



Helping Hands

Welcome

It is the moment when death may be near which most rivets our attention. In a hospital, many of those moments take place in the Intensive Care Unit (ICU). For both physicians and patients, the ICU is the crucible, the place where the most critical decisions are made and where the consequences of those decisions are greatest. The ICU inevitably becomes a model for what modern medicine can achieve - the best is expected there. That is exactly why, for those of us who seek to extend the benefits of Palliative Care to all patients, no area of medicine is more important to address than Intensive Care.

Many of the critical decisions made in the ICU have to do with advanced science and technology: medications that are only used in the ICU, mechanical ventilators to sustain breathing, and a host of other equipment and interventions sometimes described as capable of "artificially prolonging life."

Patients are often incapable of communication or decision-making when in the ICU, and families and physicians must define the goals of care together. This difficult process includes understanding the emphasis each patient has placed on their quality of life and determining whether they would want the aggressive treatment that is the traditional purpose of the ICU. It also includes finding a way to skillfully address patient and family suffering and to provide comfort and dignity to patients and loved ones even when concurrently pursuing recovery and cure.

The articles in this issue of Helping Hands describe a new project of the Overlook Hospital Palliative Care Program, focused on the ICU. The project's developers and funders—and the directors and staff of the Overlook ICU—believe that the ICU offers an unparalleled challenge and opportunity for providing comfort, support and the relief of suffering for patients and families.

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Palliative Intensive Care

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Traditionally, palliative care has been provided only to the dying person, usually at a point very near death. But more recently it's been recognized that palliative care should be available to all seriously ill patients, started during the long periods of chronic illness that typically precede death, and be available even while curative efforts are still underway.

Palliative care is especially important on the intensive care unit (ICU) because all unit patients are seriously ill and suffering and it is difficult to predict who will live and who will die and when. Statistics indicate how important the ICU is and how ill ICU patients are. Over four million people are treated annually in ICU's. Among patients who die in the hospital, half are in the ICU within three days of death and a third spend over ten days in the unit during their final hospitalization. One in five Americans dies in an ICU and more deaths occur in the ICU than anywhere else in the hospital. Families of ICU patients are under great stress and require a high level of communication and support.

The ICU is traditionally a place where patients receive aggressive curative treatments, where advanced medical technology is used to save and sustain lives. But many of the seriously ill ICU patients will die despite the technology. Excellent care for the dying patient requires good knowledge of the patient and family and a high level of attention to their preferences and needs. This is the special expertise of palliative care professionals. But currently, both nationally as well as at Overlook, palliative approaches are not a sufficient part of ICU care.

We therefore developed a new Palliative Intensive Care Project with specific interventions designed for the Medical-Surgical and Neurologic ICUs. With support from Atlantic Hospice and the Overlook Foundation, project services will be provided to a target population

of seriously ill ICU patients over the next two years. Based on a study of 1217 ICU admissions during 2002, we expect the project to serve approximately 500 patients per year. A palliative care approach to the ICU patient includes vigorously managing pain and other symptoms, avoiding inappropriate prolongation of the dying process, helping patients and families achieve a sense of control, relieving family burdens as much as possible, addressing patient and family spiritual and emotional needs, and facilitating effective communication between the patient, family and ICU staff and specialists.

Services are delivered by an ICU Palliative Care Team (PCT), consisting of the physician directors of the ICU and of the Palliative Care Program, a Pain Management physician and nurse practitioner, two newly hired part-time nurses with training in critical care and palliative care, a social worker, a spiritual care provider, an ICU concierge, and the Ethics and Palliative Care Program Coordinator. Specific interventions include an assessment and family meeting within 48 hours of admission for all identified patients with a team nurse, information for the family on available options for palliative care, and the team's help in establishing effective ongoing communication between patient, family, staff and specialists about the patient's prognosis and the goals of care. Other measures include a "Person in the Patient" bulletin board in each patient room, inspirational posters, a 'quiet area' in the waiting room with sleeping recliners, a family consultation room, pagers for family members and a two-hour 'quiet time' for uninterrupted patient sleep.

A team member meets with the family every day and an ICU Family Journal is provided to the family of each project patient to encourage communication between visiting family mem-

bers and the team and other ICU staff. The family is encouraged to use the journal to write down their observations and questions; a team member then reviews the journal on a regular basis, with the family's permission. As the number of patients served by the project grows, weekly multi-family educational programs will be held. A new computer-based information kiosk is being installed in the ICU waiting room (see box). And, finally, if death occurs, the team provides post-ICU follow-up and bereavement services for the family.

Our goal is to demonstrate significant improvement in such palliative care outcomes as reduced pain and improved management of other symptoms, increased family satisfaction, better staff communication with patient and family, and a reduction in the delivery of inappropriate (unwanted and ineffective) aggressive care at the end of life for project patients. When an intensive palliative care program is provided in an ICU such as Overlook's, which already provides excellent traditional care; the combination should create a model approach to the needs of the seriously ill hospitalized patient and the family.

Palliative Intensive Care: Critical Care Information Center

A core goal of Palliative Intensive Care is to ensure that the families of critically ill patients have all the information they want and need. One modern means of meeting this goal is the Critical Care Information Center. The project has placed in the ICU Waiting Room a computer 'kiosk' — a freestanding computer and touch screen — through which families can obtain a wide range of important and relevant information and services.

The kiosk provides access to ICU-USA.com, the website of the Society of Critical Care Medicine. Designed for patients and families, the site provides detailed descriptions of all roles and functions of ICU physicians, nurses and other staff, as well as the medical equipment and methods commonly used. Overlook's customization of the site's services and the kiosk's display also provides access to information about services in Summit - especially important for families visiting from other areas - and to a full range of supportive services provided by the hospital's Coalition on Family Caregiving.

The kiosk is dedicated to the memory of Dorothea (Doe) Dunn, RN, CNS. Doe was a critical care nurse and educator at Overlook Hospital

for over 25 years. She played an important role in the development and functioning of Overlook's Bioethics Committee and the Palliative Care Program. She had a longstanding and special interest in support for families of the seriously ill and dying patient. Even after she retired in 1992, she continued to do ethics consultations and helped guide the development of programs which addressed family needs. The kiosk is supported by a memorial fund contributed in honor of Doe Dunn's life and work.

Creating a Community of Care

The Coalition on Family Caregiving is a group of community-based organizations and health care providers whose mission is to assist family caregivers by offering support, education and information on resources and services. Initially a project of the Overlook Hospital Palliative Care Program, started in 2004, the Coalition has already grown! With over 40 participating organizations, across 3 counties (Union, Morris and Essex), and covering the entire spectrum of supportive services needed by families of the seriously ill, the Coalition is definitely in a growth phase.

With support from Robert Wood Johnson's Rallying Points program and membership dues the Coalition uses its familiarity and sensitivity to the unique needs and concerns of family caregivers to advocate for family caregivers, to bring caregiver-relevant issues into public forums, and to provide free educational programs and information on topics of vital interest to caregivers and their families.

Most recently, with support from Senior Bridge of Montclair, the Coalition has produced a Family Caregiver Resource Guide, providing information about a wide range of caregiver services.

For membership, a copy of the Guide or more information, the Coalition on Family Caregiving can be contacted through its Website (www.familycaregivingcoalition.org) or by phone (908 522-5495).



A View from the Palliative Intensive Care Project Nurses

Kathleen Lynch, RN, BSN, CCRN and Tracey Appgar, RN, BSN, CNRN

Our major role in the Palliative Intensive Care Project has been to educate patients and families about the course of their illness and treatment options. We work closely with the ICU bedside nurses, physicians and other caregivers to increase communications among the health care team and ensure that the patient's and family's voices are heard. We also provide access to the full palliative care team, and identify and arrange provision of the multiple resources needed when serious illness affects both the patient and family.

We often spend extensive time on the phone with families from out of state to discuss the clinical status of the patient and to explain the burdens and benefits of the various treatment options. When the family arrives to meet with the physician, they are better prepared to help make necessary decisions and the ICU staff is better able to support and guide the family.

Critical care staff is understandably focused on expert provision of extremely complex medical regimens to fragile patients. Our position as palliative care nurses allows us the necessary time to fully explore the family's understanding of the clinical picture as well as previously expressed wishes of the patient. The combination of expert critical care and intensive palliative care helps reduce the suffering of seriously ill patients and their families at a time of great need. The work is extremely gratifying.

If you are interested in supporting the work of the Palliative Intensive Care project, a contribution can be made to: Palliative Care Program, Overlook Hospital Foundation, 36 Upper Overlook Rd., PO Box 220, Summit, NJ 07902-0220.



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