

Quality of Life Matters™

End-of-life care news & clinical findings for physicians

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The Physician's Letter of Condolence: A Concrete Gift of Healing

The physician's responsibility for care is not ended by a patient's death, says a team of Boston physicians. In an article published in the April 12, 2001, issue of *The New England Journal of Medicine*, the authors say bereaved family members need both **a sense of closure in their relationship with their loved one's physician and a feeling of support** as they work through the natural process of grief.

One of the finest ways for a physician to promote this healing is by writing a letter of condolence, the authors note.

"A letter that addresses the reality of death **aids the family in accepting 'the discomfort of bereavement' and affirms the importance of the relationship between the deceased person and the doctor,**" write Susanna E. Bedell,

MD, and colleagues at Brigham and Women's Hospital, Boston.

"Unlike expressions of condolence made by telephone or in person, **a letter of condolence is a concrete gift** that the recipient can and will review over and over."

PERCEIVED BARRIERS

Physicians may perceive a number of **barriers to writing such a letter**, note the authors. These barriers can include: the lack of time; a feeling that one did not know the patient well enough; being part of a clinical team with no clear assignment for contacting the family; not having seen the patient in some time; and finally, just not knowing what to say.

But **failure to communicate** with the family conveys a lack of concern about

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SUGGESTIONS FROM BEDELL & COLLEAGUES

Begin the letter with a direct expression of sorrow: "I am writing to send you my condolences on the death of your husband."

Avoid superficial attempts at comfort, such as: "It was meant to be" or "I know how you feel."

Try to include a personal memory of the patient and a specific reference to the patient's family, work, or character.

Focus on the sadness of the death rather than on clinical details of the illness, and avoid possible issues of legal liability.

Tell the family it was a privilege to have participated in the patient's care.

Mention the comfort the patient received from the family's love.

Conclude with an expression of support: "My thoughts are with you."

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Hospice Care in Forefront As National Initiative Aims to Improve Care of Children

Not just cancer: Focus includes many other life-threatening illnesses

In the wake of a recent Institute of Medicine (IOM) report emphasizing the need for better palliative and end-of-life cancer care for children, a new national effort has been launched to improve the care of children with a variety of life-threatening conditions.

The Educational Development Center, Inc. (EDC), a nonprofit research center based in Newton, Massachusetts, has announced the receipt of funding to begin its quality improvement project, **Enhancing Family-Centered Care for Children Living with Life-Threatening Conditions**.

"Whereas the IOM report focuses specifically on pediatric cancer care, our goal is to improve the care of children with a wide variety of life-threatening

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National Initiative for Care of Children *(from Page 1)*

conditions — including traumatic injury, complications of prematurity, congenital anomalies, AIDS, as well as cancer — which together represent the major causes of childhood death,” says Mildred Z. Solomon, EdD, director of the new initiative and of the EDC’s Center for Applied Ethics and Professional Practice.

The EDC has brought together seven children’s hospitals nationwide to serve as pilot sites for the project. **The initiative plans to:**

- Conduct qualitative and quantitative **research** on clinicians’ and parents’ perspectives of pediatric palliative care
- Establish **quality indicators** of family-centered care for children with life-threatening conditions
- Develop **new curriculum materials** to upgrade the clinical skills of physicians, nurses, and other health care professionals caring for gravely ill children

After being pilot tested at the participating hospitals, the newly developed quality improvement materials will be disseminated nationally by the National Association of Children’s Hospitals and Related Institutions. That organization will ask its members to identify palliative care “champions” for the fostering of innovations among the broader pediatric health care community.

The first two **curriculum modules** will address:

- **Pain** and symptom management
- **Family involvement** in decision-making

As the initiative continues, further funding will be used to develop **additional modules** on such topics as:

- **Ethics** and law
- **Communication** skills
- **Bereavement**

Another partner in the project, the New York Academy of Medicine, will help develop strategies for integrating the project’s curriculum into **medical schools and continuing medical educational settings**. As well, the Society of Pediatric Nurses will assist in the development of educational resources and in the dissemination of quality improvement materials through the **efforts of pediatric nurses**.

Start-up funding for the initiative has been provided by the Nathan Cummings Foundation and the Open Society Institute’s Project on Death in America, both based in New York City, along with an anonymous

third foundation donor.

“Childhood death and life-threatening illness have been taboo subjects in the country for too long. We hope that our actions will spur other funders to join with us. This is just the beginning,” says Andrea V. Kydd, health program director at Nathan Cummings.

For further information and a list of participating hospitals, visit www.edc.org.

*About **one million** American children are currently living with life-threatening conditions; approximately **54,000** children die each year, with most deaths occurring in the hospital.*

—Source: EDC

Primary Care Physicians Essential to Patients' Palliative Care

In their introduction to a new series on palliative care issues in the September 2001 issue of the *Western Journal of Medicine*, the series editors remind primary care physicians of the essential role they play as guides to the direction that their patients’ end-of-life care will eventually take.

During the early phases of treatment for chronic and life-limiting conditions, say the editors, **primary care physicians set patterns for future care in areas of:**

- Patient-physician communication
- Medical decision making
- Negotiating through systems of care

Although patients in the terminal stages of illness may no longer be under their primary physicians’ care, **“how well these physicians do with this communication and decision making has an important effect on patients’ experiences as they are dying,”** write Anthony L. Back, MD, and J. Randall Curtis, MD, both of the University of Washington School of Medicine, Seattle.

The series will present evidence-based case reviews illustrating clinical situations familiar to primary care physicians. These situations are intended to serve as markers for that transition point when palliative care should become a central fea-

ture of standard medical care.

Primary care physicians need to recognize when key issues in palliative care present themselves, note the editors, because this often occurs long before a palliative or hospice care service is involved. Topics in the series will include:

- Symptom assessment and management
- Communication about prognosis and treatment preferences
- Treatment of depression in seriously ill patients

For more information, visit the journal's website at www.ewjm.com.

VA Training Program Hailed As 'One of the Most Important Developments in Palliative Care'

More than half of the physicians now practicing nationwide have received at least part of their professional education in the VA health system

The federal Department of Veterans Affairs (VA) has announced the selection of the six health care sites that will launch its fellowship program aimed at **changing the way physicians, nurses, social workers and other caregivers approach end-of-life care for veterans across the nation.**

Called the Interprofessional Fellowship Program in Palliative Care, the VA initiative will fund four one-year fellowships at each training site. **Up to one half of the trainees will be physicians;** the rest will come from the professions of nursing, social work, psychology, pharmacy, and clinical pastoral care.

SHIFTING PHYSICIANS' FOCUS

"The training changes the focus of health care providers who are treating the terminally ill," says Stephanie Pincus, MD, chief of the VA Office of Academic Affiliations. **"In the past, doctors saw death as a failure,** so they consequently focused on medical cures and preventing death at any cost. We are training medical care staff now to **refocus on the patient** by jointly managing the patient's symptoms and the disease."

The new fellowship program will have a **strong emphasis on education.** The hub site, located at the VA facility in Palo Alto, California, will develop and implement the core curricula and coordinate with other sites, while selected VA facilities will commit to spreading information beyond the training site.

"This program is one of the most important developments in the field of palliative care," says Susan Block, MD, head of the department of adult psychosocial oncology at the Dana-Farber Cancer Institute, Harvard Medical

As resident physicians move from VA facilities out into the community, they will take their new training with them, thus affecting how palliative care is provided nationwide.

School, Boston. "The fellowships will train a cadre of expert clinicians who will serve as beacons for others interested in improving care at the end of life throughout the VA and the country."

HOSPICE CARE SEEN AS A MODEL

The VA has strongly supported the integrated approach of hospice care for terminally ill patients. As one of the nation's largest health care systems, it initiated the Faculty Leaders Project for Improved Care at the End of Life in 1998, and promoted the **importance of an interdisciplinary approach to assessing and treating pain** in its National Pain Management Strategy, launched in 1999.

Pincus foresees multiple **benefits for the terminally ill veteran** arising from

the new palliative care fellowship program. Patient benefits include:

- ✓ Greater **comfort** from improved symptom management
- ✓ Treatment by a **caring partnership** of professionals trained in palliative care
- ✓ The opportunity to **die at home,** rather than in an intensive care unit
- ✓ The **inclusion of the patient's family** in decision making and caregiving

"There comes a time when all the modern medicine in the world can't cure the illness," says Pincus. "That's when treating the pain, communicating with compassion, and providing support and counseling become paramount. That's what these fellowships are all about."

In addition to the hub site in Palo Alto, the selected VA facilities are located in Los Angeles; Milwaukee; New York City; Portland, Oregon; and San Antonio.

For more information: www.va.gov/oaaf/rlp.

Letter of Condolence *(from Page 1)*

their loss, the authors warn. **"In a medical world shaped by technological advances in the care of patients, we must maintain our humanity in our interactions with patients and their families,** particularly when we share with them some of the most profound moments of life and death."

Sending a written message to the family has the added benefit of relieving the physician's own sense of loss or failure, adds the team. **Physicians, like families, need to have a sense of closure about the death of a person in their care.** "After a patient dies, when we all feel helpless, the best care we can provide is our expression of concern and sympathy in a letter of condolence."

Hospice Care in Nursing Homes May Reduce Hospitalization Rates for All Dying Residents

'Hospice referral and presence can assist physicians in managing the care of dying nursing home residents,' say Brown University researchers

Elderly nursing home residents who receive hospice care through Medicare are less likely than their nonhospice peers to be hospitalized in the last 30 days of life, a new study has found.

Further, nonhospice residents who die in nursing homes with a moderate hospice presence have lower rates of end-of-life hospitalization than those in facilities with little or no hospice use.

“Our data suggest that the greater the hospice presence in the nursing home, the lower hospital use is for all dying patients,” write the study authors. “If hospice penetration signifies diffusion of hospice palliative care philosophy and practices, we believe it must emerge from interorganizational collaboration between the hospice and nursing facility.”

The presence of hospice philosophy in a facility can improve quality of life by maintaining those patients who choose hospice in one place, under the close medical supervision of one staff, and without the hazards of aggressive — and often inappropriate and costly — nonpalliative interventions associated with end-of-life hospital stays, the authors note.

The researchers retrospectively compared a cohort of 9,202 nursing home residents in 5 states (Kansas, Maine, Mississippi, New York, and South Dakota) who were enrolled in hospice between 1992 and 1996, and who died before 1998, to a matched cohort of 27,500 nonhospice residents. Median age of subjects in both cohorts was 84 years.

In the 30 days before death, 24% of the hospice cohort

was hospitalized, while the rate for the nonhospice cohort was 44%. In multivariate analysis, receiving hospice care for any portion of the last 30 days of life was significantly associated with a reduced likelihood of hospitalization (odds ratio 0.43; 95% confidence interval: 0.39 to 0.46). Further, **residents enrolled in hospice for the entire last 30 days of life had a hospitalization rate of 1%, compared with a rate of 42% for their nonhospice cohort matches.**

When all 226,469 nonhospice residents who died in the United States during the same time period were considered, 47% of those in facilities with no hospice were hospitalized within the last 30 days of life, compared with 41% in facilities with low hospice use (0.1% to < 5% of patients) and 39% in facilities with a moderate hospice concentration ($\geq 5\%$).

“Reductions in hospitalizations associated with hospice care may potentially improve the quality of life at the end of life for nursing home residents, as well as result in Medicare inpatient expenditure savings and perhaps in total Medicare expenditure savings for nursing home residents,” they write.

“Research is needed to evaluate whether these associated benefits do indeed occur. Nevertheless, these findings, as well as other related research, suggest that **hospice referral and presence can assist physicians in**

managing the care of dying nursing home residents.”

Source: “Hospice Enrollment and Hospitalization of Dying Nursing Home Patients,” The American Journal of Medicine; July 2001; 111(1):38-44. Miller SC, Gozalo P, Mor V; Center for Gerontology and Health Care Research, Department of Community Health, Brown University, Providence, Rhode Island.

The Study At A Glance:

Improved Quality of Life for All

- The greater the hospice presence in a nursing home, the lower the hospital use for all dying patients, investigators found.
- Costly, aggressive, and often inappropriate end-of-life hospital stays might be reduced in nursing homes where hospice care is provided, the authors note.
- The use of hospice care for nursing home residents might result in potential savings in Medicare inpatient expenditures and in total Medicare expenditures, researchers say.

Few Physicians Share Frank Prognosis with Terminally Ill Cancer Patients

A Chicago study of terminally ill cancer patients and their physicians found that even if cancer patients requested survival estimates, **in 63% of cases, physicians would provide no estimate or an inaccurate estimate (usually one that was overoptimistic).**

In the prospective cohort survey, researchers set out to determine if physician behavior contributes to observed disparity between patients' and physicians' prognostic expectations. Such disparity has been documented in other studies and found to **hinder patients' ability to make informed medical and personal decisions at end of life.**

"Physicians want to give patients hope...."

"At some point, patients might benefit more from having their doctors shift the focus from providing hope for recovery to hope for a good death."

—The Co-Authors

Investigators conducted a telephone survey with 258 Chicago-area physicians who referred 326 patients to local hospice care in 1996. Each physician was asked a number of questions, including, **"what is your best estimate of how long you think this patient has to live."** Twenty questions later, the physician was asked what he or she would tell the patient if the patient or family insisted on knowing a specific estimate of survival.

Researchers compared the physicians' formulated and communicated prognoses. Among their findings:

- ✓ In 22.7% of cases, physicians stated they would provide **no estimate.**
- ✓ In 37% of cases, physicians said they would communicate the **exact survival estimate** they had formulated.
- ✓ In 40% of cases, physicians said they would communicate a **different estimate** from the one formulated. Of these, a wide majority (70.2%) were overly optimistic in their prognoses.

The researchers comment: **"If physicians infrequently provide frank disclosure to hospice patients with cancer who request it, they may be even less likely to provide it to nonhospice patients, with or without cancer."**

Their multivariate analysis revealed in part that:

- ✓ Physicians were more willing to share their predictions if they **felt certain of their prognostic skills.**
- ✓ Physicians were more likely to share frank prognoses with **patients who were older.**
- ✓ **Older physicians**, trained to "protect" patients from disheartening news, were less willing to offer any prognosis at all.

"How long have I got, Doc?" is a fundamental question, the researchers note. "When physicians can't or won't make predictions about a patient's future, patients may die deaths they deplore in locations they despise."

Source: "Prognostic Disclosure to Patients with Cancer Near the End of Life," Annals of Internal Medicine; June 19, 2001; 142 (12):1096-1105. Lamont, EB, Christakis, NA; University of Chicago Medical Center, Chicago.

Colonic Stenting May Help Patients with Malignant Intestinal Obstruction

Endoscopic placement of a self-expanding metal stent may have important applications in the treatment of patients with advanced bowel obstruction, and — because of the rapid symptomatic relief and improved quality of life associated with the procedure — is appropriate for use in the hospice setting.

That is the conclusion of a new report from a team that successfully deployed the device in a 64-year-old man with sigmoid colon obstruction caused by metastatic prostate cancer. The patient, who had recent radiation treatment and a

very limited life expectancy, presented to the emergency department with severe abdominal pain and obstructive symptoms. Treatment with enemas and nasogastric suction was ineffective. Within 48 hours of hospitalization, the patient developed severe pain refractory to high doses of opioids, along with tachycardia, fever, and leukocytosis.

Colonoscopy revealed a 3 cm stricture at the rectosigmoid junction. The team placed a 0.035-inch guidewire across the stricture and, using combined fluoroscopic and endoscopic

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RESEARCH MONITOR

Colonic Stenting *(from Page 5)*

guidance, deployed a 22 mm by 90 mm self-expandable metal stent across the stricture.

Within hours of the procedure, the patient's severe abdominal pain resolved. The following morning, he was discharged to follow-up hospice care at home, where he was able to resume eating and to have normal bowel function. He died at home 3 weeks later.

Successful decompression has been achieved in up to 90% of cases.

“Treatment of colonic obstruction utilizing self-expandable metal stents has the potential to significantly improve the quality of life for patients with advanced, incurable malignancies,” the authors write, adding that the technique is a particularly attractive option in these patients “because **palliation of the obstruction can generally be accomplished immediately with a single procedure.**”

“We believe stent placement in a select population of patients with advanced colorectal disease may provide superior results and should be considered as a treatment option in the care of hospice and palliative care patients,” they conclude.

Recent studies have shown both a **high rate of initial success and a low rate of recurrent obstruction in the deployment of the metal stents**, with recurrence due to tumor overgrowth or ingrowth appearing to be much less common than with other nonsurgical modalities, the authors note. Successful decompression has been achieved in up to 90% of reported cases, while complications include a 2% mortality rate and a 6% perforation rate.

“We believe stent placement in a select population of patients with advanced colorectal disease may provide superior results and should be considered as a treatment option in the care of hospice and palliative care patients,” they conclude.

Source: “Stenting the Sigmoid Colon in a Terminally Ill Patient with Prostate Cancer,” Journal of Palliative Medicine; Summer 2001; 4 (2):153-156. Friedland S, Hallenbeck J, Soetikno RM; Endoscopy Unit, Veterans Affairs, Palo Alto Health Care System, Stanford University School of Medicine, Palo Alto, California.

NHPCO Launches Innovative Hospice Care Improvement Study

A first-of-its-kind clinical practice improvement (CPI) study to **identify best care protocols and clinical practices** in hospice care has been launched by the National Hospice and Palliative Care Organization (NHPCO).

“Applying the CPI methodology to hospice care outcomes is an innovative approach that will likely set the standard for future studies exploring **further improvement and consistent quality in end-of-life care,**” says Stephen Connor, PhD, NHPCO vice president for research and development.

With the support of a grant from the Robert Wood Johnson Foundation, based in Princeton, New Jersey, the NHPCO has begun to implement the third phase of its two-year, four-phase initiative, entitled the **National Hospice Outcomes Project**. The first two phases involved planning the study and confirming the applicability of CPI methodology to hospice care.

The project will now gather data from 15 selected hospices and review 1,800 patient charts to determine the effectiveness of clinical practices on the quality of care in areas the NHPCO deems crucial to maintaining the best possible quality of life for hospice patients. These areas are:

- ✓ **Pain management**
- ✓ **Relief of respiratory distress**
- ✓ **Achieving self-determined life closure**

The ultimate goal of the research is to develop solid information for hospice providers and professionals to use in the delivery of consistently high-quality end-of-life care for patients served by hospices nationwide, the NHPCO has stated. Thus, the fourth and final phase of the project will be the evaluation and implementation of best care protocols.

In its 25-year history in the U.S., hospice has delivered care to more than 6 million Americans.

The NHPCO, based in Alexandria, Virginia, is the largest nonprofit membership organization for hospice and palliative care programs and professionals in the country, with a declared **commitment to “profoundly enhancing” the quality of life** for dying patients and their families. For this new study, it will be working in collaboration with the Institute for Clinical Outcomes Research in Salt Lake City.

“In its 25-year history in this country, hospice has delivered quality end-of-life care to more than six million Americans, with clinical practices based upon expert opinion and experience,” notes Connor. **“Identifying, documenting, and establishing these proven end-of-life care protocols and best practices through research will allow us to raise hospice’s standards of care even higher.”**

For more information, log on to www.nhpc.org.

PHYSICIAN RESOURCES

COMPENDIUM FEATURES WIDE SELECTION OF END-OF-LIFE CARE DOCUMENTS

Last Acts, a national communications campaign for mobilizing professional and consumer organizations to improve care near the end of life, has compiled a **collection of 75 end-of-life care guidelines and statements** that have been released in recent years by nearly 40 national health care organizations.

Entitled “**Compendium of Health Care Organization Guidelines and Position Statements on Issues Related to the Care of the Dying**,” the work presents — in single-page format — a description of each guideline, standard, consensus document, and/or policy statement available from the alphabetically-listed organizations.

Each description includes contact and source information, including websites, and a summary of the document or statement, often followed by an editorial comment. The entries are also cross-indexed by topic. The topics include:

- Critical Care Medicine
- Geriatric Health Care
- Pediatric Health Care
- Palliative Care - General
- Venue for Care
- Disease Entity

The documents were chosen with a **focus on practical patient management** through the progressive phases of care, from preliminary discussions through bereavement. According to the compilers, these phases cover:

- Preliminary **physician-patient communication** about the patient’s wishes regarding the dying process
- **Issues that arise** when death is anticipated in the not-too-distant future
- The period **when clinical death is imminent**
- The **grieving process**, during which care is shifted to the bereaved

Among the **physician organizations** included in the compendium are: the American College of Cardiology, the American College of Chest Physicians, the American College of Physicians-American Society of Internal Medicine, the American Medical Association, and the American Society of Clinical Oncology.

To order a copy of the compendium, or to access it online, log on to www.lastacts.org and follow the “Last Acts Activities” link to “Publications.”

THE MORAL CHALLENGE OF ALZHEIMER DISEASE: ETHICAL ISSUES FROM DIAGNOSIS TO DYING

By **Stephen G. Post, PhD**, this is the second edition of a consideration of ethical issues relating to dementia care, such as: overcoming the stigma attached to the disease; the debatable value of burdening advanced dementia patients with invasive, life-prolonging medical treatments; and **the obligation to facilitate a humane and dignified death** for these patients, one that is unencumbered by the artificial life-sustaining measures of modern technology.

New sections in the second edition cover such topics as:

- End-of-life issues • Hospice care • Cognitive-enhancing drugs • Spirituality

Addressed to physicians and other health professionals, family caregivers, and bioethicists, the work now includes a summary of practical advice on how to handle common but difficult ethical dilemmas in the care of Alzheimer patients.

Post is professor of biomedical ethics, School of Medicine, Case Western Reserve University, Cleveland. *Published by Johns Hopkins University Press, 2000; ISBN: 0801864100 (paperback); 162 pp.*

End-of-Life Care Websites

www.eperc.mcw.edu

End of Life Physician Education
Center (EPERC)

www.aahpm.org

American Academy of Hospice &
Palliative Medicine

www.epec.net

The EPEC Project (Education for
Physicians on End-of-Life Care)

www.nhpco.org

National Hospice & Palliative Care
Organization (formerly the NHO)

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

The Hospice and Palliative Care
Nurses Association

www.medicaring.org

Center to Improve Care of the Dying

www.abcd-caring.org

Americans for Better Care
of the Dying

www.lastacts.org

Last Acts Coalition

www.mcw.edu/pallmed/

Palliative Medicine Program at the
Medical College of Wisconsin

[www.medsch.wisc.edu/
painpolicy](http://www.medsch.wisc.edu/painpolicy)

University of Wisconsin Pain and
Policy Studies Group

www.capcmssm.org

Center to Advance Palliative Care

www.stoppain.org

Pain Medicine & Palliative Care, Beth
Israel Medical Center

www.growthhouse.org

Online community for end-of-life care

www.partnershipforcaring.org

America's Voices for the Dying

'Physician's Guide to End-of-Life Care'

This book provides the physician who is not an expert in palliative care with authoritative, practical information — often accompanied by illustrative case studies — on the care of the terminally ill patient. It contains three main sections:

- The Interview and Relationship Building
- Pain, Depression, Delirium, and Intractable Problems
- Legal, Financial, and Quality Issues

The guide is a compilation of 13 papers developed by the American College of Physicians-American Society of Internal Medicine (ACP-ASIM) Consensus Panel on End-of-life Care. As part of an ongoing series, the papers presented in the book were originally published in the *Annals of Internal Medicine* and the *Journal of the American Medical Association*. The titles include:

- *Discussing Palliative Care with Patients*
- *Beyond Symptom Management: Physician Roles and Responsibility in Palliative Care*
- *Assessing and Managing Depression in the Terminally Ill Patient*
- *Life after Death: A Practical Approach to Grief and Bereavement*
- *Legal Barriers to End-of-Life Care: Myths, Realities and Grains of Truth*
- *Financing Care for Those Coming to the End of Life*

The book can be ordered online at www.acponline.org/catalog, or by calling ACP-ASIM customer service at **800-523-1546, ext. 2600**. Edited by Lois Snyder, JD, and Timothy E. Quill, MD, published by the American College of Physicians-American Society of Internal Medicine, 2001; ISBN: 1930513283; 267 pp.

Note: Due to the number of conference postponements announced in Sept. 2001, our regular department—Upcoming Meetings for Clinicians—does not appear this issue.

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- *Introduce key personnel, or*
- *Announce upcoming events.*

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Quality of Life Publishing Co. specializes in clinical and grief support publications for hospices and other end-of-life care organizations. Members of the National Hospice & Palliative Care Organization since 1999.

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