



MENTORING PHYSICIANS

Supportive Care of the Dying: A Coalition for Compassionate Care (SCD:CCC) begins 1998 with new leaders, new members, and a new project.

The coalition was born three years ago, shortly after Oregon voters approved a referendum legalizing physician-assisted suicide.¹ Realizing that such legislation was driven by genuine public fears concerning end-of-life treatment, three Catholic healthcare systems with facilities in the Pacific Northwest—Sisters of Providence Health System, Seattle; PeaceHealth, Bellevue, WA; and Franciscan Health System, Aston, PA (now part of Catholic Health Initiatives, Denver)—joined with the Catholic Health Association in December 1994 to create SCD:CCC, an attempt to deal with those fears.

In 1995 the coalition, recognizing that the issues it addressed were national rather than regional, invited Daughters of Charity National Health System, St. Louis, and Carondelet Health System, St. Louis, to become members as well.

During 1996 the coalition conducted and evaluated research into public attitudes about care for

Coalition Is Developing Curriculum on End-of- Life Issues

the dying. The results of that research—a series of focus groups involving patients with life-threatening illnesses, professional caregivers, family caregivers, bereaved people, and community members—were unveiled in a dramatic presentation at the 1997 Catholic Health Assembly and in a booklet titled *Living and Healing During Life-Threatening Illness* (see Box).

SCD:CCC is now beginning a new stage of its journey. At its October 1997 meeting, Patrick J. Cacchione, vice president, public policy and government affairs, Daughters of Charity National Health System and Carondelet Health System, was elected the board's chairperson for 1998. Sylvia McSkimming, PhD, RN, former director, nursing quality and research, Providence/St. Vincent Medical Center, Portland, OR, was appointed SCD:CCC's new executive director. Sisters of Mercy Health System, St. Louis; Catholic Healthcare Partners, Cincinnati; and St. Joseph Health System, Orange, CA, became coalition members.



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1996 FOCUS GROUP RESULTS

SCD:CCC brought together 407 people at 11 sites for its 1996 focus groups. From them the coalition learned, among other things, that:

- People with life-threatening illnesses tend to focus on *living* rather than *dying*.
- Friends or family members who provide care for a person with a life-threatening illness often refer to it as "our" illness.
- Healthcare professionals frequently ignore or misinterpret patients' living wills and advance directives.
- Many clinicians, admitting that productivity concerns tend to make them insensitive about end-of-life issues, worry about the effect of this on their own health and well-being.

PROFESSIONAL MENTOR PROGRAM

SCD:CCC's new project—the Professional Mentor Program—grew out of the professional caregivers' focus groups, according to Alicia Super, RN, director of Supportive Care Research and Development Services, Providence Health System.

Data from those groups indicated that few healthcare professionals receive sufficient training in end-of-life issues. This seems to be especially true of physicians, said Super, who is designing the Professional Mentor Program with Marian



Hodges, MD, MPH, and Melinda Lee, MD.

"Physicians aren't taught the skills and behaviors they need to help persons and families facing life-threatening illness," Super said. Aware of this lack of training, physicians tend to feel inadequate when dealing with such illnesses. This sense of inadequacy keeps them from performing the interdisciplinary work and filling the community roles that other focus group participants saw as vital, she said.

"We hope to teach physicians both clinical skills and the holistic behaviors that enable them to address physical, emotional, and spiritual issues," Super said. "These skills and behaviors will help them become more confident and competent in the way they provide end-of-life care. We know they want to learn."

Super, Hodges, and Lee are creating a curriculum to educate healthcare professionals. This curriculum-in-progress will integrate current academic knowledge with insights garnered from a new series of focus groups, Super said.

The Professional Mentor Program focus groups will be conducted in three phases, she said.

Phase 1 In these groups, which began in January and are for physicians only, participants are discussing:

- The hypothesis that lack of training in end-of-life issues undermines physicians' ability, both professionally and psychologically, to meet the needs of people experiencing life-threatening illness

- The training and support services that would help physicians better meet such needs

Among other topics, participants are discussing the "last days" phenomenon and the ways physicians can help patients and their families experience the end of life as a time of healing.² Two of the focus group sites, one rural and one urban, are in Oregon; another two are in other states.

Phase 2 In providing end-of-life care, physicians will learn to function as members of a team that includes not only such professionals as nurses and pharmacists, for example, but also the patient and his or her family members.

Phase 3 These teams will learn to provide end-of-life care that is centered in the community rather than in hospitals.

Dates and sites for Phases 2 and 3 have not yet been established. Super said that, during each of the phases, the researchers will conduct pilot programs to evaluate the developing curriculum's impact on physicians, other caregivers, patients, and families. "This has been our general method since SCD:CCC's beginning," she said. "The need for reform is so urgent that we feel we can't, as scientists usually do, spend years conducting studies and then even more years disseminating

the results to others. We're walking through this project and giving it away as we go."

Once the Professional Mentor Program's curriculum is complete—the deadline is June 30, 2000—it will be offered to Catholic healthcare systems around the nation to employ as they see the need.

OTHER COALITION EFFORTS

In the meantime, SCD:CCC continues its research and advocacy work. For example, McSkimming said, the coalition is currently developing a new model of care delivery at the end of life. Data for this model will come from focus groups and "advisory groups" (composed by community leaders) in Evansville, IN; Albuquerque, NM; and Los Angeles. "Coalition members are also conducting their own local focus groups, based on the method described in *Living and Healing During Life-Threatening Illness*," she said.

In November SCD:CCC convened a two-day teleconference involving 70 representatives of its constituent organizations, including physicians, mission leaders, and nursing executives. Participants discussed the findings of the *Living and Healing During Life-Threatening Illness* research, especially as they apply to patients and staff in their own organizations. More people asked to participate in the conference than could be accommodated by the format, so two additional sessions are being planned for the new year, McSkimming said.

Also in November, McSkimming appeared before the California legislature's Select Committee on Palliative Care and called for reform in end-of-life care.

Cacchione sees SCD facing two challenges in the future:

First, we're amassing a huge amount of data through our focus groups. How do we

Continued on page 38

In providing end-of-life care, physicians will learn to function as members of a team that includes the patient and family members.

MEMBERS OF THE COALITION

- PeaceHealth, Bellevue, WA
- Providence Health System, Seattle
- Catholic Health Initiatives, Denver
- Daughters of Charity National Health System, St. Louis
- Carondelet Health System, St. Louis
- Catholic Health Association of the United States, St. Louis
- Sisters of Mercy Health System, St. Louis
- Catholic Health Partners, Cincinnati

MENTORING PHYSICIANS

Continued from page 33

build on that data? And, second, our data have increased awareness concerning the care of people facing life-threatening illness. How do we provide the needed guidance and products while continuing to do research and develop innovative approaches? These approaches require rigorous scientific testing. That takes time—but our member organizations are ready to make changes now. We hope the local focus groups and sessions like the November teleconference help us close the gap between research and reform.

Cacchione said two more Catholic healthcare organizations may be joining SCD:CCC at the coalition's January board meeting. "Although still others have said they would like to join, we may soon find ourselves reaching a point of no return," he added. "If the board is too large, it might become unmanageable. The issue seems to be controlled growth versus broad participation. But we remain committed to creating a cultural change for the care of persons with life-threatening illness."

—Gordon Burnside

NOTES

1. In November 1994 Oregon voters narrowly approved Measure 16, making physician-assisted suicide legal. In November 1997, in a second referendum, voters defeated Measure 51, an attempt to strip physician-assisted suicide of its legal status.
2. "These last days are full of opportunities for growth and healing in the spiritual, emotional, and relational realms, for both the person with the illness and those who love him or her. Unfortunately, these opportunities are often missed because professional caregivers, focused on physical signs and symptoms, cannot recognize other symptoms." Supportive Care for the Dying: A Coalition for Compassionate Care, *Living and Healing During Life-Threatening Illness*, Portland, OR, 1997, p. 7.

BUILDING HEALTHIER COMMUNITIES

Continued from page 35

Other Albany projects include housing initiatives and advocacy on numerous issues.


build new models for responding to their needs.

• Ambulatory Care Working Group, an effort to develop coordination between Catholic Charities services sites (such as emergency shelters, transitional housing, and childcare centers), a community center, parish outreach sites, and Mercycare healthcare services. Projects may include community forums, health education services, health screenings, and clinic services.

Other Albany projects include housing initiatives and advocacy on welfare reform, housing issues, Medicare/Medicaid issues, and children's health.

EFFECTING SYSTEMIC CHANGE

"Building Healthier Communities aims at enlivening and engaging the social ministry of Catholic-sponsored institutions in an effort to meet human and financial needs in impoverished communities," says McAuley Executive Director JoAnn Kane. "Ultimately, we hope that this initiative will serve the housing, healthcare, and human service needs of people who are poor while it promotes relationships that can effect systemic change," concludes Lillian Murphy, RSM, president and CEO of Mercy Housing, Inc. —Ann Stockho

 For more information, contact Maggie Grieve, 301-588-8110, or Sr. Mary Kay Dobrovolny, RSM, 402-398-5979.

CHA BOOKS

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