



“Hospice care is an active process that seeks to optimize what time the patient has left, not only in terms of survival, but in terms of pain and symptom control, psychosocial and spiritual well-being...”



There's Nothing More We Can Do

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All too commonly, Hospice care is presented in a manner similar to this: “I am sorry Mrs. Edwards. Your cancer has not responded to any of the treatments we have tried. There is nothing more we can do, so I am recommending Hospice care.” With this approach, many patients respond that they are not yet ready for Hospice, putting services off until they are imminently dying. Hospice appears, then, to be a point of hopelessness, the giving up of life, simply waiting to die. One of my colleagues said as much, “you just sit around and watch them die, don't you?”

In fact, nothing could be further from the truth. Hospice care is an active process that seeks to optimize what time the patient has left, not only in terms of survival, but in terms of pain and symptom control, psychosocial and spiritual well-being, and the maintenance of purpose for patients whose life end is now predictable.

Survival

There have been interesting studies published in the last two years regarding survival in Hospice care. In a study of over 1300 hospice patients, data revealed that the aggressive use of opioids in the treatment of pain and dyspnea made no difference in survival. Another study revealed that survival in several cancers and in congestive heart failure was actually longer in Hospice care than it was in standard treatment. This was particularly true for heart failure. On average, survival was 88 days longer in Hospice care than it was with aggressive hospital-based treatment.

Pain and Symptom Control

To quote Martha Twaddle, a nationally-known Palliative Medicine physician, “it is difficult to transcend your illness when you are nailed to your body by pain.” Indeed, survival alone loses its attractiveness when sur-

vival implies uncontrolled pain, nausea, restlessness or dyspnea. In the headlong pursuit of additional days of survival, physicians often perceive the symptoms above as an acceptable price for survival, and even consider a patient, who finds these prices of survival unacceptable, to be depressed, mentally ill. When faced with the certainty of their deaths, however, most patients admit that uncontrolled pain or dyspnea particularly are more frightening than the prospect of dying itself.

It is likewise of little value to control symptoms by rendering the patient unresponsive. The quality of a patient's last days or weeks hinges largely on his/her ability to interact with the people who are important in their lives. Thus the task of symptom control is a careful navigation between the symptoms themselves and the side-effects of the agents used to control them, a process which is actively negotiated with the patient, whose wishes are pivotal to decision-making.

Psychosocial and Spiritual Well-being

Particularly where pain is concerned, it is impossible to treat symptoms without addressing the patient's anxiety, depression, life/family conflicts and personal/spiritual concerns. Fear of dying, particularly, can be rooted in concern for what follows death for the patient himself, for those who have depended on the patient in the past, for things left undone. Healing relationships, receiving forgiveness, reassurance that those who remain will be taken care of, doing one more thing that has importance to the patient or those he loves have huge impacts on the ability to control symptoms, and on the quality of living that remains for the patient.

A Sense of Purpose

If Hospice care were simply “standing around and waiting for the patient to die,” it would be dismal work indeed. Patients do not wish to be a burden, but, instead, want there to be value to whatever survival

they have. Some have found it in volunteering while they have strength, some by visiting family or places they have always wanted to see. One patient of mine chose continuing to teach while he could over spending that time in treatment.

Hospice Care Provides Extensive Service

When enrolled in Hospice care, the patient receives a variety of services:

Medications and durable medical equipment pertinent to the management of the terminal illness are provided at no cost to the patient

Services are brought to the patient, wherever he/she calls home, including nursing services social work services, spiritual care services, home health aid services, and treatment of emergencies.

The care environment includes not only the patient, but those who provide care for the patient, allowing caregiver respite.

Hospice Inpatient Care is available for patients whose symptoms are particularly difficult to control, or cannot be managed well by the patient's caregiver(s).

There is no established list of treatments that a Hospice patient may not receive. Treatments are

weighed as to their likelihood of providing benefit to the patient versus their likelihood of inflicting harm on the patient.

A Better Way

Perhaps then, there is a better way to present Hospice care to a patient.

We can start with the recognition that Hospice care is not passive, but contains very active elements that are actually germane to patient well-being long before the patient is imminently dying. The statement that "there is nothing more we can do," is simply not accurate. There is much we can do, though much of it may not be directed at cure. This is not a new concept. We cannot restore infarcted brain following a stroke, or a gangrenous limb after amputation, but we work diligently to restore what independence and quality of life we can through physical therapy, prosthetics and the like.

We can look honestly at the burdens imposed by ongoing heroic treatment, particularly when the likely benefit is vanishingly small.

We can be guided by the evidence that actually supports longer survival in specific diseases under

Hospice care than under standard medical care.

When we propose Hospice care, we can consider doing so along these lines: "I am sorry Mrs. Edwards. Your cancer has not responded to any of the treatments we have tried. I have no treatment that can cure you or materially lengthen your life, but I can offer you treatment that will help you make the best of your remaining time. It provides you medical services in your home, medications, medical equipment, and emotional and spiritual support. In some instances, this approach provides longer survival than any of the treatments I would otherwise have available. I am suggesting Hospice care for you, because that care has the most to offer you. Far from giving up on you, I am proposing Hospice because I believe that will be the most effective for you."

The most common response we get from families we survey after a patient dies is, "I wish we had started Hospice care much sooner than we did." It is possible that starting Hospice care as late in the course of illness as we do is a direct result of that care being thought of as "there is nothing more we can do."



Recommended End-of-Life Care Books for Physicians

A Practical Guide to Palliative Care

By *Jerry L. Old and Daniel L. Swagerty*

This manual for health care professionals offers a multidimensional approach to the assessment and management of the end-of-life care needs of patients and their families.

Formatted for quick reference at the bedside, the book features an "In a Nutshell" summary of key points for each chapter, along with bullet points and quick-reference tables. The multiple appendices include tables of medical guidelines for specific diseases and an equianalgesic dosing chart for opioids.

Topics include:

1. Communicating with patients and families
2. Cultural diversity in end-of-life care
3. Predicting life expectancy
4. Non-pain symptom management
5. Pain control
6. Terminal care
7. Ethics at the end of life

The book outlines the palliative care services available through Medicare, reminding

physicians that although eligibility for hospice care requires a prognosis of six months or less, there is no penalty if a patient lives longer.

Published by Lippincott Williams & Wilkins, 2007; ISBN: 9780781763431 (hardcover); 240 pp.

Principles and Practice of Palliative Care and Supportive Oncology, Third Edition

Edited by *Ann M. Berger, John L. Schuster, Jr., and Jamie H. Von Roenn*

This revised and updated interdisciplinary textbook serves as a practical guide to managing the wide range of symptoms and quality-of-life issues found among patients with cancer — from the newly diagnosed to those nearing the end of life.

Contributions from experts in such fields as hospice and palliative care medicine, oncology, neurology, nursing, psychiatry, anesthesiology, and pharmacology provide a blend of current scientific knowledge with detailed descriptions of related therapeutic options.

The section on pain has been widely remodeled, with summarized tables

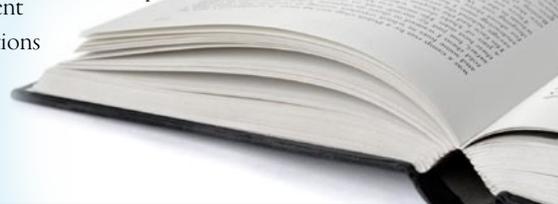
accompanying the text in the chapter on opioid therapy, and the inclusion of visceral pain and neuropathic pain (along with bone pain) in the chapter on difficult pain syndromes.

New chapters cover such topics as: Hot flashes, hepatic failure, pulmonary failure, caregiver stress, research issues in palliative care, and beginning a palliative care program.

The content has been designed to correspond to the needs of the recently accredited palliative care fellowship training programs, and includes new figures and protocols, tables on therapeutic management of various conditions, and guidelines for decision making.

Published by Lippincott Williams & Wilkins, 2007; ISBN: 9780781795951 (hardcover); 944 pp.

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From the President: What's New at The Center for Hospice and Palliative Care?

Mark M. Murray
President/CEO

New Hospice Conditions of Participation

Earlier this summer I had the pleasure of being one of three people from Indiana to participate in a two-day intensive in Baltimore, MD on the new Medicare Hospice Conditions of Participation (Hospice CoPs), which were released on June 5. This is the first time that the rules and regulations for hospice care under Medicare have been revised since they were created in 1983, and this revision alone was a process that took nine years.

The two-day meeting brought together more than 300 hospice leaders, representing 46 states. Main presenters were the two Centers for Medicare and Medicaid (CMS) staff members involved in the 700+ page revision project from its beginning. Over the course of writing these updated hospice regulations, the lead authors have survived six CMS Administrators and three U.S. Presidential Administrations. The new Hospice CoPs focus heavily on quality and providing patient-centered care, giving hospices more flexibility in meeting the intent of the regulations.

Like all Medicare-certified hospices, CHAPC has until December 2, 2008 to meet the new requirements. Following that date, all inspections or "surveys" by the Indiana State Department of Health will be using these new rules, regulations, and the soon-to-be published "Interpretive Guidelines" which will contain detailed instructions for their enforcement.

New Faces

David Tribble, MD, ABHPM, FFAFP has been named Chief Medical Officer for Alive Hospice in Nashville, TN. He will begin his new role in mid August. With Dr. Tribble's departure, Jon Kubley, M.D., will serve as CHAPC's Interim Chief Medical Officer. On June 1, 2008, Dr. Kubley joined the CHAPC staff as a full time medical director after serving part time since 1995. We wish Dr. Tribble success in his new opportunity.

The Foundation for The Center for Hospice and Palliative Care, Inc., our new separate charitable corporation, whose focus is fundraising and development for CHAPC, continues to evolve. The Foundation has named Michael J. Wargo Vice President & Chief Operating Officer.

Wargo has been a CHAPC volunteer for the past 11 years. During that time he has served in a variety of capacities, including chairmanship of the Personnel, Finance, Investments and Executive Committees of the Board of Directors and two years as Chairman of the Board. During the past year, he has chaired the \$3 million Elkhart Hospice House Capital Campaign, which has to date raised more than \$2.3 million. Besides CHAPC, his board service and community involvement has included key leadership positions with various local not for profit organizations, including the IU South Bend Board of Advisors, the IUSB Alumni Association, the PHM Education Foundation, and the American Institute of Banking. He currently serves as Chairman of the Board for the Workforce Development Group, Inc., regional operator for the Northern Indiana Workforce Board. He is both a local and national member of the Society for Human Resource Management (SHRM) and is a member of the Downtown South Bend Rotary Club. Wargo's responsibilities include administration of all Foundation for CHAPC operations, philanthropic development, financial/investment management, project management accountability for current and future CHAPC construction projects and their associated capital campaigns, and the development of an exciting new, free community-based education initiative called The Institute for Advance Care Planning.

New Elkhart Hospice House

Construction continues on our new Elkhart business office and Hospice House. See the progress at our website, centerforhospice.org and click on the Elkhart Hospice House banner. The

facility is approximately 12,000 sq. ft. with two separate wings, one for Hospice House, a seven-bed inpatient unit, and the other for home care staff offices, volunteer training, and bereavement services. It has been architecturally designed for uncomplicated future expansion of either or both wings.

New Record

So far in 2008, patient care at CHAPC has been record-breaking. Our census has hit all time highs and continues to climb. In June we were caring for 343 patients on a single day. We are currently on target to care for more than 1,600 patients and their families this year and are currently running about 10% higher than last year. This of course necessitates staffing needs, particularly for Registered Nurses. We have several openings right now, and of course will have many openings at our Elkhart Hospice House. If you know of any RNs who might like to join our team, please have them contact our Human Resources department at 1-800-413-9083. Current openings are always posted on our website at the "Careers" link.

New Web Updates

Speaking of our website, centerforhospice.org receives more than 100,000 hits every month and is being updated with new content and a new look (stay tuned). The CHAPC website is a great resource for physicians and your patients with free, downloadable information regarding Advance Directives, downloadable forms for referrals, consents and election forms, admissions information, a complete listing of our bereavement services, and explanations of all of CHAPC services including the differences between our palliative care and hospice care programs. Please take a look and let others know about this valuable resource.



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Palliative Care Yields Lower Costs, Greater Patient Satisfaction

Results of a trial delivering in-home palliative care services modeled after hospice programs – without the 6-month prognosis restriction – to patients with end-stage chronic obstructive pulmonary disease, congestive heart failure, or cancer, provide strong evidence for the reform of the Medicare hospice benefit, researchers report.

“Providing an interdisciplinary palliative care team within the home of terminally ill homebound patients earlier in the disease trajectory has a positive effect on patient satisfaction with the medical care, in addition to influencing costs of care at the end of life,” write the investigators in a recent issue of the *Journal of the American Geriatrics Society*.

The team analyzed the interview responses of 297 homebound patients with a prognosis of one year or less who were receiving health care services from health maintenance organizations in Colorado and Hawaii. Participants were randomized into groups

receiving usual care (n = 152) or usual plus palliative care (n = 145).

Findings include:

- 93% of those receiving palliative care were very satisfied with their care, compared with 81% of those in the usual care group.
- 36% of patients in the palliative care group were hospitalized during the 90-day follow-up period, compared with 59% of those with usual care.
- Overall costs of care for those in the palliative care program were 33% less than for those receiving standard care.

“Hospice patients with a short length of stay often require intensive care to initiate the care plan, resulting in higher per diem costs of care than for patients who receive longer periods of stabilized, low-cost palliative care,” write the authors.

Source: “Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care,” *Journal of the American Geriatrics Society*; July 2007; 55(7):993-1000. Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, McIlwaine J, Hillary K, Gonzalez J; Kaiser Permanente Southern California Medical Group, Downey, California; Partners in Care Foundation, San Fernando, California; Kaiser Permanente Hawaii Medical Group, Honolulu; Kaiser Permanente Colorado Medical Group, Aurora, Colorado. Reprinted with permission from *Quality of Life Matters*, copyright 2008. Published by *Quality of Life Publishing Co.*, Naples, FL.

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