

Quality of Life Matters®

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

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National Clinical Practice Guidelines Enable Physicians to Incorporate Palliative Care into Routine Practice

Clinicians Urged to Offer Comprehensive Care and Relieve Suffering

In the first national initiative of its kind, five major palliative care organizations have collaborated to develop evidence-based clinical practice guidelines for quality palliative care across the United States.

The National Consensus Project for Quality Palliative Care (NCP), a consortium of leading professional and consumer palliative care organizations, has released its report, "Clinical Practice Guidelines for Quality Palliative Care," which is available free of charge on the project's website. The full text can be downloaded at www.nationalconsensusproject.org.

The clinical guidelines aim to:

- Promote palliative care clinical services of consistent and high quality
- Assist clinicians in incorporating palliative care into routine practice

- Foster continuity of palliative care across all care settings

"These guidelines couldn't be more timely, with increasing numbers of Americans who suffer from advanced, chronic illness and need the relief and support that palliative care provides," says Charles von Gunten, MD, PhD, medical director, Center for Palliative Studies in San Diego, and one of the authors of the NCP report.

PREVENTING AND RELIEVING SUFFERING

According to the authors, palliative care is both a philosophy of care and a structured delivery system. Its goal is to prevent and relieve suffering while supporting the best possible quality of life for patients and their families.

Palliative care addresses suffering by:

- Treating pain and other symptoms
- Relieving stress
- Providing support for daily living
- Assisting patients and families in difficult medical decision making
- Arranging for continuity of care across settings
- Ensuring that patient and family wishes for care are followed

There is an urgent need for consistently high quality palliative care for the growing number of those living with debilitating and life-threatening illnesses, the authors note. Thus, the report recommends the integration of palliative care into all health care at every stage of serious illness — from diagnosis, through cure or

"When a patient moves into the late stages of a life-threatening or debilitating condition, the relative need for palliative care increases, and access to hospice programs must be enhanced."

—Clinical Practice Guidelines for Quality Palliative Care

death, and into the family's bereavement period.

Intended as a resource for primary practitioners as well as for the growing specialist component of palliative care, **the guidelines can aid practitioners in improving care for their sickest patients by integrating palliative approaches into their daily clinical practice.**

"Because palliation is a critical dimension of health care, all patients should have access to primary health care practitioners who are skilled and knowledgeable about basic palliative therapies," states the report.

HOSPICE HAILED AS MODEL PALLIATIVE CARE

The established and proven model of palliative care at the end of life is hospice care, the report notes. "Hospice programs have developed important and effective approaches to meeting the needs of patients and families, and those approaches are now being broadly applied

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Oncologists Launch Program to Educate Practitioners in Optimal End-of-Life Care

The American Society of Clinical Oncology (ASCO) has announced plans to launch a new educational initiative to ensure that all physicians — especially oncologists — have the skills and knowledge needed to provide effective end-of-life care.

“ASCO has pledged to take every responsible measure to ensure that all physicians are well versed in providing optimal end-of-life care and to remove all barriers to the delivery of such care,” says Charles M. Balch, MD, ASCO executive vice president and CEO.

Entitled “Education on Palliative and

End-of-Life Care—Oncology” (EPEC-O), the ASCO educational program is being adapted from the original EPEC Project published in 1999 by the American Medical Association. EPEC teaches fundamental palliative care skills and conducts train-the-trainer conferences for physicians and other health care professionals. Its core curriculum encompasses such areas as:

- Communication
- Ethical decision making
- Psychosocial considerations
- Symptom management

The oncology adaptation, EPEC-O, will

use the existing EPEC structure of didactic sessions, videotape presentations, and practical exercises. An oncology-related training manual and train-the-trainer course are currently in development. Oncology topics will include:

- Sentinel events in cancer detection
- First recurrence
- Experimental therapy
- Further curative options
- Symptom emergencies

For more information on EPEC-O, visit www.asco.org; on EPEC, visit www.epeconline.net.

National Clinical Guidelines in Palliative Care (from Page 1)

to patients at all stages of illness through palliative care,” says co-author J. Donald Schumacher, PsyD, president and CEO of the National Hospice and Palliative Care Organization.

Hospice care and palliative care have in common both their treatment philosophy and their clinical characteristics, notes the report. These include:

- ✓ Acknowledgment of the patient and family as the unit of care
- ✓ Reliance on interdisciplinary assessment, treatment, and evaluation
- ✓ Energetic response to the consequences of illness faced by the patient and family. This includes:
 - Symptom management
 - Provision of practical guidance and support of care at home
 - Anticipatory counseling, education in crisis prevention, and critical decision support
 - Recognition of the need for health promotion, even during physical decline
 - Addressing common forms of patient abandonment
 - Incorporation of a human development perspective on life-altering illness

“Palliative care should be integrated into the care continuum for all patients and families dealing with advanced illness,” states the NCP. **“Close coordination between palliative care and hospice programs is critical to achieving continuity of palliative care throughout the full course of an illness and across care settings.”**

The guidelines focus on the following eight domains of palliative care:

1. Structure and Processes
2. Physical Aspects
3. Psychological and Psychiatric Aspects
4. Social Aspects
5. Spiritual, Religious, and Existential Aspects
6. Cultural Aspects
7. Care of the Imminently Dying Patient
8. Ethical and Legal Aspects

The NCP is a consortium of the following national organizations: American Academy of Hospice and Palliative Medicine (www.aahpm.org); Center to Advance Palliative Care (www.capcmssm.org); Hospice and Palliative Nurses Association (www.hpna.org); Last Acts Partnership (www.lastactspartnership.org); and National Hospice and Palliative Care Organization (www.nhpc.org).

For more information, visit www.nationalconsensusproject.org.

Pediatric Palliative Care: Helping Children and Families from Diagnosis Through Cure or Death

Although recent research has contributed substantially to improvement in care that addresses the needs of adults living with life-threatening and terminal illness, similar research among children remains rare, and a “good death” in a child is as yet undefined. Nonetheless, seriously ill and dying children and their families “require comprehensive, compassionate, and developmentally appropriate palliative care,” from diagnosis through cure or death.

That is according to lead author Bruce P. Himmelstein, MD, of Children’s Hospital of Wisconsin, Milwaukee, and colleagues, whose review of pediatric palliative care appeared in *The New England Journal of Medicine*.

“Generalists and specialists alike can and should provide palliative care when needed,” the authors state. Their paper offers physicians practical tools for assessing and planning pediatric palliative care, managing symptoms, and working within a child’s developmental level of understanding of spirituality and death.

“Palliative care is a philosophy of care that evolved from the hospice philosophy to meet the gaps in care for seriously ill and dying patients,” the authors write.

BOTH HOSPICE AND PALLIATIVE CARE:

- Recognize that people of all ages die
- Focus on relieving pain and suffering
- Treat the patient and family as a unit, providing support to family members both before and after death
- View the physician as a key member of an interdisciplinary team

The primary care physician works as one member of a pediatric palliative care team that should at minimum include a care coordinator and available support as needed from a bereavement specialist, child psychologist, and/or child-life specialist, recommend the authors.

PRIMARY CARE PROVIDERS MUST BE TRAINED TO:

- Identify a child’s need for palliative care
- Assess emotional and spiritual needs of the child and family members
- Facilitate advance care planning
- Assess and manage the child’s symptoms and suffering
- Provide bereavement care to the family
- Recognize the indications for referral to a specialist

Palliative Care for Children Is Appropriate When:

- Curative treatment is possible but may fail
- Intensive long-term treatment is required to maintain quality of life
- Treatment is exclusively palliative after diagnosis of a progressive condition
- A severe, nonprogressive disability causes extreme vulnerability to health complications

—Himmelstein, Hilden, et al
New England Journal of Medicine

“Once the need for palliative care is identified, primary providers have a central role in initiating critical discussions about the trajectory of illness and about advance care planning,” write the authors.

Further, while the palliative care support team is being gathered, physicians should be prepared to anticipate and address pain and symptom management. Pediatric palliative care and pain specialists or local hospice directors with pediatric expertise can be consulted regarding pharmacologic and nonpharmacologic symptom management.

Physicians can also provide support to parents and other family members throughout the course of the child’s illness and during bereavement. Parents who lose a child may be at risk not only for complicated grief reactions, but also for death from both natural and unnatural causes, the authors note. **Children also grieve, and seriously ill or dying children may grieve their loss of function, activity, and impending loss of life.**

“For an adult, particularly one who is elderly or suffering from a long, debilitating illness, death is often an acceptable, and even a desired, outcome,” they point out. “In contrast, a child’s death remains emotionally difficult, unnatural, and unexpected for families and health care providers alike.”

The authors list resources offering new information on such topics as clinical care standards, program development, research, and education in pediatric palliative care.

Source: “Pediatric Palliative Care,” *The New England Journal of Medicine*; April 22, 2004; 350(17):1752-1762. Himmelstein BP, Hilden JM, Boldt AM, Weissman D; Children’s Hospital of Wisconsin, Milwaukee; Medical College of Wisconsin, Milwaukee; Children’s Hospital at the Cleveland Clinic, Cleveland; Froedtert Memorial Lutheran Hospital, Milwaukee.

Tube Feeding, Lack of DNR Orders: Dying Dementia Nursing Home Residents Receive Poor Care

In their last months of life, patients with advanced dementia in nursing homes are not perceived as having a terminal condition and do not receive care promoting palliation and comfort, a team of Boston investigators has found.

“We believe that palliation is a primary goal of care for most older persons dying with advanced dementia. The results of this study suggest that the end-of-life care provided to these residents in the nursing home setting is suboptimal,” report the researchers in the *Archives of Internal Medicine*, a journal of the American Medical Association.

Susan L. Mitchell, MD, and colleagues at Beth Israel Deaconess Medical Center analyzed data on patients 65 years of age and older who died with advanced dementia (n=1609) and terminal cancer (n=883) within one year of admission to any of the 643 New York State nursing homes between 1994 and 1997.

At the time of admission, only 1.1% of advanced dementia residents were recognized as having a life expectancy of less than 6 months. Yet within 6 months, 71% of the demented residents had died. All cancer patients were understood upon admission to have a prognosis of less than 6 months to live; 92% died within that period. Other findings include:

- Residents with advanced dementia were 8 times less likely than those with terminal cancer to have a do-not-resuscitate (DNR) order just before death. Only 55.1% of demented residents compared with 86.1% of cancer patients had a DNR order.
- Advanced dementia residents were more likely to receive aggressive interventions at the end of life. For example, 25% of demented residents died with a feeding tube, compared with 5.2% of terminal cancer residents.

“This widespread practice of tube feeding in end-stage dementia is concerning amid growing empirical data and expert opinion that the intervention has no demonstrable health benefits in this population...”

—Mitchell, Kiely, et al
Archives of Internal Medicine

The study was limited by lack of data on hospice enrollment, note the researchers. **“Hospice services in nursing homes can improve pain management, promote advance care planning, and reduce the use of invasive treatments.”** Since nursing home residents with dementia have been found less likely than those with cancer to receive hospice care, it is possible that the difference in hospice exposure between the two cohorts may explain some of the findings, the authors point out. “If this is true, it only further emphasizes the underrecognition of advanced dementia as a terminal condition

for which hospice services would be appropriate.”

Source: “Dying with Advanced Dementia in the Nursing Home,” Archives of Internal Medicine; February 9, 2004; 164(3):321-326. Mitchell SL, Kiely DK, Hamel MB; Beth Israel Deaconess Medical Center; and Division on Aging, Harvard Medical School, Boston.

Use of Acute Care for Dying Patients Linked to Supply of Local Resources

Hospice Care Associated with Shorter Hospital Stays, Fewer Deaths in Acute or Intensive Care

In corroboration with previous findings, a recent study of 77 best-rated U.S. hospitals has found that intensity of care delivered to terminally ill Medicare patients varies greatly, both across and within regions, and is associated not with appropriateness of care or patient preferences, but with specific hospitals and with the per capita supply of local hospital beds and physicians.

During the last six months of life, days in hospital per decedent (n=115,089) ranged from 9.4 to 27.1; days in intensive care units ranged from 1.6 to 9.5; number of physician visits ranged from 17.6 to 76.2; percentage of patients seeing 10 or more physicians ranged from 16.9% to 58.5%. Percentage of hospital deaths ranged from 15.9% to 55.6%; percentage of deaths associated with an intensive care stay ranged from 8.4% to 36.8%. Hospice enrollment ranged from 10.8% to 43.8%.

Hospice care was inversely correlated with: more hospital

days in the last six months of life; probability of dying in a hospital; and higher percentage of deaths associated with a stay in an intensive care unit.

“Variations in end-of-life care among the best hospitals in the United States raise further questions about the appropriate role for acute hospital care in the management of chronically ill patients,” write the authors. “We hope that the international research community will focus on learning...how to provide end-of-life care determined by the needs and wants of patients and not the capacity of the acute care system,” they conclude.

Source: “Use of Hospitals, Physician Visits, and Hospice Care During Last Six Months of Life Among Cohorts Loyal to Highly Respected Hospitals in the United States,” British Medical Journal; Wennberg JE, Fisher ES, Stukel TA, et al; Dartmouth Medical School, Hanover, New Hampshire; VA Outcomes Group, White River Junction, Vermont; Institute for Clinical Evaluative Sciences, Toronto.

COPD: Expert Offers 'Common Sense' Guidelines for Referral to Hospice and Palliative Care

Because death in patients with chronic obstructive pulmonary disease (COPD) frequently occurs after a prolonged functional decline and much suffering, **many of the more than 220,000 American adults who die with this disease each year have a particular need for palliative care**, states a report in the January 2004 issue of *Respiratory Care*, the journal of the American Association of Respiratory Care.

But due to difficulties inherent in predicting death for patients with COPD — the rate of disease progression is variable and exacerbations occur suddenly and unpredictably — physicians are hesitant to broach the subject of terminal prognosis, notes author John Hansen-Flaschen, MD, chief of the Pulmonary, Allergy, and Critical Care Division, University of Pennsylvania Medical Center, Philadelphia.

Disclosure of prognosis opens the way for discussion of medical advance planning, allowing patients to speak openly of their hopes and fears, and to plan for their deaths. Physician guidance in this planning is a major component of palliative medical care, which Hansen-Flaschen defines simply as “symptom relief and

counseling during the final 6 to 12 months of life.”

DETERMINING AND DISCLOSING PROGNOSIS

Severity of chronic airflow obstruction alone has not proven to be a reliable predictor of death in COPD patients, says Hansen-Flaschen; nor have federal guidelines for hospice referral or medical specialty standards been found useful. Drawing on recent research observations, he presents an “emerging profile” of terminally ill COPD patients.

Characteristics of COPD patients most likely to die within 6 to 12 months may include:

- Severe, irreversible airflow obstruction
- Severely impaired performance status, with declining activities of daily living
- Uninterrupted walk distance of merely a few steps
- More than one hospitalization for acute care in the past year
- Cardiovascular and/or other comorbid disease
- Older age

A patient with many of these characteristics may benefit from an honest and compassionate disclosure of prognosis. A physician might say: “*We are not very good at predicting death from COPD. You could live for another one or two years, or even longer. If your condition turns for the worse, you could die much sooner.*” Discussion can then be guided by the patient’s responses and questions.

Physicians are encouraged to test the patient’s comprehension at the end of the visit or during a subsequent one: “*I want to be certain that you understand. How would you explain your prognosis to someone else?*”

HOSPICE CARE

Hansen-Flaschen suggests that those **patients with advanced, irreversible lung disease and little or no cardiopulmonary reserve are most likely to benefit from the specialized services provided by hospice.** [See sidebar.]

Medicare’s hospice benefit and most insurers require that both the hospice medical director and the referring physician certify that the patient is expected to live six months or less if the disease takes its usual course. But, reiterates Hansen-Flaschen, for patients with advanced COPD, there *is* no “usual course.” However, **there is no penalty if a patient does not die within the specified time.** Provided the patient is terminally ill, hospice care can be extended indefinitely.

“Physicians, nurses, and respiratory therapists who care for patients with advanced COPD are encouraged to recognize that death is not a failure, but an opportunity to practice a form of professional care that is as old as medicine,” he concludes.

Source: “Chronic Obstructive Pulmonary Disease: The Last Year of Life,” *Respiratory Care*; January 2004; 49(1):90-97. Hansen-Flaschen J; University of Pennsylvania School of Medicine, Philadelphia.

'Common Sense' Guidelines

Patients should be considered for hospice referral if all three of the following apply:

1. Cardiopulmonary functional reserve is so limited that the patient may die at any time from an ordinary respiratory infection.
2. The patient can be expected to benefit from the specialized services offered by a hospice program, due to distressing symptoms or severely limited performance status.
3. The patient accepts that death might occur in six months or less and does not want to suffer needlessly.

—Hansen-Flaschen
Respiratory Care

PHYSICIAN RESOURCES

Bereavement Support: From Clinical Assessment to Skilled Interactions, Physicians Play Key Role

Following a patient's death, physicians may be uncertain about their role in caring for the grieving family. Yet physicians can play an important part — either separately, or coordinated with

organized support services — in supporting bereaved loved ones as they work through the process of normal grief.

That is according to a California bereavement expert and colleague in their article published in the *Journal of Palliative Medicine*.

“Even in the absence of a thorough understanding of any model [of grief and bereavement], the physician can intervene in appropriate ways that allow the bereaved to feel supported and find meaning in their own process,” write the authors. Their article includes a table

of common grief reactions, and a tool of bereavement interventions and strategies for physicians (the EASE Tool). **some other cause for the patient's distress) as well as know how to be clinically helpful.”**

After the Death, Physicians Can:

- ✓ Send a condolence card
- ✓ Offer a handout on the normal process of grief
- ✓ Encourage mourners to discuss their loss with others in their life
- ✓ Identify other resources, such as local hospices, support groups, and spiritual and grief counselors

— Adapted from Carrington and Bogetz
Journal of Palliative Medicine

CLINICAL ASSESSMENT OF GRIEF

During the clinical assessment of grief, the physician not only identifies patients' needs, but also points out their strengths and coping abilities. This can reassure mourners and encourage them to draw upon abilities they have used before.

Areas of assessment include: physical health; emotional and/or mental health; personal situation; and loss history. Suggested opening inquiries for grief assessment include:

- “What concerns you most today?”
- “What else is going on in your life at this time?” Or, “Tell me about your life since the death.”
- “What physical sensations do you notice when your grief is most intense?”
- “What comforts you?”
- “Who do you have that you can talk with? Are they available when you need them?”

Patients' understanding of the grief process can alleviate the isolation and confusion they may be experiencing. Because their lives, thoughts, and feelings are so different from what they have known, mourners may fear they are “going crazy” or “having a breakdown.” The physician can:

- Explain the normal and natural process of grief
- Educate the mourner regarding the range of possible feelings and reactions that can occur
- Point out that there are individual differences in mourning
- Discuss normal grief patterns and themes

Continuing to assess symptoms that persist will help in identifying those not associated with the normal process of grief. Exploration of the patients' needs and support requirements can guide the physician to the appropriate response and referral.

The authors note that **end-of-life-care experts believe a physician's responsibility for the care of a patient does not end when the patient dies.** “The good news,” they conclude, “is that with teamwork this becomes an even easier task.”

Source: “Normal Grief and Bereavement: Letters from Home,” *Journal of Palliative Medicine*; April 2004; 7(2):309-323. Carrington NA, Bogetz JF; Center for Palliative Studies, San Diego Hospice and Palliative Care, San Diego; The Burnham Institute, La Jolla, California.

of common grief reactions, and a tool of bereavement interventions and strategies for physicians (the EASE Tool).

PHYSICIAN SUPPORT CAN INCLUDE:

- **Actively listening** to the mourner's concerns and interests
- **Expressing compassion** and concern
- **Validating** and **normalizing** the manifestations of grief
- **Reassuring** patients that what they experience as abnormal usually has a good prognosis with time and support

Physician support of the family can begin before death, note the authors. “Supporting families while affirming the reality of the situation may assist families in their grief following the death.” Mourners may be helped by the understanding of their loved one's illness and death that was provided them by the physician during the course of the disease.

When a patient making an office visit is known to be bereaved, the physician has an opportunity to assess for grief. **“Physicians need to be able to make the diagnosis of grief (as opposed to**

PHYSICIAN RESOURCES

BOOKS FOR CLINICIANS

Geriatric Palliative Care

By R. Sean Morrison, MD (Editor), and Diane Meier, MD (Editor), this recent work stresses the importance of the palliative care approach for maintaining quality of life in chronically ill and frail elderly patients. Emphasis is placed on providing support for functional independence and on determining goals of care based on the patient's values, across a variety of settings.

Intended as a medical reference for all clinicians caring for older adults with serious illness, the work addresses the palliative care approach relevant to both individual symptoms and to specific disorders, such as: heart disease, cancer, stroke, and dementia. Chapter titles include:

- Variability in End-of-Life Care in the United States
- Assessing Quality of Life and Quality of Dying in the Elderly: Implications for Clinical Practice of Palliative Medicine
- The Place of Love in the Care of Persons with Advanced Dementia
- Palliative Care in the Nursing Home
- Family Caregivers: Burdens and Opportunities

Published by Oxford University Press, 2003; ISBN: 0195141911 (hardcover); 430 pp.

The Four Things That Matter Most: A Book About Living

By Ira Byock, MD, this collection of stories of people using expressions of forgiveness, gratitude, and love as a way to mend, tend, and nurture relationships is designed to provide clinicians with a valuable and compassionate tool when discussing life-threatening illness or injury with patients and families.

Distilled from experiences of people who were forced by serious illness to face the impending end of their relationships, these stories convey practical wisdom that can help bring emotional healing.

Byock, who draws from 15 years' experience in emergency medicine as well as more than 25 years in hospice and palliative care, says, "Even as people confront death (their own or others'), they can reach out to express love, gratitude, and forgiveness. When they do, they consistently find that they — and everyone involved — are transformed for the rest of their life, whether those lives last for decades or just days."

The "four things" Byock identifies revolve around the following statements:

1. Please forgive me.
2. I forgive you.
3. Thank you.
4. I love you.

"The specter of death reveals our relationships to be our most precious possessions," Byock notes. "Ask a man who is being wheeled into transplant surgery or a woman facing chemotherapy for the third time what's on his or her mind and the answer will always involve the people they love. Always."

Byock is Professor and Director of Palliative Medicine at Dartmouth Hitchcock Medical Center in Lebanon, New Hampshire.

Published by Free Press, 2004; ISBN: 0743249097 (hardcover); 240 pp.

End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

End of Life/Palliative Education Resource Center (EPERC)

www.epeconline.net

The EPEC Project (Education on Palliative and End-of-Life Care)

www.nhpco.org

National Hospice & Palliative Care Organization

www.promotingexcellence.org

Promoting Excellence in End-of-Life Care

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

Hospice and Palliative Nurses Association

www.medicaring.org

Center for Palliative Care Studies

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/

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

An online community for end-of-life care

www.partnershipforcaring.org

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