

# THREE FACTORS CRITICAL FOR END-OF-LIFE CARE

*Leadership, Resource Commitment, and a Rights and Responsibilities Statement Can Enhance Care of the Dying*

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Organizations committed to appropriate care of the dying are experiencing transformation. They see and respond to the dying process systemically, as a natural part of life's journey. The effort they devote to service planning; to coordination of care across the delivery continuum; to education and training for patients, care givers, and providers; and to ensuring that the patient's and family's values are integrated into the care plan—all this will be the same as the effort dedicated, for example, to pregnancy, childbirth, and parenting.

In many respects, appropriate care of persons with life-threatening illnesses requires a different, perhaps higher level of response from organized healthcare than has been typical in the past. This article describes three critical components for ensuring that appropriate care is accessible for those who are dying.

## LEADERSHIP INVOLVEMENT

Leaders must be committed, visible advocates of high-quality end-of-life care.

**Summary** Appropriate care of persons with life-threatening illnesses requires a different, perhaps higher level of response from organized healthcare than has been typical in the past. This involves three critical components:

- Leaders must be committed, visible advocates of high-quality end-of-life care. This enables them to plan changes, deploy resources, and integrate this commitment throughout the organization's strategic plan.

- Ensuring appropriate care of the dying requires adequate human and financial resources. First, the organization must fully identify the educational and service needs of patients, families, and care givers

As many organizations learned in implementing continuous quality improvement or total quality management, a critical factor in achieving outstanding results is leadership commitment and involvement. This same lesson is applicable to appropriate care of the dying.

Top leadership in today's integrated healthcare delivery system includes the senior medical and administrative directors from the system office, health insurance plans, medical or physician groups, hospitals, nursing departments, home health agencies, and long-term care organizations. These committed leaders must be informed, knowledgeable, visible, passionate, and goal oriented in order to:

- Communicate and emphasize the value and importance of appropriate care of persons with life-threatening illnesses

- Nurture a commitment to improving the quality of end-of-life care through all levels of the organization

- Allocate adequate resources and provide support

Senior leaders' personal involvement in appro-

experiencing life-threatening illnesses. The organization must work well with other community-based organizations to address identified needs. Senior managers can improve care by personally commissioning teams, acknowledging success, and rewarding performance. Finally, organizational goals, strategies, and performance objectives must be shaped by a commitment to ensure appropriate care of the dying.

- Our commitment to the dying must be based on our values. An organizational "statement of rights and responsibilities" is one way of providing a visible expression of the mission, core values, and mutual responsibilities among care givers and patients, residents, HMO members, and clients.





## Supportive Care of the Dying

appropriate care of the dying enables them to plan changes, deploy resources, and integrate this commitment throughout the organization's strategic plan. Leaders must demand adherence to standards of care and scrutinize the kinds of people and organizations they collaborate with to achieve compassionate, competent, and skilled care of the dying.

### RESOURCE COMMITMENT

Ensuring appropriate care of the dying requires adequate human and financial resources.

Senior management must articulate a commitment to appropriate care of the dying, but commitment alone will not result in the organizational transformation necessary to provide such care. The type of change required is fueled by appropriately timed and placed resources, primarily financial and human. These resources must be deployed throughout the delivery system to foster organizational learning and process and system change. Such change includes involvement with external organizations that have similar values and commitments, frequent acknowledgment of accomplishments, and measures that explicitly delineate what the organization values.

**Identifying Needs** One of the premises underlying the activities of Supportive Care of the Dying: A Coalition for Compassionate Care (see **Box**) is that providers do not fully know the educational and service needs of patients, families, and care givers experiencing life-threatening illnesses. Not only does the provider community need to communicate with those it serves; it also must match identified needs with usable benefits. A learning organization welcomes this opportunity and is able to gather information from those it serves and educate staff, physicians, and partners about new ways to care for dying patients. By following formal education with practical tools and modeled behaviors—including mentoring—the organization can reinforce the learning and achieve a durable impact.

Information from patients, families, and care givers will help leaders identify the need for process and system change. Simple problem solving will not always produce the desired results, since the underlying causes may be process or structural. Re-engineering or redesign may be necessary to achieve desired outcomes (e.g., a single access point for information and advice for patients and care givers, care coordination across the continuum of services). The organization must have the patience to empower collaborative

teams of frontline staff in problem identification and solution design, testing, and implementation. This patience is exhibited in a willingness to provide staff-replacement time, facilitation, and just-in-time training to commissioned teams.

**Working with the Community** In caring for the dying, no organization can be an island. Meeting all the needs of patients, families, and care givers is, in most cases, practically and financially impossible. Besides, many individuals in our society have some type of support network (e.g., church, friends, professional colleagues, social organizations). Social, spiritual, and community connections are invaluable to individuals in times of crisis and change. If it takes a whole village to raise a child, it takes a whole community to care for the dying—and healthcare is just one part. How can we strengthen community-supported programs, hospice programs, and long-term care facilities and foster involvement in this important work?

In the Catholic healthcare ministry, we emphasize that we are an integral part of the community. One litmus test of that connectedness is how well we work with other community-based organizations to address identified needs. If we are providing appropriate leadership, we will support the projects and activities of community organi-

## SUPPORTIVE CARE OF THE DYING: A COALITION FOR COMPASSIONATE CARE

The Supportive Care of the Dying coalition was founded in 1995 by the Catholic Health Association and five Catholic healthcare systems: Carondelet Health System, St. Louis; Catholic Health Initiatives, Denver; Daughters of Charity National Health System, St. Louis; PeaceHealth, Bellevue, WA; and Providence Health System, Seattle. The coalition's goals are to:

- Assess the current level of care to identify, develop, and share delivery models pertaining to all dimensions of care for the suffering and dying
- Develop and implement a paradigm of compassionate care that integrates ethical, clinical, and spiritual dimensions
- Develop educational programs for professional care givers, families, and the broader community
- Establish criteria and measurement guidelines to assess processes, outcomes of education, compassionate care services, and methods of assigning accountability for these guidelines and processes
- Foster networking among care givers and identify resources within the broader community that support compassionate care of persons with life-threatening illness



zations that have similar values and commitments and are filling an unmet need. This community connectedness not only prevents wasteful duplication and competition; it also helps society weave a seamless safety net in which individuals and families can be heard and supported.

When this is truly working, all service providers in the community have a thorough knowledge of their own and others' resources. A simple telephone call results in the appropriate hand being extended to a person in need. To make this vision a reality, healthcare organizations must give of their time, treasures, and talents. They must provide leadership and resources by:

- Encouraging the volunteerism of employees and affiliated physicians
- Providing technical expertise (e.g., planning, grant writing) and trained staff to community-based projects
- Making donations, grants, and long-term funding commitments

## STATEMENT OF RIGHTS AND RESPONSIBILITIES

The dying person can expect:

1. To be treated respectfully and with dignity at all times
2. To be given all necessary information, to have questions answered honestly, and to never be deceived
3. To be the primary decision maker (or to have his or her surrogate be such) concerning care, and not to be judged for his or her decisions, even if they are contrary to the beliefs and values of others
4. To be cared for by a compassionate, knowledgeable, interdisciplinary team that attempts to understand the needs of the dying, seeks necessary consultations, and makes appropriate, timely referrals to enhance the comfort care needs of the individual and his or her loved ones
5. To receive holistic, compassionate, skillful care throughout the trajectory of illness—care that promotes healing for individuals and families with attention to the patient's changing needs (i.e., the transition from aggressive care [cure] goals to palliative, supportive, and terminal care)
6. To be able to express feeling, emotions, and religious or spiritual needs, and to have his or her ethnic, cultural, or religious values respected
7. To receive optimal and effective pain and symptom management
8. To have help from and for his or her family, friends, care givers, and significant others in accepting death
9. To die in peace and dignity, and not alone, with meaningful presence, generous hospitality, and faithful companionship

**Celebrating Accomplishments** Leadership can also be expressed in the celebration of accomplishments. Frequent recognition is critical in fostering and sustaining organizational transformation. Recognition of teams or individuals who have completed a project, made a difference for a patient and family, or performed exceptionally well is a way to highlight organizational values.

Senior managers can hasten the achievement of high-quality end-of-life care by personally commissioning teams, acknowledging successes, and rewarding performance. Providing protected time for preparing presentations and writing papers that share an organization's experiences gives employees and the organization deserved recognition, as well as the opportunity to compare their activities with those of others.

**Using Measurement Tools** In modern organizations, what is measured is what is valued, and what is not measured is not done. If we measure something, we draw attention to it, and in so doing can achieve intended, as well as unintended, behavior modifications.

It is interesting that most healthcare organizations do not measure whether pain was effectively controlled, whether the delivery of services to individuals with life-threatening illnesses was seamless, or whether the care for the dying was appropriate. Do we even know our own organization's values and attitudes toward dying, let alone those of the individuals we serve? Do we credential physicians because they are committed and skillful in their care of the dying? Do we hire nurses and allied care givers who champion competent and compassionate care of persons with life-threatening illnesses?

Embedded in our metrics must be the force of change. How are we explicitly using measurement tools to assess provider skills, quantify outcomes, and establish organizational standards and guidelines that focus on care of the dying? Our goals, strategies, and performance objectives must be shaped by a commitment to ensure appropriate care of the dying.

### VALUES-BASED ASSURANCE

Our commitment to the dying must be based on our values.

Healthcare organizations are accountable to those they serve. This is not a new concept, but insurers' and payers' insistence on documentation (e.g., in the form of a quality report card; outcomes measurement; and the Health Plan Employer

*Continued on page 44*



## SCHOOL-BASED CARE

*Continued from page 43*

# Parents who are nurses have heard about the program and volunteered.

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schools in Mishawaka. Currently students from three nursing schools—Indiana University of South Bend, Saint Mary's College, and Bethel College—work with the volunteer nurses to provide services.

### **VOLUNTEERS—THE PARTNERSHIP'S BACKBONE**

What motivates health professionals to give of their limited time? "I just saw the need," said Deb Ketchum, RN, who volunteers at St. Matthew's Grade School in South Bend. "My children attend St. Matthew's. And when I heard about what had happened, it seemed like the natural thing to do to step in. But believe me, the school needs more than I can give. They all do."

Ketchum works as a nurse in the public school system during the day. At night and on weekends throughout the school year, she fills out the health cards needed for each St. Matthew's student's record. During her spring break she conducted vision and scoliosis screenings at the Catholic school.

Bettye Green, the parish health ministry coordinator at Saint Joseph's Medical Center, also serves as the School Health Partnership coordinator. The Parish Health Ministry Program is similar to the School Health Partnership in that it trains volunteers to provide services. Green trains the parish health ministry volunteers, most of whom are not nurses, to perform health screenings and basic testing right in the churches, usually following Sunday services.


Her work with the school program is similar. She arranges for volunteer

training and sees that the needs of each school are met. Recruiting the volunteers has not been a problem. In some cases, the principals know which parents are nurses and have approached them directly. Other nurses, like Ketchum, have heard about the new program and stepped forward themselves. The volunteer staff also recruits non-nurse parents to take care of the endless paperwork.

"The schools are still identifying their needs and finding out what we have to offer," said Kathy Decker-Burrous, administrator of family and community services at Saint Joseph's Medical Center. "A lot of our existing programs, such as emergency response training, CPR, AIDS education, and babysitting training, could be tailored to a school's needs."

Superintendent Barrett-Jones sees this partnership as one that could benefit other persons, as well the students. "I really hope that the staff can also benefit from the health fairs and other planned programs," she says. "We are all learning more about health concerns, such as the benefits of fitness programs and good nutrition."

Shrinking dollars combine with a growing need for health education, testing, and treatment to challenge healthcare organizations to do more with less. But through innovative efforts like the School Health Partnership in South Bend and Mishawaka, hospitals can pursue creative ways to keep their community healthy. □

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## END-OF-LIFE CARE

*Continued from page 32*

Data and Information Set, or HEDIS, which keeps track of various kinds of medical data) has added to the competitiveness in today's healthcare environment. Why do those we serve have to demand accountability? Are we unprepared to respond to the thousand "moments of truth" that confront us each day? And, more important, are we afraid to assure patients near the end of life that they will have a dignified and painless death, a death that honors Catholic values and traditions?

Death is an experience from which the survivors can learn much. Unfortunately, healthcare has historically veiled death within its walls. Healthcare providers must share the dying experience with families and the community, and they must also ensure that the dying person is respected.

One vehicle for expressing our commitment to high-quality end-of-life care is an organizational "statement of rights and responsibilities." In this statement, which is our visible expression of the mission, core values, and mutual responsibilities among care givers and patients, residents, HMO members, and clients, we promise to meet certain expectations of a dying person (see **Box**, p. 32)

If we cannot carry out all these promises today, we should at least identify those which we *can* carry out, and commit ourselves to expanding the list. If the cross is the symbol of who we are, then our statement of rights and responsibilities—our values-based assurances—must be the symbol of what we do.

Clearly leadership, resources, and the physical expression of our values are critical components in ensuring appropriate care of the dying. Even when other important factors are present, the absence of these would make it impossible to achieve the transformation essential for providing competent, compassionate care. □

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