Quality improvement programs to enhance end-of-life care in nursing facilities can have spillover benefits for everyone who resides there—not just those identified as nearing the end of life.

That is one of the key lessons of an initiative called Promising Practices to Improve End-of-Life Care in Nursing Homes, sponsored by the California Coalition for Compassionate Care (CCCC).

CCCC, a Sacramento-based, statewide coalition of organizations representing health care providers, consumers and state agencies committed to improving end-of-life care, offered two-day seminars on end-of-life care for California nursing facilities in 2000, 2001 and 2002. (The California Association of Homes and Services for the Aging is a founding member of CCCC.) Teams from 109 providers participated and then implemented action plans for improvement within their facilities.

Promising Practices, funded by the Archstone Foundation, was a next step for CCCC to identify providers doing something particularly well and give them free technical assistance and mentoring to refine their practices into replicable models. Three competitively chosen projects focused on different areas of improvement: documenting conversations with physicians about residents’ care preferences, identifying when patients are entering a terminal decline, and teaching certified nursing assistants (CNAs) how to use touch to strengthen bonds with their patients.

“If nursing homes get end-of-life care right, the culture within the facility will change,” says CCCC executive director Judy Citko. “A facility that has instituted good end-of-life care is more likely to provide good, person-centered care for all of its residents. It will know its residents better and the care it provides will better address their personal goals of care.”

**What Is Good End-of-Life Care?**
The goal of improving end-of-life care can be intimidating for the staff of long-term care facilities, both because of the regulatory and fiscal pressures they face but also because of misconceptions about what end-of-life care means. Hospice, the best-known model of end-of-life care (see the sidebar on page 42), is an important collaborator with nursing homes in caring for terminally ill patients, but it is not the only avenue for pursuing improvements.

Palliative care, a growing field of medicine
that provides aggressive, interdisciplinary symptom management, encompasses hospice principles of comfort care but can be provided simultaneously with disease-modifying therapies. “Our philosophy about end-of-life care is helping people to live fully throughout the last chapters of their lives, enriching their quality of life and honoring their values and expressed care preferences,” Citko says. Advance care planning and values clarification are thus paramount.

Although nursing providers focus on rehabilitation and restoration of residents’ physical function, a quarter of all deaths in this country take place in nursing homes. Two-thirds of those admitted to nursing homes will die there, one-third within a year, notes Mary Cadogan, professor of nursing at UCLA and the primary consultant for Promising Practices. Mentorship of the type provided under Promising Practices can be helpful, Cadogan says, but it is not essential if the project has a committed internal champion and administrative support.

One such champion is Dr. William Morris, medical director of Driftwood Healthcare, Santa Cruz, Calif. His facility, one of the three sites selected to participate in Promising Practices, implemented a project called OPTIONS (Offering Palliative Treatment in Ongoing Nursing Settings). It emphasized clarifying goals for care and treatment and informing residents and families about palliative care and the option of choosing comfort-oriented care.

“A lot of what we did was gathering data to better understand how and when people get access to palliative care and, eventually, to hospice,” Morris says. The project compiled data on its residents’ demographics, length of stay, discharge destinations and rate of hospice referrals, in order to get a clearer sense of their experience of dying. “Even just defining where people were in that process, we believed, would help trigger discussions of goals of care.”

Under the OPTIONS project, all new admissions were given encouragement and assistance in completing an advance directive, as well as education about palliative care principles and options. Based on their initial assessments, residents were categorized as primarily “rehab,” “custodial/long-term” or “terminal.” They continued to be monitored as usual for signs of decline such as weight loss, infection, decubiti, cognitive decline or uncontrolled symptoms such as pain.

When evidence of decline was identified by the facility’s clinical team at regular interdisciplinary team meetings, two key questions were asked: Is this decline believed to be reversible or irreversible? And do the patient and family desire a curative or palliative approach in dealing with the observed decline? Based on the answers to those two questions, any patient could be categorized within a status grid.

“The essence of the project is that it required us to have discussions around goals of care. That doesn’t mean the conversations were easy—they still took a lot of art and skill and experience,” Morris says. But asking staff to fit residents with declining status into the grid helped to clarify overall direction for care. The hardest cases were when the staff believed the condition was reversible but the resident wanted a palliative approach or when the staff believed the condition was not reversible but the patient and family wanted an aggressive, curative approach to treatment, Morris says.

Experience under the project also clarified that conversations introducing palliative care options are best held two weeks or so after admission, giving the provider time to establish rapport with the resident and family. Another important data-gathering tool was the brief mortality review. Conducted after each resident’s death using a single-page form to guide the chart review, this five-minute process asked if the resident’s care preferences were documented, if symptoms were assessed and treated, if the death was anticipated, and if a hospice referral was made.

“It’s important to emphasize that palliative care ideally means shifting resources to intensive symptom management and attention to quality of life, not the withdrawal of care and resources,” Morris says. “When we explain that, patients often say, ‘That’s what I want.’”

**The Power of Touch**

Pilgrim Haven in Los Altos, Calif., is a continuing care retirement community combining residential, assisted living and a 65-bed skilled nursing facility. A team from the facility attended CCCC’s end-of-life training in 2000 and came back to implement a number of quality improvement efforts in the areas of pain management and discussing end-of-life treatment preferences with residents and families before a crisis occurs.

The facility offered its staff a “spa day” with a professional masseuse as a job perk, and its activities director implemented sessions of music, aromatherapy and massage for residents, who loved it, relates Rosemary Resch, Pilgrim Haven’s director of staff development. When the Promising Practices opportunity was announced, Resch says, “I was looking for a new project to expand contacts and communication between CNAs and residents and to make the interactions more meaningful. Each resident has individual needs and some have difficulty making those needs known. I began thinking of touch as a way of enhancing communication with residents.”

Her proposal was to incorporate “tender touch” into the daily work routines of Pilgrim Haven’s CNAs, based on a training video called Compassionate Touch: Benefits and Effects in Long-Term Care. The project was introduced to 27 CNAs in an in-service presentation that combined a baseline survey about their attitudes and experience, the video, instruction in hand massage and an opportunity to practice the technique on each other and experience what it felt like to give and receive tender touch.

Experienced CNAs were called upon to endorse the benefits. Participants were provided with lavender-scented massage lotion and asked to choose a resident for a
Hospice Partnerships Can Help

Relationships with community hospices provide another avenue for enhancing end-of-life care for residents of skilled nursing facilities (SNFs). Medicare, along with most Medicaid and private insurance plans, covers hospice care for patients with a prognosis of six months or less to live. Terminally ill residents of SNFs who are dually eligible for Medicare hospice and Medicaid long-term care can have their facility room and board and hospice care costs covered simultaneously.

However, this dual payment mechanism is complex and the partnership requires a contract between the nursing facility and the hospice. Equally important is the quality of the relationship and communication between the provider's staff and the hospice team that comes in to manage residents' terminal care.

"If you can establish a close, positive working relationship with a hospice program, you get significant support services and staff training. Hospice brings into the facility hands-on expertise ranging from the clinical (nursing) to the spiritual (pastoral counseling)," says Dr. Terry Hill, consultant to the California Coalition for Compassionate Care's Promising Practices initiative.

One resident was often angry at staff, and suffered from limited and painful range of motion in her hands. CNA Trang Nguyen would offer to massage the resident's hand every day, and each time her fingers opened a little more. "With tender touch, the residents feel like you really care about them," Nguyen says.

Evidence of Advance Planning

In contrast to the other two Promising Practices facilities, the 35-bed Transitional Care Unit at Presbyterian Intercommunity Hospital in Whittier, Calif., has a short-term focus reflecting its transitional care role for a 350-bed suburban hospital and its 15-day average length of stay. Physicians may have assumed that end-of-life issues were not relevant for this rehabilitation-oriented unit, but a retrospective chart review quickly established that a significant proportion of residents were in the latter stages of life, says Karen Butler, administrative director of the unit during the project.

Butler, who has since retired, encouraged several of her staff to attend the CCCC training and get comfortable with end-of-life issues and a more assertive role as patient advocates. When the hospital implemented a new resuscitation orders form, the SNF implemented a requirement for evidence of an advance care planning discussion with the physician and documentation of the patient's resuscitation preferences within 72 hours of admission to the unit. Evidence of the hospital's resuscitation orders in the chart was considered sufficient to satisfy the requirement.

Introducing this mandate required considerable physician education, including an article in the medical staff newsletter and one-on-one meetings with doctors. But the results were immediate. In a baseline chart audit covering two months prior to launching the project, only one of 49 charts had any evidence that the patient's care preferences had been discussed. In the two months after the requirement was instituted in April 2003, 84 percent of charts were compliant, and the rate has since remained consistently high. The change reflects a higher level of communication between physicians and patients, and between physicians and nurses, about care goals, Butler says. Some of the doctors quickly got on board and one of them developed a "talking points" checklist to guide such discussions with patients.

Basic QI for End-of-Life Care

Here are some lessons learned on changing the culture of long-term providers to enhance end-of-life care:

A champion who is committed and has a vision that can permeate throughout the facility is important, but so is visible support from the...
facility’s administrators.

*: Changing end-of-life care at the level of an organization’s culture can be frightening to staff. Try to introduce the concept in a way that makes staff feel more comfortable, with opportunities to discuss their concerns and fears.

*: Each facility is unique—with its own culture—and thus requires its own approach and answers.

*: Quality improvement should be started on a small scale. Simple things can have a big payoff and small victories should be celebrated.

*: Data gathering is important, although it needn’t be complicated or burdensome. Data can validate the organization’s commitment and, when results are shared with staff, they can see the logic behind the program’s development.

*: It is instructive to review charts for several recent deaths, using the death review form developed by CCCC and posted on its Web site. Call the family members of patients who died and ask for their assessment of how things went.

*: One helpful approach to identifying who might benefit from end-of-life care is to ask not if the person has a six-month prognosis, but whether staff would be surprised if this person died within the next six months.

“If the nursing facility’s leadership can make a commitment to providing very good end-of-life care, then the staff will get excited because it is so heart-centered,” says Dr. Terry Hill, another CCCC long-term care consultant and medical director for quality improvement for the Lumetra Medicare quality improvement organization in San Francisco. “Providing high-touch, compassionate care is why many of us went into health care in the first place. If you give your staff an opportunity to actually implement the caring that they feel, a lot of good things start happening.”

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Resources

California Coalition for Compassionate Care, Sacramento, Calif.
Contact: Judy Citko, executive director, jcitko@calhealth.org or (916) 552-7573.
Web: www.finalchoices.org.

Pilgrim Haven, Los Altos, Calif.
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Driftwood Healthcare, Santa Cruz, Calif.
Contact: William Morris, M.D., medical director, billanddarc@aol.com or (831) 475-6323.

Presbyterian Intercommunity Hospital, Whittier, Calif.
Contact: Karen Butler, R.N., M.A. (retired), kobutler@msn.com or (562) 438-8367.

Compassionate Touch Video
The training video, Compassionate Touch: Benefits and Effects in Long-Term Care, is produced by Brianna Allen, Aquarius Productions, www.aquariusproductions.com.

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