



**What to Do When There's Nothing More to Do**  
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**Case:** MC was a 45 year-old female from a rural community who considered herself to be healthy. She was the wife of a traveling salesman. She and her husband had two young adult sons who were living nearby and a daughter still at home. The daughter was about to graduate from high school. In June of 2006, MC began to experience weakness, shortness of breath, ankle edema, numbness and tingling in her feet. By March of 2007, she had been diagnosed with hypothyroidism, primary amyloidosis, restrictive cardiomyopathy, autoimmune neuropathy, and acute renal failure. Her illness was ravaging and she was told that her only chance for survival was to undergo bone marrow, heart, and kidney transplantation. By this time she was in an intensive care unit and gravely ill. Although everybody knew transplantation was "a long shot," they chose transplantation because MC wanted to survive and see her daughter graduate from high school.

MC was "life-flighted" to our hospital's cardiac intensive care unit (CCU) from the regional hospital several states away. MC was worked up for bone marrow, heart, and kidney transplantation but it was soon determined that her disease was too advanced and that she was not a candidate for transplantation.

By this time MC's pain was "all over." She was on an intra-aortic balloon pump and on dobutamine, dopamine, and milrinone to sustain function. Defeated in their quest, the patient and family asked for transport "home," which was out of the question because of MC's dependence on cardiac/pressor drugs and the balloon pump.

**Palliative Care (PC) Consultation:** We were asked to see this patient and family and make recommendations on symptom management, and to guide psychosocial support because the various attending teams and the CCU nurses felt helpless. In particular, the nurses had become quite attached to this patient and family and felt defeated because "there was nothing else they could do for them."

**Subjective PC assessment of the patient:** MC explained that she was tired because she hadn't slept in days, yet when asked, she denied that she was in pain. Her husband refuted this and explained that pain and worry were at the root of her sleeplessness. He said that, in fact, MC had experienced generalized pain for the last few months and that this pain had escalated over the past few days. MC agreed with her husband's assessment and went on to explain that her pain was 8 out of 10 (on a scale of 1-10) and would escalate to a "10" upon the slightest touch or movement. MC said she was willing to take morphine for the pain, which was ordered at 2 mg IV every hour PRN, and she agreed to take special boluses of morphine prior to repositioning.

However, when the medication was offered, she refused to take it. According to reports from the nurses, she also refused zolpidem 10 mg PO HS PRN for sleep. MC had always been stoic about her pain but now she also seemed withdrawn and frightened. It hurt her family to see her suffering with her past decline in health and now to see her in such pain.

**Objective PC assessment of the patient:** MC was "wide awake," yet was quiet and lay very still in the bed. She also had a flat affect. She was slow to answer questions and her voice was trembling and weak. MC fought back wincing and groans with every touch or movement (e.g., position changes; hand holding). She had deeply icteric sclera, a regular yet tachycardic heart rate and had the balloon pump in place and functioning. Her extremities were cool and slightly cyanotic and she was jaundiced. However, she answered questions appropriately and was oriented to person and place. Respiratory systems were negative, her abdomen was distended and non-tender, but she had no bowel sounds. There was no myoclonus, no seizures, and there were no gross musculoskeletal abnormalities. MC's lab values indicated that she was in severe renal failure.

**PC social support/family assessment:** MC's husband, an adult son age 26, and a daughter age 18 were at the bedside almost continuously. The husband's extended family was on the way from an adjacent state. A family member, who was a member of the priesthood, was present with plans to stay with the patient and family throughout what was anticipated to be the rest of her shortened life. Upon further assessment and observation, MC and her family were "frozen" in their existential distress and in their respective forms of suffering. The family realized that MC was medically at the end of her life, but they didn't expect her to be awake near the end, and they didn't expect her to be so "out of reach" as they tried to comfort her. While patient and family had been medically prepared for what was to come, they weren't psychologically and existentially/spiritually prepared.

**Subjective assessment of the nursing staff:** MC's stoicism was a trial for her nurses. They were aware of her escalating pain and were afraid to touch or move her. The patient was motionless in the bed because she was afraid to move because of the pain and because of the balloon pump. The family was motionless because they felt they couldn't touch her or physically comfort her. Therefore both the patient and family members were "frozen," not talking, and not touching the patient or each other. Everyone seemed afraid and the nurses felt foiled in all attempts to bring the relief they knew they could offer if the patient would allow them to medicate her for her symptoms.

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**PC impression:** The end points of MC's overall plan of care were already clear: "DNR/DNI," the use of the balloon pump, and continued pharmacological supports would continue only until MC lost consciousness from renal failure. When that happened, and it was expected to be soon, the cardiac/pressor drugs and the balloon pump were to be withdrawn and MC would be allowed to die, probably from cardiac arrhythmia due to excessive potassium in her blood. What could a palliative care consultation team do?

**PC recommendations:** Our first recommendations involved treatment of the patient's pain and her sleeplessness. The next recommendations involved psychosocial and existential/spiritual support for MC, her family and CCU staff.

1. We recommended changing the pain medicine from morphine to hydromorphone (Dilaudid) and delivering it continuously IV via a PCA pump for the steady state pain. We used hydromorphone because it has fewer adverse side effects (such as myoclonus) in renally challenged patients. We also suggested using scheduled bolus IV doses of hydromorphone for major position changes, allowing that MC could refuse it or that the nursing staff could withhold the "as needed" bolus if the MC was too sedated. It was our hope that, with better pain management, MC could finally get some sleep. MC readily accepted these recommendations, as did her family, the CCU nurses, and the attending teams.
2. Then the PC nurse consultant asked MC and her family to talk together about how MC felt about being so ill and "in the bed." To our surprise, MC readily explained that she was afraid to go to sleep -- afraid for fear of not waking up, which was why she refused pain medications. She also explained that she was angry with her PCP for not doing a more thorough assessment "in time" and she felt guilty because she delayed seeking further treatment, treatment that might have forestalled this untimely ending. MC's husband and her daughter then expressed their own feelings about the illness course, of how each of them also felt guilty for not seeing how sick she was and of not acting sooner. They were able to cry together. MC let her family members touch her and hold her as they comforted each other. She said that because of her religious convictions she wasn't afraid to die, if that was what had to be, she just did not want to leave them so soon.
3. After a time, the PC nurse consultant asked MC and her family to describe a "vision" of MC in better days; of a favorite place where MC spent her time, of a vision of her healthy and happy. MC immediately spoke of sitting on her front porch. She shared the view and then her husband and son filled in the pieces. She loved to "torment" their cats on the front porch. They were young and loved to romp and play...they would chase anything and everything. MC had a "mouse on a string" that she juggled and tossed and the cats

play with it. As her health waned this game brought her laughter and, in fact, brought laughter back into the room. We then talked with her daughter about her aspirations and wishes upon graduation. She was planning to study meteorology. The jokes resumed as we teased her about standing out amidst hurricanes to tell the TV watchers just how windy hurricanes are. Talk relieved tension and soon the family was reminiscing with MC about favorite things they shared.

4. Finally, we left medication orders for PRN Haldol and Lorazepam to be used in the event of terminal restlessness and seizure. Constipation, obstipation, and bowel obstruction were not treated because of her relative degree of abdominal comfort and because of her very short expected lifespan.

**Outcome:** MC died 12 hours later. While alert she was able to talk with her family and open up to their caring. She even allowed them to show her a DVD of her parent's latest anniversary party, a DVD that she previously refused to view. As she got sleepier the family gathered around her bedside and continued to fill the room with visions of happier times. And, as her death drew near, extended family and the family priest arrived and prayed with her until the end.

**Summary:** There are major things that can be done to improve comfort at end of life, even when there is nothing else medically to do. While attention to the physical dimensions of comfort care is an important aspect, open, honest, and sensitive communication among health care providers, staff, patients and families is also required and these interventions allowed all caregivers to prepare for death in an appropriate manner.

**Epilogue:** The CCU nurses were grateful for the transition away from pain and toward the comfort that they witnessed. They were so grateful that they asked for guidance as they develop "Comfort Care Champions" who are now working on an "End-of Life" Quality Improvement project for their CCU using the strategies and techniques learned from this case.

## References:

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- Wilson SA, Coenen A, Doorenbos A (2006). Dignified dying as a nursing phenomenon in the United States. *Journal of Hospice and Palliative Nursing*, 8 (1), pp 34-41.

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.



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### **The Institute's Administrative Director Leaves to Help Direct the University's New Clinical and Translational Science Institute**

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Nicole Fowler, Administrative Director for the Section of Palliative Care and Medical Ethics for the past six years and the Institute to Enhance Palliative Care since its inception in 2003, has been named Assistant Director of the Clinical and

Translational Science Institute (CTSI), Education and Career Development Core. She will be responsible for the implementation of the Ph.D. Program in Clinical Research as well for overseeing 20 education programs being developed and implemented under the CTSI Education Core.



The CTSI at the University of Pittsburgh is one of the first 12 created at academic health centers throughout the nation by funding through Clinical and Translational Science Awards. It is part of a national consortium being created by National Center for Research Resources of the National Institutes of Health to "transform how clinical and translational research is conducted, enabling researchers to develop new treatments faster and deliver them to patients more efficiently and quickly."<sup>1</sup>

Nicole has a Masters Degree in Health Administration and Policy and is a Ph.D. Candidate in Public Policy and Administration. She will transition full time into her new role at the beginning of July.

More information on the CTSI is available at <http://www.ctsi.pitt.edu/default.asp>.

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<sup>1</sup> National Center for Research Resources: National Institutes of Health. *Clinical and Translational Science Awards to Transform Clinical Research*. [http://www.ncrr.nih.gov/clinical\\_research\\_resources/clinical\\_and\\_translational\\_science\\_awards/index.asp](http://www.ncrr.nih.gov/clinical_research_resources/clinical_and_translational_science_awards/index.asp)

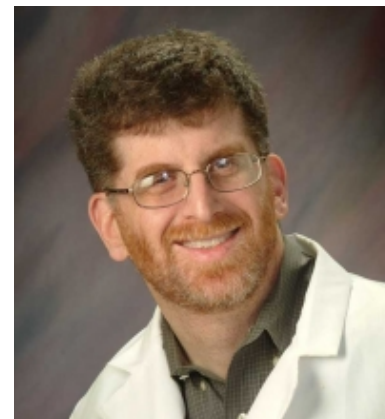
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### **National Palliative Care Research Center awards Dr. Robert Arnold Pilot Support for his Critical Care Communication (C3) Project**

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The National Palliative Care Research Center has awarded Robert M. Arnold, M.D., Chief of the Section of Palliative Care and Medical Ethics and Co-Director of the Institute to Enhance Palliative Care a two-year Pilot Project Support Grant. Together with funding from the Jewish Healthcare Foundation, this grant will support Dr. Arnolds' Critical Care Communication (C3): Teaching Intensivists' Communication Skills project. Dr. Arnold will examine ways to improve the ability of intensive care physicians-in-training (critical care fellows) to communicate effectively and empathetically about end-of-life topics. The aim of the project is to develop, pilot, and evaluate a comprehensive, evidence-based, ICU-specific training program in communication skills for critical care fellows, including a skills course and a portable curriculum.

Robert M. Arnold, M.D. is a Professor in the Division of General Internal Medicine, Department of Medicine at the University of Pittsburgh and in the University's Center for Bioethics and Health Law. He formed the Section of Palliative Care and Medical Ethics in 1997 and, in 2000, was named the first Leo H. Creip Chair of Patient Care, which emphasizes the importance of the doctor-patient relationship. He is the Director of the Institute for Doctor-Patient communication and Co-Director of the Institute to Enhance Palliative Care. He is clinically active in both HIV and palliative care.



Additional information about the National Palliative Care Research Center is available at <http://www.npcrc.org/>.