

America's end-of-life care

There's light at the end of the tunnel

By ROBERT MILCH
AND J. DONALD SCHUMACHER

When 53-year-old Barbara Wein was diagnosed with ovarian cancer three years ago, she faced what has become the end-of-life dilemma for most critically ill Americans.

Like many baby boomers, Wein was used to being in control of her life. She was a National Ski Patrol member, physically active and independent. She and her husband of 26 years traveled widely. She had no children but enjoyed an extensive family circle — both her parents were alive, and she had two sisters and several nieces and nephews.

She read extensively about her disease, harbored no illusions about its seriousness and decided to fight it. She tried surgery, then months of chemotherapy followed by another operation and continuing rounds of other therapies.

"Early in my struggle with ovarian cancer," the Buffalo, N.Y., homemaker told friends this year, "my goal was to beat it, despite the odds. Probably six months into my diagnosis, I realized I might not."

When she tried to talk to her medical team, they had no problem discussing the physical effects of her disease, but were reluctant to talk about its emotional impact.

"They seemed uncomfortable about it, and I didn't push it," she said. But Wein wanted to live the rest of her life with hope and desperately needed guidance.

Last winter, she got sicker, and she had to lean more heavily on others for her care, something she never expected nor wanted. Her husband's work frequently kept him away from home, and she finally moved in with her mother. Abdominal pain from a recurrent tumor kept her indoors much of the time. Doctors predicted her death within a year, but the only treatment they offered was a course of "salvage" chemotherapy.

But the chemotherapy caused weeks of nausea and vomiting. Wein had a tube in her stomach to vent a bowel obstruction. She was in continual pain. She couldn't sleep. Anxiety and depression took hold until she couldn't think straight. After 10 days in the hospital, she was sent home, where she was kept going by an intravenous feeding tube.

As death drew closer, Wein nearly lost her will. "My symptoms had taken over my life," she later said. "I wanted to die. Death had to be better than feeling sick." Wein knew only one thing — this was not how she wanted her life to end.

The questions Wein faced in the months before her death now hang before 76 million baby boomers who are approaching old age and caring for ailing parents: How can the critically ill make the most of their time? How can we gracefully prepare for death? And how as a nation can we start to rethink the way we live with dying?

Wein's experience is mirrored in a June report from the National Cancer Policy Board, a committee of the Institute of Medicine and National Research Council, that found half of the 550,000 Americans who die of cancer each year suffer needlessly from pain, nausea, depression, fatigue and other symptoms. Yet only 1 percent of the National Cancer Institute's \$2.9 billion budget went to research and training related to palliative care, which focuses on pain management and comfort for the critically ill in a hospital setting.

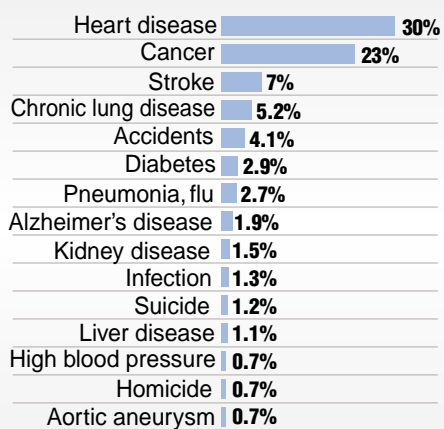
Because of American medicine's "single-minded focus on finding a cure for cancer, many cancer patients and their families are receiving inadequate pain and symptom control, as well as poor psychological, so-

Americans and dying

Every year about 2.4 million people die in the United States.

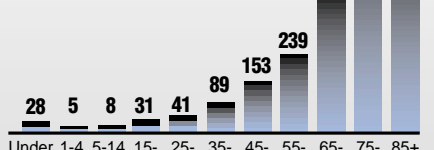
Leading causes of death

Preliminary figures for 1999



Age of people who die

Number of deaths, 1999, in thousands



Source: National Center for Health Statistics

cial and spiritual support," the report found.

This year, in a landmark decision, a California jury awarded \$1.5 million to the family of a deceased California man after finding a doctor negligent in treating his pain. The decision is the first in which a jury determined that inadequate treatment of pain translates into abuse of an elderly person and could affect how medical licensing boards and the legal system view complaints about people in pain.

The medical and legal professions are just now recognizing serious deficiencies in care of the dying first identified in a pivotal 1995 study funded by the Robert Wood Johnson Foundation. Of 9,000 critically ill people in the study, half had poorly controlled pain. Many of their doctors were unaware their patients had expressly asked not to be resuscitated or simply disregarded their wishes.

The report, known as the SUPPORT study, alarmed the health care profession by putting a very public spotlight on the pervasiveness of inadequacies in care planning and delivery, the lack of communication among those charged to care for the dying and the resistance of hospital culture to change.

There are signs of both great longing and great promise ahead. This is America's other budding crisis in health care — while research for cures of life-threatening diseases barrels ahead, more and more Americans are also looking for better ways to die.

In a 2000 survey of seriously ill patients, bereaved families and health-care practitioners published in the *Journal of the American Medical Association*, Americans listed the goals for the end of their lives this way: Control of their care, time to build stronger relationships with loved ones, relief of care-

What should you expect?

What kind of medical treatment are you entitled to at the end of your life? The following "core principles," developed in 1999 to guide treatment for dying patients, have been adopted by major medical organizations:

- Respect the dignity of both patients and caregivers.
- Be sensitive to and respectful of the patient's and family's wishes.
- Use the most appropriate measures that are consistent with patient choices.
- Encompass alleviation of pain and other physical symptoms.
- Assess and manage psychological, social and spiritual/religious problems.
- Offer continuity (the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers).

- Provide access to any therapy that may realistically be expected to improve the patient's quality of life, including alternative or nontraditional treatments.
- Provide access to palliative care and hospice care.
- Respect the right to refuse treatment.
- Respect the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences.
- Promote clinical and evidence-based research on providing care at the end of life.

From *The Milbank Memorial Fund's "Principles for Care of Patients at the End of Life: An Emerging Consensus Among the Specialties of Medicine,"* by Dr. Christine Cassel and Dr. Kathleen Foley.

giving burdens on others, and most of all, the choice to avoid a prolonged, painful death.

The path toward more compassionate end-of-life care is well lit. Kathleen Foley is one of the American pioneers in pain management and palliative care and attending neurologist at Memorial Sloan-Kettering Cancer Center in New York. She said the SUPPORT study pointed out "the critical need to apply the knowledge we have now to prevent needless suffering."

"We have made extraordinary advances in pain management and palliative care," said Foley, "and we need to ensure that all Americans have access and availability to state-of-the-art symptom control and supportive therapies."

What Foley is referring to is medical care that can be as simple as pain medication offered by a primary doctor to entire teams offering treatment and counseling to dying patients and their families, even while still searching for a cure.

In the six years since the SUPPORT study was released, America's health care system slowly has started to respond. Hospice care, mainly for dying patients at home, has become more familiar to Americans, and according to a 1999 survey by the American Hospital Association, 20 percent of hospitals now have some type of palliative services.

Influential medical groups such as the American Board of Internal Medicine, the American College of Surgeons and the American Cancer Society are redefining their roles in end-of-life care. Insurers throughout the country — including Blue Cross-Blue Shield, Kaiser-Permanente and the National V.A. Healthcare system — are looking at expanding coverage of end-of-life care.

The focus on compassionate care is especially important in the doctor-patient relationship. A study of medical textbooks published in the *Journal of the American Medical Association* found doctors are taught little about palliative and hospice care as part of traditional training. Less than one-third of medical

schools and residency training programs integrate palliative care; the same is true of schools of nursing and social work.

The result: Physicians who have a hard time listening and talking honestly and compassionately with patients as they navigate the shoals of end-of-life issues — from breaking bad news to planning treatment to preparing a patient for death.

"Understanding the concerns, needs, hopes and fears of patients and their families is an essential first step in providing optimal care in this situation," said Dr. Bernard Lo, director of the Program in Medical Ethics at the University of California, San Francisco. To help doctors do this, the American College of Physicians/American Society for Internal Medicine has published articles and brochures that doctors can give out to patients and their families.

Hospitals, too, are looking more closely at institutional training and programs.

"Hospitals strive constantly to improve care for all our patients, especially those at the end of life," said Dick Davidson, president of the American Hospital Association. "Can we do a better job? Always, and the key is education and innovation."

Many Americans got a first glimpse of the new possibilities in 2000, when PBS broke a major cultural taboo with its critically lauded four-part series, "On Our Own Terms — Moyers on Dying." The series, which examined alternative ways to approach death, pulled in 60 percent more viewers

than any show ever aired on the public network.

The momentum from that series flowed nationwide, resulting in spirited grass-roots efforts to get out the end-of-life message. In Kansas alone, 21 coalitions are leading their communities in identifying and addressing issues such as pain management and planning for end-of-life care.

Kathleen Foley, who also is director of Project on Death in America, a nonprofit group that encourages innovations in end-of-life issues, has watched awareness and treatment options steadily grow over the past 30 years.

"As we focus attention on transforming the culture of death in America, it's useful to look at the history of death and dying in this country," Foley said. "At the beginning of the 20th century, Americans died at home. With the professionalization of medicine and the institutionalization of medical care, the care of the dying shifted from home to hospital.

"Although there is wide variation in the place of death," Foley said, "the majority of Americans continue to die in hospitals."

Despite that fact, the message is spreading, from hospice bed to nursing-school classroom: Baby boomers, accustomed to knowing what they want and how to get it, are beginning to demand the ultimate right.

As the end draws near, Americans are saying, give us the time, information and guidance to move to the final reprieve of palliative and hospice care. Allow us in our last days to live smart, to embrace the life we have left and to make our deaths our own.

Which, finally, is what Barbara Wein did.

After doing her own research, Wein called her local hospice, asked her physician for a referral and was admitted to its inpatient unit.

At the Center for Hospice and Palliative Care in Buffalo, Wein found solace. First, medications promptly controlled her pain, nausea, vomiting and depression. She was able to sleep and rest, and over the next days, she had rich discussions with family, friends and staff, exploring what her goals were for the rest of her life. From these were derived a plan of care to maximize her stamina while maintaining her comfort.

She still had "a few things to tie up, a few things I want to do."

Barbara elected to resume getting her nutrition intravenously. She took a number of brief road trips — a last time to her home, a visit to a lighthouse on the lake. She had a "hen party" and numerous visits with friends. She and her mother discussed her experiences with a group of medical students who came to the hospice as part of their Family Medicine rotation. They kept her for more than an hour, questioning, talking and listening.

A few days later, she decided it was time to stop the intravenous fluids that had tided her over as she took control of her life.

Five days later, Barbara Wein did beat the odds. She died the way she chose.

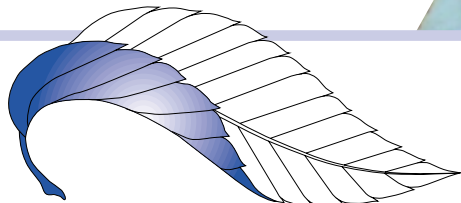
Dr. Christopher Kerr also contributed to this article. For more resources and contacts on end-of-life issues, go to www.findingourway.net.



Barbara Wein in 1998

Barbara Wein, shown with her husband, Bob, just two weeks before her death this year at age 56, confronted many issues faced by critically ill Americans.

COURTESY OF PARTNERSHIP FOR CARING



FINDING YOUR WAY THROUGH END-OF-LIFE RESOURCES

These nonprofit organizations provide a wealth of state-of-the-art resources to help you make thoughtful health-care decisions for yourself and your family at the end of life:

Finding Our Way: Living with Dying in America: Get up-to-date information on advanced illnesses and end-of-life care, including links to all of the resources in the accompanying series. www.findingourway.net

Partnership for Caring: America's Voices for the Dying: Download forms for advance directives tailored to your state; join a consumer advocacy group focused on improving end-of-life care. www.partnershipforcaring.org

The Last Acts Campaign: Research latest news on legislative, educational and policy initiatives from local, state and national organizations. www.lastacts.org

The National Hospice and Palliative Care Organization: Search for hospice and palliative care, two types of care dedicated to comfort at the end of life. www.nhpc.org

Growth House: Search this "Yahoo of Death and Dying" for comprehensive links to end-of-life care, including many that focus on diversity. www.growthhouse.org

The Center for Advanced Illness Coordinated Care, in collaboration with the Veterans Administration Healthcare Network of Upstate New York at Albany: Find guidance on coping with the complexities of serious illness

through the "Walking the Advanced Illness Road" section. www.coordinatedecare.net

AARP: Offers extensive information on and support for caregiving, illness, grief, widowhood, funerals, wills and estate planning, and advance directives. www.aarp.org/endoflife

Aging With Dignity: Download Five Wishes, a planning document. www.agingwithdignity.org

Project on Death in America: Lists end-of-life innovations in the arts, social work, education and public poli-

cy. www.soros.org/death

Center to Advance Palliative Care: Search the latest resources in palliative care available to hospitals and health care systems. www.capcmssm.org

Missoula Demonstration Project: Research this site for communities interested in setting up models for improved care at the end of life. www.dyingwell.com/MDP.htm

Community-State Partnerships to Improve End-of-Life Care: Find out what individual states are doing to organize health care professionals, educators and policymakers. www.midbio.org

Promoting Excellence in End-of-Life Care: Research programs that have received grants and technical support to change the face of dying in America. www.endoflifecare.org

Americans for Better Care of the Dying: Track changes in public policy, as well as reforms in pain management and support for family caregivers. www.abcd-caring.org

American Academy of Hospice Physicians: Find board-certified hospice and palliative care physicians. www.aahpm.org

For more resources, go online to www.findingourway.net

ABOUT THE AUTHORS



Robert Milch, M.D., is medical director at the Center for Hospice and Palliative Care in Buffalo, N.Y., and associate clinical professor of surgery and adjunct assistant clinical professor of family medicine at the State University of New York at Buffalo School of Medicine and Biomedical Sciences.



J. Donald Schumacher, Psy. D., is president and chief executive officer for The Center For Hospice and Palliative Care in Buffalo, N.Y.