



# WHEN THE COMMUNITY CARES

In the spring of 1997 Clayton Holmes began to complain that he lacked his usual energy. He was also having back pain and appetite loss, but he and his wife, Winnie, attributed those to an old back injury and a bout of diverticulitis. Neither of them was prepared to learn, in June, that Clayton was suffering from a rare form of liver cancer. They were unprepared, not long after, for him to enter hospice. And when he died—in July 1997—they were unprepared for that too.

Clayton's last days had been particularly difficult for both him and Winnie. Because Clayton could no longer swallow, his physician had replaced his oral pain medication with a morphine patch. Unfortunately, the patch took 24 hours to become fully effective. Winnie blamed herself for the pain her husband endured in those hours. "I felt I didn't do enough," she said later. "I felt terrible because I couldn't help him. I felt pretty inadequate."

It was her memory of this experience—especially her sense of inadequacy—that, after Clayton's death, led Winnie to join a group some of her neighbors had formed to improve end-of-life care in our community.

## THE END OF LIFE CARE COALITION

Our community is in the largely rural area of south-central Wisconsin. We launched the



Life Care Coalition.

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## *Coalition in Southern Wisconsin Works to Improve End-of-Life Care*

BY REV. WILLIAM  
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Baraboo-Wisconsin Dells Area End of Life Care Coalition in January 1998. Our 30 members include—besides interested citizens like Winnie Holmes—healthcare professionals (from St. Clare Hospital and Health Services and St. Clare Meadows Care Center, both members of SSM Health Care, St. Louis; Wisconsin Dells Health and Rehabilitation Center; Home Health United Hospice; and Sauk County Public Health), social workers (from Sauk County Human Services), and clergy (from the Baraboo Area Christian Ministerial Association).

The coalition's goal is to provide its community with the highest possible quality of end-of-life care. In our first two years, we have:

- Written and disseminated a pain-and-symptom management pathway to be used by local physicians.
- Published a booklet on death and dying for the community. The booklet includes a glossary that facilitates communication between caregivers and the public.
- Sponsored six continuing medical education programs for local healthcare professionals.
- Begun work on an educational video.

We've been able to accomplish most of this with existing resources. We're proud to note that St. Clare Hospital serves as a model for the Joint Commission on Accreditation of Healthcare Organizations's standards for pain management in rural hospitals. If other communities wish to construct their own end-of-life care coalitions, our experience may provide some ideas.

## THREE TEAMS

At our first meeting, in February 1998, we held a brainstorming session, coming up with nearly 100 ideas for improving local end-of-life care in the community. We then organized ourselves



into three teams—on clinical care decisions, education and information, and family and spiritual concerns—each of which would deal with an aspect of the problem as we understood it.

After that, we met once a month, each time gathering first as a group, then breaking off for team sessions, and then coming together again to report on our discussions. In addition, the teams met frequently between coalition meetings. This approach facilitated cohesiveness and effective communication.

#### **The Care Decisions Team**

Knowing that pain and symptom management is a significant problem for people suffering from a life-threatening illness, this team developed what it called Comfort Care Pathway Standing Orders, based on best practices. These orders address pain, anxiety, and other symptoms; the use of oxygen; family involvement; end-of-life education; and spiritual concerns.

The Comfort Care Pathway Standing Order has been adopted by both St. Clare facilities, Wisconsin Dells Health and Rehabilitation Center, and Home Health United Hospice. Disseminating best practices in our area is made easier by the fact that the same group of physicians practice at the hospital, the nursing homes, and the hospice program.

**The Education and Information Team** During coalition meetings, family members often expressed their frustration in trying to communicate patients' needs to physicians. Physicians, in turn, related their struggle to know what to say and how to say it. Together we identified as a top priority reaching agreement on a common language about death and dying.

The team accordingly wrote a 60-page booklet called *Information about Death and Dying*. Intended for the general public, the booklet

answers questions frequently raised in end-of-life care, defining some of the words and phrases commonly used (see **Box**, p. 45).

The team is also writing and shooting an educational video. In a series of interviews, local physicians, nurses, members of the clergy, and others discuss life-threatening illnesses and the care needed by those who suffer from them. As with *Information about Death and Dying*,

the video is being made with our own community in mind (though we think both could be adapted by other communities). Knowing that people are often reluctant to talk about death and dying, we hope the video will serve as a catalyst for discussion.

Finally, the team has developed Growing through Grief, a six-week educational and support program for people grieving the death of a loved one. Coalition representatives facilitate this program; another representative leads a support group for people suffering from cancer.

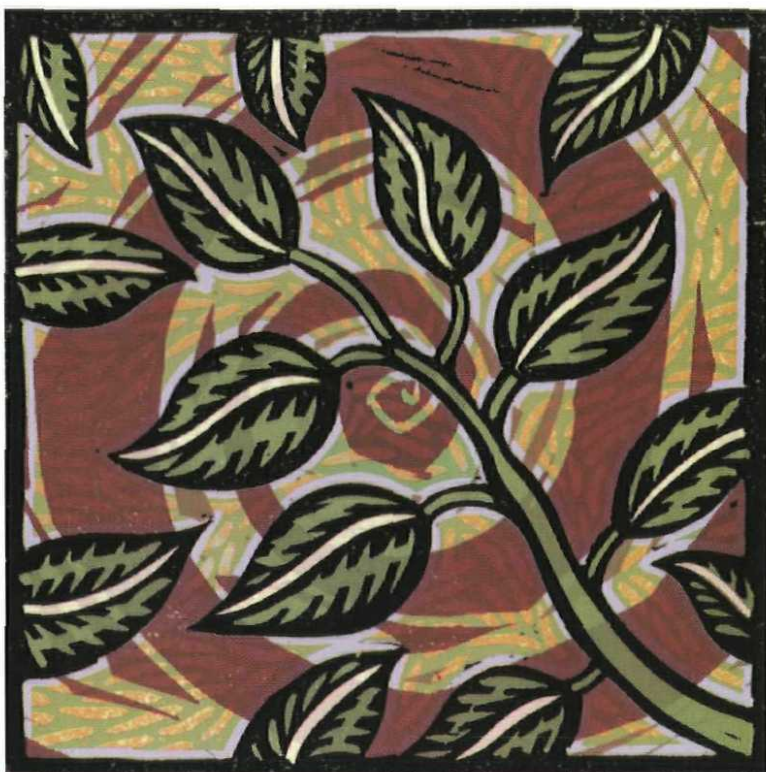
#### **The Family Care and Spiritual Issues Team**

Fears inspired by serious illness can be terrible for both the patient and his or her family members. Knowing that, this team is developing spiritual and psychosocial interventions for such situations. The team members, local clergy people, share their own fears and uncertainties about death in hopes of serving as a "learning laboratory."

#### **MEASURING THE COALITION'S EFFECTIVENESS**

The coalition has four ways to measure progress in its efforts to improve end-of-life care.

**Continuous Quality Improvement (CQI)** Since 1990 CQI has been an integral part of the culture at St. Clare Hospital and St. Clare Meadows Care Center. When the coalition was formed, the representatives of the St. Clare facilities





acquainted their coalition partners with the CQI process.

CQI allows us not only to identify opportunities for improvement but also to implement innovations. First, we employ brainstorming, focus groups, and patient and family surveys. Given these results—and considering strategic and financial planning, regulatory parameters, and quality control requirements—we create a conceptual design to fit the opportunity. Then, we implement a new process based on that design. We measure outcomes, leading to either modification or standardization of the process. By adhering to these principles, we avoid decisions based on assumptions, waste less energy and fewer resources, and are always open to further improvement.

**Organizational Assessment** In 1998 St. Clare Hospital joined eight other healthcare organizations in a pilot project conducted by Supportive Care of the Dying: A Coalition for Compassionate Care. The Organizational Assessment Project (see p. 49) surveyed patients, family members, healthcare professionals, and others on the quality of end-of-life care provided by those organizations. Feedback from St. Clare patients and family members was within a point or two of the aggregate response in those categories. Today the coalition uses the project's data to improve care for patients and their families.

**Public Assessment Survey** In 1998 the coalition administered a Public Assessment Survey at a meeting of a local service club, the members of which are fairly representative of our community. The members indicated that although end-of-life issues were important to them, they lacked knowledge about those issues. This fall, after giving club members copies of *Information about Death and Dying*, we surveyed them again and found that the booklet had sharpened their awareness and improved their knowledge of end-of-life issues.

**Comfort Care Pathway Tracking** Using this instrument, St. Clare Hospital is able to quantify patient satisfaction regarding pain management. Currently the data for it are obtained on a monthly basis according to patient type and nursing unit. But by classifying data according to diagnoses and demographic groups, we will soon be able to track improvements and identify opportunities for improvement.

A top priority for the coalition was agreeing on a common language about death and dying.

#### FOUR KEYS TO SUCCESS


Through its educational and symptom management initiatives, the coalition hopes to change the way the people of south-central Wisconsin experience death. Realizing that there are no easy answers, we nevertheless believe that no one should have to go through the helpless suffering Clayton and Winnie Holmes endured.

In the future the coalition plans to:

- Work with our local newspaper to publish a series of articles on end-of-life issues
- Form a Palliative Care Clinical Support Team—made up of nurses, social workers, ministers, and others—to provide support for the patient and his or her family and physician.

To communities planning to create their own end-of-life care programs, the coalition offers five key recommendations:

- Remember that end-of-life care is ultimately about relationships. The creation of good end-of-life care teams requires the use of personal contacts to form trusting relationships.
- Recruit as many local physicians as possible.
- Develop active, broad-based community support.
- Use CQI methods and base decisions on data.
- Collaborate with local healthcare providers, social service agencies, and churches. □

 For more information call Rev. William Beers, 608-356-1511.

#### "WORDS WE USE"

*Information about Death and Dying*, a booklet published by the Baraboo-Wisconsin Dells Area End of Life Care Coalition, includes a glossary of terms commonly used in end-of-life care. For example:

**Hospice** Hospice is more of an idea than an actual place. In ancient times, a hospice was a dwelling for travelers and the dying. Today "hospice" can be provided in private homes, nursing homes, and hospitals. . . .

**Crisis** When dealing with death and dying, the term "crisis" may refer to a physical, biological crisis when the person's condition changes suddenly, or "crisis" may refer to urgent, distressing spiritual, emotional or social matters affecting the person and family.

**Palliative** When a person's health has diminished to the point where remedies are not effective, comfort care may be all that remains. Palliative care means providing pain management, nutrition, emotional and spiritual care during the dying process.