

A Newsletter for Healthcare Professionals

Summer 2010

In This Issue:

Management of Dyspnea	1
Helping Patients Determine if Hospice is for Them	2
Benefits of Palliative Care	3
End-of-Life Care Websites	3
Symptom Management Fall Symposium	4

Hope Hospice Team Managers

Peter P. Wong, MD
Medical Director

Michael Abdel-Malek, MD
Associate Medical Director

Daniel Dinaburg, MD
Consulting Psychiatrist

Helen Meier, MA
Executive Director

Ann Noll, BSN, CHPN
Director of Patient Services

Barbara Hepner
Director of Marketing

Karen Archer, RN, CHPN
Clinical Coordinator

Ann Felter, LCSW
Social Work & Spiritual Care Supervisor

Michael Stephens, MFT
Director of Grief Support Center

Marci Crothers, RN, BSN, PHN
Nurse Supervisor, RN Case Manager

Jennifer Natsch-Jensen, RN,
BSN, CIC
Nurse Supervisor, RN Case Manager



Accredited by:
The Joint Commission

Management of Dyspnea in Patients with Advanced Heart or Lung Disease: An Ethical Obligation

As with pain, assessment of dyspnea begins with asking the patient

Consensus Statement Key Points Include:

- Health care professionals are ethically obligated to treat dyspnea. Patients and their families should be reassured that they will be provided the means to effectively treat this symptom.
- Patients should be asked to routinely rate the intensity of their breathlessness as part of a comprehensive care plan and such ratings should be routinely documented.
- Concerns about contributing to addiction and/or physical dependence should never limit effective treatment or palliation of dyspnea.
- It is important for clinicians to communicate about palliative and end-of-life care with their patients.

— American College of Chest Physicians

The need for improved treatment of a highly prevalent symptom among patients with advanced lung or heart disease has prompted the American College of Chest Physicians (ACCP) to issue a consensus statement on the management of dyspnea.

“Although assessment of a patient’s intensity of pain is a requirement, it is not standard practice for health care providers to ask patients to provide a rating of dyspnea,” writes an expert panel of pulmonologists, cardiologists, nurses, and palliative care specialists reporting in *Chest*, the official journal of the ACCP.

Over 90% of patients with advanced chronic obstructive pulmonary disease and more than 60% of those with advanced heart disease report problems with breathlessness, the panel found in its systematic review of the topic in the literature from 1966 to 2008. Further, about 94% of patients with chronic lung disease experience dyspnea in the last year of life.

The topic condition was defined as “dyspnea that persists at rest or with minimal activity and is distressful despite optimal therapy of advanced lung or heart

disease.” The stated aim of the paper is to influence clinical practice in the “care of the patient in whom medical therapy has been optimized, and the focus of treatment is on symptom management, relief of suffering, and maintenance of quality of life.”

“Many patients with advanced lung or heart disease have a tremendous concern about the experience of dying, and a large component of this anxiety is focused on their breathing difficulty and ‘suffocating,’” the panel writes. They emphasize the importance of physician communication in reassuring patients their needs will be met.

However, they point out, “patients with advanced lung or heart disease receive poor quality palliative and end-of-life care” compared with cancer patients. One reason the panel found is that “patient-physician communication about end-of-life care is unlikely to occur.”

Source: “American College of Chest Physicians Consensus Statement on the Management of Dyspnea in Patients with Advanced Lung or Heart Disease,” *Chest*; March 2010; 137(3):674-691. Mahler DA, Selecky PA, Harrod CG, Benditt JO, et al; Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire; Hoag Hospital, Newport Beach, California; the American College of Chest Physicians, Northbrook, Illinois; University of Washington Medical Center, Seattle.

Helping Patients Determine Whether and When Hospice Fits Their Needs

The importance of eliciting patients' individual goals regarding how they hope to live the end of their lives is emphasized in a review of hospice care published in the *Journal of the American Medical Association*. The discussion is based on the case report of an 86-year-old woman with progressive congestive heart failure and multiple chronic conditions.

While still enjoying certain aspects of her life, the patient dreads becoming more incapacitated and fears losing control over the circumstances of the end of her life. Although her life expectancy is uncertain, she wonders if hospice can help her.

“[This patient] is not thinking just about hospice. She is also considering how she envisions the end of her life,” writes Jean S. Kutner, MD, MSPH, professor of medicine and head of the Division of General Internal Medicine, University of Colorado at Denver School of Medicine, Aurora.

In the context of this case discussion, notes Kutner, “I consider the ‘end of life’ to begin with the onset of advanced illness that is beyond cure, rather than limiting it to the time of imminent death.”

There is significant agreement among the many studies that have explored the meaning of a “good death,” in that it includes such components beyond pain and symptom management as: spending time with family and friends; not being a burden; maintaining dignity and self-respect; avoiding prolongation of dying; and achieving a sense of control.

“However,” states Kutner, **“the process of dying and death remains highly individualized, making it essential that clinicians both ask questions**

An Approach to Presenting the Hospice Option to a Patient with Uncertain Prognosis

- Understand what is known about the patient's current status, treatment options, and prognosis.
- Ascertain the patient's understanding of her prognosis.
- Learn about her goals, asking “What do you hope for most in the next few months?” and “What are you afraid of?”
- Identify her symptoms and psychosocial support needs, and the needs of her family.
- Introduce hospice as a service that might help meet her needs, explaining both what it can and cannot offer her at the present time.
- Understand her desired place of death and how she envisions it.
- Remind her and her family that a decision to enter hospice is not permanent.
- Provide additional resources to help her understand her options.

— Adapted from Kutner, *Journal of the American Medical Association*

and listen to their patients to ascertain their priorities and facilitate achievement of their stated goals.”

HOSPICE WORKS TO ACHIEVE PATIENT GOALS

“Hospice would work with [the patient] to help her determine the story of the end of her life — how she lives her last months, weeks, days, and hours,” states Kutner. In fact, she adds, hospice “excels” at working with patients to achieve their goals.

The Medicare Hospice Benefit defines hospice not simply as a service for patients who have decided to stop curative treatment, but also as “a health care delivery system focused on caring for the patient and family after treatment efforts aimed at changing the course of the terminal illness substantially are no longer effective.”

Although the Medicare hospice requirement for 6-month life expectancy may be difficult to meet in a heart failure patient, notes Kutner, patients

remain eligible for as long as this criterion is met. Further, patients can choose to disenroll from hospice at any time, retaining the option of enrolling again as their goals or health conditions change.

For patients with heart failure and most other noncancer diseases characterized by a prolonged state of poor health with spikes of intermittent exacerbations, no definitive threshold marks the time when decisions about changing treatment modes should be made. A health crisis can occur with no contingency plan outlined. “Thus,” Kutner asserts, “the patient's individual end-of-life goals are critical.”

A continuing education course based on Kutner's review is available at <http://cmejama-archives.ama-assn.org/>.

Source: “An 86-Year-Old Woman with Cardiac Cachexia Contemplating the End of Her Life: Review of Hospice Care,” *Journal of the American Medical Association*; January 27, 2010; 303(4):349-356. Kutner JS; Division of General Internal Medicine, Department of Medicine, University of Colorado Denver School of Medicine, Aurora, Colorado.

‘Palliative Care: The Relief You Need When You’re Experiencing the Symptoms of Serious Illness’

The National Institute of Nursing Research (NINR) of the federal National Institutes of Health has produced a 14-page brochure highlighting the benefits of palliative care, and directing patients and caregivers on how and when to request it.

“Our goal is to increase the number of provider-patient conversations about palliative care resources, so that fewer patients suffer needlessly from pain and distressing symptoms,” says NINR director Patricia A. Grady, PhD, RN.

The brochure explains how to decide if palliative care is needed, how it differs from hospice care, how it is paid for, which specialists participate on a care team, and how to ask a physician for a referral.

The team approach to patient-centered care is presented as providing:

- Coordination of care with the primary care physician and all other health care providers
- Open discussion about treatment choices
- Expert treatment of pain and other symptoms
- Emotional support

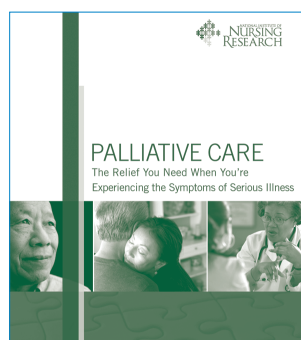
Palliative care “not only relieves pain and suffering, but also provides critical emotional support to family members who are faced with difficult end-of-life decisions while grappling with the impending loss of a loved one,” Grady points out. But palliative care should not be seen as restricted to those in the last months of life, she notes. “[P]alliative care provides relief to patients dealing with chronic

illnesses as well, including AIDS, cystic fibrosis, and diseases of the heart, lungs, and kidneys.”

One section of the brochure encourages patients to start palliative care as soon as needed: “There is no reason to wait. Serious illnesses and their treatments can cause exhaustion, anxiety, and depression. Palliative care teams understand that pain and other symptoms affect your quality of life and can leave you lacking the energy or motivation to pursue the things you enjoy. They also know that the stress of what you’re going through can have a big impact on your family. And they can assist you and your loved ones as you cope with the difficult experience.”

Entitled “Palliative Care: The Relief You Need When You’re Experiencing the Symptoms of Serious Illness,” the brochure is available for free downloading and reproduction from the NINR website, or small quantities can be ordered free of charge in print form. A state-by-state list of palliative care programs from the online Palliative Care Provider Directory of Hospitals is available at www.getpalliativecare.org.

To access the brochure, visit www.ninr.nih.gov/newsandinformation/ninrpublications.



End-of-Life Care Websites

www.aahpm.org

American Academy of Hospice and Palliative Medicine

www.eperc.mcw.edu

End of Life/Palliative Education Resource Center (EPERC)

www.epec.net

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

www.nhpc.org

National Hospice & Palliative Care Organization

www.caringinfo.org

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

www.promotingexcellence.org

Promoting Excellence in End-of-Life Care

www.hospicefoundation.org

Hospice Foundation of America

www.americanhospice.org

American Hospice Foundation

www.hpna.org

Hospice and Palliative Nurses Association

www.medicaring.org

Palliative Care Policy Center

www.abcd-caring.org

Americans for Better Care of the Dying

www.mcw.edu/palliativecare.htm

Medical College of Wisconsin Palliative Care Center

www.painpolicy.wisc.edu

University of Wisconsin Pain and Policy Studies Group

www.capc.org

Center to Advance Palliative Care

www.stoppain.org

Pain Medicine & Palliative Care, Beth Israel Medical Center



Supporting You with
Compassion, Dignity
and Excellence

6377 Clark Avenue, Suite 100
Dublin, CA 94568-3024
www.HopeHospice.com

(925) 829-8770 | (510) 439-4917
1 (800) Hospice
Fax (925) 829-0868 | (510) 439-4918

Non-profit Org.
US Postage
PAID
Permit 201
Pleasanton, CA

ADDRESS SERVICE REQUESTED

Summer 2010

Don't Miss "Symptom Management: A New Twist on an Old Concept" November 3, 2010

Please join us at the Hope Hospice offices on Wednesday, November 3, 2010, from 5:30 to 8 pm, for an informative and thought-provoking seminar, "Symptom Management: A New Twist on an Old Concept." The seminar will focus on the importance of palliative care as an indicator of quality and how it can help improve physician practice patterns. Our physician experts will discuss proactive approaches in comfort care and symptom management for COPD, CHF and dementia. Topics include:

- "To Force Feed or Not to Force Feed: that is the Question." - Ethics of Artificial Hydration and Nutrition. Speaker: Michael Rabow, M.D., Director, Symptom Management Service, UCSF Helen Diller Family Comprehensive Cancer Center; Professor of Clinical Medicine, University of California San Francisco
- "Cure Sometimes, Treat Often, Comfort Always" - Adding Feeling Better to Getting Better: COPD, CHF and Dementia. Speaker: Chante Buntin, M.D., Director, SXM Symptom Medicine, Pain Medicine, Palliative Care, Anesthesia

Symposium Steering Committee:

Michael Abdel-Malek, M.D., Internal Medicine; Hope Hospice Associate Medical Director
Ralph Camacho, M.D., Gastroenterology; Director, Palliative Care Services, ValleyCare Health System
Steven Oppenheimer, M.D., Internal Medicine-Infectious Diseases; Hope Hospice Board of Directors
Peter P. Wong, M.D., Medical Oncology; Hope Hospice Medical Director

For more information, please call Hope Hospice, Medical Outreach Department, (925) 826-8770 or (510) 439-4917 or email: info@hopehospice.com. Watch for our brochure in the mail outlining the program. Fee: \$20 includes Buffet Dinner and Materials.

Hope Hospice Medical Directors



Peter P. Wong, M.D.
Medical Director



Michael Abdel-Malek, M.D.
Associate Medical Director

Why choose Hope Hospice?

Your patient will be cared for by a highly experienced, caring team of hospice trained professionals. Hope Hospice has been providing care for patients in the Tri-Valley, San Ramon Valley and Castro Valley-Hayward and surrounding areas for 30 years. We are pleased to report that 99 percent of families served by Hope Hospice would refer their family and friends to Hope Hospice in the future.

Are you in the (510) area code? Now call us directly at: (510) 439-4917 or fax: (510) 439-4918.

Pre-hospice Consultations | 24-hour Advice and Emergency Care | Extensive Adult, Teen and Child Grief Support Programs