INSTITUTE TO
ENHANCE
PALLIATIVE
CARE

PALLIATIVE CARE CASE OF THE MONTH

With News from the Institute

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The Foundling

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Case: A 38-year-old man was admitted to the hospital with a history of metastatic renal cell carcinoma, bilateral leg weakness, and intractable pain. He also had a history of amyotrophic lateral sclerosis and a left nephrectomy. This particular admission patient had surgical removal of a metastatic tumor on his spine and spinal fusion with hardware. The majority of Mr. G's prior care had been provided in another health care system. The Palliative Care Team was consulted to assist the primary service in helping the patient to establish goals of care and by managing pain and symptoms, coordinating care, and providing emotional support.

Mr. G had lived independently in a recently acquired apartment for three weeks prior to this admission. Mr. G was estranged from his family and had been so for five years. He had developed a network of friends while he was attending vocational classes, and these friends had become his "surrogate family." He survived on the limited income that Social Security Disability provided. He had also received support through various area social service agencies.

Mr. G had an angry demeanor. His long history of alcohol and drug use, combined with his refractory pain, made it difficult to assess the legitimacy of his pain medication requirements. It was the perception of the medical caregivers on the primary team that the patient was drug seeking. In social work jargon, it is called "blaming the victim."

The Palliative Care Team worked with Mr. G and his primary care team during three hospital admissions over the following two months. The complexity of his care, from both physical and psychosocial points of view, can be appreciated by reviewing the following list of the team's goals as they emerged during this time:

- Advocating for the patient's right to self-determination
- Facilitating interdisciplinary communication and collaboration
- Building trust and consistency across disciplines
- Clarifying the patient's goals across the continuum of care
- Empowering the patient's need to safely deny the reality of his "terminal illness"
- Identifying and ensuring safe disposition upon discharge from the acute care setting
- Supporting the patient emotionally and psychologically through the progression of his illness
- Facilitating coordination and collaboration of various medical services to provide symptom management
- Thinking outside traditional disciplinary boxes to manage complicated pain in the hospital and in hospice care
- Facilitating discussions around end-of-life care issues

Near the end of Mr. G's last admission, in contrast to his previous preferences, he requested that staff attempt to locate his brother and sister-in-law. We were asked to invite some specific people in his life to come to the hospital and say goodbye. He directed staff to give his belongings to particular members of his surrogate family. As he requested, it was arranged that Mr. G's body would be donated to the Humanity Gifts Registry.

Mr. G was transferred to an inpatient hospice unit. Amazingly enough, on that same day, contact was made with his brother. Members of both Mr. G's surrogate family and family of origin congregated at the hospice facility to be present and support him. Mr. G was no longer alert, but family and friends united and surrounded Mr. G with love as he peacefully slipped away.

Discussion: Caring for Mr. G was both demanding and rewarding. Palliative care's multidisciplinary approach helped with his pain management, which also helped to resolve tensions that had caused such distress at the beginning. Beyond that, Mr. G left a tender mark on those whom he allowed to participate in his living and dying. Caring for him embodied and confirmed the reason many of us have chosen to do this work. The last stanza of Robert Frost's "The Road Not Taken" seems an appropriate end to this Case of the Month.

> *I shall be telling this with a sigh*
> *Somewhere ages and ages hence:*
> *Two roads diverged in a wood, and I—*
> *I took the one less traveled by,*
> *And that has made all the difference.*

Recommended Readings:

Arnold, R. M. Back, A.L. Discussing Prognosis: "How Much Do You Want to Know?" Talking to Patients Who Do Not Want Information or Who Are Ambivalent. Journal of Clinical Oncology. September 1, 2006.Vol 24, No. 25

Christ G. H., Blacker, S. Series Introduction: The Profession of Social Work in End-of-Life and Palliative Care. Journal of Palliative Medicine. Vol.8, No.2, 2005

For further information please contact the *Palliative Care Program at PUH/MUH*, 647-7243, beeper 8511,, *Shadyside Dept. of Medical Ethics and Palliative Care*, 623-3008, beeper 263-9041, *Perioperative/ Trauma Pain* 647-7243, beeper 7246, *UPCI Cancer Pain Service*, beeper 644 – 1724, *Interventional Pain* 784-4000, *Magee Women's Hospital*, 641-2108, beeper 917-9276, *VA Palliative Care Program*, 688-6178, beeper 296. For ethics consultations at UPMC Presbyterian-Montefiore, and Children's call 647-5700 or pager 958-3844. With comments about "Case of the Month" call David Barnard at 647-5701.

November is *National Hospice & Palliative Care Month* & *National Family Caregivers Month*

Former President Jimmy Carter signed the first National Hospice Month proclamation 28 years ago, and President Bush upheld that tradition by signing a similar proclamation on October 30, 2006 http://www.whitehouse.gov/news/releases/2006/10/20061031-1.html. The National Hospice and Palliative Care Organization (NHPCO) (http://www.nhpco.org) reports that there are more than 4,000 hospice programs in the United States, and these programs cared for more than 1.2 million people last year. The NHPCO's *History of Hospice* can be viewed at http://www.nhpco.org/i4a/pages/index.cfm?%20pageid=3285&openpage=3285

In celebration of **National Hospice and Palliative Care Month**, the Institute to Enhance Palliative Care invites you to explore an electronic version of our newly released brochure http://www.dgim.pitt.edu/iepc/IEPC_brochure.pdf and find out more about what the Institute is doing in Western Pennsylvania to improve the access to and quality of palliative care.

National Family Caregiver Month is nationally recognized to draw attention to the many challenges facing family caregivers, advocate for stronger public policy to address family caregiving issues, and raise awareness about community programs that support family caregivers. According to the National Family Caregivers Association (NFCA), http://www.nfcacares.org/, more than 50 million family caregivers across the country currently provide an estimated $306 billion in "free" caregiving services annually. This November the NFCA is emphasizing "the need for all of us to help family caregivers protect their health in order to have a more satisfying life and be better able to provide their loved one with the best care possible."

To further that focus, the Institute would like to direct your attention to the following recently published articles by one of our leading faculty researchers Randy Hebert, M.D.

- Hebert RS, Prigerson HG, Schulz R, Arnold RM. *Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research.* J Palliat Med. 2006 Oct; 9(5):1164-71. http://www.dgim.pitt.edu/iepc/RecentPublications/Preparing_caregivers_for_death_of_a_loved_one.pdf

- Hebert RS, Schulz R. *Caregiving at the end of life.* J Palliat Med. 2006 Oct; 9(5):1174-87. http://www.dgim.pitt.edu/iepc/RecentPublications/Caregiving_at_end_of_life.pdf

- Hebert RS, Koenig HG, Arnold RM, Schulz R. *Caregiver intervention research: an opportunity for collaboration between caregiving investigators and African-American faith communities.* Natl Med Assoc. 2006 Sep; 98(9):1510-4. http://www.dgim.pitt.edu/iepc/RecentPublications/Caregiver_intervention_research.pdf

- Hebert RS, Weinstein E, Martire LM, Schulz R. *Religion, spirituality and the well-being of informal caregivers: a review, critique, and research prospectus.* Aging Ment Health. 2006 Sep; 10(5):497-520. http://www.dgim.pitt.edu/iepc/RecentPublications/Religion_spirituality_well-being_of_informal_caregivers.pdf

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University of Pittsburgh Named One of Five Performance Sites for National Palliative Care Research Center's $5 Million NCI Grant

The University of Pittsburgh has been designated by the National Palliative Care Research Center at Mount Sinai School of Medicine to be one of five performance sites in a multi-million dollar study recently funded by the National Cancer Institute of the National Institute of Health. This new multi-site study will assess the structure, processes, and clinical outcomes of care among hospitalized persons with advanced cancer that receive palliative care consultation team services. They will be compared to similar patients receiving usual hospital care in an effort to build a body of evidence about which components of palliative care programs are central to their effectiveness.

The five performance sites include:

- Medical College of Wisconsin, Milwaukee, WI
- Mount Carmel Health Systems, Columbus, OH
- Mount Sinai School of Medicine, New York, NY
- University of Pittsburgh, Pittsburgh, PA
- Virginia Commonwealth University, Richmond, VA

The University of Pittsburgh Schools of the Health Sciences, in collaboration with Family Hospice and Palliative Care, established the Institute to Enhance Palliative Care in 2003 to improve access to and quality of palliative care in Western Pennsylvania. The Institute's mission is to educate health care providers, conduct research, raise awareness among the community, and advance public policies regarding palliative care.