

# Helping Hands

## Welcome

This issue of Helping Hands is about hospice. While the concept of hospice dates back to the middle ages, the modern hospice and the palliative care movement which champions its use dates back only to the 1960's and to the work of one specific English physician, Cecily Saunders. She was the founder of the first modern hospice, St. Christopher's, in Sydenham, England, in 1967. Concepts we today take for granted in the care of the dying and seriously ill – attending to patient preferences and perspectives, including and supporting families in care, providing spiritual and psychosocial care concurrently with expert and proactive attention to pain and other distressing symptoms – arose first in her observations and ideas. She lived to see a world of medicine transformed as much by her work as by any new technologies. Her life and work are inspiration and role modeling of the first order, testimony to the impact of exemplars and the social movements they create. A social worker and nurse as well as a physician, she would be the first to point to the work that remains to be done. Adequate, effective hospice and palliative care for all would be the finest and most fitting tribute to the extraordinary life which ended this year, at the age of 87, on July 14, 2005.

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## Hospice at Home: The Role of the Physician Home Visit

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**"To be alone and in pain."**

These feelings are what many patients fear as they face a terminal illness. Patients who are seriously ill and likely to die are often too weak to leave their homes. Many feel abandoned and isolated, not only from the lives they once knew but also from their physicians whom many are unable to see. A primary care physician who makes home visits can bridge this gap and offer a source of support for dying patients and their families.

The physical presence of the physician in the home brings added expertise to the caregiving provided by the family, nurses and aides. By simply being there, the physician demonstrates a strong commitment to the patient and family and offers the reassurance that the medical community will continue with the patient through any adversity. The physician also has the opportunity to see the patient in his or her environment and can develop a more complete understanding of the patient's needs.

A home visit allows for more intimate and supportive conversations to take place. On a recent home visit to a patient who was dying from ovarian cancer, the patient, while bed-bound due to weakness and instability, was comfortable and responsive. After discussing her physical symptoms and the progression of her illness, the physician asked about her mood and the feelings surrounding her condition.

Something in the questions and subsequent conversation allowed the patient to express deep sadness and sorrow to the physician, and subsequently to her family. The patient and family valued these moments of openness, communication and caring. This kind of experience might not have taken place in a hospital environment.

Physicians who make regular home visits to dying persons are aware that much of the care provided and the goals accomplished are psychological and social in nature, in addition to more physically focused medical caregiving. These goals include assuring the patient that they will not be abandoned as death approaches, helping them anticipate and prepare for the dying process, and providing information and support for the family caregivers. This integrated approach to care is exemplified in the treatment of pain and other uncomfortable symptoms. Pain and suffering is addressed psychosocially and spiritually as well as pharmacologically and procedurally.

Despite the value, physician home visits are still very underutilized in care of the dying. One reason is that physicians are often inadequately trained in hospice and home-based care during medical school and residency. While training in end of life care has increased in recent years, there is still too little mentoring and experience and physicians remain uncomfortable.

Aside from lack of familiarity and training, the physician may feel that a patient succumbing to a terminal illness is a failure of medical science and professional competence. To avoid a sense of discomfort and loss, the physician may retreat from the dying patient as a person and concentrate on narrower aspects of medicine more comfortable to them. Many physicians fail to understand the tremendous value to patients of having a doctor who maintains close, personal contact through the end of life. Physicians also may not appreciate the personal and professional satisfaction of truly making a significant difference in the life of a patient and family.

Another significant reason many doctors do not make home visits is the lack of adequate reimbursement of the service by Medicare and other insurers. Without adequate reimbursement, traveling to a patient's home is a costly use of physician time and financial resources. However, most physicians have only a handful of patients unable to visit the office and a doctor's home visit at the end of the workday could make a significant difference in many lives. Even if regular home visiting is not possible, the patient's doctor can request a consultation from a local hospice physician who may have more availability to make home visits.

Even with hospice service and physician home visits, the family may not be able to maintain a dying person's care at home. Caring for a dying person usually requires that someone, usually a family member, be available day and night. This job often falls to an adult daughter, who

may have a family of her own to care for. Hiring extra caregivers is extremely costly and many families do not have the resources to do so. And the nature of some medical conditions may make home care impossible. Extreme pain, for example, sometimes can not be controlled, even with home-based hospice pain regimens and may require intensive hospital-based medical intervention. Extraordinary agitation or confusion in

dying persons may also require more supervision than family members can provide.

Fortunately, in these complicated situations, other alternatives exist. Atlantic Health System's new Inpatient Hospice in Morristown (see article, this issue) provides excellent care for hospice patients who are unable to be cared for at home. In other cases, a patient can be hospitalized at Overlook in a specially designed hospice

room. In these alternate settings, in addition to consults from experts in pain management and other specialists, it is ideal if the patient's primary care physician can continue following the patient.

Physicians caring for patients in their homes at the end of their lives, while not as common as it was a century ago, still has an important role to play in medical care today.

## Inpatient Hospice Care: New Support for Patients and Families

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and dementias, and multiple concurrent medical problems, including infections and organ failure. The inpatient hospice medical director provides palliative care consultations in the hospital, some of which result in a recommendation for inpatient hospice admission. The consultations also cover a wide range of issues,

A family – the adult children of a very seriously ill elderly woman – was taking care of their mother at home. The family was committed and capable, intending that, with help from home-visiting hospice staff, their mother would be able to die amidst familiar surroundings and people. But, as their mother's condition progressed, she became agitated and very combative whenever the family tried to provide her care. Despite their loving attention and efforts, they could not bring her any peace. She was, therefore, admitted to Atlantic's new inpatient hospice. There, palliative care expert physicians and nurses worked to find medications that would calm her while still allowing her enough clarity to recognize and appreciate her family's continuing presence. Inpatient hospice staff monitored her carefully, systematically identifying the discomforts and problems which increased her agitation and devising means to relieve her. With adjusted medications and family and staff providing comforting talk and gentle touches, it was possible to make a plan for the patient to return home. Staff worked with the family before discharge, teaching them how to evaluate her condition, address her agitation, appropriately administer the new medication regimen and use non-medication calming approaches. The patient died peacefully soon after.

Inpatient hospices are a vital link in the provision of hospice care. Addressing issues of acute pain and urgent symptom management, inpatient hospices offer short-term stays when issues arise that exceed a family's capacity or in which no family support is available. In some cases, the family may experience changes in a loved one so quickly – an intracranial bleed from a fall, or a stroke – that there is no time to plan for care at home. In some cases, concerns about small children at

home, or multiple conflicting needs and stresses, may make home-based care impossible to start or not sustainable if already begun. Family caregivers may themselves become ill and in need of care.

The new eight-bed unit, in Morristown, staffed every day around the clock by Atlantic Hospice registered nurses and home health aides, accepted its first patient in October 2005. The need for an inpatient hospice is evident in the number of calls coming in from Atlantic's three hospitals, from assisted living facilities and from families receiving home-based care. In addition to palliative care physician and nurse consultation, the inpatient hospice staff includes social workers for family counseling and support, a very active chaplaincy program to address the spiritual issues which commonly arise in serious illness and near the end of life, and the availability of hospice volunteers for an additional layer of support. Relationships with local faith communities and caregiver organizations are quickly developing.

Patients admitted to the inpatient hospice suffer from a wide range of conditions, including advanced cancer

including patients and families considering starting or withdrawing interventions such as dialysis and feeding tubes. Many consultations are called to provide patients and families with additional explanation and support in life-threatening medical situations, or address issues of decision-making capacity, advance care planning and related concerns. The consults often result in identifying social and spiritual issues and arranging for referrals and care, including to inpatient hospice when needed.

The Atlantic Hospice Inpatient Unit, built in a former mansion, provides hospice care in a warm and home-like environment. Visiting is encouraged at any time and there are facilities for family members to stay overnight at the patient's bedside. Patients and families can celebrate a special occasion or share a simple family dinner in the kitchenette/dining area of the unit's Family Room. The same room has a small children's play area for the youngest visitors as well as a "living room" area. Families served have been appreciative that they and their loved one were able to spend their last days in a safe and peaceful setting.

### New Volunteer Opportunity: Help Older Adults Remain Independent in Their Own Homes

Overlook Hospital's Palliative Care Program and Atlantic Home Care and Hospice, with major support from the Grotta Fund for Senior Care, have collaborated to develop a program to help keep older adults independent and in their own homes in the community. If you are at least 18 years old and have a fondness for older adults and some time to spare, Atlantic Home Care and Hospice will train you and support your volunteer efforts to provide services which allow older adults to continue living on their own. The services include companionship, phone contact, help with chores at home and with errands in the community. Making friends with an older adult will not only assist them but make you feel good as well! As one of our volunteers said, "Volunteering with older adults is teaching me how to live life fully."

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