San Diego Hospice

San Diego Hospice Corporation is a not-for-profit, community-owned health care provider. Our specially trained staff provides compassionate, specialized care for patients with terminal or chronic illnesses, and emotional and spiritual support for them and their loved ones. The San Diego Hospice professional staff also offers ongoing education and support services for other health care professionals managing seriously ill patients throughout San Diego County.

Practical Palliative Care Today is published quarterly each year by the Center for Palliative Studies at San Diego Hospice to update physicians and medical professionals about trends and advances in modern palliative care.

The San Diego Hospice administrative offices are located at 4311 Third Avenue, San Diego, California 92103. Our website address is www.sdhospice.org.

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The Role of Palliative Medicine Within the Long-Term Care Facility

by Wendy Stein, MA, NHA, MD, CMD

Palliative medicine is well described as "the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life" (Oxford Textbook, 1993). Applying this definition, good palliative care should be aggressively practiced regardless of whether a patient has been labeled "terminal" or not, and regardless of the setting in which the patient presents.

The goals of geriatric medicine include early recognition of treatable medical conditions, avoidance of iatrogenic illness, and restoration and maintenance of function, while ensuring autonomy, quality of life, comfort and dignity. The science of palliative medicine, therefore, fits well with the goals of geriatric medicine.

Although aggressive symptom management is not exclusive to the care of the patients at the end of life, it is at this time that it is most often considered. This is one reason why the general public often confuses the terms "hospice" and "palliative care." The term "hospice" refers to an approach to medical care in patients who are at the end of life where palliation of distressing symptomatology is the prime concern of an interdisciplinary team of health professionals, spiritual leaders, patients and their families. Hospice is not a person or a place, but rather a philosophy of care where compassion and comfort take precedence. The concept of hospice views the patient as a total individual, and seeks to meet his/her needs physically, emotionally and spiritually. It is a concept based not on dying but on living.

The concept of hospice dates back to Fabiola, a Roman matron, who opened her home to weary travelers seeking respite on their pilgrimages. The term "hospis" at that time meant both guest and host, and "hospitium" the place where hospitality was given. Today the modern hospice provides services to patients at the end of life living in inpatient hospice units, nursing homes, hospitals and most often in the patient's own home.

Palliative care, although not restricted to patients at the end of life, is the type of medicine practiced with patients in the hospice program. Long-term care offers some specific challenges as well as advantages in the provision of palliative care services to nursing home residents with limited prognoses.

Nursing homes, by regulation, already have an interdisciplinary team in place responsible for both the development and ongoing success of a specific plan of care. Palliative care strategies should be integrated within the existing plan of care in such a way as to maximally utilize the special expertise and perspectives of all disciplines repre-

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Sometimes our light goes out but it is blown into flame by another human being. Each of us owes deepest thanks to those who have rekindled this light.

—Albert Schweitzer, M.D.

From the desk of the editor …

This issue of *Practical Palliative Care Today* is primarily dedicated to hospice and palliative care issues in long-term care facilities. This special population has special needs and the environment demands and requires a cooperative relationship between hospice and nursing home staff and physicians in order to provide the best palliative care possible for residents.

In an attempt to improve long-term palliative care, San Diego Hospice has created a special SNF (Skilled Nursing Facility) team. The team members are individuals skilled in the specialized area of hospice and palliative care and who are also experienced in long-term care. Understanding the regulations of both environments is critical to providing appropriate care, and yet, it is always apparent to hospice providers that we are guests in the long-term care facility. Integration of care planning is essential to providing consistent care and staff interrelationships are crucial to the success of this care.

In the section on "Meet the Staff," we will introduce Dr. Wendy Stein, a geriatrician who now helps lead the San Diego Hospice SNF team. Wendy, who has been with us since August, has already had a significant impact on the quality of palliative care of the nursing home residents we serve. She is available to you as a consultant expert in hospice and palliative care for assistance in managing your frail elderly patients who reside in SNFs.

Dr. Stein, in fact, contributed one of the articles in this issue of the newsletter. It expresses her philosophy of care and her perspective on dealing with common issues in the nursing home environment. Another article is a summary reprint of an AAFP article on palliative care and hospice in long-term care written by Ron Schonwetter M.D. and Tim Keay M.D. It provides a slightly broader perspective on nursing home issues.

Another article presented is not specifically about long-term care. It addresses the EPEC curriculum (Education for Physicians in End-of-Life Care) which was designed by the AMA. Frank Ferris, M.D. and Charles von Gunten, M.D. who are full-time physicians at San Diego Hospice, are principal authors of this curriculum. Modules of EPEC have been presented nationally and in the San Diego area to improve knowledge of end-of-life issues for all physicians.

Lastly, I would like you to recognize that November was National Hospice Month. Please take the time to wish hospice staff well and to thank them if you have been pleased with the care they have provided your patients and families this past year. We could not do what we need to do as physicians without such caring allied professional colleagues.

Thank you for taking the time to read this newsletter. As always, all comments and submissions are accepted gratefully. Have a happy holiday season.

Michael E. Frederich, M.D., Editor

Meet the Staff

Dr. Wendy Stein is Named Medical Director of the San Diego Hospice Skilled Nursing Facility (SNF) Team

Wendy M. Stein, MA, NHA, MD, CMD, joined San Diego Hospice on August 1, 2000 as full-time staff physician and Medical Director of the Skilled Nursing Facility Team. Wendy is a board certified physician in internal medicine, geriatric medicine, hospice and palliative medicine, and most recently, was granted the title of Certified Medical Director in Long Term Care (CMD) from the American Medical Directors Association.

Wendy, as she says, literally "grew up in a nursing home." Her father was a nursing home administrator and owner in Massachusetts, and Wendy spent many a Saturday visiting her "adopted grandparents".

Dr. Stein received her A.B. from Brown University, Magna Cum Laude, in Classics and Community Health. She then completed an M.A. in Medical Sociology, during which time she trained and

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sented. The care setting is far more informal than the acute care hospital, which allows greater flexibility for families and friends to visit and stay for extended periods of time. Pets can usually be brought into the facility and are well appreciated by other residents as well. In many areas of the country, long-term care staffs are often stable enough for nurses and assistants to really get to know the needs and preferences of their patients, providing a more homelike atmosphere. Rooms can be personalized with pictures and special mementos, which is particularly important to the resident at the end of life, and aids in life review.

Challenges in long-term care include limited access to diagnostic facilities and on-site pharmacy services, limited routes of administration for medications to ease distressing symptoms, and limited research on the efficacy of certain interventions or assessment techniques in dying patients in nursing homes. There may be regulatory or policy barriers which make access to pain relieving medications difficult, especially in states where separate triplicate prescriptions are required for Class II drugs. The ease in integrating palliative care principles into long-term care also relies heavily on institutional commitment to and support of such policies where none may exist. This is where the role of the medical director is vital in helping facilities and care systems recognize the need for appropriate and aggressive symptom management, and establish practice policies and ongoing review to ensure success.

In the list of symptoms requiring aggressive palliation, pain is one of the most distressing and frustrating, not only to patients with advanced disease, but also to their families and health care providers. The best judge of pain is the patient. Pain is best treated when it is assessed on a continual and consistent basis. A complete discussion of the assessment and treatment of pain is beyond the scope of this paper; however, the AHCPR Guideline on the "Management of Cancer Pain" serves as an excellent reference for the primary care practitioner on the treatment of not just cancer pain, but of other forms of chronic pain as well. Additionally, it also has a good section on additional

"Palliative care is where the true 'art' of medicine meets science. The most important thing a physician can do is to truly listen to the needs of the patient and his/her family."

concerns in treating pain in the elderly population. Other appropriate references include "Pain in the Nursing Home" in the August 1996 volume of Clinics in Geriatric Medicine which includes a sample one page initial pain assessment form, sample pain flow sheet form, and interdisciplinary diagram delineating the organization, responsibilities, and relationships between the interdisciplinary team members and nursing home residents with pain problems. Also helpful to the practicing clinician is Ferrell et al's article on "Pain in Cognitively Impaired Nursing Home Patients" from the November 1995 volume of the Journal of Pain and Symptom Management. The findings of this study confirmed that pain can be effectively assessed in elderly patients with significant cognitive impairment, however, assessment in this population needs to be done more frequently than in the cognitively intact because of their inability to assess pain in the past. Other helpful references in this area have been included in the reference section.

Other symptoms can be problematic as well. Nausea and vomiting, constipation and diarrhea, dyspnea, depression, restlessness, and dry mouth can be as bothersome as pain, and deserve aggressive and ongoing assessment and treatment. Dehydration, anorexia, and confusion should be treated when symptomatically uncomfortable to the patient, not the provider. Research has demonstrated that oftentimes what bothers families is not what patients find bothersome, and patient concerns should take precedence over all others in patients with limited prognoses where symptom palliation is the central focus of care. The May 1996 volume of Clinics in Geriatric Medicine on "Care of the Terminally Ill Patient" serves as an excellent reference for the practicing nursing home medical director, along with the August 1996 volume on "Pain Management in the Elderly."

Issues of suffering, emotional, spiritual or otherwise are just as important to address as physical symptoms such as nausea or pain. The patient's questions should guide discussions with the health care team. It is neither appropriate to attempt to keep information from a patient seeking answers, nor to overburden a patient who is not yet ready to hear some truths. The needs of the patient should take precedence over those of the family, although they should be considered. After all, each family member is losing someone s/he cares about, but the dying patient is losing everyone.

No one wants to lose someone they love; however, it is a comfort to family members to bear witness to a patient who dies symptom-free and in peace. A "bad" death leaves a terrible emotional scar that family members carry for a lifetime.

Palliative care is where the true "art" of medicine meets the science. The most important thing a physician can do is truly to

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Hospice Care in the Nursing Home

Patients, families and physicians are becoming increasingly aware that the terminally ill may be more comfortable and may receive more comprehensive and satisfying care when palliative measures, rather than life-prolonging goals, are pursued. Since the Hospice Medicare Benefit (HMB) was introduced, many terminally ill patients and their families have relied on interdisciplinary, comprehensive end-of-life care given in the home. As early as 1986, Medicare recognized that the nursing facility was the home of its residents. Consequently, the rapidly increasing knowledge and skills of palliative care should be applied in the nursing home setting, where more than 20 percent of Americans die.

Nursing home patients may differ from the usual outpatient hospice population because most of the former have a non-cancer-related disease. The National Hospice Organization's (now called the National Hospice and Palliative Care Organization) Guidelines for Prognostication in Non-Cancer Diseases is a useful resource. Based on the guidelines, an example of an eligible patient would be one who has less than six months to live, who has advanced dementia at stage seven of the Functional Assessment Staging Scale, and who has co-morbid medical conditions of sufficient severity to have required medical treatment within the past year. In addition, the patient should exhibit all of the following characteristics: inability to ambulate without assistance; inability to dress without assistance; inability to bathe properly; urinary and fecal incontinence, and inability to speak or communicate meaningfully.

The guidelines require frequent re-evaluation of the patient's condition to monitor disease progression. Perhaps a useful initial method might be to screen all new nursing home residents for hospice eligibility, just as many nursing facilities currently screen new residents for physical therapy.

This raises an issue that bothers many physicians. This is simply the feeling that somehow hospice services in the nursing home are providing duplication of services already provided by nursing home staff, particularly nursing and aide staff members. The recognition that many interdisciplinary hospice services supplement the usual care provided by an overextended nursing facility staff resolves this problem. Simply explained, Medicare does not view hospice services in the nursing home as duplication of service, and therefore, any anxiety felt by physicians should be lessened.

Apart from providing nursing expertise beyond the usual skill levels of nursing home personnel, particularly in the areas of complex pain and symptom management, the hospice team provides care that is simply unavailable outside of hospice. Because these areas are not strictly medical, they are often undervalued and under appreciated by physicians. These areas most commonly are bereavement care and volunteer services.

One major hospice benefit is bereavement services for nursing home staff and residents who have become attached to the dying patient. These services are in addition to the support provided to surviving

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The above article is a synopsis of an article published in the The American Family Physician in February 1998, by Timothy J. Keay, MD and Ronald Schonwetter, MD, and we greatly appreciate their permission to publish it here.

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grieving family members. Because these services are provided for a year after the patient's death, hospice staff and volunteers can, over the course of the bereavement period, assess and counsel those who cared for and about the patient. Providing support groups and memorial services for nursing home staff also help in this area.

Hospice volunteers are the antidotes for loneliness. Because this is such a large problem for nursing home residents, this service is greatly appreciated by them. Often calls are received asking for a volunteer to come and sit with a patient who is actively dying. This is often a role that nursing home staff do not have the time to provide, and yet human touch is a strong intervention for suffering at the end. Earlier in the course of disease, the volunteers are able to form close friendships with the nursing home residents and truly improve the quality of their remaining lives.

The Hospice Medicare Benefit (HMB) also provides some financial relief for individuals and families above and beyond traditional Medicare. By paying for pharmaceuticals related to the terminal illness and for durable medical equipment, including oxygen, which may not be otherwise reimbursed, the financial burden on the family may be somewhat relieved.

The physician works cooperatively with the interdisciplinary team but is responsible for medical services and continues to bill as the attending physician.

During the provision of all hospice services, the attending physician remains in charge. The physician works cooperatively with the interdisciplinary team but is responsible for medical services and continues to bill as the attending physician. It is comforting for the patient and family members to know that the attending physician will remain involved during the patient's time of greatest need and will be working in collaboration with a team of experts who are skilled in end-of-life care.

No matter where or to whom end-of-life care is delivered within the nursing home, the physician is responsible for assessing the quality of the terminal medical care that is given. Three general areas can be regularly assessed. These minimum standards of care include documentation of advance directives, attention to pain control and relief of dyspnea that often accompanies the last moments of life. Other areas that require evaluation include management of the other symptoms, patient hygiene and psychosocial support for the patient and family members. If indicators in these areas are regularly measured and addressed within a general nursing home program, good quality terminal care can be assured.

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served as a volunteer for Hospice Care of Rhode Island, helping to care for the organization's first nursing home resident. After completing a six-month internship, Wendy spent six years as a nursing home administrator and executive director. She returned to Brown University and completed her M.D. in 1992, and subsequently completed a three-year residency in primary care and internal medicine at Rhode Island Hospital. This residency program included extensive training in hospice and palliative medicine. During this time, Dr. Stein also served as chairperson of the Rhode Island Cancer Pain Initiative.

California was the next stop for Dr. Stein. She completed a two-year fellowship in geriatric medicine at UCLA School of Medicine. During this time, Wendy served as a part time medical director for TrinityCare Hospice, Valley Division. F or the last three years, she has worked as Medical Director of Clinic Services and End of Life Care at the Los Angeles Jewish Home for the Aging, and as an Assistant Professor of Geriatrics at The UCLA School of Medicine. While at the Jewish Home, Dr. Stein developed an innovative teaching program for geriatric medicine fellows in hospice and palliative medicine, as well as an integrated clinical program called Supportive Care Services to bridge the gap between primary care, geriatrics and hospice care.

Wendy has been intimately involved with both hospice and nursing homes for most of her life. Her new position at San Diego Hospice will enable her to capitalize on her wealth of expertise and meld together her two fields of interest: hospice and long term care. San Diego Hospice is pleased to have Dr. Stein as the new Medical Director of the SNF Team.

The EPEC Project: Education for Physicians on End-of-life Care

The EPEC Project is supported by the American Medical Association (AMA) and a grant from The Robert Wood Johnson Foundation. It is designed to educate all U.S. physicians on the essential clinical competencies required to provide quality end-of-life care. Housed within the End-of-life Care Section of the Institute for Ethics at the AMA, the EPEC Project comprises several complementary components.

The *EPEC Curriculum* has been designed with input from nationally respected experts in the field and feedback from participants of early training conferences. The EPEC Team has been led by Linda Emanuel, MD, PhD, Charles F. von Gunten, MD, PhD (San Diego Hospice), Frank D. Ferris, MD (San Diego Hospice) and Russell Portenoy, MD.

At the heart of the project is a core *curriculum* that provides physicians with the basic knowledge and skills needed to appropriately care for dying patients. The EPEC *Curriculum* consists of four 30-minute plenary modules and twelve 45-minute workshop modules, and is uniquely practical, transportable and self-contained. It combines didactic sessions, videotape presentations, interactive discussions, and practical exercises. It teaches fundamental skills in communication, ethical decision-making, palliative care, psychosocial considerations, and pain and symptom management. The module and plenary titles and objectives are listed on the facing page.

Dissemination of the *EPEC Curriculum* began with two national conferences held in the spring of 1998 to introduce an abbreviated version of the *Curriculum* to invited groups of national leaders in medicine. In the first half of 1999, six regional conferences presented the *Curriculum* to a select group of 500 physician-educators for implementation in their own institutions or communities, and to provide feedback to the writers of the *Curriculum*.

Final EPEC Curriculum

The final version of the first edition of the EPEC *Curriculum* was published in print in October 1999. It is comprised of a set of two loose-leaf binders: The Trainer's Guide with accompanying computer disks with 540 slides in Power Point and videotapes contains all the materials needed for a presenter to teach the subject. The Participant's Handbook has the written material for use as handouts at educational sessions. A CD-ROM version was also produced. All of these products are available to be purchased at cost through the AMA catalog.

In keeping with the EPEC Project goal to teach end-of-life care to all physicians in the U.S., CD-ROMs of the *Curriculum* will be provided to all renewing AMA physician members; presidents of state, county and national specialty societies; medical school deans; and major medical organizations. It is anticipated that recipients will use it as a "self-teacher" or to print the *Curriculum*, or parts of it, and establish educational programs in their group practices, organizations, schools, institutions, and so forth.

For more information and additional resources, visit the EPEC web site at www.ama-assn.org/ethic/epec.

EPEC Modules and Objectives

Module 1 – Advance Care Planning:

- Define advance care planning and explain its importance
- Describe the steps of the advance care planning process
- Describe the role of patient, proxy, physician, and others
- Distinguish between statutory and advisory documents
- Identify pitfalls and limitations in advance care planning
- Utilize planning to help the patient put affairs in order

Module 2 – Communicating Bad News:

- Know why communication of "bad" news is important
- Understand the 6-step protocol for delivering "bad" news
- Know what to do at each step

Module 3 – Whole Patient Assessment:

- Describe elements of suffering: physical, psychological, social, spiritual.
- Demonstrate ability to assess each

Module 4 – Pain Management:

- Compare and contrast nociceptive and neuropathic pain
- Know steps of analgesic management
- Know use of adjuvant analgesic agents
- Know use of non-pharmacological approaches
- Know adverse effects of analgesics and their management

Module 5 – Physician-Assisted Suicide:

- Identify root causes of suffering that prompt PAS or euthanasia requests
- Define P AS and describe its current legal status
- Explain key steps for responding to requests
- Understand alternative strategies for addressing a patient's suffering and fears

Module 6 – Anxiety, Delirium, Depression:

- Identify major depression in patients facing the end of life
- Distinguish major depression from normal reactions
- Describe management plans for depression, anxiety and delirium

Module 7 – Goals of Care:

- Name at least 5 potential goals of care that patients may have
- Identify clinical junctures at which priorities should be clarified
- Discuss how priorities should be determined
- Know how to assist the patient to identify reasonable goals

Module 8 – Sudden Illness:

- Describe the features of sudden illness that require special skills
- Know how to communicate effectively in the face of sudden illness
- Know how to guide decision-making in the face of sudden illness
- Explain the benefits and risks of using a time-limited trial approach.

Module 9 – Medical Futility:

- List factors that might lead to futility situations
- Know how to assist in resolving each factor

Module 10 – Common Physical Symptoms:

- Describe general guidelines for managing non-pain symptoms
- Explain the impact of symptom control
- Assess and treat each non-pain symptom
- Explain how the principle of double-effect applies to symptom management

Module 11 – Withholding/Withdrawing Treatment:

- List medical orders relevant for terminally ill patients
- Apply this knowledge to clinical situations
- Describe common misconceptions about withholding or withdrawing therapy

Module 12 – Last Hours of Living:

- Prepare and support the patient, family and caregivers (professional and volunteer) through the dying process
- Assess and manage the pathophysiological changes of dying
- Identify and manage initial grief reactions

Plenary One – Gaps in End-of-life Care:

- Describe the current state of dying in America
- Contrast this with the way people wish to die

Plenary Two – Legal Issues in End-of-life Care:

- Describe legal consensus points
- List common legal myths and pitfalls

Plenary Three – Elements of End-of-life Care:

- Describe a conceptual framework for suffering
- Describe the elements of end-of-life care
- Define palliative care
- Compare and contrast palliative care with hospice care

Plenary Four – Next Steps:

- List the important themes from the conference
- Identify barriers to good end of life care
- Develop potential solutions

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listen to the needs of the patient and his/her family. Often the thoughts and feelings not expressed may speak louder than what is spoken aloud. The nursing home medical director plays a pivotal role in helping to direct the interdisciplinary team and obtain ongoing institutional support for appropriate palliative care in the long-term care facility .The goal of symptom palliation, however, is not in achieving simply a “good” death, but in substantially improving the quality of life. In so doing, physicians translate thought into action, fulfilling the commandment, often credited to Hippocrates, “to cure sometimes, to relieve often, to comfort always.”

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