

## New Hampshire Partnership for End-of-Life Care

The New Hampshire Partnership for End-of-Life Care (NH Partnership) is a group of organizations that helps people to plan for their health care, talk about their choices, and have them respected. The Foundation for Healthy Communities founded the NH Partnership in 1998 and its first activity was a voluntary statewide medical chart review on anyone who died while being cared for in a hospital, nursing home, hospice, or by a home care agency. This medical chart review captured more than half the adult deaths in the state and helped us to develop a focus on advance care planning because there were very few deaths where any advance directive was noted in the patient chart. A companion survey of more than 1,000 adults in primary care settings found that only 7 percent who had a conversation about end-of-life care had ever talked treatment choices near the end of life with their health provider. None of the NH Partner organizations were addressing the issue of advance care planning, yet all felt that it was important for people to understand their medical choices and to be engaged in decisions about their treatment or care near the end of life.

In 1999, we received a three-year grant from The Robert Wood Johnson Foundation's Community-State Partnerships to Improve End-of-Life Care to help our efforts. Our project goal was to create a statewide advance care planning initiative to increase understanding about end-of-life care and promote policy changes that support the delivery of quality, comprehensive end-of-life care. We partnered with Gunderson Lutheran Medical Center in La Crosse, Wisconsin to bring the *Respecting Choices* program to New Hampshire. Our state has 1.2 million people with a majority living in the southern tier and others more dispersed in the rural northern counties. We recruited 32 volunteer professionals from across the state to be trained over three days and to form eight regional teams with one "float team" to serve more isolated rural areas. Each trainer committed to training at least 15 people from their region in the 16-hour *Respecting Choices* program within two years. There were 26 two-day sessions that trained 469 community facilitators. Our community facilitators came from several disciplines (38 percent nurses, 23 percent social workers, 8 percent clergy/faith community leaders, and 31 percent other). Almost one-third of the community facilitators (30 percent) were affiliated with social service agencies or faith communities, 24 percent with hospitals, 24 percent with long-term care facilities, and 22 percent with home care or hospice agencies.

The project's Community Coordinator was instrumental in managing activities of the volunteer network of trainers and community facilitators. Statewide meetings for the 32 trainers were held twice a year, and in 2001 we offered the trainer certification that was developed by Gunderson Lutheran Medical Center. In 2002, we shifted our focus from training new community facilitators to encouraging and motivating them to hold community events. We conducted a statewide "Community Advance Care Planning Campaign" to motivate facilitators to lead community events and to collectively learn what activities are successful and those that do not work. We celebrated the results of the Campaign in October 2002 with a special recognition program where Bill Colby, author of *Long Goodbye: The Deaths of Nancy Cruzan*, was our keynote speaker. More than 100 leaders from across the state attended this event. We recognized organizations and individuals for their innovative community advance care planning strategies, among which included: focusing on staff in

a health care organization; focusing on staff or employees of a non-health care organization; creating a new community event; engaging the greatest number of people in learning about advance care planning; engaging local media in increasing awareness of advance care planning (the event that was the biggest failure—but a learning opportunity!); and focusing on the needs of a special segment of the population (oncology patients, minorities, etc.).

In addition to the training strategy, the NH Partnership for End-of-Life Care employed other complementary strategies to improve advance care planning.

- We created a new *Advance Care Planning Guide* to replace the decade old *Advance Directives* booklet that was found to be difficult to read and focused solely on the legal forms. The new *Advance Care Planning Guide* was released by the Governor in 2001 and more than 100,000 copies were sold in the first year. The Guide is available in English, Spanish, French, Braille, and on audiocassette, and can also be downloaded from our website. [Go to [www.healthynh.com](http://www.healthynh.com) and click on the first "Quick Link" at the top left to access the free pdf of the *Advance Care Planning Guide*.]
- We worked with our state government to create a new Medicaid benefit "Targeted Case Management: Advance Care Planning Services for the Severely Ill Medicaid Client." This benefit engages Medicaid clients in decision making about their preferences for care earlier in their illness. The target population is individuals with illnesses or medical conditions that are expected to continually deteriorate, and may be expected to result in death *within two years*. Providers of the service must be state licensed to provide home health and certified Medicare hospice providers.
- We worked closely with the faith community and organized a Compassionate Care program that surveyed all 750 congregations in the state, from 15 different denominations, on what services they offered to the terminally ill and their families. This resulted in their largest response ever to any survey of congregations. We found that while 68 percent had one or more requests per month for help, many felt did not feel "well prepared" to respond to these requests and more than three-quarters did not have programs in place to help with advance care planning. A conference and training for congregations was held in 2002.
- We have proposed legislation to create a NH State Commission on End-of-Life Care that has been introduced to the legislature in 2003 to help move our NH Partnership work into a public policy realm.

For more information about the NH Partnership for End-of-Life Care please contact Shawn LaFrance, MS, MPH, at the Foundation for Healthy Communities ([slafrance@nhha.org](mailto:slafrance@nhha.org)) or visit [www.healthynh.com](http://www.healthynh.com).

—Shawn LaFrance, MS, MPH