

# Quality of Life Matters<sup>®</sup>

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

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## 96% of Physicians Favor Enhancing Quality of Life for Seriously Ill Patients over Extending Life as Long as Possible

Nearly all physicians believe this country should place a higher priority on providing palliative care to all patients who need and want it, and that it is more important to enhance terminally ill patients' quality of life than to try to extend it by any means, a nationwide survey released by *National Journal* has found.

Results of the poll of 500 board-certified physicians were presented this past November at a Washington, DC, policy summit as the third and final part in the series entitled, "Living Well at the End of Life: A National Conversation." The presenter was Brent McGoldrick, senior vice president and general manager of FTI Consulting, the firm that conducted the survey for *National Journal*.

### KEY FINDINGS INCLUDE:

- 96% of physicians believe it is more important to enhance the quality of life for terminally ill patients than to attempt to extend life by any means.
- 96% think that patients and their families should be educated about palliative and end-of-life care and the options available to them.
- 94% agreed that palliative care should be made available to all seriously ill patients, should be offered alongside curative treatment, and should be fully covered by health insurance and Medicare.
- 79% think the nation's health care system spends too much in an attempt to extend the lives of terminally ill patients.

However, the data revealed some noteworthy hesitations about palliative care and barriers to its full adoption, McGoldrick pointed out.

Similar to patient groups, many physicians (42%) are concerned that emphasizing palliative care could interfere with cure-directed treatment. This concern was found less frequently among those physicians most familiar with palliative care, showing that more education is needed to explain that palliative care is not an either/or choice.

A dramatic "generation gap" found in physicians' early education and training in palliative and end-of-life care indicates encouraging progress in the last 15 to 20 years, said McGoldrick. Among physicians younger than 39 years, 73% reported having received at least some training in pal-

liative care and end-of-life care counseling in medical school, compared with only 25% of respondents aged 40 years or older. Further, 60% of all respondents say they have pursued continuing medical education in this area.

Physicians are aware of the limitations of their training; while 49% feel somewhat prepared to discuss palliative care, only 35% say they feel very prepared. And only 30% feel very prepared to counsel patients on end-of-life care options.

### BARRIERS TO PALLIATIVE CARE

Physicians identify the following as barriers to the implementation of palliative care:

- Patients are not adequately informed and don't ask (91%).
- Patients are reluctant to accept palliative care because it means admitting they may not recover (84%).
- Health insurance companies and Medicare do not reimburse adequately for consultations (82%).
- There are insufficient palliative care physicians and services (78%).
- Patients lack the resources to afford the care (78%).

### PHYSICIAN COMMUNICATION AND COMPENSATION

Two areas of crucial importance to physicians wishing to improve delivery of palliative care are training in the end-of-life conversation and compensation for such discussions, according to summit pan-

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## The Bad News Encounter: Helping Patients Move Forward

Most guidelines for delivering bad news that have been developed over the past 20 years focus effectively on diminishing patient distress. But physicians can provide more than protection from emotional pain as they relay the facts of terminal illness to a patient — physicians can help the patient to find “actionable hope” and move forward into a changed life.

That is according to an article published in the *American Journal of Hospice & Palliative Medicine*, in which the authors outline an approach physicians can use to support hope by assisting the patient in establishing realistic therapeutic and personal goals to match the values to be found in the patient’s new reality.

To illustrate the importance of changing the concept of “hope” from a state of mind to action, the authors use the example of a female acquaintance who has young children and is about to be newly diagnosed with metastatic disease.

“The best hope for this young mother of four is not a *noun* that sits with head in hands and wishes for a life that cannot be, but a *verb* that moves forward, seeking goals that will bring value into an altered world,” states lead author Alva Bowen Weir, MD, professor of medicine-hematology at the University of Tennessee Health Science Center in Memphis. “If I am to provide such hope for this patient... then movement toward realizable value must begin early, even with the first presentation of bad news.”

### PREPARING FOR A BAD NEWS ENCOUNTER

To prepare for that first presentation of bad news, physicians can:

- Allow adequate time for discussion.
- If circumstances permit, review the latest literature on the disease, so as to have data available for decision making.
- Review the patient’s social history to

### Goals for Presenting Bad News

1. **Provide information** that leads to diagnostic, therapeutic, and social decision making.
2. **Strengthen the relationship** with the patient and family, so that movement toward health and well-being can proceed in an environment of trust.
3. **Provide hope**, and begin to help the patient reorder his or her life to maximize value in a changed world.

— Adapted from Weir and Brint, *American Journal of Hospice & Palliative Medicine*

understand which areas and issues of importance might need to be addressed.

- Have one’s own directional goals in mind. The physician should prepare his or her own best plan, which can then be merged with the patient’s best plan.
- Address one’s own personal fears and anxieties, particularly if the patient’s situation hits close to home.

### DELIVERING INFORMATION, BUILDING PARTNERSHIP AND TRUST

In deciding how much information to impart, physicians can ask themselves beforehand how much this patient wants to know, and how much this patient needs to know. While some patients wish to have all available information, which is certainly their right, not all patients do, nor will all patients be capable of processing a great deal of information during a delivery of bad news.

Family and friends brought by the patient for the encounter should be deliberately included in the conversation and incorporated into the patient’s care team from the beginning, suggest the authors. This

will not only enrich the physician’s understanding of the patient’s situation and build trust, but will also give the patient support for remembering and complying with therapeutic plans, and for constructing a new vision of hope and value.

### MAKING PLANS THAT FOSTER HOPE AND VALUE

“From the initial visit where we deliver bad news, doctors should begin to navigate patients towards *hope* and *value*,” write the authors. Patients describing their hopes most often relate them to quality of life and goal fulfillment. “Such hope leads to value. Value is the perception that life is worth living.”

Physicians can help patients detach value from the life they will no longer have and reattach value to their life as it has become by redirecting such questions as “How long will I live?” and “How broken are my dreams?” to “How can I find value in each day of life?” and “What goals can I still accomplish?” Then physicians can help patients to make plans, which means moving toward realistic life and true hope. “I do my best to never tell a patient *what I can’t do* without laying out a plan for *what I can do*,” states Weir.

Because patients appreciate conversations that move them forward toward therapeutic goals, physicians would do well to remember that they are the experts concerning the circumstances of their patients’ health, and that “patients prefer to *partner* with their doctors in the decision making, rather than being left on their own.” Physicians are encouraged to recommend a care plan, confirm the next steps, and “end with commitment and hope.”

*Source: “Hope Is a Verb: A Course Correction in Delivering Bad News,” American Journal of Hospice & Palliative Medicine; December 2011; 28(8):525-527. Weir AB and Brint JM. University of Tennessee Health Science Center of Memphis and Veterans Affairs Medical Center, Memphis, Tennessee.*

## Effectiveness of Advance Directives May Not Depend on Whether They Are Used, But Where

Wide regional variations in the level of aggressive care delivered in the last six months of life have been well documented, and seem to be linked to medical practice patterns rather than to patient preferences. A team of Michigan researchers has found that the effectiveness of advance directives (ADs) is significantly related to the practice patterns of the region in which they are used, according to a report published in the *Journal of the American Medical Association*.

“Advance directives are associated with important differences in treatment during the last six months of life for patients who live in areas of high medical expenditures, but not in other regions,” write the authors. “This suggests that the clinical effect of advance directives is critically dependent on the context in which a patient receives care.”

Investigators analyzed survey and claims data on 3302 fee-for-service Medicare beneficiaries (mean age at death, 82.8 years; female, 56%) who died between 1998 and 2007, and had been respondents in the nationally representative Health and Retirement Study. Each proxy was interviewed

after death regarding the respondent’s treatment-limiting AD, living will, or durable power of attorney for health care.

### OVERALL RESULTS

- 61% of subjects had either a living will or written durable power of attorney; 39% had a written treatment-limiting AD.
- 41% died in a hospital, and 70% had been hospitalized at least once during the last six months of life.

### KEY FINDINGS

- ADs were more common in hospital referral regions with lower levels of spending in the last six months of life.
- Patients with ADs in high-spending areas had lower expenditures, were less likely to die in a hospital, and had significantly higher odds of hospice enrollment than patients with no ADs in these regions.
- There was no association between having an AD and end-of-life expenditure in regions with low or medium levels of spending.

“It is sometimes overlooked that an ad-

vance directive can only influence treatment when the patient’s wishes are inconsistent with what would be provided absent an advance directive,” comment the authors. If a region’s “default level” of care (and spending) is high, patients in those locations who do not want aggressive end-of-life measures are best served by making sure their treatment-limiting wishes are documented.

“We urgently need studies to examine the extent to which greater advance directive use in high-intensity regions would result in treatment that is more concordant with patient preferences and to understand the patient, physician, and health system characteristics that lead to higher rates of use in low-spending regions,” urge the authors.

*Source: “Regional Variation in the Association between Advance Directives and End-of-Life Medicare Expenditures,” Journal of the American Medical Association; October 5, 2011; 306(13):1447-1453. Nicholas LH, Langa KM, Iwashyna TJ, Weir DR; Institute for Social Research, University of Michigan; Department of Medicine, University of Michigan Medical School; and Veterans Affairs Health Services Research and Development Center of Excellence, Ann Arbor, Michigan.*

## 96% of Physicians Favor Enhancing Quality of Life for Seriously Ill Patients over Extending Life as Long as Possible

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elist Ezekiel J. Emanuel, MD, chair of the Department of Medical Ethics and Health Policy, University of Pennsylvania, Philadelphia. Patients don’t want to ask about end-of-life care, he noted, but neither do physicians want to initiate these discussions.

“You resist that conversation as long as possible,” he said. “It’s emotionally draining, it takes time, it’s difficult, you have

no way of knowing how the patient and family are going to react. That is enormously difficult.

“Figuring out how to start that conversation is the most important thing we can do to try to transform this. That requires education in better communication skills specific for end-of-life care.” Also needed, said Emanuel, is improved training in addressing and managing specific symptoms,

as well as better research and the development of more effective interventions.

Emanuel feels strongly that physicians must be compensated for the time needed for end-of-life conversations, just as they are compensated for taking a patient’s history.

*Results of the survey and a video of the November 2011 policy summit are available at: <http://nationaljournal.com/events/event/74/>.*

## Hospice Use among Ovarian Cancer Patients Rises as Late Referrals and Sociodemographic Disparities Remain Unchanged

Elderly women with ovarian cancer are enrolling in hospice in increasing numbers each year, but nearly 40% of these patients receive no hospice care, many receive such services close to death, and hospice use in this population varies significantly by race and socioeconomic status, a team of Maine researchers has found.

“More older women with ovarian cancer are receiving hospice care over time; however, a substantial proportion receive such care very near death, and sociodemographic disparities in hospice care exist,” write the authors of a report published in *Gynecologic Oncology*.

“Timely hospice referral is an essential component of quality end-of-life care, although a growing body of research suggests that for patients with various types of cancer, hospice referrals often occur very late in the course of care, and are marked by sociodemographic disparities.”

Investigators analyzed data representative of the U.S. population captured by the Surveillance, Epidemiology, and End Results registries and Medicare claims from 2001 through 2005. The study cohort included women aged 66 years or older (white race, 87.1%; aged 80 years or older, 41.0%) who were diagnosed with ovarian cancer during that period and died before the end of 2007.

### KEY FINDINGS

- Overall, 39.7% of women with ovarian cancer received no hospice care during the last six months of life.
- A higher proportion of black women (46.5% vs 38.4% white), women in the lowest income tertile (42.8% vs 37.0% in the highest tertile), and those with fee-for-service plans (41.3% vs 33.5% in managed care) never enrolled in hospice.

- Although the overall use of hospice during the study period rose from 49.7% in 2001 to 74.9% in 2005, the proportion of patients with ovarian cancer entering hospice programs within three days of death did not improve.

- Of those who did receive hospice care, 26.2% were enrolled within the last seven days of life and 11.2% were enrolled within the last three days of life.

**“Because hospice care improves pain and symptom control, it should be offered to patients at the point when medical interventions to extend life are futile, and when death is expected within six months,”** state the authors. “Physicians treating these patients have an opportunity to talk with patients about their end-of-life care options and preferences before they are gravely ill.”

### FACTORS ASSOCIATED WITH LACK OF HOSPICE CARE INCLUDED:

- Non-white race (odds ratio [OR], 1.44; 95% confidence interval [CI], 1.26 to 1.65)
- Fee-for-service vs managed care Medicare (OR, 1.39; 95% CI, 1.24 to 1.56)
- Age younger than 80 years (OR, 1.27; 95% CI, 1.15 to 1.40)
- Low income (OR, 1.17; 95% CI, 1.04 to 1.32)

“Our study identifies opportunities to improve the quality of care for older women dying of ovarian cancer, particularly with regard to timely hospice referral,” write the authors. “Our data also support the need to target lower-income and minority women in efforts to increase optimally timed hospice referrals in this population.”

One limitation to the study was lack of data with which to assess whether hospice

use was a reflection of patient preferences, note the authors. It could be that some populations are less accepting of hospice care or are poorly informed about their choices. It is also possible that areas with low-income populations or a high density of minority groups simply have fewer hospice programs available.

“Our findings also suggest the need for increased efforts to educate patients and families about the availability of hospice care and the benefit of timely referral,” write the authors. “Outreach to populations at risk for not receiving hospice, particularly minority, lower income populations, and patients with fee-for-service coverage may help improve knowledge of the hospice benefit and timely access to this care.”

The finding that women in fee-for-service Medicare programs were less likely than those in managed care plans to enroll in hospice is consistent with previous studies, the authors point out, further reinforcing the growing awareness of the importance of health care system factors in the utilization of hospice services.

**“Appropriate use of hospice care across the cancer population may help improve quality of care at the end of life for individual patients, but also may be beneficial to society by avoiding inappropriate resource use,”** comment the authors.

*Source: “Disparities in Hospice Care among Older Women Dying with Ovarian Cancer,” Gynecologic Oncology; Epub ahead of print, November 30, 2011; DOI: 10.1016/j.ygyno.2011.11.041. Fairfield KM, Murray KM, Wierman HR, Han PK, Hallen S, Miesfeldt S, Trimble EL, Warren JL, Earle CC; Center of Outcomes Research and Evaluation; Department of Medicine; and Department of Geriatrics, Maine Medical Center Research Institute, Maine Medical Center, Portland, Maine; Cancer Therapy Evaluation Program and Applied Research Program, National Cancer Institute, Bethesda, Maryland; and Institute for Clinical Evaluative Sciences, Sunnybrook Health Sciences Centre, Toronto, Ontario.*

## National Survey Finds Lack of Progress in Cancer Pain Management

Although most U.S. oncologists agree with the accepted practices for cancer pain management and give their discipline high ratings for its ability to relieve pain, many perceive serious barriers to effective pain treatment and demonstrate deficiencies in knowledge about appropriate opioid prescribing, according to a national survey.

“Limitations in oncologists’ knowledge and practices relating to pain management may be contributing to a substantial unmet need in populations with cancer,” write the authors of a research report published in the *Journal of Clinical Oncology*. “The longstanding acceptance of pain management as a best practice in oncology provides a foundation for renewed efforts to educate in this critical area.”

The team analyzed survey responses of a randomly selected sample of 610 practicing oncologists (median age, 56 years; female, 20%;  $\geq 9$  years in oncological practice, 89%). The current survey was modeled on a similar one conducted by the Eastern Cooperative Oncology Group in 1990 — the last time U.S. oncologists were systematically polled on their attitudes, knowledge, and practices related to pain management — and little has changed since then, the authors note.

“[M]edical oncologists continue to perceive barriers to best practices in pain management and continue to reflect negatively on their training in a manner similar to that of survey respondents 20 years ago,” write the study authors, led by Brenda Bruera, PhD, director of epidemiologic research at Beth Israel’s Department of Pain Medicine & Palliative Care.

Respondents were asked to indicate their responses to the itemized questionnaire using a numeric scale with ratings of 0 to 10, and were also presented with two challenging clinical scenarios requiring their recommendations for opioid

management changes.

### KEY FINDINGS

- Oncologists rated the ability of their medical specialty to relieve cancer pain highly (median rating, 7 on a 10-point scale), but rated their peers as more conservative than themselves in prescribing opioids (median rating, 3).
- Pain management training was rated low for both medical school (median rating, 3) and residency (median rating, 5).
- Only 14% reported making frequent referrals to pain or palliative medicine specialists.
- In their responses to the two clinical scenarios, 87% and 60% of oncologists selected a recommendation considered unacceptable.

### MAJOR BARRIERS

According to oncologists, major barriers to optimal pain management include:

- Patient reluctance to report pain (median rating, 6)
- Patient reluctance to take opioids, out of fear of addiction or fear of adverse

### Recommendations for Improving Cancer Pain Management

- Practicing oncologists can access the educational materials on cancer pain management mentioned in this study, and incorporate some simple methods for symptom assessment into their daily practice.
- At its annual scientific meeting, the American Society of Clinical Oncology can incorporate short, practical presentations on cancer pain into other sessions, rather than scheduling this topic separately and thus often in conflict with other sessions important to medical oncologists’ primary area of interest.
- Administrators can consider establishing structures and processes that allow rapid and effective consultation with palliative care and/or cancer pain programs in their institutions.
- Clinical researchers can design clinical trials on simple clinical pathways and educational interventions aimed at achieving better pain management.

— Bruera, *Journal of Clinical Oncology* podcast

effects (median rating for both, 6)

- Inadequate assessment of pain by physicians and/or nurses (median rating, 6)
- Patient inability to pay for services or analgesics (median rating, 5)
- Lack of available pain or palliative medicine specialists (median rating, 4)

“The most important lesson of this study is that while we have made dramatic improvements in our education and clinical care of patients with most cancers, in the last 20 years we have made minimal or no progress in our education, attitudes, and beliefs about the symptom that our patients and families fear the most,” states Eduardo Bruera, MD, in a commentary podcast on the study.

Bruera, who chairs the Department of Palliative Care and Rehabilitation Medicine at the University of Texas MD Anderson Cancer Center in Houston, offers recommendations for addressing some of the problems identified by the survey, such as inadequate pain assessment, lack of education, and poor access to palliative care and pain specialists. A survey conducted

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# CLINICIAN RESOURCES

## American Hospital Association Offers Online Resource to Help Clinicians Communicate with Patients about Treatment Options and Palliative Care

The physician's task of understanding a patient's priorities and goals begins at diagnosis of a life-limiting illness, when questions regarding the patient's hopes and fears can prepare the way for future discussions of palliative and hospice care. These questions will become necessary as the disease progresses and the patient feels ready, according to a publication newly available online from the American Hospital Association (AHA).

Originally created by the National Hospice and Palliative Care Organization (NHPCO), the two-page brochure, entitled, "Talking about Treatment Options and Palliative Care: A Guide for Clinicians," offers suggestions for incorporating discussion of palliative care early on in clinical encounters with seriously ill patients.

"Introducing the concept of palliative care — as care focused on alleviating symptoms even as you work to cure the illness — will allow you to continue referencing palliation of symptoms, optimization of functional capacities, and the importance of psychosocial support for the patient and the family," states the guide.

Finding the most effective way to communicate treatment options to patients with potentially life-limiting illnesses can be challenging, and sometimes the traditional phrasings are not necessarily the best. The guide offers new and alternative ap-

proaches for introducing and explaining palliative and hospice care options. [See sidebar, below.]

During these discussions, it helps to focus on the following goals:

- Make sure you are heard.
- Make sure you listen to the patient and family.
- Provide information that helps them to understand their options and to make choices based on their individual needs.

Also included in the guide is a list of

suggested questions for opening/continuing the topics of palliative and hospice care preferences and options, as well as a "translation" of what patients might really be thinking or want to know when they ask general or traditional questions.

The guide is available on the AHA's Community Connections via the "Partner Tools" link at [www.caringforcommunities.org](http://www.caringforcommunities.org). It is also available in brochure form on the NHPCO's Caring Connections site through the "Resources" link at: [www.caringinfo.org](http://www.caringinfo.org).

### New Approaches to Explaining Treatment Options

- Instead of saying: "XYZ treatment has a 5% success rate," try: *This treatment works for one in 20 people. The people it works for live an average of X number of years or months. Or: In my experience, this treatment works for very few people. Those people may gain a few extra months, but many of them have told me that the side effects are not worth it.*
- Instead of saying: "Some patients experience XYZ side effects as a result of the treatment protocol," try: *You can expect the following side effects. I will work with you to manage these side effects as best as I can. But, if the side effects become too troublesome, we can talk about other options, including stopping or changing the treatment.*
- Instead of saying: "This is what I recommend," try: *I can explore options with you, but decisions about how to care for you are yours. Or: I want to be completely honest with you. Even with treatment, I think it is very unlikely you will live more than X months.*
- Instead of saying: "Do you have any questions?" try: *I've presented you with a lot of information. What questions do you have?*
- Instead of saying: "At some point, we may have to look at hospice as an option," try: *With the disease you have, it is very likely that hospice care will be the best option for you at some time in the future. We can discuss this over time, so you can make decisions that best suit your needs.*

— NHPCO, "Talking about Treatment Options and Palliative Care: A Guide for Clinicians"

## National Survey Finds Lack of Progress in Cancer Pain Management

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by his group, he notes, found that only 60% of National Cancer Institute (NCI) comprehensive cancer centers and 22% of non-NCI cancer centers have outpatient palliative care programs.

"Without access to outpatient palliative

care consult services, many oncologists find it difficult to access support, not only for pain, but for multiple other physical and psychosocial problems in their patients," he points out.

Source: "Medical Oncologists' Attitudes and Practice in Cancer Pain Management: A National Survey," *Journal of Clinical Oncology*; *Epub ahead*

*of print, November 14, 2011; DOI: 10.1200/JCO.2011.35.0561. Breuer B, Fleishman SB, Cruciani RA, and Portenoy RK; Beth Israel Medical Center, New York City. "Medical Oncologists' Attitudes and Practice in Cancer Pain Management: A National Survey" [podcast], November 14, 2011; <http://jco.ascopubs.org>. Bruera E; Department of Palliative Care and Rehabilitation Medicine, University of Texas MD Anderson Cancer Center, Houston.*

# CLINICIAN RESOURCES

## BOOK FOR CLINICIANS

### ***Oxford American Handbook of Hospice and Palliative Medicine***

Published just months ago, this handbook offers U.S. physicians, nurse practitioners, fellows, residents, and students an up-to-date, practical, and concise source of information on most of the day-to-day clinical and administrative needs of those caring for people with progressive incurable illnesses and their families.

The handbook was written by an expert team of clinicians and edited by Eduardo Bruera, MD, and Sriram Yennurajalingam, MD, the department chair and clinical medical director, and assistant professor, respectively, of the Department of Palliative Care and Rehabilitation Medicine, Division of Cancer Medicine, The University of Texas MD Anderson Cancer Center, Houston, TX.

#### **KEY FEATURES OF THE HANDBOOK INCLUDE:**

- Guidance on the assessment and management of palliative patients is evidence-based, succinct, and topically focused.
- The design is aimed at the clinical and administrative structure within the U.S. health care system, including the Medicare hospice benefit.
- Content follows the core curriculum of the American Board of Hospice and Palliative Medicine.
- Supplemental material includes extensive tables and algorithms.

The editors note that within the last decade, there has been a major increase in the number of patients using hospice for end-of-life care, and the number of inpatient and outpatient palliative care programs has increased significantly. Yet, the education of clinicians needed to care for these patients has lagged behind, they state, even with the establishment of hospice and palliative medicine as a subspecialty recognized by the American Board of Medical Specialties.

“We believe this book will provide rapid access to most of the daily bedside clinical and administrative needs, and we hope it will help our colleagues in the delivery of excellent palliative and hospice care,” the editors write.

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

- Definitions and Key Elements in Palliative Care
- Clinical Decision Making
- Emergencies in Palliative Care
- Management of Cancer Treatment Related Adverse Effects
- Palliative Care in End-Stage Heart Failure
- Prognostication in Palliative Care
- Hospice Approach to Palliative Care, Including Medicare Hospice Benefit

*Published by Oxford University Press, USA, July 2011;  
ISBN-13: 978-019538156 (Paperback); 504 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

[www.stoppain.org](http://www.stoppain.org)

Pain Medicine & Palliative Care, Beth Israel Medical Center

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