for Health Care Act to permit either two qualified witnesses or one notary public to witness a Durable Power of Attorney for Health Care form. The revised Durable Power of Attorney for Health Care became law in July 2002.

The Medical-Legal Steering Committee tackled another obstacle preventing people from engaging in advanced care planning. The Statutory Durable Power of Attorney for Health Care form was written by attorneys; however, the Durable Power of Attorney for Health Care form is interpreted by health care providers. The language used in the Statutory Durable Power of Attorney for Health Care form was written above the average reading level and in legalese. Health care providers were having difficulty interpreting it because it did not contain sufficient information to help guide the agent and the health care provider to honor a patient's wishes for medical treatment. The Medical-Legal Steering Committee drafted a revised Durable Power of Attorney for Health Care form, which was user-friendly and provided agents and health care professionals with relevant information to honor the patient's wishes. The revised Durable Power of Attorney for Health Care form is available in English and Spanish on the Attorney General's web page, [www.riag.state.ri.us](http://www.riag.state.ri.us).

The Task Force and its members have sponsored numerous educational programs for health care providers and the public. The Department of Elderly Affairs, a member of the Task Force, is providing educational programs on advance care planning at senior centers and assisted-living facilities.

To date, the Department of Attorney General has not been involved in litigation involving honoring a patient's wishes. The Department of Attorney General, however, has assisted numerous families and health care providers in resolving confusion about patient's wishes for end-of-life treatment.

**Will I receive competent care?**

The Department of Attorney General is aware of the importance of competent care, not just for end-of-life care, but for quality health care. To assist the citizens of Rhode Island, the Department of Attorney General has established two units that are involved with competent care issues. The Office of Health Care Advocate is a statutory position authorizing the Health Care Advocate to appear in amicus and civil actions involving health care quality standards; to intervene in administrative actions related to health care insurance; to review complaints and conduct investigations concerning the quality of health care delivery; to assist directors of state agencies related to inadequacies in health care or health insurance; to take all necessary and appropriate action, including public education, legislative advocacy; and to institute formal legal action to secure and ensure compliance with Rhode Island health and safety laws and insurance laws.

The Medicaid Fraud Unit has been renamed the Medicaid Fraud and Patient Abuse Unit. The unit not only looks at the financial aspects of Medicaid fraud, but also at the impact of Medicaid fraud on patients, such as incompetent care. The failure to adequately treat pain is a type of patient abuse, which the unit investigates.

There are several quality initiatives within the state in which members of the Department of Attorney General participate. By law, the Rhode Island Department of Health is required to develop quality indicators for all sectors of health care and publicly report the quality status of health care entities. The Rhode Island Quality Institute is a health care quality initiative consisting of hospitals, doctors, nurses, insurers and businesses seeking to collaborate to reduce medical errors, improve quality of health care and contain health care costs. The Rhode Island Quality Institute is implementing a pilot program for electronic prescription writing for non-hospital based physicians. This is a pilot program for Sure Script, a national program. The Rhode Island Quality Institute is also developing an initiative, eICU, which would permit hospitals that do not have intensivists on staff to be electronically connected to hospitals that have 24-hour intensivists, so that real time assessment of ICU patients could be performed by an intensivist.

The Department of Attorney General seeks to improve end-of-life care, as well as health care in general, through legislative initiatives, outreach and satisfying its statutory duty under Rhode Island law.

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Greg Abbott

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**TEXAS**

**Will my pain be managed?**

The Chief of the Elder Law and Public Health Division of the Office of Attorney General issued a memo and met with key staff at the Texas Department of Human Services to discuss relevant health care issues, including NAAG's initiative on pain assessment and management.

The Office of Attorney General intends to become more aggressive in pain violation detection, writing violations and enforcement. The office also has addressed the topic in numerous speeches and addresses delivered to both state-side nursing home regulators and private industry nursing home staff and management. In addition,

Elder Law and Public Health attorneys and staff have been educated on pain assessment and management issues. Currently, the office has one case pending.

**Will my wishes be known and honored?**

The Chief of the Elder Law and Public Health Division of the Office of Attorney General sat as an advisory member of the Texas Advance Directives Coalition. The coalition recommended amendments to the Texas Advance Directives Act, which have been incorporated into bills pending before the state legislature. The Senate Health and Human Services Committee completed its hearing on the Senate version of the Advance Directives Act, SB 1320, and unanimously reported the bill back to the full Senate with the recommendation that the Senate pass it and send it to the House of Representatives. The committee also recommended the bill for the Senate Consent Calendar, which should ensure that the bill makes its way rapidly through the Senate and help assure its final passage.

In an effort to educate the public regarding the importance of planning for end-of-life care, the office published an Advance Directives pamphlet and newspaper column. The pamphlet is currently being revised. The Chief of the Elder Law and Public Health Division and the division’s outreach coordinator have included the topic of advance directives in their speeches to seniors across the state.

The office has provided education on advance directive issues to Elder Law and Public Health attorneys and staff. Currently, the office has four cases/investigations --- one of which was settled in March 2003. In one particularly egregious case, the facility stored the resident’s directives in the basement; had no system in place for determining whether a resident was “do not resuscitate” (DNR) or full code; and attempted life-sustaining treatment on one resident who was a DNR, while the facility failed to take any measures on another resident who was full code. (All of the office’s Elder Law cases arguably involve a failure to provide competent care.)

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Christine O. Gregoire

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**WASHINGTON**

**Will my pain be managed?**

In 1996, the Washington State Medical Quality Assurance Commission published the Guidelines for Pain Management in Washington State. The document clearly indicates that opiates can be prescribed, dispensed or administered, when there is medical need, without fear of discipline. The guidelines establish standards for prescriptions, etc. Last Acts’ publication, Means to a Better End, gave Washington an A grade for its pain laws and policies because they do not create barriers for good pain management. The Washington Attorney General’s Office has not issued any formal opinions on this matter.

**Will my wishes be known and honored?**

In the publication, Means to a Better End, the report notes that Washington laws do “an average job of supporting good advance care planning in the form of living wills and medical powers of attorney, which designate a health care decision-maker should the patient become unable to communicate.” Relevant laws include the Washington Natural Death Act (RCW 70.122), which allows an individual to determine his or her wishes in the event of a terminal or permanent unconscious condition. There is also Durable Power of Attorney (RCW 11.94), which allows a person to appoint an agent to make health care decisions on their behalf, should the person become incompetent.



Nancy Reller (l), of Sojourn Communications, and Victoria Weisfeld (r), of the Robert Wood Johnson Foundation, gather information from health care providers

In order to increase the public's understanding of end-of-life issues, the Attorney General's Office has prepared and distributed a brochure and a website entitled, *Dealing with Death*. The publication guides citizens through the "business process" surrounding the death of a loved one. Among other things, it covers living wills and other directives. *Dealing with Death* is available on the Attorney General's Office website at [www.wa.gov/ago](http://www.wa.gov/ago).

The success of these efforts has garnered much attention from experts. According to the policy paper entitled, *End of Life Care in Washington State* (August 14, 2002), prepared by the Washington End of Life Consensus Coalition (WEOLCC) and published by the Rainier Institute, "Washington State is an excellent example . . . , where state sponsored trainings have spawned several community forums and new coalitions are forming statewide because of the interest piqued at these forums and other activities." The policy position is available on the Rainier Institute web page at [www.rainierinstitute.com](http://www.rainierinstitute.com)

#### **Will I receive competent care?**

Means to a Better End gave Washington a C grade in the percentage of palliative care-certified physicians and nurses. The following is excerpted from the WEOLCC position in *End-of-Life Care in Washington State*:

"Palliative care physicians are spearheading the promotion of interdisciplinary team management, where the expertise of each team member plays a vital role in the overall patient treatment plan. Whether one is in the hospital, homebound, in a long term care facility or assisted living facility, the interdisciplinary nature of palliative care teams allows for flexibility. Palliative care resource teams act as consultants, allowing the most appropriate member of the team to do the initial assessment. Many models exist currently, including hospitals with palliative care units, home care agencies with hospices or hospice-like teams, nursing homes with designated palliative care beds, or assisted living facilities with access to any of the above."

In the state of Washington, a model of care was developed by a hospice team using physician-directed symptom management algorithms established guidelines for pain and distressing symptom care. These guidelines also addressed issues of spiritual distress, psychological distress and cultural differences. Along with pharmacists who received prescriptive authority from the State Board of Pharmacy and an interdisciplinary hospice team, this model allowed pain and other distressing symptoms to be alleviated within two hours in the home care arena, when previously it took more than 48 hours. This resulted in overall greater patient, caregiver and physician satisfaction, a hospitalization rate of less than one percent for the home care patients, and minimal emergency room utilization. This model has now been adapted to other locations of care and is one example of how an integrated effective team approach can greatly improve care and contain costs. The effectiveness of the interdisciplinary team model has brought a richness of expertise into the palliative care arena that other areas of medicine could benefit from modeling.



**“IT IS ABOUT ACCESS TO CARE THAT COMPORTS WITH THE NEEDS, VALUES, AND CULTURAL BACKGROUND OF CONSUMERS. IT IS ABOUT CARE THAT ASSURES THAT THE VALUES OF INDIVIDUAL AND FAMILY AUTONOMY AND INFORMED CONSENT ARE REALIZED.”**

**KAREN ORLOFF KAPLAN, SCD, MPH  
NATIONAL PROGRAM DIRECTOR, LAST ACTS**

## SECTION 4: RESOURCES

# NATIONAL END-OF-LIFE CARE ORGANIZATIONS

### AARP

AARP is a nonprofit, nonpartisan membership organization dedicated to making life better for people 50 and over. It works to promote and support advocacy, education, and community service activities in states and communities. AARP gives support around end-of-life care issues, including providing advice on legal issues, grief and loss, and caregiving.

WASHINGTON, DISTRICT OF COLUMBIA

[www.aarp.org/endoflife](http://www.aarp.org/endoflife)

### AGING WITH DIGNITY

Aging with Dignity provides people dying in America with the practical information, advice, and legal tools needed to ensure that their wishes and those of their loved ones will be respected. Aging with Dignity works to safeguard the rights of the sick, aging, or dying.

TALLAHASSEE, FLORIDA

[www.agingwithdignity.org](http://www.agingwithdignity.org)

### AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE

The American Academy of Hospice and Palliative Medicine (AAHPM) is the only organization in the United States for physicians dedicated to the advancement of hospice/palliative medicine. AAHPM members are physicians from many medical specialties who are committed to fostering the practice of hospice/palliative care for the terminally ill and their families.

GLENVIEW, ILLINOIS

[www.aahpm.org](http://www.aahpm.org)

### AMERICAN ALLIANCE OF CANCER PAIN INITIATIVES

The American Alliance of Cancer Pain Initiatives (AACPI) is dedicated to promoting cancer relief nationwide by supporting the efforts of State Cancer Pain Initiatives. AACPI provides national leadership and advocacy for the Initiative movement, recommends program direction, supports Initiative growth and development, facilitates regular communication among Initiatives, fosters collaborations with other organizations, and organizes an annual national meeting.

MADISON, WISCONSIN

[www.aacpi.org](http://www.aacpi.org)

### AMERICANS FOR BETTER CARE OF THE DYING

Americans for Better Care of the Dying (ABCD) aims to improve end-of-life care by learning which social and political changes will lead to enduring, efficient, and effective programs. ABCD works with the public, clinicians, policymakers, and other end-of-life care organizations to make change happen.

WASHINGTON, DISTRICT OF COLUMBIA

[www.abcd-caring.org](http://www.abcd-caring.org)

### AMERICAN HOSPICE FOUNDATION

The American Hospice Foundation supports programs that serve the needs of terminally ill and grieving individuals of all ages. Its programs include training school professionals who work with grieving students, educating employers and managers about the needs of grieving employees, and creating tools to help hospices reach out to their communities.

WASHINGTON, DISTRICT OF COLUMBIA

[www.americanhospice.org](http://www.americanhospice.org)

### BROWN UNIVERSITY CENTER FOR GERONTOLOGY AND HEALTH CARE RESEARCH

The Center for Gerontology and Health Care Research, with funding from The Robert Wood Johnson Foundation, is engaged in a five-year research effort to use both existing and new data collections to describe the dying experience in the United States utilizing maps that display geographical data about quality of end-of-life care.

PROVIDENCE, RHODE ISLAND

[www.chcr.brown.edu/dying/factsondying.htm](http://www.chcr.brown.edu/dying/factsondying.htm)

### CENTER TO ADVANCE PALLIATIVE CARE

The Center to Advance Palliative Care (CAPC) is a resource for hospitals and health systems interested in developing palliative care programs. The Center serves a broad constituency of providers and interested groups-including physicians, nurses, educators, policymakers, health researchers, and, ultimately, patients and their families-in an effort to improve the availability and quality of palliative care.

NEW YORK, NEW YORK

[www.capc.org](http://www.capc.org)

### CHILDREN'S HOSPICE INTERNATIONAL

Children's Hospice International (CHI) serves as an advocate in meeting the needs of children with life-threatening conditions and their families. Its programs include support systems and a referral network for children with life-threatening conditions and their families, and support of health care providers and organizations that engage in the treatment of children with life-threatening conditions and their families.

ALEXANDRIA, VIRGINIA

[www.chionline.org](http://www.chionline.org)

### CITY OF HOPE PAIN/PALLIATIVE CARE RESOURCE CENTER

The City of Hope Pain/Palliative Care Resource Center (COHPPRC) is a clearinghouse for disseminating information and resources to assist others in improving the quality of pain management and end-of-life care. The COHPPRC is a central source for collecting a variety of materials, including: pain assessment tools; patient education materials; quality assurance materials; end-of-life resources; research instruments; and other resources.

DUARTE, CALIFORNIA

[www.prc.coh.org/](http://www.prc.coh.org/)

### END-OF-LIFE NURSING EDUCATION CONSORTIUM

Funded by a grant from The Robert Wood Johnson Foundation, the End-of-Life Nursing Consortium (ELNEC) project is a comprehensive, national education program to improve end-of-life care by nurses. ELNEC works to develop a core of expert nursing educators and to coordinate national nursing education efforts in end-of-life care.

WASHINGTON, DISTRICT OF COLUMBIA

[www.aacn.nche.edu/elneec](http://www.aacn.nche.edu/elneec)

### EDUCATION FOR PHYSICIANS ON END-OF-LIFE CARE

Supported by a grant from The Robert Wood Johnson Foundation, Education for Physicians on End-of-Life Care (EPEC) works to educate all physicians on the essential clinical competencies required to provide quality end-of-life care.

CHICAGO, ILLINOIS

[www.epec.net](http://www.epec.net)

**END OF LIFE/PALLIATIVE EDUCATION RESOURCE CENTER**

The End of Life/Palliative Education Resource Center (EPERC) works to assist physicians and other educators involved in all aspects of physician end-of-life education. EPERC provides brief abstracts describing peer-reviewed instructional and evaluation materials, a list of core resources for End-of-Life educators, and opportunities for training, extramural funding, and pending conferences.  
MILWAUKEE, WISCONSIN  
[www.eperc.mcw.edu](http://www.eperc.mcw.edu)

**HOSPICE FOUNDATION OF AMERICA**

The Hospice Foundation of America is a non-for-profit organization that provides leadership in the development and application of hospice and its philosophy of care. Through programs of professional development, research, public education and information, the Hospice Foundation of America assists those who cope either personally or professionally with terminal illness, death, and the process of grief.  
WASHINGTON, DISTRICT OF COLUMBIA  
[www.hospicefoundation.org](http://www.hospicefoundation.org)

**HOSPICE AND PALLIATIVE NURSES ASSOCIATION**

The Hospice and Palliative Nurses Association (HPNA) seeks to promote excellence in hospice and palliative nursing. HPNA works to exchange information, experiences, and ideas; to promote understanding of the specialties of hospice and palliative nursing; and to study and promote hospice and palliative nurses.  
PITTSBURGH, PENNSYLVANIA  
[www.hpna.org](http://www.hpna.org)

**INITIATIVE TO IMPROVE PALLIATIVE CARE FOR AFRICAN-AMERICANS**

The Initiative to Improve Palliative Care for African-Americans (IIPCA) works to educate key stakeholders and leadership organizations in the black community, build coalitions with palliative care health, education and policy groups, encourage and support rigorous and innovative educational activities and research, and shape public policy through forums and publications.  
NEW YORK, NEW YORK  
<http://iipca.winhost2.atlantic.net>

**LAST ACTS**

Last Acts is a national coalition of organizations engaged in an unprecedented education campaign to improve care for people who are dying and their families. Last Acts serves as a clearinghouse for sharing information and ideas at the national, state, and local levels.  
WASHINGTON, DISTRICT OF COLUMBIA  
[www.lastacts.org](http://www.lastacts.org)

**LIFE'S END INSTITUTE: MISSOULA DEMONSTRATION PROJECT**

The Missoula Demonstration Project, now known as Life's End Institute, researches the experiences of dying persons and their families to demonstrate that a community-based approach of excellent physical, psychological, and spiritual care improves the quality of life among those who are dying and their families.  
MISSOULA, MONTANA  
[www.lifes-end.org](http://www.lifes-end.org)

**MIDWEST BIOETHICS: COMMUNITY-STATE PARTNERSHIPS TO IMPROVE END-OF-LIFE CARE**

The Midwest Bioethics Center helps communities find practical solutions to ethical problems in the health and health care arenas. Housed at the Midwest Bioethics Center, Community-State Partnerships to Improve End-of-Life Care awards grants that support statewide coalitions working with citizens, health care professionals, educators, and policymakers to identify problems, make recommendations, and build public support for practical policies, regulations, and guidelines to improve care of the dying.  
KANSAS CITY, MISSOURI  
[www.midbio.org](http://www.midbio.org)

**NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION**

The National Hospice and Palliative Care Organization (NHPCO) is the largest non-profit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America.  
ALEXANDRIA, VIRGINIA  
[www.nhpco.org](http://www.nhpco.org)

**NATIONAL RESOURCE CENTER ON DIVERSITY IN END-OF-LIFE CARE**

The National Resource Center on Diversity in End-of-Life Care (NRCD) works to maximize the involvement of diverse cultures in the national dialogue about end-of-life care. NRCD serves as a place for networking, a clearinghouse for minority leadership, research findings, best practices, and as a technical resource to the Rallying Points Regional Resource Centers and the National Coordinating Center.  
WASHINGTON, DISTRICT OF COLUMBIA  
[www.nrcd.com](http://www.nrcd.com)

**OPEN SOCIETY INSTITUTE'S PROJECT ON DEATH IN AMERICA**

The Open Society Institute's programs support initiatives in a range of social areas, including improving care of the dying. The Project on Death in America works to understand and transform the culture and experience of dying and bereavement through initiatives in research, scholarship, the humanities, and the arts, and to foster innovations in the provision of care, public education, professional education, and public policy.  
NEW YORK, NEW YORK  
[www.soros.org/death/](http://www.soros.org/death/)

**ONCOLOGY NURSING SOCIETY**

The Oncology Nursing Society (ONS) is a professional organization of more than 30,000 registered nurses and other health care providers dedicated to excellence in patient care, education, research, and administration in oncology nursing. It is also the largest professional oncology association in the world.  
PITTSBURGH, PENNSYLVANIA  
[www.ons.org](http://www.ons.org)

**PARTNERSHIP FOR CARING: AMERICA'S VOICES FOR THE DYING**

Partnership for Caring: America's Voices for the Dying is a national, nonprofit organization devoted to raising consumer expectations for excellent end-of-life care and increasing demand for such care. It is the only end-of-life organization that partners individuals and organizations-consumers and professionals-in a powerful collaboration of voices.  
WASHINGTON, DISTRICT OF COLUMBIA  
[www.partnershipforcaring.org](http://www.partnershipforcaring.org)

**PROMOTING EXCELLENCE IN END-OF-LIFE CARE**

A national program office of The Robert Wood Johnson Foundation, and housed at the Practical Ethics Center of the University of Montana, Promoting Excellence in End-of-Life Care works to improve health care for dying persons and their families by providing technical assistance to innovative demonstration projects addressing particular challenges to existing models of hospice and palliative care.  
MISSOULA, MONTANA  
[www.promotingexcellence.org/](http://www.promotingexcellence.org/)

**SUPPORTIVE CARE OF THE DYING**

Supportive Care of the Dying is a non-profit coalition that works to bring about cultural change regarding pain and symptom management and relief of suffering for persons living with, and affected by, life-threatening illness. To accomplish this goal, Supportive Care of the Dying focuses on interventions with health care professionals, health care organizations, the community, and the Church.  
PORTLAND, OREGON  
[www.careofdying.org](http://www.careofdying.org)

**UNIVERSITY OF WISCONSIN PAIN & POLICY STUDIES GROUP**

The University of Wisconsin Pain & Policy Studies Group (PPSG) works to balance international, national, and state policies to ensure adequate availability of pain medications for patient care while minimizing diversion and abuse. The group supports a global communications program to improve access to information about pain relief, palliative care, and policy.

MADISON, WISCONSIN

[www.medsch.wisc.edu/painpolicy/](http://www.medsch.wisc.edu/painpolicy/)



Oklahoma Assistant Attorney General Annette Prince and Maryland Assistant Attorney General Jack Schwartz discuss presentations given by health care experts

# RELATED NATIONAL ORGANIZATIONS AND WEBSITES

**AARP** – <http://www.aarp.org>

**Aging with Dignity** – <http://www.agingwithdignity.org>

**American Academy of Hospice and Palliative Medicine (AAHPM)** – <http://www.aahpm.org>

**American Alliance of Cancer Pain Initiatives (AACPI)** – <http://www.aacpi.org>

**American Pain Foundation** – <http://www.painfoundation.org>

**American Pain Society (APS)** – <http://www.ampainsoc.org>

**Americans for Better Care of the Dying (ABCD)** – <http://www.abcd-caring.org>

**Center to Advance Palliative Care (CAPC)** – <http://www.capcmssm.org>

**City of Hope National Medical Center PRC** – <http://prc.coh.org>

**Children’s Hospice International** – <http://www.chionline.org>

**Community-State Partnerships to Improve End-of-Life Care** – <http://www.midbio.org>

**Education for Physicians on End-of-Life Care** – <http://www.epec.net/>

**End of Life Nursing Education Consortium** – <http://www.aacn.nche.edu/el nec>

**Hospice and Palliative Nurses Association (HPNA)** – <http://www.hpna.org>

**Last Acts** – <http://www.lastacts.org>

**Midwest Bioethics Center** – <http://www.midbio.org>

**National Hospice and Palliative Care Organization (NHPCO)** – <http://www.nhpco.org>

**Open Society Institute Project on Death in America** – <http://www.soros.org/death.html>

**Southern California Cancer Pain Initiative (SCCPI)** – <http://sccpi.coh.org>

**Supportive Care of the Dying** – <http://www.careofdying.org>

# NATIONAL EXPERTS IN END-OF-LIFE CARE

## SUBJECT AREAS

ADVANCE CARE PLANNING  
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ETHICS  
FINANCING  
PAIN MANAGEMENT  
PALLIATIVE CARE  
PROFESSIONAL EDUCATION  
PUBLIC POLICY

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A conference participant (l) and Cheryl Matheis (r), of AARP, discuss consumer options



**“TO MAKE AN END IS TO MAKE A BEGINNING...  
AND THE END OF ALL OUR EXPLORING WILL  
BE TO ARRIVE WHERE WE STARTED AND  
KNOW THE PLACE FOR THE FIRST TIME.”**

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