// University of Pittsburgh Medical Center

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UPMC SHADYSIDE PALLIATIVE CARE SERVICE EVOLVES

Dr. Beth Chaitin, director of the Medical Ethics and Palliative Care Service at UPMC Shadyside, notes that the service has grown and changed during the previous six months. Of the current mix of patients referred for consultation, 50% come from oncology services (hematology, oncology, surgical oncology, and orthopedic oncology;) 43.5 percent from family practice and internal medicine; and the remaining percentage from pulmonary, cardiology, cardiothoracic surgery, geriatrics, nephrology, and endocrinology. The service sees 62 percent of all patients admitted to any of the four ICUs at Shadyside, and there have been an increasing number of consultations for patients under the age of 55. The cases are more complex, and there has been an insurgence of psychiatric patients. Janet Kasden, crisis coordinator and clinical social worker, and Skye Fleming, physician's assistant, have joined the service; physician time has increased by 50 percent; and a rotation for medical residents has been added.

PHYSICIAN SURVEY (See perforated attachment)

The perforated end page of this newsletter is a survey for physicians who practice at UPMC hospitals. The survey takes only a few minutes to complete, can be easily removed by tearing along the perforated edge, and can be faxed to the number on the bottom of the survey form. The survey has been designed to elicit physician opinions about the palliative care services available at UPMC hospitals so that we can improve them and tailor them to more nearly meet the needs of physicians and patients in the future.

UPMC PRESBYTERIAN PALLIATIVE CARE NEWS

The palliative care clinical service at UPMC Presbyterian continues to grow. The most obvious evidence that the program is maturing is the stage at which patients are seen. When the program began, approximately 70 percent of patients seen died in the hospital, indicating that the service was seen as an "end-of-life" service. Currently, only 37 percent of patients die in the hospital, indicating that they are seen at an earlier point in their illness. By following local patients as either outpatients or hospice patients, the program has been able to play a larger role in symptom management and advance care planning.

NEW REPORT: FINANCING END-OF-LIFE CARE

The Health Care Financing & Organization Initiative of The Robert Wood Johnson Foundation has issued an important report, *Financing End-of-Life Care: Challenges for An Aging Population.* The report notes, "Unfortunately, the current financial incentives governing how hospitals and physicians provide (end-of-life) care are not conducive to palliative approaches." The report also suggests that in both public and private financing systems for end-of-life care " … the financial incentives for hospitals and physicians be shifted away from reimbursing providers for aggressive, inpatient medicine toward rewarding them for providing palliative care and consultative services outside of the acute-care setting." The full report can be read at: www.hcfo.net.

PALLIATIVE CARE REFERRAL NUMBERS

UPMC SHADYSIDE: 412-263-3008; On-call pager: 263-8347
UPMC PRESBYTERIAN: 412-647-7243; pager: 8511
MAGEE-WOMENS HOSPITAL OF UPMC: 412-641-2108
FAMILY HOSPICE AND PALLIATIVE CARE: 1-800-513-2148

PALLIATIVE CARE CASE: *RECOGNIZING RELIGIOUS AND CULTURAL PREFERENCES*

From the day she was diagnosed with breast cancer, we knew that Sara was extremely intelligent, highly spirited, and eager to make sure her preferences were not only known, but also acknowledged. Sara had strong feelings about everything in her life: her diet, her medications, her professional life, etc. Sara also lived her life as a Tibetan Buddhist. Sara would refer to herself as "different" than almost everyone she knew. As her cancer progressed, she would attend support groups and talk openly about the end of her life, at times so openly in fact, that others around her would be uncomfortable with the "matter of fact"-ness she would so often apply. Sara would talk about her family who lived on the West Coast and believed that she was "alone" in the world with few resources to assist her if and when her daily routine became intolerable for her. Sara would implicitly state that it was not her intent to be a burden on anyone in her life. Sara taught us about a specific desire to practice the traditional Buddhist belief of not moving a body for 72 hours after death has occurred. This practice is believed to preserve the body and spirit as the body passes through 8 levels of consciousness. Within this belief it is understood that disturbing a body during the immediate post-death period will make it difficult for the person to accomplish certain spiritual purposes during the latter stages of transition. As Sara's cancer progressed and her body and mind were too weak to act independently, we were considering that she could die as an inpatient in the hospital and we would be confronted with the task of meeting her needs and wishes AND complying with policies, procedures, and regulations regarding patient deaths on a hospital unit.

Admitted to the hospital with vague physical symptoms of unclear etiology, her condition seemed to worsen yet her appearance and demeanor seemed more at ease as the hours passed. Social Work and Palliative Care worked closely to plan for Sara and to make sure staff didn't lose sight of her wishes and beliefs. We began focusing our efforts on getting Sara home so her wishes could be met but the reality was that it was uncertain who would be available to help her. A local Zen Buddhist priestess advised us on "compromises" that might be acceptable to maintain the sanctity of her beliefs and be sure that she had the support and physical care she now needed. We accepted that a physical move would not be possible at this point because she was actively dying. The local Zen priestess was extremely helpful with explaining the importance and meaning of various rituals.

Sara's need for physical care was minimal as she seemed extremely comfortable and required no medications for pain or other symptoms. Sara was as candid about this new reality as she had been about her disease throughout its course.

In a last visit with Palliative Care, Sara quietly smiled and said simply "I guess this is it. Thank you." Sara died quietly just two days after admission. We were assured that it would be acceptable to physically move Sara's body after prayers and instructions were offered both at her bedside and at a Tibetan temple in Maryland. We learned in caring for Sara that Tibetan Buddhism and Zen Buddhism are different in some respects and in order to adhere to Sara's beliefs, it was important to include the work and support of Tibetan monks and a priest that Sara had known in her life. When Sara died, the Zen priestess called and prayers, blessings and anointing were done here at Sara's bedside and also in Maryland at the temple. It is also custom in Tibetan Buddhism for the body to not be left alone. Sara's friend never left her side from the moment of her death. The Tibetan monks called to notify us when the prayers were completed in Maryland and we were given permission to move Sara's body. Approximately 7 hours after her death, Sara was moved from the hospital to a friend's home, where she was accompanied and anointed for several hours. Sara's body was cremated within 24 hours of her death. The local Zen priestess and the Tibetan monks and priests from Maryland worked closely together to host a Buddhist service in Sara's memory a few days after her death.

As we reflect and remember Sara, we continue to smile quietly that we had been able to care for Sara according to her beliefs. We are grateful for the opportunity to respect her beliefs and values and have been forever changed by the experience. Was it difficult for us to allow Sara's beliefs to drive our care and decisions? Yes. Did we have to constantly "argue" the value in doing so? Yes. Did we meet resistance and questioning about utilization, length of stay, etc.? Yes. But more importantly, was it important for us to do it anyway? YES! We learned in caring for Sara that it is easy to misunderstand, misinterpret, or even ignore cultural and religious practices that are different from our own or the "norm". We took the risk and never stopped advocating for Sara. When our comments and concerns were laughed at, or we were confronted with "rolling eyes," we continued to explain the rationale and importance of our actions and plans. Everyone involved knew they made a difference in her care, and pride still resounds from our hearts and our faces because we know we helped fulfill her dying wish as best we could. We now look eagerly for the next opportunity to learn from those we care for and challenge ourselves to recognize, accept, and adhere to the wishes and beliefs of our patients and families.

References:

1. Johnson, Christopher J. and McGee, Marsha G. *How Different Religions View Death and Afterlife* (1991).

Reprinted with permission: Case of the Month, Comprehensive Palliative Care Program, October 2002, Vol.2, No. 2
Kathy Purcell, MSW and Denise Stahl, RN, MSN, Magee Womens Hospital

Means to a Better End: A Report on Dying in America Today[*]

The Robert Wood Johnson Foundation, November 2002

Some of the key findings:

- Nationally, only 25 percent of deaths occur at home, although more than 70 percent of Americans say that this is where they would prefer to die.
- About half of all deaths occur in hospitals, but less than 60 percent of the hospitals in any given state offer specialized end-of-life services.
- Nationally, an average of 14 percent offer palliative care, 23 percent offer hospice care, and 42 percent offer pain management services. Although these programs are becoming more available, reimbursement issues are still a challenge. Funding for such programs often depends on inconsistent sources, such as donations and private grants.
- Experts agree that patients need at least 60 days of hospice care to maximize its benefits, but the report found that hospice stays range from 14 to 43 days per state.
- On average, the percentage of U.S. physicians certified in palliative care is 0.33 percent (33 physicians for every 10,000 people); the average percentage of nurses certified in hospice and palliative care is 0.41 percent (41 nurses for every 10,000). This lags far behind the needs of the U.S. population.
- Between 16 and 37 percent of deaths among Medicare recipients in any given state include hospitalization in an intensive care unit during the last six months of life. ICU care is often uncomfortable and unwanted: A study of cancer patients in the ICU found that 55 to 75 percent had moderate to severe pain, discomfort, anxiety, sleep disturbance or unsatisfied hunger or thirst.
- Twenty-four states have pain management policies that explicitly address the needs of the terminally ill, and 18 policies express concern about the undertreatment of pain in this group. Experts agree that up to 95 percent of serious pain can be effectively treated, but half of all dying people still experience severe pain.

[*]The entire report can be read on The Robert Wood Johnson Foundation's Web Site, www.rwjf.org.

CERTIFIED PALLIATIVE CARE AND HOSPICE NURSES IN SOUTHWESTERN PENNSYLVANIA

The National Board of Certification of Hospice and Palliative Nurses (NBCHPN®) certifies knowledge and competency in hospice and palliative nursing. NBCHPN® originated in 1992 after identification of a need for certification in the specialty of hospice nursing care. The first certification examination was offered in 1994 and in 1999 the examination was expanded to include palliative care. Successful candidates are awarded the credentials CHPN® (Certified Hospice and Palliative Nurse). This exam was awarded a 4-year accreditation by American Board of Specialties in February 2002. As of September 2002 there are 328 CHPNs in the state of Pennsylvania with 69 CHPNs residing in Southwestern PA. Nationally, there are 6,000 Certified Hospice and Palliative Nurses.

In September 2002 the Certification Examination for the Hospice and Palliative Nursing Assistant became available. This exam was developed through grant monies received from the Fan Fox and Leslie R. Samuels Foundation. Those who successfully pass this examination are awarded the credentials CHPNA (Certified Hospice Palliative Nursing Assistant). Nationally there are 290 CHPNAs, with over 500 applicants for the second national offering of the exam to be given March 15, 2003. The 2 CHPNAs in Pennsylvania reside in Southwestern PA.

In May 2003 certification in hospice and palliative care will be available for advanced nurse practitioners. Administrative support is provided to NBCHPN® by the National Office of the Hospice and Palliative Nurses Association, a membership organization of over 5000 providing educational materials and programs on end of life care. More information is available at: www.hpna.org.

Recent Comprehensive Palliative Care Service Staff News

David Barnard, PhD and Nicole R. Fowler, MHSA wrote *The Section of Palliative Care and Medical Ethics at the University of Pittsburgh: An Academically-Based Palliative Care Program.* The Association of Academic Health Centers commissioned this paper. It will be sent to all academic health centers in the United States. Copies of the report may be ordered online at www.ahcnet.org.

Robert Arnold, MD, along with co-authors Timothy Quill, MD, and Anthony Back, MD, published "Hope for the Best, and Prepare for the Worst" in the *Annals of Internal Medicine*, Vol. 138, No. 5, March 4, 2003. The authors state, "Although it may seem contradictory, hoping for the best while *at the same time* preparing for the worst is a useful strategy for approaching patients with potentially life-limiting illness. By acknowledging all the possible outcomes, patients and their physicians can expand their medical focus to include disease-modifying and symptomatic treatments and attend to underlying psychological, spiritual, and existential issues."

Linda King, MD, was selected as one of six winners of an award sponsored by the Robert Wood Johnson Foundation for excellence in end-of-life care textbook content.

> *All knowledge attains its ethical value and its human significance only by the humane sense in which it is employed. Only a good man* (or woman in today's world) *can be a great physician.*
>
> Hermann Nothnagel [1841-1905]

Carolyn Longest, MA, Editor. The newsletter is published twice a year. It is intended to be an informational resource for UPMC physicians. If you have questions or comments about this issue, or suggestions for future issues, email fowlernr@msx.upmc.edu. This newsletter can be found online at www.upmc.edu/palliativecare.

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Please Complete This PHYSICIAN SURVEY & FAX To 412-692-4315

The following survey asks for your opinion on **palliative care**. By palliative care, we mean care that is focused on relieving suffering and improving quality of life. This care can be offered at the same time as curative or disease-modifying treatment. Palliative care integrates all needed services, including pain management, symptom control, psychosocial support and spiritual support, for those who are seriously ill and their families.

1. Which of the following **palliative care services** for patients with chronic, serious or life-threatening illness do you think should be expected at a hospital offering a high quality of care? **(Circle ranking for each item)**

   a. Consultations to ensure effective analgesic therapy for pain
   Not important at all 1 2 3 4 5 Very important

   b. Consultations to ensure effective control of symptoms such as dyspnea, nausea, and constipation
   Not important at all 1 2 3 4 5 Very important

   c. Consultations to ensure assessment and management of psychiatric disorders and psychological distress in patients with life-limiting illnesses
   Not important at all 1 2 3 4 5 Very important

   d. Services to support patients and their families, such as counseling, psychosocial needs, spiritual care and bereavement
   Not important at all 1 2 3 4 5 Very important

   e. Assistance with referrals to hospice or palliative home care
   Not important at all 1 2 3 4 5 Very important

   f. Services to assist patients and their families with end-of –life decision-making
   Not important at all 1 2 3 4 5 Very important

(Please check the appropriate box or boxes in the next sections)

2. Do you think that time demands on physicians at our hospital make it difficult to provide palliative care to patients and families?

   ☐Yes ☐No ☐Sometimes

3. When do you think it is most appropriate for patients to begin receiving palliative care services?

   ☐ When a patient has a chronic illness
   ☐ As soon as a patient is diagnosed with a serious or life-threatening illness
   ☐ Only after all reasonable life prolonging care efforts have been exhausted
   ☐ In the last few months of life
   ☐ In the last few days of life

4. Which of the following palliative care services would you use if they were made available for a patient with chronic, serious or life-threatening illness? Check all that apply.

   ☐ Pain consultation
   ☐ Symptom management consultation
   ☐ Chronic disease case management
   ☐ Psychosocial assessment and management consultation
   ☐ Assessment and management of psychiatric disorders
   ☐ Assistance in obtaining advance directives and DNRs
   ☐ Assistance with end-of-life planning, such as spiritual or existential issues at the end of life
   ☐ Assistance with referrals to hospice, palliative home care, or other placements
   ☐ Assistance in resolving complicated ethical issues
   ☐ Comprehensive care plan for those requiring comfort care

(over)

5. Which of the following situations do you think are faced by physicians at our institution when treating patients with chronic, serious or life-threatening illness? Check all that apply.

- ☐ Don't know enough about how to treat pain and other symptoms in patients with life-limiting illnesses
- ☐ Don't know enough about hospice and home care services
- ☐ Don't know enough about palliative care
- ☐ Don't feel comfortable talking about "bad news" with patients and families
- ☐ Not enough options for terminally ill patients in our community
- ☐ Patients and families are not receptive to hospice and other services
- ☐ Patients and families are not familiar enough with palliative care to choose it as a treatment option
- ☐ Patients in need of services do not meet hospice requirements
- ☐ Patients in need of services do not meet palliative care requirements
- ☐ Patients do not have coverage or resources to pay for hospice and other needed services
- ☐ Patients do not have coverage or resources to pay for palliative care services
- ☐ The institution lacks comfortable settings for dying patients and their families

6. Which of the following best describes your current role, practice, or specialty?

- ☐ Administration/Management
- ☐ Primary care
- ☐ Hospitalist
- ☐ Gerontology
- ☐ Cardiac Care
- ☐ Respiratory Care
- ☐ Emergency
- ☐ Oncology
- ☐ Gynecology/Urology
- ☐ Pulmonology/Critical Care Medicine
- ☐ Other:________

7. For how many years have you worked in the medical profession?
_____________year(s)

8. Do you have formal training in palliative or end-of-life care, such as EPEC or ABHM Certification?

- ☐ Yes
- ☐ No

9. Would you consider attending or participating in one of the following palliative care related activities? Please check all that would be of interest.

- ☐ One hour in-hospital seminar
- ☐ One-half day educational seminar
- ☐ Help in setting up an inpatient palliative care consultation service

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10. The following information is optional.

Name ____

Hospital ____

Thank you very much for completing this survey. Your feedback will be greatly appreciated.

PLEASE FAX THE COMPLETED SURVEY TO 412-692-4315.