

# Quality of Life Matters®

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

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## Hospital Discharges to Hospice Increased 15-Fold in Ten Years, National Study Finds

Patients with serious illness hospitalized in the U.S were much more likely to be discharged to hospice services at the closing of the last decade than at its beginning, according to a report published in the *Journal of Palliative Medicine*.

“The past decade has been a dynamic period for hospice and palliative care,” write the authors. “Our findings show that over the study period, hospital deaths declined and there was an increase in discharges to hospice. These findings indicate a significant shift in end-of-life care in the United States.”

Investigators analyzed data from the federally supported National Inpatient Sample on patients who died while hospitalized or were discharged to hospice

(home or medical facility) during the years 2000 to 2009. Data on the total number of hospice enrollees each year were obtained from the annual reports of the National Hospice and Palliative Care Organization.

“While there have been other studies looking at characteristics of total hospice enrollment, to our knowledge this is the first study to look specifically at the population of hospital discharges to hospice on such a large scale,” comment the authors.

### KEY FINDINGS

- Admissions to hospice directly from the hospital increased 15-fold, from 27,912 in 2000 to 420,882 in 2009.
- Predictors of discharge to hospice included female gender, advanced age,

dementia, chronic obstructive pulmonary disease, and frailty.

- Congestive heart failure, renal failure, and mechanical ventilation were inversely associated with discharge to hospice.
- The percentage of African-American and non-white patients referred to hospice increased throughout the study years, albeit modestly.
- Although cancer was the most prevalent comorbidity throughout the decade studied, its presence declined from 57.5% of discharges to hospice in 2000 to 43.6% in 2009.

However, all referral trends over the past decade may not reflect good news

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## Oncologists Struggle with Grief at Patient Loss

*Impact may spill over into personal life, patient care*

Oncologists describe their grief at the loss of a patient as having components of normal grief, with added elements related to their sense of responsibility for their patients' lives. Most try to maintain a balance of their emotional boundaries, but few feel they do this effectively, according to a research letter published in the *Archives of Internal Medicine*.

“Of greatest significance to our health care system is that some of the oncologists' reactions to grief reported in our study (e.g., altered treatment decisions, mental distraction, emotional and physical withdrawal from patients) suggest that the failure of oncologists to deal appropriately with grief from patient loss may negatively affect not only oncologists personally, but also patients and their families,” write the authors.

Canadian researchers analyzed the responses of 20 oncologists (average age, 45 years; range, 30 to 65 years) from interviews conducted at three cancer centers across Ontario between November 2010 and July 2011. Participants varied in subspecialty, gender, and ethnicity, with a length of practice ranging from 1.5 years (residents) to

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## Hospital Discharges to Hospice Increased 15-Fold in Ten Years, National Study Finds

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for terminally ill patients, note the authors. Although previous research has shown that patients prefer to die in the comfort of their own homes, and that home hospice increases that likelihood, the current study found a much more rapid increase in hospital referrals to hospice than in non-hospital referrals, “suggesting that end-of-life care is still focused on hospitalizations,” the authors observe.

“Hospice care is a palliative care option which benefits the dying patient in part by limiting exposure to the risks of harm from a hospital stay while also reducing total health care costs,” they note. For example, while the total paid by Medicare for hospice services in 2009 was

\$12 billion, hospital costs that same year for patients discharged to hospice totaled \$19.5 billion (72% of which was paid by Medicare), suggesting that these patients’ hospitalizations alone cost more than the year’s total Medicare costs.

“The introduction of palliative care options, including hospice, in the early phase of serious illness may curtail the initiation of interventions that are unlikely to alter outcomes significantly or that are inconsistent with patients’ wishes, while offering the potential gain of improving quality of life and prolonging survival,” the authors suggest.

In addition to the past decade’s increase in hospice enrollment in general, and in discharges from hospitals to hospice programs in particular, the number of

patients enrolled in nursing home hospice programs has more than doubled, the authors point out.

Furthermore, there has been a change in clinical characterization of hospice patients in the past decade, with an increasing number of patients enrolling in hospice with non-cancer diagnoses. “It is likely that these transformations to the field have contributed to the observed changes in hospital discharges to hospice,” they conclude.

*Source: “Evolution of End-of-Life Care at United States Hospitals in the New Millennium,” Journal of Palliative Medicine; May 2012; 15(5):592-601. Lin RY, Levine RJ, Scanlan BC; Department of Medicine, New York Downtown Hospital, New York City; Department of Medicine, School of Medicine, New York Medical College, Valhalla, New York.*

## Clinicians Offered Guidelines for Optimal Support of Family Caregivers

A set of recently developed clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients is summarized in a report published in the *Journal of Palliative Medicine*. The guidelines, which are being disseminated widely in Australia, have received the endorsement of key national and international palliative care, caregiver, and bereavement organizations.

The consensus-based guidelines were developed for use by multidisciplinary health care professionals and clinical services caring for patients in a variety of settings in Australia. However, the authors intend that these recommendations will also prove useful to the international palliative care community and to generalists worldwide who care even occasionally for palliative care patients.

“There is a shortage of evidence-based

strategies to guide health professionals in providing optimal support while the caregiver is providing care and after the patient’s death,” write the authors. Many family caregivers of chronically or seriously ill patients have unmet needs and express a desire for more information, preparation, and support, they note.

The 20 recommendations are organized into four categories:

- Setting Up Family Caregiver Support
- Assessing Need and Establishing a Plan of Care
- Preparing for Death
- Bereavement Support

The complete guidelines are available in booklet form to download or print at no charge on the St. Vincent’s Hospital/University of Melbourne’s Centre for Palliative Care website. The 56-page booklet

provides accompanying case examples, sample comments and questions for clinicians to use, as well as the methodology and literature review used to develop and support the recommendations.

The authors encourage the adaptation of the guidelines (with due acknowledgment) to meet pertinent local needs, and suggest additional research to evaluate their impact on the quality of support family caregivers receive.

To view or download the guidelines in booklet form, visit [www.centrefor-pallcare.org](http://www.centrefor-pallcare.org).

*Source: “Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients,” Journal of Palliative Medicine; June 2012; 12(6):696-702. Hudson P, Remedios C, et al; Centre for Palliative Care at St. Vincent’s Hospital and a collaborative centre of The University of Melbourne, Melbourne, Australia; and Queen’s University, Belfast, United Kingdom.*

## Oncologists Struggle with Grief at Patient Loss

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more than 30 years (senior oncologists).

### NEGATIVE IMPACTS OF GRIEF

- 85% of oncologists mentioned compartmentalization of emotions as either a coping strategy or an impact of patient loss, using such expressions as “dissociation” and “denial” to describe the process.
- 55% of participants referred to “burn-out” as an impact of grief.
- 65% acknowledged spillover into their personal lives.
- Grief was described as causing feelings of powerlessness (65%), emotional exhaustion (60%), self-doubt (60%), and failure (55%).
- 65% of oncologists had these feelings before a patient death, due to holding hard medical knowledge such as poor test results.
- 55% said their treatment decisions for other patients were affected by their grief, 25% felt distracted with other patients, and 50% mentioned distancing themselves from those patients nearing death and their families.

### POSITIVE IMPACTS OF GRIEF

- 45% of oncologists indicated that frequent exposure to patient death gave them a better perspective on life.
- 25% of participants felt motivated to improve patient care.

“One of the main findings was that because oncologists were not expecting to have these feelings in the workplace, there was nowhere to talk about it,” said lead author Leeat Granek, PhD, in an author interview on the journal’s website. “They didn’t learn about it in school, they didn’t expect it to be there, and they had a really hard time knowing what to do with it.”

To address the potentially negative effects of grief at patient loss, Granek

recommends physician education efforts such as training programs on coping with loss for physicians at the residency stage and throughout their careers, good mentorship programs, and grief intervention support groups and forums for sharing experiences.

“It is an important point to remember that whatever educational strategy or intervention is used, it should always include both skilled training and the validation of emotions — the acknowledgement that feelings of grief and loss are normal, valid, and an expected part of the job,” said Granek, who is a critical health psychologist and postdoctoral fellow at the Hospital for Sick Children in Toronto.

“Also very important for any proposed program on an institutional level is that it recognize that grief is a sensitive and often stigmatized topic, not just for oncologists, but within the culture of the medical community.”

### A STAFF GRIEF SUPPORT MEETING

“Since death and loss are intrinsic aspects of oncologists’ practice, grief is common, whether it be over the physical absence of a patient or the more abstract surrender of a meaningful joint struggle,” write the authors of an invited commentary to Granek’s report.

If grief is unaddressed or unprocessed over time, it can lead to burnout, an occupational hazard for many physicians, but especially for oncologists, note Michelle Shayne, MD, and Timothy E. Quill, MD, of the divisions of hematology/oncology and palliative care, respectively, at the University of Rochester Medical Center, Rochester, NY. “The recognition, expression, and exploration of grief in itself may be considered a coping strategy,” they write.

Physician grief can be explored in a safe, nonjudgmental setting among one’s peers rather than in isolation, note the

commentators. They provide the personal example of the regularly scheduled support group meetings held at their facility about every two months. Oncology fellows are required to attend, and all other members of the care team are strongly urged to participate.

Components of the staff support meeting often include:

- Reflection on self-care strategies
- Telling stories of work-related personal experiences
- Sharing reactions to losses, successes, and disappointments
- Remembrance of patients who have recently died, spoken aloud or with a moment of silence

“This approach allows oncology staff and trainees to systematically share their loss and grief with others who have common experiences and values,” write Shayne and Quill. Although their support group may be a helpful step in the right direction, they call for further research to develop coping strategies that help oncologists “not only to survive, but also to potentially experience personal growth from their work.”

*Source: “Nature and Impact of Grief over Patient Loss on Oncologists’ Personal and Professional Lives,” Archives of Internal Medicine; Epub ahead of print, May 21, 2012; DOI: 10.11/archinternmed.2012.1426. Granek L, Tozer R, Mazzotta P, Ramjaun A, Krzyzanowska M; Department of Psychology, Hospital for Sick Children, Toronto; Department of Medical Oncology, Juravinski Cancer Centre, Hamilton, Ontario; Palliative Care Consult Team, Sunnybrook Health Sciences Centre, Toronto; Department of Family and Community Medicine, University of Toronto, Toronto; McGill Clinical and Health Informatics, Montreal; and Department of Medical Oncology & Hematology, Princess Margaret Hospital, Toronto. “Oncologists Responding to Grief,” *ibid.*; DOI: 10.1001/archinternmed.2012.2035. Shayne M and Quill TE; Divisions of Hematology Oncology and Palliative Care, University of Rochester Medical Center, Rochester, New York. Archives of Internal Medicine Multimedia 2012-05-21, Author Interview.*

## Goal-Oriented Care: Setting Goals, Measuring Outcomes Based on the Patient's View of What's Important in Life

For patients with multiple chronic conditions, severe disability, or a short life expectancy, current disease-specific measurements of quality care may not reflect the health outcomes these patients are looking for. Care that is truly patient-centered must aim for health goals patients consider meaningful in the context of both their medical conditions and their life priorities, according to an article published in *The New England Journal of Medicine*.

"So far, assessments of quality of care and health outcomes have not incorporated patient-centeredness," write the authors. "For patients with multiple chronic diseases, severe disability, or limited life expectancy, any accounting of how well we're succeeding in providing care must above all consider patients' preferred outcomes."

Current quality of care measurements address disease-specific care processes, while outcomes measurements focus on condition-specific indicators (both short- and longer-term) and on overall mortality. These measures, while appropriate for relatively healthy patients with a single disease, do not work well for those patients under discussion, observe the authors.

"An alternative approach to providing better care would be to focus on a patient's individual health goals within or across a variety of dimensions (e.g., symptoms; physical functional status, including mobility; and social and role functions) and determine how well these goals are being met."

The authors offer the example of a patient with Parkinson's disease who might set a high priority on decreased rigidity and no falls, the ability to get to the bathroom unassisted, and the ability to use the Internet or attend church

services. This patient might set a lower priority on such traditional long-term quality indicators as reducing tremor or walking without a walker.

The article includes a sidebar comparing traditional and goal-oriented outcomes for five common diseases, listed by measurement domain. For instance, under the signs and symptoms domain for heart failure, chronic obstructive pulmonary disease, and arthritis, the traditional outcome would be "inventory of disease-specific signs and symptoms." The goal-oriented outcome is "symptoms that have been identified as important by the patient."

### ADVANTAGES OF GOAL-ORIENTED CARE

**1. Framing the discussion.** "The goal-oriented approach frames the discussion in terms of individually desired rather than universally applied health states."

The authors offer the example of a patient with prostate cancer who may not consider it personally worthwhile to try a new therapy found to extend survival for an average of a few months. Similarly, a patient with a fractured hip may prefer using an assistive device to committing to the amount of effort required for prolonged physical therapy.

**2. Simplifying decision making.** "This approach simplifies decision making for patients with multiple conditions by focusing on outcomes that span conditions, and aligning treatments toward common goals."

Treatment for one condition can be optimized while treatment for another is de-emphasized, depending on which therapy is most likely to achieve the patient's goals. For example, a patient with hypertension and postural hypotension may choose the short-term benefit of being able to walk with less fear of

falling, and opt to forego treatment to lower blood pressure.

**3. Eliciting patient priorities.** "Goal-oriented care prompts patients to articulate which health states are important to them and their relative priority." Patients can feel more in control of their choices requiring "trade-offs" when clinicians have elicited and understood their preferences, needs, and values. An example of such a trade-off would be when patients choose to forego aggressive treatment of their disease in favor of comprehensive symptom management through hospice care.

**4. Sharing decision making.** "If they know what health states are most desired, patients and clinicians can agree on steps that can be taken to achieve these goals and monitor progress in reaching them." A further advantage to focusing on specific, preferred patient outcomes is that treatment success or failure can be easily determined.

### CLINICIANS CAN:

- Explain what is possible and negotiate potentially achievable goals
- Provide a treatment plan, encouragement, and advocacy
- Readdress the goals if the situation changes

"Ultimately, good medicine is about doing right for the patient," conclude the authors. "Quality metrics that capture individual goal elicitation and attainment must be developed as we move toward goal-directed, patient-centered decision making."

*Source: "Goal-Oriented Patient Care — An Alternative Health Outcomes Paradigm," The New England Journal of Medicine; March 1, 2012; 366(9):777-779. Reuben DB, Tinetti ME; Division of Geriatrics, David Geffen School of Medicine at UCLA, Los Angeles; and Department of Medicine, Yale School of Medicine, and Yale School of Epidemiology and Public Health, New Haven, Connecticut.*

## More Than Half of Radiation Oncology Patients Still on Treatment at Death

Unlike chemotherapy, for which there are quality metrics and goals relating to its provision near the end of life, radiation therapy has no similar established measures and few data describing its frequency of use among dying patients, according to a report published in the *Journal of the American College of Radiology*.

“Nevertheless, oncology practices that consistently deliver active therapy to patients in their last days of life are considered to be providing suboptimal care,” write the authors.

Researchers analyzed data on patients receiving radiation therapy within 30 days of death ( $n = 63$ ) whose cases were reviewed at the morbidity and mortality conferences held by radiation oncologists at Indiana University, Indianapolis, between 2008 and 2011. Overall:

- The most frequent diagnoses were lung cancer (38%) and lymphoma (11%).
- 38% of patients were being treated for brain metastases.
- 67% had Karnofsky Performance Status Scale scores  $< 60$ ; 22% had Karnofsky scores  $> 80$ .

### KEY FINDINGS:

- 52% of patients were still receiving radiation treatment at the time of death.
- 54% had completed less than half of their original radiation therapy plans.
- 69% had their final treatments within 10 days of death, and nearly 10% had their final treatments on the day of death.
- 21% received radiation therapy for more than half of their final month.

“These data are valuable in ongoing discussions of radiation therapy use at the end of life, especially as related to hospice underutilization,” observe the authors. “We maintain that even 21% of patients receiving radiation therapy for more than half of their last month of life is too many. Few would argue that half of patients receiving radiation therapy within a week of death is extreme.”

Although it is thought that some patients may receive a benefit from a brief course of radiation therapy near death, “it is by no means certain that such palliation will occur,” observe the authors. They note that a 2010 study of palliative radiotherapy

delivered to patients with end-stage cancer found that while 25% had symptom improvement before death, 50% had worsening symptoms, and 25% died on treatment. “Given these data,” write the authors, “there is no conceivable benefit to a prolonged radiation therapy course under these circumstances.”

The authors emphasize that a morbidity and mortality conference, such as the one from which they obtained their data, is a teaching conference, not a punitive one. “An open atmosphere is essential to accurate reporting of error in all disciplines,” they write. “Clearly, further data are necessary to aid in understanding how physicians alter treatment plans for palliative patients and for patients with declining health status.”

*Source: “Radiation Oncology Quality: Aggressiveness of Cancer Care Near the End of Life,” Journal of the American College of Radiology; March 3, 2012; 9(3):199-202. Toole M, Lutz S, Johnstone PAS; Department of Radiation Oncology, Indiana University School of Medicine, Indianapolis; and Department of Radiation Oncology, Blanchard Valley Health System, Findlay, Ohio.*

## Palliative Sedation for Refractory Suffering Does Not Affect Survival, Review of Literature Finds

The use of palliative sedation as a therapeutic intervention for refractory symptoms in cancer patients nearing death appears to have no effect on survival, according to a team of Italian researchers whose findings were published in the *Journal of Clinical Oncology*.

According to the European Association for Palliative Care, “palliative sedation is a medical intervention, totally different from euthanasia in aim, procedure, and result,” the authors point out. The common

concept of palliative sedation as found in their study articles can be summarized as “the use of sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness.”

The investigators analyzed the impact of palliative sedation on survival as reported in 11 articles selected from a systematic review of the literature published in English from 1980 through 2010. Findings:

- Delirium was the most frequent indica-

tion for sedation in the terminal stages of illness (57.1%) although there was wide interstudy variability (range, 13.8% to 91.3%).

- Other frequent reasons for sedation were dyspnea (range, 8.7% to 63.0%) and pain (range, 9.5% to 49.2%).
- Benzodiazepines (most often, midazolam) were the most common drug category prescribed.

The authors note that the chief draw-

*Continued on Page 6*

# RESEARCH MONITOR

## 93% of Adults Have Heard of Hospice and Believe Dying Should Be Free of Suffering

Most older, community-dwelling adults are familiar with hospice as a concept, and believe that hospice care makes people feel better, but only 30% are familiar with the term “palliative care,” according to a report in the *American Journal of Hospice & Palliative Medicine*.

“Our findings highlight the need for enhancing education about palliative care among older patients, especially since we found favorable views and general acceptance of palliative care principles among our community-dwelling older adult respondents,” the authors state.

Researchers analyzed survey responses of 187 community-dwelling adults (mean age, 78 years; range, 55 to 101 years) receiving outpatient care at a geriatric clinic in Ann Arbor, MI, which serves patients within the urban area as well as those from surrounding suburban and rural communities. Overall, 68% reported their health as

excellent/good, and 14% reported that they were currently working. Findings:

- 93% of respondents were familiar with the term “hospice,” but only 30% had heard of palliative care.
- 82% felt that hospice can make people feel better.
- While 58% believed that losing hope makes people die sooner, only 20% thought that talking about death would cause people to lose hope.
- 56% of respondents agreed that most physicians know how to treat pain; 41% thought that caring for dying patients causes stress for physicians.

“We found that older adults’ attitudes related to end-of-life care were in the great majority of instances consistent with the current hospice and palliative approach to care,” observe the authors. For instance, 93% agreed that dying patients have the right to be free of suffering, and only 13%

thought that the use of morphine for dying patients causes addiction. However, 59% agreed that hospice is offered when “nothing more can be done.”

“Prior studies have shown that older adults are often preoccupied by end-of-life issues, but that these concerns are seldom addressed by professionals,” conclude the authors. “Providing families and caregivers of older adult patients with the opportunity to learn about hospice and palliative care early in the disease process may help facilitate more informed and timely decisions about palliative care services and hospice utilization.”

*Source: “Perceptions and Attitudes about Hospice and Palliative Care among Community-Dwelling Older Adults,” American Journal of Hospice & Palliative Medicine; Epub ahead of print, May 2, 2012; DOI: 10.1177/104909112445305. Manu E, et al; Division of Geriatric and Palliative Medicine, Department of Internal Medicine, University of Michigan Health System, Ann Arbor.*

## Palliative Sedation for Refractory Suffering (from Page 5)

back of their study — as in any study of patients suffering severe refractory symptoms — is the lack of evidence from randomized controlled trials, in which patients would be randomly allocated to sedation or non-sedation groups. “[B]ut this is an impossible task, because it cannot be ethically justified,” they state.

“However, our systematic review seems to show that apart from observational clinical studies, a certain level of evidence on the absence of an impact of palliative sedation on survival can be affirmed, and palliative sedation can therefore be considered as an integral part of the palliative medicine approach to end-of-life care.”

### HOW TO APPROACH PALLIATIVE SEDATION?

“Perhaps one of the most important findings of this carefully conducted review is that only 11 articles were identified, and seven of them were retrospective [while the other four were prospective],” comments Eduardo Bruera, MD, in his editorial accompanying the report.

The analysis of retrospective studies in these patients is seriously limited by the lack of regular assessment of delirium and symptom severity in clinical practice, points out Bruera, of the MD Anderson Cancer Center, Houston.

Bruera suggests that a more thorough definition of a refractory symptom is needed. Until more evidence becomes available, physicians should try whenever possible to consult with palliative medicine specialists in the case of severe symptoms. Further, the decision to begin palliative sedation should be taken in consensus, not only with the patient and family, but also with all health care professionals involved in the patient’s care.

“As with many other medical interventions, the controversy that surrounds palliative sedation is not linked to the question of ‘yes or no?’ but rather, ‘when and how?’” concludes Bruera.

*Source: “Palliative Sedation in End-of-Life Care and Survival: A Systematic Review,” Journal of Clinical Oncology; April 20, 2012; 30(12):1378-1383. Maltoni M, et al; Istituto Scientifico Romagnolo per lo Studio e la Cura dei Tumori, Meldola. “Palliative Sedation: When and How?” *ibid.*, pp. 1258-1259; Bruera E; The University of Texas MD Anderson Cancer Center, Houston.*

# CLINICIAN RESOURCES

## **BOOK FOR CLINICIANS**

### ***The Best Care Possible: A Physician's Quest to Transform Care Through the End of Life***

Written by Ira Byock, MD, director of palliative medicine at Dartmouth-Hitchcock Medical Center, Lebanon, NH, this book explains how we as a nation are failing to provide our patients, our loved ones — and eventually, ourselves — with the care at the end of life that all of us want and need.

“In medicine,” says Byock, “we haven’t integrated the fact of dying, or attention to the quality of care and quality of life of someone when they’re dying, into our top-priority goals.” This both reflects and promotes the attitude of American culture: prolong life and avoid death and discussion of death at all costs.

Because our society has yet to hold a conversation about what a morally acceptable end-of-life experience would look like, notes Byock, our health care and social systems lag greatly behind our technological advances, making care for those in the last phase of life “needlessly convoluted, complex, and costly.”

#### **THE BOOK IS DIVIDED INTO FIVE SECTIONS:**

- The Best Care Possible
- Life-and-Death Decisions
- Palliative Care: Completing the Therapeutic Continuum
- Real Doctoring for the Twenty-first Century
- Transforming Medicine and Society

#### **CHAPTER TITLES INCLUDE:**

- Palliative Care — A Surprising New Specialty (Hint: It’s Not Just for Dying)
- What Are Doctors For?
- Fixing Health Care
- Imagining a Care-full Society
- Standing on Common Ground

Using patient stories and clinical experiences from his academic medical center, Byock describes what palliative care is, explains how hospice teams work, and shows how challenging yet “life-affirming” individualized best care for a dying person can be. In the final chapters, he offers practical solutions for reforming the health care system, and calls for a collective cultural transformation. “I am convinced that Americans across the social and political spectrum can come to broad agreement on what the best care possible looks like and what it means to die well.”

*Published by Avery Books, an imprint of Penguin Group (USA), Inc., March 2012; ISBN-13: 978-1583334591 (Hardcover); 336 pp.*

## **End-of-Life Care Websites**

**[www.aahpm.org](http://www.aahpm.org)**

American Academy of Hospice and Palliative Medicine

**[www.eperc.mcw.edu](http://www.eperc.mcw.edu)**

End-of-Life/Palliative Education Resource Center (EPERC)

**[www.epec.net](http://www.epec.net)**

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

**[www.nhpco.org](http://www.nhpco.org)**

National Hospice & Palliative Care Organization

**[www.caringinfo.org](http://www.caringinfo.org)**

Caring Connections: National Consumer Engagement Initiative to Improve End-of-Life Care

**[www.promotingexcellence.org](http://www.promotingexcellence.org)**

Promoting Excellence in End-of-Life Care

**[www.hospicefoundation.org](http://www.hospicefoundation.org)**

Hospice Foundation of America

**[www.americanhospice.org](http://www.americanhospice.org)**

American Hospice Foundation

**[www.hpna.org](http://www.hpna.org)**

Hospice and Palliative Nurses Association

**[www.hospicenet.org](http://www.hospicenet.org)**

Resources for patients and families

**[www.abcd-caring.org](http://www.abcd-caring.org)**

Americans for Better Care of the Dying

**[www.mcw.edu/palliativecare.htm](http://www.mcw.edu/palliativecare.htm)**

Medical College of Wisconsin Palliative Care Center

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

University of Wisconsin Pain and Policy Studies Group

**[www.capc.org](http://www.capc.org)**

Center to Advance Palliative Care

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- A Hospice Caring Story
- When You Are Grieving
- When Death Is Near: A Caregiver's Guide
- What Do We Do Now?: When a Child Is Seriously Ill

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