



PALLIATIVE CARE CASE OF THE MONTH

Legacy Projects at the End of Life Sonia Malhotra, MD

Volume 14, No. 35

April 2014

Case: L.S. is an 88-year-old woman who initially presented with chest pain and shortness of breath and was found to have a large descending aortic aneurysm. Her aneurysm was not amenable to surgical correction, so L.S. was discharged home with hospice for medical management. She was interested in sharing her life's experiences, so a legacy project was initiated. During the course of the legacy project, L.S. became withdrawn from her friends and family and often felt anxious and depressed. A long conversation was held with her, and she admitted the legacy project brought back memories of her husband whom she missed dearly. She also admitted that through the project she was reminded of asset allocation and felt sad by her daughter's anger regarding distribution of the items. L.S. eventually completed her legacy project but had difficulty with a segment that involved recording a message to her daughter. She often expressed worry about the legacy she was leaving behind and how materialistic her life's memory had become.

Discussion: Suffering, both physical, psychological and existential, is an important topic for seriously ill patients (1). The 2005 National Consensus Project on Quality Palliative Care highlighted the importance of understanding and addressing patients' emotional and spiritual needs (2). Emotional and spiritual suffering are important factors that can contribute to the development of patients' and caregivers' depression and anxiety (3,6). Various interventions are available to address emotional and spiritual distress. One example is legacy project. These projects provide meaning-based coping through the creation of a lasting memento summarizing one's life.

Everyone has a story to tell. This is a basic summary of legacy project's purpose.

Legacy projects are individually tailored to help patients discuss life review, accomplishments, and heritage at the end of their life.

Hospices offer legacy projects to all patients well enough to communicate. Examples of legacy projects include videotaping or writing stories or letters, creating handprints, recording music, or collating artwork, pictures, recipes, favorite prayers, or poems. Some legacy projects are larger than others but all leave a mark on the patient completing the memory, the family and friends who receive the memory, and the staff and volunteers who help complete the work.

Most organizations depend on trained social workers and volunteers to create and maintain legacy projects. There is no cost to the patient or caregiver for the project. Hospices often receive money from donors and grants to fund legacy projects.

StoryCorps, an independent nonprofit organization that partners with National Public Radio (NPR), helps collect stories nationwide to archive in the Library of Congress. They offer grants to smaller nonprofits and provide a mobile unit with equipment and transcription training to collect stories of patients and families. Recently StoryCorps completed a project with Forbes Hospice in which several patients and families told their stories.

There is little data on the impact of legacy projects on patient and caregiver rates of depression and anxiety. Two small studies demonstrated decreased rates of depression and anxiety in patients at the end of life who were involved in legacy projects (4, 9). However, as demonstrated in our case, legacy projects can bring up questions that are uncomfortable and distressing to patients, affecting their quality of life.

Personal details in the case published have been altered to protect patient privacy.

For palliative care consultations please contact the Palliative Care Program at PUH/MUH, 647-7243, beeper 8511, Shadyside Dept. of Medical Ethics and Palliative Care, beeper 412-647-7243 pager # 8513, Perioperative/ Trauma Pain 647-7243, beeper 7246, UPCI Cancer Pain Service, beeper 644-1724, Interventional Pain 784-4000, Magee Women's Hospital, beeper 412-647-7243 pager #: 8510, VA Palliative Care Program, 688-6178, beeper 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore and Children's page 958-3844. With comments about "Case of the Month" call Dr. Robert Arnold at (412) 692-4834.



References:

1. Spirituality, religion, and healing in palliative care; Puchalski CM, Dorff RE, Hendi IY; Clin Geriatr Med. 2004 Nov;20(4):689-714
2. Clinical Practice Guidelines for Quality Palliative Care. 2005. (Accessed at <http://www.nationalconsensusproject.org>.)
3. Irwin S, Block S. What Treatments are Effective for Depression in the Palliative Care Setting? In: Goldstein N, Morrison RS, ed. Evidence Based Practice of Palliative Care. Philadelphia: Elsevier; 2013:181-9.
4. Seriously ill patients' discussions of preparation and life completion: An intervention to assist with transition at the end of life; Steinhauser K, Alexander A, Byock I, George L, Tulsy J; Palliative and Supportive Care (2009), 7, 393–404
5. About Us and Programs & Initiatives. 2014. (Accessed at <http://www.Storycorps.org>)
6. Bryant RA. Prolonged grief: where to after Diagnostic and Statistical Manual of Mental Disorders, 5th Edition? Current opinion in psychiatry 2014;27:21-6
7. Improving Psychological and Psychiatric Aspects of Palliative Care: The National Consensus Project and the National Quality Forum Preferred Practices for Palliative and Hospice Care; Hultman T, Keene E, Dahlin C; Omega 2008; Vol. 57(4) 323-339
8. The Legacy Project Intervention to Enhance Meaningful Family Interactions: Case Examples; Allen R; Clin Gerontol. 2009 ; 32(2): 164–176. doi:10.1080/073171110802677005.
9. Allen, R., et al. (2008). Legacy activities as interventions approaching the end of life; Allen, R., et al.; Journal of Palliative Medicine. 2008; 11(7): 1029-1037

Personal details in the case published have been altered to protect patient privacy.

For palliative care consultations please contact the *Palliative Care Program at PUH/MUH, 647-7243, beeper 8511, Shadyside Dept. of Medical Ethics and Palliative Care, beeper 412-647-7243 pager # 8513, Perioperative/ Trauma Pain 647-7243, beeper 7246, UPCI Cancer Pain Service, beeper 644 –1724, Interventional Pain 784-4000, Magee Women's Hospital, beeper 412-647-7243 pager #: 8510, VA Palliative Care Program, 688-6178, beeper 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore and Children's page 958-3844. With comments about "Case of the Month" call Dr. Robert Arnold at (412) 692-4834.*