



## American College of Physicians Advises Early End-of-Life Discussions for All Seriously Ill Patients

Conversations about goals of care should be initiated early, and integrated into routine clinical practice by all physicians caring for patients with life-threatening illness, as a “low-risk, high-value” intervention for improving end-of-life outcomes, according to Boston researchers reporting for the task force of the American College of Physicians (ACP) High Value Care Initiative.

“A large, diverse, and consistent body of evidence demonstrates that early discussions of serious illness care goals are associated with beneficial outcomes for patients, without harmful adverse effects,” they write in a paper published in *JAMA Internal Medicine*. “Thus, we believe that there is a strong rationale for recommending that clinicians initiate early discussions

**Basic Principles of End-of-Life Communication**

- Patients want the truth about prognosis.
- You will not harm your patient by talking about end-of-life issues.
- Anxiety is normal for both patient and clinician during these discussions.
- Patients have goals and priorities besides living longer.
- Learning about these goals and priorities empowers you to provide better care.

— Bernacki and Block, *JAMA Internal Medicine*

with all patients with serious illness.”

The authors use the term “serious illness care goals” to include all discussions about goals of care, advance care planning, or end-of-life care preferences. In a review of the medical literature from 2006 to 2014, they found that these key discussions are most effective when targeted to patients throughout the course of serious illness. “Effective communication supports not only end-of-life care, but quality of life throughout the illness trajectory, even if death is not an imminent outcome.”

Early goals-of-care discussions are associated with:

- Improved quality of life
- Less non-beneficial medical care near death
- Greater likelihood of care consistent with patient goals
- Positive family outcomes
- Reduced health care costs

The paper summarizes the ACP task force’s advice for delivering evidence-based, high-value communication inter-

ventions, and includes tables of information on: triggers for end-of-life communication by disease; a list of therapies with potential for overuse and underuse; a conversation guide to addressing key elements with seriously ill patients [see sidebar, page 2]; communication do’s and don’ts; and basic principles of end-of-life communication. [See sidebar, above.]

The advice is focused primarily on the ambulatory care setting, and the most relevant conditions for these discussions are among the most common causes of death in the U.S.: cancer, congestive heart failure, chronic obstructive pulmonary disease, and chronic kidney disease and/or end-stage renal disease.

Every patient with serious illness should have a personalized care plan, states the paper. The ACP advises that a discussion about care goals should be initiated while the patient’s condition is relatively stable, and is best conducted by the patient’s primary care physician, or by a single, mutually agreed-upon physician who then

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## American College of Physicians Advises Early End-of-Life Discussions for All Seriously Ill Patients (from Page 1)

shares the outcomes of end-of-life discussions with other clinicians involved in the patient's care.

Best clinical practices in discussing goals of care include:

- Sharing prognostic information
- Eliciting decision-making preferences
- Understanding fears and goals
- Exploring views on trade-offs and impaired function, as well as preferences for family involvement

Without conversations about prognosis, goals, and outcomes of treatment, patients lack the opportunity to express their values and preferences, the authors note. This can lead physicians to assume that aggressive care is still desired, even late in the illness. Patients who are not aware that they are nearing the end of life risk overusing life-prolonging therapies and underusing those services that support quality of life.

“One effect of delay in discussions about end-of-life goals is that discussions of care options, such as hospice, which are associated with consistently superior outcomes for both patients and family members, occur very late in the patient's disease trajectory,” write the authors. “Fifteen percent of hospice patients are referred in their last week of life, where benefits that accrue over time to the patient and family may be limited.”

### NO HARM TO PATIENTS

Discussion of end-of-life care issues has not been found to harm patients, note the authors. Research shows that patients and families want a balance between appropriate hope and realistic, honest information.

“It is important for physicians, patients, and their families to know that the evidence does not support the commonly held belief that communication about end-of-life issues increases depression, anxiety, or loss of hope among patients,”

### Conversation Guide: Key Elements

1. Understanding of Prognosis. “What is your understanding now of where you are with your illness?”
2. Decision Making and Information Preferences. “How much information about what is likely to be ahead with your illness would you like from me?”
3. Prognostic Disclosure. This should be tailored to information preferences.
4. Patient Goals. “If your health situation worsens, what are your most important goals?”
5. Fears. “What are your biggest fears and worries about the future with your health?”
6. Acceptable Function. “What abilities are so critical to your life that you can't imagine being without them?”
7. Trade-offs. “If you become sicker, how much are you willing to go through for the possibility of gaining more time?”
8. Family Involvement. “How much does your family know about your priorities and wishes?”

— Bernacki and Block, JAMA Internal Medicine

says ACP president David Fleming, MD, of the University of Missouri School of Medicine in Columbia.

“The ACP supports the need for improving our approach to serious illness and end-of-life care, as well as the system changes needed to assure thoughtful and timely communication with patients and their family members across all health care settings.”

Important elements for system improvement include:

- Better end-of-life care education and discussion training for clinicians
- Systemized “triggers” for early discussions with appropriate patients
- Patient and family education
- Structured formats for goals-of-care discussions
- Dedicated systems to document discussions in the electronic health records
- Metrics to gauge performance

“[C]ommunication about serious illness care goals is an intervention that should be

systematically integrated into our clinical care structures and processes,” conclude the authors. “Earlier discussions about the realities of an advancing illness and the role of hospice care in meeting patient goals allows patients to choose the care trajectory that will best meet their goals.”

ACP's High Value Care initiative is designed to help physicians and patients “understand the benefits, harms, and costs of tests and treatment options for common clinical issues so they can pursue care together that improves health, avoids harms, and eliminates wasteful practices.”

Source: “Communication about Serious Illness Care Goals: A Review and Synthesis of Best Practices,” JAMA Internal Medicine; Epub ahead of print, October 20, 2014; DOI: 10.1001/jamainternmed.2014.5271. Bernacki RE, Block SD, for the American College of Physicians High Value Care Task Force; Division of Adult Palliative Care, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute; Ariadne Labs, Brigham and Women's Hospital & Harvard School of Public Health; Division of Aging, Department of Medicine, Brigham and Women's Hospital, all in Boston.

## Hospice Care Associated with Lower Risk of Aggressive Cancer Care, Lower Costs in Final Year of Life

Medicare patients with poor-prognosis cancer who enroll in hospice have lower rates of hospitalization, intensive care unit (ICU) admissions, invasive procedures, and total health care costs in the last year of life, Boston researchers have found. Further, hospice patients are five times more likely than non-hospice patients with similar characteristics to die at home.

Nearly three-quarters of non-hospice patients studied died in hospitals or nursing homes, compared with just 14% of hospice patients, according to a report published in *JAMA Internal Medicine*. In addition, non-hospice patients had a higher rate of costly health care utilization (hospitalizations, ICU admissions, and invasive procedures), largely for acute conditions unrelated to their cancer.

“Our study shows very clearly that hospice matters,” says lead author Ziad Obermeyer, MD, MPhil. “Hospice and non-hospice patients had very similar patterns of health care utilization, right up until the week of hospice enrollment — then, the care started to look very different.

“Patients who didn’t enroll in hospice ended up with far more aggressive care in their last year of life, most of it related to acute complications like infections and organ failure, and not directly related to their cancer diagnosis.”

Investigators analyzed Medicare data on a nationally representative 20% sample of 86,851 beneficiaries with poor-prognosis cancer (e.g., lung, pancreatic, brain, or any metastatic malignancy) who died in 2011. Of these, 60% entered hospice. Median length of time from first poor-prognosis diagnosis to death was 13 months. In the matched cohort study, those who enrolled in hospice were matched to a control group of those who died without hospice care, creating 18,165 matched pairs (mean age, 80 years).

Investigators found that non-hospice patients had higher rates of:

*“Our findings highlight the potential importance of frank discussions between physicians and patients about the realities of care at the end of life, an issue of particular importance as the Medicare administration weighs decisions around reimbursing physicians for advance care planning.”*

— Obermeyer et al, *JAMA Internal Medicine*

- Hospitalization (65.1% vs 42.3%; risk ratio [RR], 1.5; 95% confidence interval [CI], 1.5 to 1.6)
- Intensive care admissions (35.8% vs 14.8%; RR, 2.4; 95% CI, 2.3 to 2.5)
- Invasive procedures (53.0% vs 26.7%; RR, 1.9; 95% CI, 1.9 to 2.0)
- Death in hospital or nursing facility (74.1% vs 14.0%; RR, 5.3; 95% CI, 5.1 to 5.5)
- Health care expenditure during the last year of life (\$71,517 vs \$62,819; difference, \$8697; 95% CI, \$7560 to \$9835)

### COSTS

Enrollment in hospice was associated with a cost difference of \$8697 during the last year of life. Those enrolled for five to eight weeks represented the greatest difference in costs (\$17,903) compared with non-hospice patients, although shorter stays resulted in lower, but still statistically significant, cost differences. Only among the 2% who stayed longer than one year in hospice did expenditures exceed those of the non-hospice group.

“Hospice enrollment of five to eight weeks produced the greatest savings; shorter stays produced fewer savings, likely because of both hospice initiation costs and need for intensive symptom pal-

liation in the days before death,” observe the authors. “Cost trajectories began to diverge in the week after hospice enrollment, implying that baseline differences between hospice and non-hospice beneficiaries were not responsible for cost differences.”

### HOSPICE STAYS TOO SHORT

Median length of stay among hospice patients in the study was 11 days. As the number of patients with cancer who use hospice continues to rise, the length of hospice stays grows shorter, while care intensity outside of hospice is increasing, note the authors.

“Patients with cancer, the single largest group of hospice users, have both the highest rates of hospice enrollment and the highest rates of hospice stays of less than three days,” they point out. Since the 1982 initiation of the Medicare hospice benefit, the number of people of all diagnoses receiving its services has increased, yet the median length of stay has decreased over the same time period.

“While patients with cancer still make up more than a third of all those cared for by hospice providers, their lengths of stay in hospice are among the shortest,” says J. Donald Schumacher, PsyD, president and CEO of the National Hospice and Palliative Care Organization.

“This points to the desperate need for clinicians treating cancer to have conversations about palliative care and hospice.”

*Source: “Association between the Medicare Hospice Benefit and Health Care Utilization and Costs for Patients with Poor-Prognosis Cancer,” JAMA Internal Medicine; November 12, 2014; 312(18):1888-1896. Obermeyer Z, Makar M, Abujaber S, Dominci F, Block S, Cutter, DM; Departments of Emergency Medicine, Health Care Policy, Medicine, and Economics, Harvard Medical School; Departments of Emergency Medicine and Psychiatry, Brigham and Women’s Hospital; Ariadne Labs; Department of Biostatistics, Harvard School of Public Health; Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, all in Boston.*

## Researchers Analyze Hospice Use to Help Inform Debate about End-of-Life Care for Nursing Home Patients

Hospice care for nursing home patients has been associated with improved pain and symptom management, reduced hospitalization, and improved family satisfaction, note the authors of a report published in the *Journal of General Internal Medicine*, the official journal of the Society of General Internal Medicine.

Nearly one-third of hospice patients in the U.S. live in nursing homes, and the number is growing, the authors point out. Concerned that proposed changes to the hospice benefit could decrease access to end-of-life care services for this vulnerable population, the investigators analyzed hospice use among nursing home and non-nursing home patients.

The team found that characteristics of hospice patients in nursing homes differ from those of community hospice patients, as do their patterns of care utilization. In addition, there are subsets of hospice patients who move in and out of these settings, and for whom appropriate palliative care services must be considered.

Researchers analyzed data from one of the nation's largest safety-net health systems merged with Medicare, Medicaid, and Minimum Data Set reports from 1999 through 2008 for hospice patients aged 65 years and older (n = 3771; mean age, 79.1 years).

Patterns of transitions across settings in this population made it difficult to dichotomize hospice beneficiaries into only nursing home vs non-nursing home patients as originally planned, the researchers found. It became apparent that there were four, not two, identified groups to be examined.

### HOSPICE COHORTS IDENTIFIED:

1. Patients who received hospice care in a nursing home only (30.3%)
2. Patients with hospice care delivered outside of a nursing home only (52.1%)
3. "Crossover" patients, who received

continuous hospice service in both settings (8.2%)

4. A "near-transition" group of patients who were not enrolled in hospice while nursing home residents, but did receive hospice care within 30 days of transition into or out of a nursing home (9.4%)

### OVERALL:

- Nursing home hospice patients were older, more likely to be female, to have dementia, and to be eligible for both Medicare and Medicaid.
- Cancer was the leading primary hospice diagnosis among all hospice patients, but nearly the same proportion of nursing home residents had dementia as a primary admitting diagnosis.
- While 76% of the entire sample were hospitalized in the year prior to hospice enrollment, only 10% were hospitalized following enrollment.

### KEY FINDINGS:

- Median length of hospice stay was relatively similar among the nursing home and community patients (23 and 21 days, respectively), but was dramatically higher for the crossover group (91.5 days), and dramatically lower for the near-transition group (8 days).
- Late hospice enrollment—less than one week before death—occurred among more than one-quarter (27.7%) of all patients, but was highest among the near-transition group (48%) and lowest among the crossover group (7.4%).
- Crossover and near-transition patients had higher Medicare costs compared with other groups [ $P < 0.05$ ].
- Nearly one-third (32.3%) of crossover patients had hospice stays > 6 months, compared with nursing home only (16%), non-nursing home (10.7%), and near-transition patients (7.6%).

The subgroup of patients with particularly long lengths of stay "must be viewed

in the context of the striking finding of a large percentage of 'late referrals' who receive hospice care for a week or less," point out the authors.

"Very short stays on hospice may make it difficult for hospice care to impact quality of life of the patient, and reduce the opportunity for cost savings by Medicare through avoided hospitalizations." Thus, they warn, policies that discourage longer lengths of hospice stay may inadvertently increase the percentage of very late and costly hospice referrals.

"If changing rules and incentives lead to reduced access to hospice care for nursing home patients, there is little existing infrastructure to provide palliative or end-of-life care to this frail population."

Among crossover patients, over half transferred from home to a nursing home facility, "presumably as their care needs became greater than they or their caregivers could manage at home," the authors suggest. About one-third transferred from nursing home to home while receiving hospice care, "transitioning back to a community setting for the very end of life."

The authors conclude, "As the debate over hospice use in nursing homes continues, many also advocate for an increase in palliative care services outside of the hospice benefit to meet the needs of patients with serious, chronic diseases, such as dementia, with an uncertain illness trajectory." They add, "The findings of this study provide data that will hopefully inform this debate."

Source: "Hospice Use among Nursing Home and Non-Nursing Home Patients," *Journal of General Internal Medicine*; Epub ahead of print, November 6, 2014; DOI: 10.1007/s11606-014-3080-x. Unroe KT, Sachs GA, Dennis ME, Hickman SE, Stump TE, Tu W, Callahan CM; Indiana University Center for Aging Research; Regenstrief Institute, Inc.; Indiana University School of Medicine; Indiana University School of Nursing; RESPECT Signature Center at IUPUI; all in Indianapolis.

## Ovarian Cancer Patients: Hospice Use Needs to Be More Than an ‘Add-On’ to Aggressive Treatment Near Death

*‘Patients are receiving more, but not necessarily better, care’*

While enrollment in hospice among patients with ovarian cancer rose from 1997 to 2007 and the number of hospital deaths fell, significantly more patients over that time period were admitted to intensive care units (ICUs), hospitals, and emergency departments within the last month of life. Further, an increasing number of patients were referred to hospice directly from acute care settings, often within the final three days of life.

“These trends suggest that patients are receiving more, but not necessarily better, care,” write the authors of a report published in the *Journal of Clinical Oncology*. “The increasing use of hospice did not offset intensive end-of-life care. These results heighten concerns that hospice may be used as an ‘add-on’ service to manage death after the failure of more intensive interventions.”

Investigators analyzed the Medicare records of 6956 individuals (aged  $\geq 66$  years) who were diagnosed with epithelial ovarian cancer between 1997 and 2007 and had died by 2007. Claims data were merged with data from the national SEER cancer registry. The majority of patients were aged  $< 80$  years (62.4%) and without significant comorbid illness (67.6%). Nearly two-thirds (64.2%) had stage III or IV disease at diagnosis.

### KEY FINDINGS:

- Between 1997 and 2007, statistically significant increases in ICU admissions, hospitalizations, repeated emergency department visits, and health care transitions were observed for patients with ovarian cancer (all  $P \leq 0.01$ ).
- The proportion of patients referred to hospice from acute care settings rose over time ( $P = 0.001$ ).
- Patients referred to hospice from inpatient hospital settings were more likely than outpatients to enroll  $\leq 3$  days before death (adjusted odds ratio, 1.36; 95% confidence interval, 1.12 to 1.66).
- Among patients who enrolled in hospice  $\leq 3$  days before death, the proportion with a preceding ICU stay in the last month of life rose dramatically from 1997 to 2007 (5.0% vs 31.3%;  $P = 0.001$ ).

### HEALTH CARE TRANSITIONS

Despite the increasing use of hospice during the 10 years studied, the proportion of patients undergoing burdensome health care transitions in the last three days of life did not change significantly. Nor did the total number of days spent in ICUs,

*“When you use hospice as an add-on service, it doesn’t really do what it’s designed to do, which is to be there and deliver care in a patient-centered way.”*

— Wright, *Journal of Clinical Oncology*

hospitals, or hospice during the last month of life vary over time. More patients were using hospice, but the quality of their care may not have been improving.

- About 70% of patients were transferred between medical facilities at least once in the last month of life ( $P = 0.008$ ).
- A greater number of patients from 1997 to 2007 underwent  $\geq 3$  transitions between care settings in their final month (adjusted mean, 1.3 vs 1.6;  $P = 0.003$ ).
- Nearly 20% experienced major transitions within the last three days of life ( $P = 0.35$ ).

“When you use hospice as an add-on service, it doesn’t really do what it’s designed to do, which is to be there and deliver care in a patient-centered way,” says lead author Alexi A. Wright, MD, MPH, of Dana-Farber Cancer Institute and Harvard Medical School, Boston. “Hospice care, which focuses on intensive symptom management at home, is an attractive option for many people. But unless people make an end-of-life care plan while they’re healthy — spelling out their preferences in advance — these important decisions are often made for them, or occur in a crisis atmosphere. That may explain why, in this study, we saw an increased use of hospital-based services even as hospice enrollment increased.

“Earlier and more regular discussions about patients’ and families’ preferences for end-of-life care — and the potential benefits and harms of intensive care near death — may help decrease the use of hospital-based care near death, although determining effective strategies for doing this requires further study, because patients’ choices may be influenced by the ways in which options are presented.”

Source: “End-of-Life Care for Older Patients with Ovarian Cancer Is Intensive Despite High Rates of Hospice Use,” *Journal of Clinical Oncology*; November 1, 2014; Wright AA, Hatfield LA, Earle CC, Keating NL; Dana-Farber Cancer Institute; Harvard Medical School; Brigham and Women’s Hospital, all in Boston; Cancer Care Ontario and Ontario Institute for Cancer Research, Toronto, Ontario.

# CLINICIAN RESOURCES

## Moments of Life: Free Online Resource for Patients with Life-Limiting Illness and Their Families

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

A recently launched patient resource from the National Hospice and Palliative Care Organization (NHPCO) has added new educational videos for patients and families on end-of-life topics that have been shown to be important to people, but are often little known or misunderstood.

“Moments of Life: Made Possible by Hospice” is a national awareness campaign launched in the spring of 2014, featuring both practical tips and guidance to help people make health care choices in the face of serious illness, along with an online library of photos and stories shared by those who have experienced hospice care. The theme of the campaign is, “Even when you’re dying, there is still a lot of living to do.”

“For many who have not seen hospice in action, it has become a common misconception that hospice patients are merely lying in bed, waiting for their end to come,” states the NHPCO. “For families who have experienced hospice, they see the focus is not on dying — it is about living as fully as possible. Hospice not only provides the highest quality care, it affords more moments, memories, and opportunities.”

New to the easy-to-navigate online resource are videos on the following relevant topics:

- **Understanding Hospice** — presents ten facts that people may not know about hospice. [See sidebar.]
- **Grief: A Part of Living** — explains the natural process of grieving and offers tips for dealing with loss.
- **Caregiver Stress** — describes signs of caregiver burnout and offers suggestions for caring for the caregiver.
- **Planning for End-of-Life Care** — provides guidance on how to start the important conversations and communicate wishes for future care.

### MAJOR SECTIONS OF THE SITE INCLUDE:

- **What Is Hospice?** — explains hospice and palliative care, addresses common questions and concerns, and provides practical information on how to learn more and take action. Links within the articles direct patients and families to information on how to decide which services may best address their needs, as well as how to choose the right facility.

An advance care planning feature includes links to downloadable brochures on how to have conversations about health care preferences before a crisis, and how to talk

about and make end-of-life decisions. There are also links to appropriate documents, listed by state.

- **Find a Hospice** — provides an interactive map of the U.S., with contact information for available hospice services. Patients and families are encouraged to call local hospice providers and ask questions to best determine how the services offered might be appropriate for their particular situation.
- **What Are My Options?** — is an interactive tool providing information and guidance on facing severe illness. Patients or loved ones can select from among four situations, ranked by degree of disease and symptom severity, and access explanations of health care choices and steps that can be taken.

“The importance of patients and families understanding the range of options when facing a serious or life-limiting illness was highlighted in the recent Institute of Medicine report, ‘Dying in America,’ so we hope these videos will add to resources available to families,” says J. Donald Schumacher, PsyD, NHPCO president and CEO.

### Ten Facts about Hospice

1. It is not a place; it is high-quality medical care focused on comfort and quality of life.
2. It does not cost the patients; it is covered by Medicare, Medicaid, and most private insurance plans.
3. It is available to anyone with a life-limiting illness, regardless of age, location, or type of illness.
4. It serves people of all backgrounds and traditions.
5. It provides a home-like environment.
6. It does not have to be at home.
7. It may continue to provide care for six months or longer.
8. It encourages the referring physician to stay involved in the patient’s care.
9. It offers counseling to the family.
10. It can provide the best of its extensive services when care is for longer than just a few days.

— Adapted from [www.momentsoflife.org](http://www.momentsoflife.org)

# CLINICIAN RESOURCES

## ***Being Mortal: Medicine and What Matters in the End***

Written for clinicians, patients, and families by Atul Gawande, MD, MPH, a surgeon at Brigham and Women's Hospital in Boston, *Being Mortal: Medicine and What Matters in the End* examines the modern experience of aging and dying, and the need for a transformation of medicine's role in affecting the quality of that experience.

Prior to the end of World War II, most deaths in the U.S. occurred in the home, notes Gawande. By the late 1980s, dying had become medicalized and institutionalized, with only 17% of Americans dying in a setting other than a hospital or nursing home. "This experiment of making mortality a medical experience is just decades old. It is young. And the evidence is, it is failing," he writes.

The recent growth of hospice care has been accompanied by a gradual reversal in this trend, but medicine often remains focused on the pursuit of longevity over what is considered a good quality of life. According to Gawande, "[o]ur reluctance to honestly examine the experience of aging and dying has increased the harm and suffering we inflict on people and has denied them the basic comforts they need most."

Having begun to move away from the institutionalized version of aging and death, we are now in what Gawande calls a "transitional phase," in which a new norm has not yet been established. He has hope that through understanding what works or does not work in our current approach to caring for those nearing the end of life, we can find "better approaches, right in front of our eyes."

The book explores medical care at the end of life through:

- Case studies of patients making the hard decision to balance longer life with better life
- Profiles of professionals who have challenged the status quo
- Stories from Gawande's practice and personal life
- Insights gathered from medical specialists and experts

Gawande tells how he learned about hospice care by seeing it through the eyes of a hospice nurse as he accompanied her on patient rounds. Until then, he had visualized hospice as "providing a morphine drip" and "letting nature take its course." But standing idly by was not the aim, he learned; instead, he discovered that hospice's efforts focus on the goal of respecting a patient's priorities and honoring what makes living worthwhile.

For clinicians, helping patients to achieve their end-of-life goals based on what is important to them means having "the hard conversation." Begin with "I am worried," suggests Gawande. This tells patients not only that the situation is serious, but that the physician is on their side. Then ask patients about their specific fears, their goals, and what trade-offs they would be willing to make. Based on that understanding, provide an interpretation of which choices would be best.

Gawande saw the good effects of this interpretive communication approach firsthand through the experience of his seriously ill father, himself a surgeon, as the older man made the decision to live to have the "best possible day today" through home hospice care. "Here is what a different kind of care — a different kind of medicine — makes possible," Gawande writes. "Here is what having a hard conversation can do."

*Published by Metropolitan Books / Henry Holt and Company, October 2014;  
ISBN: 9780805095159 (Hardcover); 304 pp.; available in e-Book format.*

## **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



### Caring for the Caregiver: A Physicians Guide

Caregivers come in all shapes and sizes. They can be adult children, spouses, siblings, friends, or neighbors, who help with daily activities such as bathing, feeding, and getting dressed. The caregiver may be the only person who can take a loved one to doctors appointments. The long-distance caregiver may call weekly, help with expenses, or support the main caregiver.

According to the National Family Caregivers Association (NFCA), more than 65 million people provide a level of care to a loved one with a chronic disease each year. Caregiving can be demanding and time-consuming; it may even increase the risk of acquiring stress-related disorders.



### Watch for issues

Mental and physical signs of caregiver stress:

- A tendency to overreact
- Anger or fear
- Digestive upsets
- Feeling depressed, isolated, or overburdened
- Headaches
- Taking on more than you can handle
- Thoughts of guilt, shame, or inadequacy
- Trouble sleeping fatigue illness
- Weight loss or gain

If you have patients who are caregivers, and notice them displaying physical signs of caregiver stress, call Hospice at Home, a Lakeland HealthCare Affiliate, at (800) 717-3811. Hospice at Home can help provide support for caregivers and alleviate some of the stress associated with providing care.

Learn more at [www.hospiceathomecares.org](http://www.hospiceathomecares.org) or contact our Referral Center at (269) 429-7189 or (800) 457-1603

Call us today at (269) 429-7100  
[www.hospiceathomecares.org](http://www.hospiceathomecares.org)

