

# **A History of Hospice Palliative Care**

## **International Hospice**

Although the hospice movement claims its origins in the 11th Century work of the Sovereign Order of St. John of Jerusalem during the Crusades, the modern hospice movement has its roots in nineteenth century France, Ireland and the USA. Some milestones include:

1843: a home for the dying was opened in Paris by L'Association des Dames du Calvaire leading to the foundation of six other establishments for the care of the dying between 1874, in Paris and 1899, in New York.

1879: the Irish Sisters of Charity opened Our Lady's Hospice for the Dying in Dublin followed by others in Australia, England and Scotland, all of which still exist today and are run by the Order as modern palliative-care units.

1900: the Dominican Sisters of Hawthorne established St Rose's Hospice in Lower Manhattan and then another in New York, followed by others in Philadelphia, Fall River, Atlanta, St Paul and Cleveland.

Although not connected with each other, the principals of these organizations shared a concern for the care of the dying, and in particular the dying poor. Although they were not places that offered sophisticated medical or nursing care, these early facilities created some of the pre-conditions for the development of modern hospices, which gathered momentum after the Second World War.

## **The Twentieth Century**

By the mid-twentieth century some important changes were occurring in western medicine and healthcare. Specialization was advancing rapidly; new treatments were proliferating; and there was an increasing emphasis on cure and rehabilitation. At the same time death in the hospital rather than at home was becoming the norm; and the dying patient or 'hopeless case' was often viewed as a failure of medical practice.

Concerns about improving care at the end of life began to surface more widely in the 1950s. In the UK, attention focused on the medical "neglect" of the dying; whereas in the United States a reaction to the medicalization of death began to take root. A new view of dying began to emerge which helped refine ideas about the dying process and explore the extent to which patients should and did know about their terminal condition. An active rather than a passive approach to the care of the dying was promoted. Within this, there emerged a determination to find new and imaginative ways to continue caring up to the end of life - and beyond it, in the care of the bereaved.

Dame Cicely Saunders founded St Christopher's Hospice, in South London, in 1967, and it quickly became a source of inspiration to others. As the first "modern" hospice, it sought to combine three key principles: excellent clinical care, education, and research. It therefore differed significantly from those homes for the dying which had preceded it and sought to establish itself as a centre of

excellence in a new field of care. Its success was phenomenal and it soon became the stimulus for an expansive phase of hospice development, not only in Britain, but also around the world.

From the outset, ideas developed at St Christopher's were applied differently in other settings. Within a decade it was accepted that the principles of hospice care could be practised in many settings: in specialist in-patient units, but also in home-care and day-care services. Hospital units and support teams were established that brought the new thinking about dying into the heartland of acute medicine.

The work of Elizabeth Kübler-Ross in challenging the medical profession to change its view of dying patients brought about great change and advanced many important concepts such as living wills, home health care, and helping patients to die with dignity and respect.

Her bestselling first book, *On Death and Dying*, 1969, made her an internationally renowned author. Even today, her trail-blazing book is required reading in most major medical, nursing, and psychology programs. A 1969 *Life Magazine* article outlining her work gave further mainstream credibility and awareness to this new way of dealing with dying patients, although her conclusions were quite revolutionary at the time.

The "five psychological stages of dying" (denial, anger, bargaining, depression and finally acceptance) outlined in her book became accepted as common knowledge throughout the world. "She was always very proud that her work helped to bring the hospice movement into the mainstream in the United States."

### **The Canadian Scene**

In Canada, hospice palliative care has developed to meet local needs largely as a result of the rapid expansion of cancer treatment programs in the 1970's whereby treatment was defined as either curative or palliative. The hospice palliative care movement began in 1974 with the creation of palliative care units in a hospital setting at Winnipeg's St. Boniface General Hospital and at the Royal Victoria Hospital in Montreal. Subsequently, hospice palliative care programs developed as divisions of larger organizations or agencies. Volunteer-based hospice societies and organizations began to develop soon after.

Just as it is difficult to think of the modern hospice movement without reference to Dame Cicely Saunders, so it is impossible to think of the Canadian hospice movement without mention of Dr. Balfour Mount. Dr. Mount, a physician who has survived two personal bouts with cancer, took his end-of-life care training with Dame Saunders in England before becoming the founding director of the Royal Victoria Hospital Palliative Care service in 1974. In fact, he created the use of the term "palliative care" in searching for an appropriate bilingual term after discovering that the word "hospice" in French was used to describe nursing homes in France. He was the Founding Director of the Palliative Care Division of the Department of Oncology at McGill and was later named to that university's Eric M. Flanders Chair in Palliative Medicine. He is the author of 130 publications and has participated in the production of 19 teaching films and audiotapes on Oncology and Palliative Care.

In the mid 1980's health care systems began using terms such as acute, chronic, geriatric, or palliative to define a category of patient. These new terms mandated specialized needs. Hospice palliative care became quickly and widely accepted as a societal movement reforming health care delivery to balance, what the Canadian Hospice Palliative Care Association refers to as, "high tech" acute care with "high touch" palliative care.

## **Future Development**

Within the professional lifetime of the founders of the modern hospice movement, a remarkable proliferation has occurred. At the same time, the definition of hospice and palliative care has come into sharper focus.

Recognition of the speciality of palliative medicine first occurred in the UK, in 1987, and was seen by some as a turning point in hospice history. It was part of a wider shift away from 'terminal' and 'hospice' care towards the concept of palliative care.

As hospice and palliative care continues to evolve, the hope remains that the benefits of a model of care previously available to just a few people at the end of life will, in time, be extended to all who need it - regardless of diagnosis, stage of disease, social situation or means.

In 2001 the Canadian Palliative Care Association changed its name to the Canadian Hospice Palliative Care Association concluding that "due to the fluidity of the English language, "hospice care" and "palliative care" are no longer recognized as separate entities. The term that is now widely accepted in Canada is "hospice palliative care".