



nesses: formal palliative care assessment, community-based care management, and promotion of primary physician involvement.

- Queens Palliative Care Network (including North Shore–Long Island Jewish Health System, the Hospital Care Network, and the Northern Queens Coalition, a group of 45 community-based organizations). This project is developing and testing a model of early patient identification for palliative care and intensive service coordination through physician practices.

- Southern Brooklyn Palliative Care Network. Coordinated by the Metropolitan Jewish Health System, this network includes the Lutheran Medical Center, Maimonides Medical Center, Bay Ridge Council on the Aging, Jewish Association of Services for the Aged, and Park Terrace Interagency Council on the Aging. The project seeks to improve access to palliative care services for people aged 65 years or older from the ethnically diverse neighborhoods of Borough Park, Sunset Park, and Bay Ridge.

These networks are forging partnerships of hospitals, hospices, long-term care agencies, home care agencies, and community organizations to

address the medical, social service, spiritual, and psychological needs of patients with chronic, progressive, life-threatening illnesses. The networks also support and assist families and caregivers throughout the dying process.

“The problem is not lack of knowledge, but the absence of coherent and accessible palliative care delivery systems rooted in the community that allow us to use this knowledge effectively,” said James R. Tallon, Jr, United Hospital Fund president. “Comprehensive and timely care throughout the dying process is a humane and achievable goal.”

The United Hospital Fund is a health services research and philanthropic organization addressing critical issues affecting hospitals and health care in New York City and the nation.

#### FINAL NURSING CARE

Another initiative, also funded by the Robert Wood Johnson Foundation, has created a comprehensive, national education program to improve end-of-life care by nurses.

The \$2.2 million grant to the American Association of Colleges of Nursing (AACN) is funding a 3½-year effort to develop a core of expert nursing

faculty in end-of-life care. The program is a partnership between the AACN and the City of Hope Cancer Center in Los Angeles.

“Nurses spend more time with patients and their families than do any other health professionals and are in the most immediate position to provide care, comfort, and counsel at the end of life when critical decisions must be reached and compassionate and highly specialized care provided,” said Andrea R. Lindell, DNSc, RN, president of the AACN.

The project closely parallels the American Medical Association’s Educating Physicians for End-of-Life Care program (*The Education for Physicians on End-of-Life Care [EPEC] Curriculum*. Chicago, Ill: American Medical Association; 1999). The nurses’ curriculum features a range of core areas, including broad issues of nursing care at the end of life; pain management; symptom management; cultural considerations; ethical and legal issues; communication; grief, loss, and bereavement; preparation and care for the time of death; and achieving quality of life—the reduction of distressing symptoms and improvement of mental health and attitudes—at the end of life. □

## End-of-Life Coalitions Grow to Fill Needs

Donald F. Phillips

DEATH AND TAXES ARE TWO OF life’s certainties that affect everyone. Societies develop codes to gain some control over taxes, but controls over the way people die have been slow in coming—until now, that is, because there are signs that this is changing rapidly throughout the United States.

Nationally, one prominent sign is a burgeoning number of newly created organizations dedicated to end-of-life care issues. During the past 3 years or so, the number of such national organizations has risen from three to 20. The

Internet teems with new Web sites, chat rooms, and e-groups that carry discussions, announcements, and resources concerning all interests in end-of-life issues.

Regionally, end-of-life care coalitions are coming into being throughout the country. Many were established prior to and in anticipation of the Public Broadcasting Service series by Bill Moyers, “On Our Own Terms,” which aired in mid September. Public Affairs Television Inc, Moyers’ production company, spent \$2.5 million on marketing and outreach throughout the year to spark community public awareness discussion groups across the na-

tion. Company data show that some type of local educational effort associated with the program series occurred in about 160 locations. Many of these local coalitions conducted town forums before the programs, then staffed telephone banks at TV stations after each of the four Moyers programs aired.

#### CHICAGO COALITION

More importantly, many of these volunteer coalitions decided to stay organized and restructure themselves into not-for-profit enterprises, build their memberships, hire staffs, apply for grants, and plan a variety of educational programs and services.



One such group is the Chicago End-of-Life-Care Coalition (CECC), which is made up primarily of individuals involved in hospice and palliative care in the greater Chicago area and funded through private donations. After establishing an organizational framework, mission statement, and projected goals, a core group of individuals interested in end-of-life care invited participants throughout the community to form the current coalition of approximately 60 active members. This group includes physicians, nurses, hospice representatives, community members, funeral directors, patient advocates, clergy members, and media representatives.

Competition among institutions, mainly medical centers, that provide hospice care is high in the Chicago area (although this is not the case in some other parts of the country). To ensure that the coalition would not become a self-serving tool for use by any one of the rival hospice organizations, coalition membership was opened to all "interested individuals," not organizations, and the coalition's initial activities were limited to and focused on publicizing and preparing for the public's response to the Moyers series. To give the coalition an organizational foundation, it was established as a working group under the umbrella of Chicago Clinical Ethics Programs (CCEP), an affiliate of the Institute of Medicine of Chicago.

For the immediate future, the CECC will continue to serve as a community resource. A speaker's bureau has been established to facilitate small discussion groups within public settings and to monitor the issues that emerge at these sessions. Letters and flyers are being sent to selected community groups, including the Chicago Public Library system, places of worship, local schools and colleges, hospitals, and community centers, offering facilitation of group discussions.

"We call this our 'poker project,'" explains Julie Goldstein, MD, secretary of the CCEP and a geriatric physician at Chicago's Illinois Masonic Medical Center. "It is named after a particularly touching segment from the

Moyers series, in which such a discussion on the issues of dying was facilitated among members of a long-time poker club. We will use video clips from the series along with other tools to assist in our discussions."

The first of these discussion groups has already met, with the goal of promoting general awareness and greater comfort in talking about and dealing with end-of-life issues, Goldstein said. "Using feedback from these initial meetings, we are planning a training course for facilitators and developing a 'tool kit' of useful items for the facilitator to bring to the groups, such as books on end-of-life care, advanced directives, Kleenex, et cetera." Feedback from these discussion groups will also provide information for future planning of educational programs for professional audiences.

The coalition has compiled a resource guide and has set up an "e-group" listserve and bulletin board, accessible only to coalition members, which is critical for rapid information exchange and decision making. The bulletin board is used to post mailing and meeting-facilitator lists, schedules of discussion groups, project assignments, and so on. A Web site is being planned. Use of the Internet, e-mail, and e-group services is a common feature among most of the local coalitions.

#### **SOLACE IN VIRGINIA**

SOLACE (Supporters of Life-Affirming Care at End-of-Life) is a coalition of community leaders and organizations in Northern Virginia that aims to encourage people to decide ahead of time, before illness affects them, what they want during their time of dying. Such decisions go much further than simply signing advance directives, and may include detailed requests for particular actions by family, clergy members, and so on.

SOLACE was formed in 1998 at the initiation of the Hospice of Northern Virginia, when 14 health care, religious, educational, legal, and civic organizations signed a "Memorandum of Understanding" regarding SOLACE's purpose. The group was originally

funded by local businesses and health care organizations but now intends to seek state and federal grants and industry support.

The mission of SOLACE is to:

- create partnerships to share knowledge, resources, and expertise in end-of-life care;
- strengthen the continuum of care in the community by filling gaps in services and increasing access to end-of-life services;
- assess the needs of people in the community affected by end-of-life issues;
- coordinate available resources and services for dying people and their loved ones, including grief and loss education and counseling; and
- stimulate public discussion at the end of the end-of-life experience and provide education to enable people to make informed health care choices.

During 2000, the coalition focused on advance care planning, encouraging people to decide what they want during life's last months. Members of the coalition—including 140 individuals and 14 local groups such as medical centers, managed care organizations, a legal firm, and religious institutions—have developed new advance directive forms that meet the legal requirements of Virginia, Maryland, and the District of Columbia. A speaker's bureau has been formed to provide information about advance care planning, including how to initiate difficult conversations with family, friends, and physicians. Outreach to religious organizations is an important part of the coalition's efforts to promote discussion of the subject. SOLACE's Web site is <http://www.hospiceonline.org>.

#### **PENNSYLVANIA PARTNERSHIP**

Another volunteer coalition, spawned to respond to public interest generated by the Moyers programs, recently became the End of Life Partnership of Western Pennsylvania (ELPWP), a network of consumers, professionals, community organizations, and corporations. "We just filed for 501c3 status, which will allow it to do fundraising on