West Virginia Clarifies End-of-Life Care Laws
Planning a statewide initiative to improve end-of-life care

SUMMARY

During the period 1999–2002, the West Virginia Initiative to Improve End-of-Life Care, Morgantown, Va., encouraged a process of policy change to aid physicians in treating patients at the end of their lives according to patients' wishes and to help patients to make those wishes clear.

The West Virginia project also helped fund palliative care teams at four hospitals and a hospice in the state.

The project was part of the Robert Wood Johnson Foundation's (RWJF) national program Community-State Partnerships to Improve End-of-Life Care.

Key Results

- Project staff helped establish palliative care teams operating in four hospitals and a hospice in West Virginia.
  - From 1999 to 2001, a hospital system served by this project's palliative care team increased referrals to hospices by 25 percent.
  - In 2001, the project's palliative care team members established the West Virginia Palliative Care Network. Network members share what they have learned, collaborate on data collection and help others establish palliative care teams.
- Project staff helped inform legislators about the need for professional education in end-of-life care, including pain management.
- To help patients communicate their wishes about end-of-life care and to assure that health professionals follow patient wishes, project staff in 2001 introduced the

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1 Palliative care—Palliative care is an approach to care that addresses the patient's physical, emotional, social and spiritual needs and seeks to improve quality of life not only for the ill person, but also for his or her family. It is usually provided by interdisciplinary teams, often including physicians, nurses, social workers, chaplains or spiritual counselors and other health care professionals. Palliative care is similar to hospice care in that it emphasizes providing comfort care to a patient including pain relief, but it can begin earlier than hospice care—the latter typically starting only when a physician certifies that a patient probably has six months or less to live. Palliative care also includes treating depression and anxiety, and helping dying patients and their families discuss their wishes at the end of life.
Physician Orders for Scope of Treatment (POST) form, a standardized form that incorporates a patient’s advance directive and is signed by a physician.

- In 2002, the state legislature incorporated the POST form into law as the West Virginia Health Care Decisions Act, which also consolidated several laws addressing advance directives and medical power of attorney, making these provisions consistent and easier to use.

**Funding**

RWJF supported the project with two grants totaling $450,000 between January 1999 and December 2002.

**THE PROBLEM**

At the end of the 1990s, West Virginia appeared to provide substandard end-of-life care for its citizens. The referral rate to hospice was lower than the national average, according to project director Alvin Moss, MD. In 1998, health professionals and others referred 13 percent of eligible patients to hospice, versus 17 percent nationally.

Nearly half of West Virginians who died did so in a hospital, the most expensive option for end-of-life care. Also, state laws conflicted in how patients could make and carry out health care decisions at the end of their lives and how physicians could participate in those decisions.

To address these issues, 37 individuals representing more than 15 organizations met in 1998 to form the West Virginia Initiative to Improve End-of-Life Care. The Center for Health Ethics and Law of West Virginia University provided a home for the initiative. See the Appendix for a list of its members.

**THE PROJECT**

In 1999, the initiative received a one-year planning grant from RWJF that supported seven task forces. During 12 months of planning, project staff and task force members sought to understand the problems faced by West Virginia physicians, social workers, nurses and pharmacists by conducting a survey.

Survey findings revealed that most rated the overall quality of end-of-life care in the state as fair to poor. Project staff also conducted 10 community meetings, and eight senior-center meetings or community focus groups to let citizens discuss end-of-life care. In those focus groups, the top concern of participants was dying in pain.

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2 **Advance directives**—An advance directive is a living will and medical power of attorney that spells out an individual's wishes for care if they can no longer speak for themselves.
This preliminary work resulted in a plan to improve end-of-life care in West Virginia. RWJF funded the plan's implementation with a three-year grant beginning in 2000 (ID# 038456).

RESULTS

Project staff reported the following accomplishments:

- **Project staff helped establish palliative care teams operating in four hospitals and a hospice in West Virginia.** From 1999 to 2002, the initiative partially funded nurse coordinators (usually a nurse practitioner with hospice or oncology experience) to manage the activities of the palliative care teams. Dying patients in these five facilities met with a team to discuss their pain and symptom management, advance care planning\(^3\) needs, and to receive support, including support for their families. Project director Moss notes that these consultations reduced hospital costs by $2,000 per consult—the result of shorter lengths of stays for patients and fewer laboratory tests, radiological examinations and days in the intensive care unit. Between 2000 and 2002, palliative care consultations doubled from 467 in 2000 to 934 in 2002. Prior to the consultation, 64 percent of the time the primary care team had identified an appropriate legal decision-maker for the patient; after the consultation, the primary care team identified the appropriate legal decision-maker 92 percent of the time. In addition to a nurse coordinator, teams included a physician director, a consultation service staffed by an advance practice nurse or nurse clinical specialist, a social worker, a chaplain and a pharmacist. A psychiatrist often assisted with evaluation and treatment of patients' anxiety and depression.

- **From 1999 to 2001, a hospital system served by this project's palliative care team increased referrals to hospices by 25 percent.** According to Barbara Mulich, palliative care coordinator for West Virginia University Hospitals, the presence of a palliative care team in this hospital system served to educate and remind physicians practicing there of the existence of hospice and may have led to an increase in referrals. Mulich:

  "Team members talked with patients and their families about their wishes including whether they wanted to continue treatment that might not necessarily prolong their lives. In one case, a man in his 70s with chronic obstructive pulmonary disease was frequently in and out of the hospital because he was not getting enough oxygen. His next step would be to go on a ventilator. After talking with the team, he elected to go home, supported by a hospice team that could provide him with oxygen at night. This patient said 'I don't want to be on a ventilator, I'm tired of going to the hospital.' Instead, we started him on low-dose morphine to avoid feelings of suffocation.... People may not realize that they can be comfortable without being in the hospital.

\(^3\) Advance care planning—Advance care planning involves talking about one's wishes for future medical care in the event one is unable to make one's own decisions about care. Those discussions typically include a doctor and people who will act as health proxies if patients are no longer able to speak for themselves.
When you feel you're suffocating you don’t think you have a choice. [Without the palliative care team] patients could continue the cycle of being in and out of the hospital.

- **In 2001, the project’s palliative care team members established the West Virginia Palliative Care Network.** Network members share what they have learned, collaborate on data collection and help others establish palliative care teams.

- **Project staff encouraged new policy statements on pain by professional organizations in the state.** In response to citizen concern expressed in this project's focus groups about dying in pain, staff invited the state boards of medicine, nursing, pharmacy and osteopathy to develop a joint policy statement with the goal of promoting better pain management at the end of life. The West Virginia Legislature later amended its Management of Intractable Pain Act to incorporate the new joint policy statement. According to project staff, the West Virginia law now:
  
  — Gives health care professionals clear guidance on the type of prescribing practices that are acceptable to control pain in dying patients.
  
  — Provides protection to health care professionals who practice according to this policy statement.
  
  — Encourages adequate pain relief for dying patients.

- **Project staff helped inform legislators about the need for professional education in end-of-life care, including pain management.** In the project’s survey of West Virginia residents, fewer than 20 percent rated the care available for the dying as excellent. The survey of doctors, nurses, pharmacists and social workers across the state revealed similar perceptions. Project staff supplied these findings to organizations that advocate for improvements in professional education. According to the staff, state boards in West Virginia recognized that in order for their joint policy statement (see prior bullet) to make an impact on patient care, physicians and other health care professionals needed education in end-of-life care. This recognition led to a 2001 law that, as a condition of license renewal, doctors, nurses, physician assistants and pharmacists must complete two hours of continuing education in end-of-life care every two years.

- **Project staff educated regulators, professional associations and others about weaknesses in existing public policy as it related to end-of-life decision-making.** To help patients communicate their wishes about end-of-life care and to assure that health professionals follow patient wishes, project staff in 2001 introduced the Physician Orders for Scope of Treatment (POST) form, a standardized form that incorporates a patient’s advance directive and is signed by a physician. A similar form had been used in Oregon for six years (Physician Orders for Life-Sustaining

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**Advance directives**—An advance directive is a living will and medical power of attorney that spells out an individual's wishes for care if they can no longer speak for themselves.
Treatment [POLST]); it was developed under an RWJF grant (see Program Results on Targeted End-of-Life Projects Initiative ID# 033903). Project director Moss:

"In the past, patients could not be certain their wishes would be followed about end-of-life treatment. While people might complete an advanced directive, it might not be specific enough to give physicians direction on the type of treatment they want or do not want. Additionally, the advance directive may not be part of a patient's medical record when it is needed. To address these challenges, the POST form spells out the specifics of the treatment a patient wishes on areas such as feeding tubes, cardiopulmonary resuscitation and ventilators. It is to accompany patients when they are discharged or transferred to another facility. The form also provides legal protection to health care professionals, hospices and nursing homes when they follow a patient's preferences about life-sustaining measures."

- **In 2002, the state legislature incorporated the POST form into law as the West Virginia Health Care Decisions Act, which also consolidated several laws addressing advance directives and medical power of attorney, making these provisions consistent and easier to use.** By law, treating physicians now must follow the provisions of the POST form; nor can another physician ignore a patient's wishes.

- **Project staff helped educate health policy-makers about disincentives at nursing homes that may limit the enrollment of their residents in hospice.** The project's review of West Virginia Medicaid program data in 1999 revealed that only 10 nursing home residents across the state were enrolled in hospice each month. Staff convened a task force to address this issue. It concluded that because nursing homes received less reimbursement if patients were enrolled in hospice, there was a disincentive to enroll them. In 2000, the task force persuaded the state Medicaid office to eliminate the disincentive through a change in regulations. Within a few months of the change, the number of Medicaid hospice enrollments from nursing homes increased to between 40 and 50 per month.

- **Project staff conducted a media and public awareness campaign to engage West Virginians in thinking about end-of-life care.** In 2000–2001, staff held 18 focus groups at local senior centers and at libraries in nine communities that sponsored end-of-life reading groups. Staff and task force members conducted about 60 presentations to civic organizations, churches, senior centers, AARP chapters and professional membership organizations. The project also supported an extensive media campaign in early 2000, featuring two 30-second television spots by U.S. Senator Jay Rockefeller and Governor Cecil Underwood of West Virginia promoting end-of-life care. The spots aired over 600 times in the state's major media markets.
A grant from RWJF (ID# 038466) funded an evaluation of this media campaign in 2000. Ryan, McGinn, Samples Research, a media research firm in Charleston, W.Va., conducted three telephones surveys in five media markets in the state. Survey findings were not encouraging:

— Most respondents were already comfortable talking about end-of-life issues; there was little change after the campaign.

— Few respondents (8%) were aware of the West Virginia Initiative to Improve End-of-life Care six months after the campaign.

— Few respondents recalled Senator Rockefeller and Governor Underwood encouraging people to talk and learn about end-of-life care before or after the campaign.

**Communications**

In addition to the educational and media activities listed above, the initiative's lead organization, the West Virginia University's Center for Health Ethics and Law, served as a statewide resource center, establishing a website and a toll-free phone number for use by citizens and interested organizations. The website includes end-of-life care statutes in force in West Virginia, information on end-of-life training, resource materials and other information. An article written by project members about their work is forthcoming at the *Journal of Palliative Medicine* (see the Bibliography for details).

**LESSONS LEARNED**

1. **A little help to those informing state legislatures on issues of end-of-life care can have a powerful leveraging effect.** While project staff could not lobby, they collaborated with a variety of organizations, including state medical, nurse and pharmacist organizations that were able to advocate for changes in state law. As a result, the state legislature passed legislation that improved end-of-life care and funded continuation of the project's work. (Project Director)

2. **Gathering reliable data is important where a project goal may be to change policy.** Staff surveyed physicians and other health professionals and held community dialogues. Others used this well-documented information to show legislators and other policy-makers what health professionals and the public thought about end-of-life care and where they wanted improvements. (Project Director)

**AFTERWARD**

In March 1999, the project team received the first of a series of grants from the Claude Worthington Benedum Foundation, totaling $1.8 million dollars over 10 years, for various projects to improve the quality of end-of-life care in West Virginia. The initial
grant of $375,000 allowed the West Virginia Palliative Care Network to improve pain management and increase hospice referrals statewide.

In 2002, the West Virginia State Legislature established and funded, at $200,000 annually, the West Virginia Center for End-of-Life Care at West Virginia University in Morgantown, W.Va. The center aims to provide and enhance coordination, education and resources to ensure that West Virginians understand end-of-life care options and are able to receive quality care according to their treatment preferences.

Funding from both the state of West Virginia and the Benedum Foundation has recently allowed the center to undertake initiatives designed to further improve the state of palliative care. Projects have included:

- A sustained media awareness campaign to educate West Virginians about palliative care.
- A series of lectures and conferences to improve knowledge of palliative care among health professionals.
- Facilitation of the development of palliative care teams in hospitals and long-term care facilities.

In 2009, the center plans to expand its training services by offering end-of-life care education to attorneys and state politicians.

Prepared by: Susan G. Parker
Reviewed by: James Wood and Molly McKaughan
Program Officers: Victoria D. Weisfeld and Rosemary Gibson
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APPENDIX

Members of the West Virginia Initiative to Improve End-of-Life Care

(Current as of the end date of the program; provided by the program’s management; not verified by RWJF.)

State Government
Bureau of Senior Services, State of West Virginia
Department of Health and Human Resources, State of West Virginia
Guardianship Commission, West Virginia Department of Health and Human Resources
West Virginia Board of Medicine
West Virginia Board of Pharmacy

Pain Management Centers
Center for Pain Management, West Virginia University Hospitals

Religious Organizations
Catholic Diocese of Wheeling-Charleston Synod of West Virginia—Western Maryland of the Evangelical Lutheran Church in America
West Virginia Council of Churches

Statewide Organizations
Hospice Council of West Virginia
West Virginia Council of Home Health Agencies
West Virginia Health Care Association
West Virginia Hospital Association
West Virginia Humanities Council
West Virginia Network of Ethics Committees
West Virginia Rural Health Education Partnership
West Virginia State Medical Association
West Virginia State Bar

Academic Departments
Center on Aging, West Virginia University
Department of Communication Studies, West Virginia University
Department of Public Administration, West Virginia University

Health Care Professional Educational Institutions
Camcare Health Education and Research Institute
Marshall University School of Medicine
West Virginia University School of Medicine
West Virginia University School of Nursing
West Virginia School of Osteopathic Medicine
West Virginia University School of Pharmacy

Community/Patient Advocacy
AARP
Carelink Health Plans
Charleston Area Medical Center
Kanawha Hospice Care
Long-Term Care Ombudsman Program, Legal Aid Society of Charleston
Monongalia County Home Care Services
Mountain Hospice
Princeton Community Hospital
St. Francis Hospice
South Central West Virginia AIDS Network
BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

**Articles**


Moss AH and Keresztury JA. "Networking Ethics Committees in West Virginia, The Infrastructure Upon Which the End-of-Life Care Initiative was Built." *Journal of Palliative Medicine*. In press.


**Reports**


Audio-Visua ls and Computer Software

*Max and Nellie's Journey with Grief*, a video that discusses the subject of death, dying and loss. The goal of the video is to provide a resource for parents and children who are facing issues of bereavement.

Public service announcements on end-of-life care by Governor Cecil Underwood and Senator John D. Rockefeller IV.

Grantee Websites

[www.hsc.wvu.edu/chel/wvi](http://www.hsc.wvu.edu/chel/wvi) (no longer available). The website contained information on end-of-life care for patients and professionals as well as notice of upcoming meetings and conferences.