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State Initiatives *in* End-of-Life Care

Issue 25, May 2006

Focus: The Way Forward

Thirty-Five Leaders Map the Future of Reform

Pictured (right) is Lilli Hill receiving a visit from her hospice nurse, Jan Kapschinske, RN, San Diego Hospice & Palliative Care. Lilli's comprehensive end-of-life care includes immediate relief of pain and other symptoms, spiritual and psychological support, continuity of services and providers, interdisciplinary teamwork, help with advance care planning, and respect for her treatment decisions.

In spite of extraordinary legal, clinical, and bioethical advances in the past 25 years, this picture remains more the exception than the rule. What must be accomplished in the foreseeable future to ensure quality care for most Americans?

To provide a forward-looking conclusion to the State Initiatives series, we asked 35 recognized and emerging leaders to answer this question. Their responses indicate the broad challenges that lie ahead and offer specific recommendations for changing state and federal policy, re-engineering and expanding palliative care services, and fostering innovations in health care decisionmaking.



Photo: Tim Chisser/San Diego Hospice & Palliative Care

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Final Issue

Huge Mountains Behind, Huge Mountains Ahead

Imagine a group of pioneers marching forward with momentum and optimism through an imposing mountain range. Although they have already scaled unimaginable heights, equally high peaks lie in successive ridges ahead, shadowed by political storm clouds and the specter of uncertain provisions. Such is the status of the end-of-life care movement today, our interviews would suggest.

"Since 1974 the changes in how people are cared for at the end of life are almost unparalleled in modern society—an achievement akin in scale to the discovery of open heart surgery," says Rev. Hugh Westbrook, retired CEO and chair of VITAS Hospice Services, LLC.

An impressive series of milestones supports this contention: between 1974 and 2004, the number of hospices grew from zero to 3,200; the Medicare Hospice Benefit was enacted (1982); some 37 percent of hospitals with over 100 beds now offer palliative care; faculty development and professional education in palliative medicine have surged; many states have struck down policy and practice barriers to good pain management; and private philanthropy, led by The Robert Wood Johnson Foundation and the Open Society Institute's Project on Death in America, has contributed \$250–\$300 million to fund ambitious change initiatives over the past 15 years.

There have also been major advances in health care decisionmaking. To protect patients from medical paternalism and the overuse of unwanted life-sustaining technology, provisions in all

states, the Patient Self-Determination Act, and a spate of high-profile court cases have created a widely accepted framework for personal and judicial decisionmaking at life's end.

Our experts concede, however, that in spite of all these gains, no one can yet *count* on good end-of-life care. Without greatly accelerated reform, "Some combination of pain, disability, financial ruin, family stress, and powerlessness awaits most of us," says Joanne Lynn, MD, former director of The Washington Home Center for Palliative Care Studies and senior scientist at the RAND corporation.¹

Why? Palliative programs are concentrated in leading medical centers in urban areas; spiritual needs have been trumped by clinical concerns; the needs of large groups marginalized by race, ethnicity, disability, sexual orientation, income, and geography are too little considered; hospice is still underutilized and misunderstood; reimbursement systems are inadequate; and accepted standards for decisionmaking face attacks from many quarters.

Yet the path to change seems clear, though the political winds and resources are uncertain. The broad strokes of our experts' "map" for reform appear in the sidebar (see pages 2 and 3). A more in-depth discussion of recommendations begins on page 4. To highlight the importance of movement leadership development, we also present five sidebars profiling emerging leaders working in new or neglected areas of the field (see pages 3, 4, 5, 6, and 7). ■

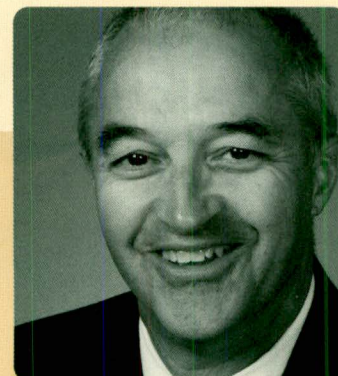
The Big Challenges in Brief

Shifting Reform Paradigms

- Understand dying as more a spiritual journey than a medical experience and help develop new cultural understandings and rituals around "the good death."
- Take end-of-life care reform public, promoting community and citizen engagement in volunteerism, policy advocacy, advance care planning, and responsible deliberation about "right-to-die" controversies.
- Make issues of discrimination and diversity in care a high priority.
- Develop population-based models of care that ensure continuity and quality across the whole illness trajectory.

Scaling Up Current Approaches

- Adjust our too rationalistic and individualistic definitions of "autonomy."
- Develop consensus standards for palliative care and strengthen its underlying science and research base.
- Expand, professionalize, and mainstream palliative care.
- Prevent reform from becoming another front in the "abortion wars."
- Promote activism at all levels.



William Sorrell

Desired Policy Initiatives

Federal Policy Change

- Convince federal regulatory agencies to adopt standards for palliative care and mandate palliative care in hospitals and nursing homes.
- Win federal support for a comprehensive palliative care faculty training program.
- Better articulate the work of palliative medicine within the field as a basis for changing Medicare payment systems—to allow adequate reimbursement for palliative care.
- Alter the Medicare Hospice Benefit: end the six-month rule, allow for concurrent care, and provide for outlier costs.
- Reconfigure nursing home reimbursement incentives to encourage better palliative care and timely hospice referral.
- Expand the use of Quality Improvement Organizations to strengthen palliative care in nursing homes.
- Win funding for bold demonstration projects of palliative care models.
- Encourage NIH to give palliative medicine a new administrative home and more research funding.
- Restore “balance” in DEA enforcement policy regarding Schedule II drugs.
- Convince the Centers for Disease Control to integrate end-of-life care into its plans and activities.

- Encourage federal engagement in public education about hospice and advance care planning.

State Policy Change

- Champion updating statutory frameworks to ensure good palliative care curriculum and good pain management and health care decisionmaking policy.
- Continue regulatory summits on pain management; urge states to adopt the model pain policies of the Federation of State Medical Boards.
- Facilitate meaningful public education and deliberation on health care decisionmaking controversies.
- Provide financial support for the work of end-of-life care reform coalitions at the state level.
- Promote surrogate selection, devise “social prompts” to encourage advance care planning (e.g., drivers’ license check-boxes), resist laws that create technical barriers to fulfilling patients’ treatment preferences, and develop dependable electronic document registries that allow patients to update wishes.
- Encourage state units on aging and departments of health to collect data on end-of-life care, include palliative care in comprehensive cancer control plans, and provide consumer education on the issue.

“We must convince all attorneys general that end-of-life care is the ultimate consumer protection issue and encourage them to become activists in this area.”

William Sorrell, Vermont Attorney General

James Brooks, MDiv

Executive Director, Project Compassion

Caring Communities

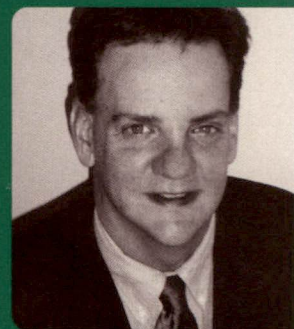
“How do you help lead the community forward so it’s not just your energy or your organization’s energy—this is the challenge of the end-of-life care movement,” says James Brooks.

His Chapel Hill-based nonprofit, Project Compassion, is meeting the challenge by bringing community resources to people struggling with serious illness, overwhelming caregiving responsibilities, and grief. By partnering with churches, hospices, neighborhood groups, businesses, and schools, Project Compassion identifies people in need of community support and pairs them at no cost with one of its 80 volunteer support teams.

For Sandra, who was undergoing breast cancer treatment, the support team ran errands, took her to doctor visits, decorated her home for the holidays, and helped her move. Team members are also available as conversational partners for spiritual questions, like “Who am I now” and “Where do I find meaning today?”

Brooks says that such conversations often lead people to begin advance care planning with the help of the project’s 125 volunteer facilitators.

The need for broad community involvement in caregiving and advance care planning is especially urgent as baby boomers age, says Brooks. “We can’t just leave this in the hands of professionals. We own this together, and it is our responsibility to be present and offer support to each other.”



Robert A. Washington, MDiv, PhD

Chaplain, Montgomery Hospice

Spiritual Journeys

"In this day and age—with the focus on technology—we have forgotten that for the patient the primary concern is spiritual," says Robert Washington.

A Harvard-trained clinical psychologist and a former commissioner of mental health for the District of Columbia, Washington gave up senior management for direct service after heading up the District's first grief center and acting as a volunteer AIDS educator. Now an integral member of the hospice's palliative care team, Washington helps attend to the spiritual needs of hospice patients. "We are talking about people's need to assess life and its meaning, to solidify beliefs, to understand why they exist and what the future holds. The medical team and I are companions on this journey." Washington is also active in the admissions process, where family

needs first begin to emerge.

He is deeply troubled that most clergy don't have the time, the training, or the "comfort level" to provide adequate spiritual support

to their own dying parishioners. To correct this situation, he recommends that seminaries offer intensive study of end-of-life care and that hospices partner with churches to offer supervised experiences to practicing ministers and deacons. He also wants to see the concepts of palliative care integrated into medical education, starting at the undergraduate level, so that those heading for clinical roles "become comfortable talking with patients about existence."



Shifting Reform Paradigms

Many experts note that reforms historically have been focused on the quest for legal rights and advances in professional education and clinical treatment for mainstream populations. While they acknowledge the importance of these achievements, they urge serious attention to other issues.

Spiritual and Cultural Matters

Polls have long shown that spiritual needs are top priorities for dying patients and their loved ones, yet these needs are often neglected. "We must realize that dying is a spiritual process with medical implications, not a medical process with spiritual implications," says Gwendolyn London, DMin, former executive director of the D.C. Partnership to Improve End-of-Life Care.

Turning the paradigm around will require new approaches. "The real challenge for the near-term is to find effective ways to teach practitioners to use nonpharmacological treatments—psychological, psychosocial, and spiritual interventions—and provide ways to integrate them into medical approaches," says Richard Payne, MD, director of the Duke Institute on Care at the End of Life. Payne urges structured training and "cross-talk" between clinicians and clergy. A groundswell of support for addressing matters of spirit and meaning, as well as new efforts to engage clergy in end-of-life care ministries will also be needed (see sidebar, left).

A larger involvement by faith communities will also bring benefits to the culture as a whole. "Faith communities can teach Americans healthy ways of dying," says Ira Byock, MD, director of palliative medicine at Dartmouth Hitchcock Medical Center. "We've only been shown what not to do: die in hospitals. We need

community-based discussions of what a good death is in our culture." Others urge schools to develop new curricula and the mass media to provide stories that create new language, myths, and rituals for dealing with death and dying.²

Greater Public Engagement

Taking the reform movement "public" is a persistent theme in experts' testimony. They imagine clinicians taking on policy issues, and community organizations and citizens more actively engaged in policy advocacy, volunteer activities, and public dialogue on hot-button issues.

Advocacy

"We really need people to be more activist and supportive of activism," says Lynn. "We need to advocate for good standards, coherent funding, and have expectations of ourselves that aren't just about caring for our patients but also taking the message public. We need a more robust policy agenda and more groups engaged: vets, labor, nursing, disease-related groups, and so on."

Volunteerism

Communities must also be mobilized to provide supportive care. "There are not enough professional resources on anybody's spreadsheet to meet baby boomers' needs, so it is in our enlightened self-interest to build models of caring in the community: intergenerational programs, programs operating out of churches, schools, and workplaces that share responsibility with the health care system," says Byock (see sidebar, page 3 for more).

Public Dialogue on Hot Issues

The legal wrangling and public controversy surrounding Terry Schiavo's end-of-life care prompted experts to note that the once widely accepted

legal framework governing end-of-life decisionmaking was under serious attack and that many Americans lacked the basic information needed to separate fact from demagoguery regarding “persistent vegetative states” (PVS), the legal rights of surrogates, and the nature of hospice care. “We have to educate the public,” says Gema Hernandez, principal, Aging and Cultural Consultants, Inc.

Many also saw in the Schiavo controversy efforts by vitalists and the “religious right” to create a specious link between abortion and the legal right to withhold life-sustaining treatment (including artificial nutrition and hydration). “From a policy perspective, the most important issue is to prevent reform from becoming another front in the abortion wars,” says Jack Schwartz, JD, Maryland’s assistant attorney general. To avert this linkage, spread science-based education, and build common ground, Schwartz calls for searching public dialogue: “Honest, sensible, humane conversation is needed,” probably best led by state officials, he says.

Schwartz acknowledges (as do others) that some elements of the legal framework are open to question. “We need to talk through unsettling issues—not as advocates but as listeners: What do responsible critics of the state courts say? What role do they see for the federal courts? If a family is disagreeing and a case is in the courts, is the ‘clear and convincing evidence’ quest—as a measure of what the ‘now’ PVS patient wants—an adequate standard?” Schwartz also challenges reformers to truly engage with disability rights advocates.

Such an advocate, Adrienne Asch, Edward and Robin Milstein Professor of Bioethics of Yeshiva University-Wurzweiler School of Social Work,

cautions against simplistic debates framed as “quality of life” versus “sanctity of life.” She argues for decisionmaking that considers “what gives life meaning and value for a particular individual” and “what circumstances or setting would permit the ill, disabled, or dying patient to derive comfort and fulfillment in existing relationships, experiences, or activities.”³

Lex Frieden, MS, professor of physical medicine and rehabilitation at Baylor College, wants to see questions of economic justice debated: “Should our culture support unlimited spending to maintain patients in PVS states though it denies adequate support to disabled people who could lead normal lives?”

Discrimination and Diversity

Many experts argue that attention to the needs of groups of color is just beginning. “It’s important to recognize and acknowledge that the diversity piece is important and undone,” London says. A full commitment to change will require additional resources, opportunities for interest groups to meet and determine needs, as well as new ways of thinking and delivering services.

“It’s not just about training health care providers to be sensitive to differences; it’s more about understanding how people of color are impacted by the health care and social systems generally, and how that affects end-of-life care,” says Diane Lewis, coordinator for policy, National Resource Center on Diversity in End-of-Life Care. “We haven’t had the time or resources to put together a comprehensive strategy for change.” Yet Lewis sees some hopeful signs. “We are beginning to have hospice that looks like diverse communities. Developing such institutions is important” (see sidebar). ■

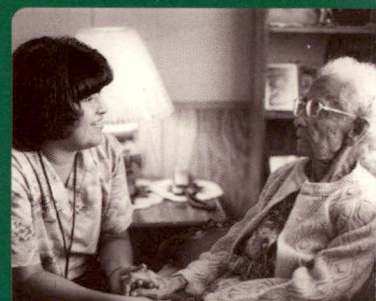
Theresa Bowannie

Administrator, Zuni Home Health

Honoring Difference

Theresa Bowannie, who is a full-blooded Zuni Pueblo Indian, has been interested in health care for as long as she can remember. When her family’s financial problems forced her to quit nursing school, she became a nurse’s assistant. Her excellent work and obvious advocacy and communication skills caught the eye of a supervisor who got her involved in health care administration.

Now she leads Zuni Home Health (ZHH), a tribally operated agency that provides culturally appropriate home health and hospice services for up to 100 clients—predominantly rural and reservation-dwelling Navajo and Zuni Indians in western New Mexico. The ZHH hospice service integrates inpatient and outpatient care through a unique collaboration with the regional Indian Health Service hospital. Bowannie’s predominantly Native American staff receives



Zuni Home Health caregiver visiting a hospice patient.

extensive training in culturally sensitive care and involves hospital doctors in home visits that, Bowannie says, “are improving cultural understanding.” She is also encouraging “other Pueblos along the Rio Grande to form their own hospices instead of relying on big corporations.”

The Medicare Hospice Benefit’s six-month rule remains ZHH’s greatest roadblock. “Putting a time frame on life goes against our prayers and beliefs and would offend many patients so deeply that they’d decline services.” Consequently, some ZHH services are unreimbursed. Yet Bowannie remains undeterred: “You must never take away the humanity that makes up a person.”

John Saroyan, MD, FAAP

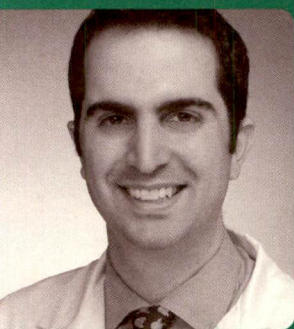
Assistant Professor of Pediatric Pain Management in Anesthesiology and Pediatrics, College of Physicians and Surgeons of Columbia University, and Assistant Attending Physician, Morgan Stanley Children's Hospital of New York-Presbyterian

Advocating for Children

It was the death of a favorite Latin teacher's son and a high school internship with a leading pediatric oncologist that set John Saroyan, MD, on a course that would lead him to his seminal work in the emerging field of pediatric palliative care.

Now, on an average workday, Saroyan, who is only 34, offers pain management consults for up to 20 children typically suffering from post-operative or solid tumor pain, sickle cell anemia crises, or chronic conditions. He also treats children with pain from trauma injuries through outpatient clinic services.

Saroyan is an impassioned advocate for more pediatric palliative research, hospice service requirements for medical students, and reimbursement systems "to allow for billing the time-consuming work of treating children both medically and psychosocially." He also wants to see more emotional support for pediatric staff. "We cannot expect anybody—no matter how passionate—to do this draining, life-altering work without help."



Saroyan actively promotes more openness about death in treatment settings. "If we continue to deny children's awareness of death, we steal away an opportunity from

parents and kids. We can give them permission to speak honestly. If we don't, we will end up contributing to more loneliness and pain."

Scaling Up and Mainstreaming Successful Approaches

Advancing Palliative Care Promoting Quality

Palliative care is often delivered too late in disease trajectories, causing patients to suffer jarring discontinuities in providers, settings, caregivers, and treatments, say experts. Lynn notes, for example, that patients with life-threatening diseases spend most of their time in an "indistinct zone of 'chronic illness' that has no specific care delivery system."⁴ This insight begs an important question: How might hospice, palliative care in other settings, and good chronic care be integrated into one seamless system?

Lynn's answer offers a provocative basis for further discussion: engineer a system to serve the vast majority of patients (85 percent) according to their three typical "trajectories of decline": cancer, organ system failure, and dementia/dwindling. Care arrangements would stay with the patient 24/7 across all settings, offer support for family caregivers, and allow for earlier palliative interventions.⁵

Many experts see standards as a way of moving toward continuity and other dimensions of quality. To address the problem of variability in care, for example, Don Schumacher, president and CEO of the National Hospice and Palliative Care Organization (NHPCO) advocates evidence-based standards to drive a Medicare "pay for performance" system. The NHPCO is, in fact, active in National Quality Forum efforts to produce such consensus standards. Once standards are developed, however, they must be translated into tools for change. "Performance assessment data must be made available to consumers, payers, businesses, and regulators so they can pressure the system to change," says Byock. "The system won't drive itself."

Institutionalizing Good Models

"Hospice care must be an expectation of consumers and the health care system just like trauma centers are," says Charles von Gunten, MD, PhD, FACP, director, Center for Palliative Studies at San Diego Hospice & Palliative Care. "And if we believe hospice should be part of comprehensive care, we must give up our sense of 'specialness' and connect with the whole house of medicine."

Von Gunten urges hospices to build training relationships with academic medical centers, schools of nursing and social work, as well as seminars so "hospices can become an integral part of the academic mission."

Hospices are also helping to shape palliative care models in hospitals and nursing homes. Hospice of the Bluegrass, designated by The Robert Wood Johnson Foundation and the Center to Advance Palliative Care (CAPC) as one of six leadership centers, has, since 2004, trained 86 partnerships between hospices and hospitals (or nursing homes) working on model building. Hospices often provide the doctors and nurses while hospitals provide social workers and chaplains. "It's a win, win, win—for hospice, hospitals, and patients," says Janet Larson Braun, RN, MSPH, leadership director, Palliative Care Leadership Center, Hospice of the Bluegrass.

Pioneers in hospital-based palliative medicine, like Diane Meier, MD, FACP, director of CAPC, says "palliative care needs to become a sub-specialty of other specialties like family medicine" in order to achieve full integration into American medicine. "Supporting that process is important." Meiers also wants the federal government to fund a 20-year initiative to train nearly 500 academic

Acknowledgments

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Special thanks go to those who contributed reflections to this final edition (in alphabetical order):

Mary Bennett

Outreach Director and Liaison with the American Cancer Society, American Alliance of Cancer Pain Initiatives

Theresa Bowannie

Administrator, Zuni Home Health

Kathy Brandt, MS

Vice President, Professional Leadership, Consumer & Caregiver Services, National Hospice and Palliative Care Organization

Janet Larson Braun, RN, MSPH

Leadership Director, Palliative Care Leadership Center, Hospice of the Bluegrass

James Brooks, MDiv

Executive Director, Project Compassion

Gretchen Brown, MSW

President and CEO, Hospice of the Bluegrass

Ira Byock, MD

*Director of Palliative Medicine, Dartmouth Hitchcock Medical Center
Professor of Anesthesiology and Community and Family Medicine, Dartmouth Medical School*

Sandy Chen-Stokes, RN, MSN

*Public Health Nurse, Sacramento County
End-of-Life Care Advocate and Educator*

June Dahl, PhD

*Professor of Pharmacology, University of Wisconsin School of Medicine and Public Health
Co-founder, American Alliance of Cancer Pain Initiatives*

Betty Ferrell, RN, PhD

*Research Scientist, City of Hope National Medical Center
Principal Investigator, The ELNEC Project*

Joseph Fins, MD, FACP

Chief of the Division of Medical Ethics in the Departments of Health and Medicine at Weill Medical College of Cornell University, where he serves as Professor of Medicine, Public Health, and Medicine in Psychiatry

Lex Frieden, MS

*Senior Vice President, The Institute for Rehabilitation and Research
Professor of Physical Medicine and Rehabilitation, Baylor College of Medicine*

Gema Hernandez, PhD

*Principal, Aging and Cultural Consultants, Inc.
Formerly Secretary, Florida Department of Elder Affairs*

David Joranson, MSSW

Director of the Pain and Policy Study Group, Comprehensive Cancer Center and the WHO Collaborating Center, University of Wisconsin-Madison

Tom Koutsoumpas

Senior Vice President, Ovations United Health Group

Sharon Latson

*Senior Director of Access Initiatives, VITAS
Innovative Hospice Care*

Diane Lewis

Coordinator for Policy, National Resource Center on Diversity in End-of-Life Care

Gwendolyn London, DMin

*Principal, London and Associates
Formerly Executive Director, The D.C. Partnership to Improve End-of-Life Care*

Judy Lund-Person

Vice President, Division of Quality End-of-Life Care, National Hospice and Palliative Care Organization

Joanne Lynn, MD

*Formerly Director, The Washington Home Center for Palliative Care Studies
Senior Scientist, the RAND Corporation*

Diane Meier, MD, FACP

*Director, The Center to Advance Palliative Care
Director, Hertzberg Palliative Care Institute, Mount Sinai School of Medicine*

Richard Payne, MD

Esther Colliflower Director of the Institute on Care at the End of Life, Duke Divinity School

Leslie Piet, RN, MA, CCM

Advance Practice Disease Manager, Johns Hopkins HealthCare, The Omega Life Program

Charles Sabatino, JD

Director, Commission on Law and Aging, American Bar Association

John Saroyan, MD

*Assistant Professor of Pediatric Pain Management in Anesthesiology and Pediatrics, College of Physicians and Surgeons of Columbia University
Assistant Attending Physician, Morgan Stanley Children's Hospital of New York-Presbyterian*

Don Schumacher

President and CEO, National Hospice and Palliative Care Organization

Jack Schwartz, JD

Assistant Attorney General, State of Maryland

William Sorrell, JD

Vermont Attorney General

Joan Teno, MD

Professor of Community Health, Brown University

Dale Thompson

President, Benedictine Health System

Susan Tolle, MD

Director, Center for Ethics in Health Care, Oregon Health & Science University

Charles von Gunten, MD, PhD, FACP

*Director, Center for Palliative Studies at San Diego Hospice & Palliative Care
Editor in Chief, Journal of Palliative Medicine*

Robert A. Washington, MDiv, PhD

Chaplain, Montgomery Hospice

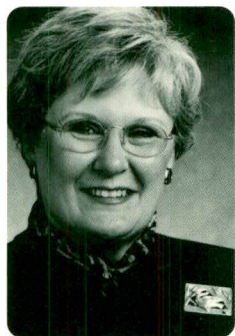
Hugh Westbrook, MDiv

*Formerly CEO and Chair, VITAS Hospice Services, LLC
Chair of the Board, Foundation for Care at the End of Life*

A Message from the Executive Editor

This policy brief began by comparing leaders of the end-of-life reform movement with pioneers heading west to achieve a better life and struggling to get beyond the daunting mountain ranges.

At least a decade ago, I heard a story about members of a wagon train who had suffered rattlesnake bites, dysentery, disease, injury, and attacks by Native American tribes as they headed west from Kansas to California.



Several had died along the way, but they pressed on because they had a vision. With strength, courage, and will, they conquered the Rockies.

But after months on the trail, they came to a place in the Sierra Nevada Mountains so steep there was no way over. After several days, the scout and wagon master reported they had not been able to find a gap in the sheer stone walls wide enough for the wagons to pass through. Winter was coming on rapidly, and supplies were running out. They recommended that they turn back.

One of the settlers, however, an ordinary farmer, had an idea and refused to give up. He said they could disassemble the wagons and pass them board by board through to the other side where they could be rebuilt. The drive and ingenuity of people with vision and commitment has always inspired me. From time to time I still think about that settler.

Over the last eight years, as I served as director of Community State-Partnerships to Improve End-of-Life

Care and executive editor of this publication, I have again and again been awed by the intelligence, ingenuity, and commitment of leaders in the end-of-life movement.

Many of those leaders have contributed to this issue and hundreds more to this publication since its beginning. To each and every one of them and the several thousand other grassroots reformers and policymakers they represent, I offer my sincerest thank you. Because of you, care of the seriously ill and dying is better than it was more than a decade ago when the SUPPORT study was published telling us that end-of-life experiences in our country were almost the negative image of what Americans say they want for themselves and their loved ones at the end of life.

There is clearly more work to be accomplished, and it is our hope that this final issue of *State Initiatives* will provide some direction for those of us who will continue this important work. We are especially excited to feature five relatively new leaders in this field—each one of them doing important and innovative work.

Making this journey with each of you has been an honor. We have made progress, and while we cannot say we are almost there, we are closer than we have ever been.

Gratefully,



Myra J. Christopher
President and CEO
Center for Practical Bioethics
(formerly Midwest Bioethics Center)

State Initiatives in End-of-Life Care

Information about the Series

"The Way Forward: Thirty-Five Leaders Map the Future of Reform" is the 25th and final issue in a series of briefs profiling promising policies and practices in end-of-life care.

Executive Editor:

Myra Christopher

President and CEO, Center for Practical Bioethics
Past Director, Community-State Partnerships National Program Office

Researcher and Writer:

Jeri Spann

President, Spann Communications, LLC, Pittsburgh, PA

Designer:

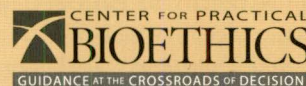
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Center for Practical Bioethics

Harzfeld Building

1111 Main Street, Suite 500

Kansas City, MO 64105-2116

Telephone (800) 344-3829

(816) 221-1100

Fax (816) 221-2002

E-mail bioethic@practicalbioethics.org

Web site www.practicalbioethics.org

CPB directed the Community-State Partnerships national program office (1998-2003), a program supported by The Robert Wood Johnson Foundation. CPB continues to provide resources and education about ethical issues in health and health care to advocates, policymakers, professionals, and consumers.

Announcing a New Series

The Robert Wood Johnson Foundation invites you to preview full-color pdfs of the first two issues of its new policy brief series, *Charting Nursing's Future*:

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charting@spanncomm.com