



**Medical Education Training Centers**

**PALLIATIVE CARE AND END OF LIFE**

The goal of this program is to update and enhance nurses' knowledge about end-of-life care and Palliative care in patients and its application in any setting.

## **Objectives**

After you study the information presented here, you will be able to-

- Describe physical and psychosocial issues associated with dying patients
- Identify the Physical changes which may occur during the stages of death.
- Identify the role of Hospice in dealing with the dying patient.
- Identify the role of Palliative care in a dying patient.
- Identify the role of pain management
- Understand the different type of Pain
- Able to Perform the step to clinically assess the severity and quality of the pain.
- Understand the purpose of an Advance Healthcare Directive

Jennifer, a nurse, receives a late-night phone call that Aunt DiDi may not make it through the night. She hops in the car and drives 30 minutes to the local hospital where her favorite aunt was admitted. Her aunt has metastatic breast cancer. As Jennifer rushes to her bedside, Aunt DiDi is barely conscious, yet she opens her glassy eyes and looks at Jennifer as if to thank her for coming. Jennifer realizes that she- a nurse who can effectively communicate in just about any situation- is now at a loss for words.

Mark, a hospice patient, has just entered an inpatient nursing unit. Although he seems to be in his last moments, he's having a conversation with his deceased mother. The family and nursing staff are baffled that he could be speaking to someone that has been dead for 30 years. That evening, he says his good-byes to his family. When they say they will be back in the morning, he remarks, "I don't think so."

Diane is dying from an incurable glioblastoma, and her family has maintained a vigil at the bedside for the past three days. After their sleepless nights and many missed meals, the primary care nurse encourages the family to go down to the cafeteria to have something to eat. When they return, Diane is no longer breathing and has passed away. They are angry that they left the bedside and abandoned Diane during her last moments of life.

These scenes are common to the practice of just about any nurse. Caring for patients approaching the end of life continues to challenge the most skilled, educated, and talented practitioners. Nurses can help people who are dying deal with their special needs and concerns, such as fear of abandonment, losing control over body functions, and being overwhelmed with pain and distress.

Goals that guide care at the end of life include keeping patients comfortable by addressing physical, social, emotional, spiritual, and financial pain, while maintaining their dignity, identity, and self-respect. Goals also extend to preserving the quality of life and providing support and grief counseling to family members, friends, and caregivers. Nurses are well-positioned to achieve these goals for their patients. Some experienced practitioners even develop an uncanny ability to predict imminent death, sensing the end of life in a patient's face or body.

In 2005 cancer was responsible for a relatively small percentage of deaths worldwide (13%), while other long term conditions caused 47%.<sup>1</sup> By 2030 the annual number of deaths around the world is expected to rise from 58 million to 74 million, with conditions related to organ failure and physical and cognitive frailty responsible for most of this increase.<sup>2</sup> Yet despite these rapid demographic changes, palliative care services typically still cater only for people with cancer.<sup>3 4</sup> For example, hospices in economically developed countries currently provide 90% of their care to patients with cancer. Moreover, people dying from cancer usually have needs lasting for weeks or months, whereas those dying from organ failure or old age often have unmet needs that extend over many months or years. It is little wonder, then, that people dying of the "wrong" condition and their carers, whether family, social, or professional, are increasingly frustrated by

the major obstacles to accessing appropriate care.<sup>5</sup>

The drive to extend palliative care beyond cancer has so far been hampered by a combination of factors: prognostic uncertainty; funding difficulties (in the United Kingdom influential cancer charities support many hospices and outreach programmes); lack of palliative care clinicians with expertise in non-malignant diseases; and a hitherto relatively weak evidence base in relation to appropriate models of care. Although the empirical evidence base remains weak, we do now have a good theoretical understanding of when and how to intervene in a range of conditions. Prognostic uncertainty can and does hinder clinicians in thinking and planning ahead. Most patients with heart failure die when they are still expected to live for more than six months, and accurate prognostication is also virtually impossible in people with chronic obstructive pulmonary disease (COPD).<sup>6 7</sup> Although this uncertainty is frustrating for doctors, its very presence can be a basis for initiating end of life discussions.<sup>8</sup>

Recent work is helpful in identifying critical events and stages when a palliative approach may be introduced.<sup>9</sup> People with progressive chronic illnesses follow three characteristic trajectories ♦ : a cancer trajectory, with steady progression and usually a clear terminal phase; an organ failure trajectory, with gradual decline punctuated by episodes of acute deterioration and eventually a seemingly unexpected death; and a trajectory of prolonged gradual decline (typical of physical or cognitive frailty).<sup>10</sup>

Hospices provide excellent and accessible care to people with cancer but are not configured to address the needs of patients who don't have cancer. So what can we do? A typical critical juncture in an organ failure trajectory, such as hospitalisation for acute heart failure or an exacerbation of COPD, should trigger a holistic assessment and care plan for the next stage of the illness.

Facilitating a good death should be recognised as a core clinical proficiency, as basic as diagnosis and treatment. Death should be managed properly, integrating technical expertise with a humanistic and ethical orientation

This is an enormous challenge in politicised, market driven healthcare models but one that will make an important difference to those most in need.

Among the therapeutic modalities available to the oncology team today are two resources that often appear to be similar: palliative care and hospice. The distinction can be a difficult one, especially because definitions of each may vary by country and the medical institution in which they are practiced.

## **HOSPICE CARE**

Hospice is not a place but a type of care. Although the term *hospice* refers back to the 11th century, when a hospice was a refuge for terminally ill people during the time of the Crusades, the foundation of modern hospice care began in London in the middle of the 20th century. <sup>1</sup> Hospice traveled to the United States, where the philosophy and principles were introduced in the 1970s. The concept gained acceptance and Medicare began covering its costs in 1982. The National Hospice and Palliative Care Organization provides the following definition of hospice care:

The focus of hospice relies on the belief that each of us has the right to die pain free and with dignity, and that our loved ones will receive the necessary support to allow us to do so.

- Hospice focuses on caring, not curing and, in most cases, care is provided in the person's home.
- Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.
- Hospice services are available to patients of any age, religion, race, or illness.
- Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.<sup>2</sup>

Hospice is built around the key concept that the dying patient has physical, psychological, social, and spiritual aspects of suffering. Hospice is a philosophy, not a specific place.... The core structure of hospice includes an interdisciplinary team that ... provides access to a wide range of services to support the primary caregiver, who is responsible for the

majority of the patient care.

Since hospice in the United States is often provided to the patient in the home, the Medicare hospice benefit provides necessary equipment and personnel. In addition to professional staff, one of the foundations of hospice is the utilization of volunteers to provide comfort and support to the patient and family.

The American Board of Hospice and Palliative Medicine, sponsored and encouraged by the American Academy of Hospice and Palliative Medicine, was incorporated in May 1996 and held its first certifying examination later that year. The American Board of Medical Subspecialties (ABMS) recognized palliative care as a medical subspecialty in September 2006 with unprecedented support by 10 cosponsoring medical boards. The first board examination under ABMS was offered in 2008. The field has grown rapidly. According to the Center to Advance Palliative Care, “Ten years ago there were almost no palliative care programs in America’s hospitals. Today, 53% of hospitals with 50 or more beds have a program. In the last 5 years alone, access to palliative care in our nation’s hospitals has more than doubled.

Nurses are an integral part of any palliative care treatment. Since palliative care nursing is so complex, the specialty requires training in subjects such as social issues and psychology. In addition, palliative care nurses should have a thorough knowledge of medications used for pain, symptom control, and psychiatric conditions. The nurses work with the patient and bring information to the treating physician, but they also work quite independently.

The End-of-Life Nursing Education Consortium (ELNEC) is a nationwide education program to improve palliative care. ELNEC provides training to undergraduate and graduate nursing faculty; staff development educators; specialty nurses in pediatrics, oncology, critical care, and geriatrics; continuing education providers; and other nurses who then educate nursing students and practicing nurses on palliative care.

By utilizing physical, social, psychological, and spiritual interventions, both hospice and palliative care practitioners prove that much can be done to improve the quality of life of seriously ill patients, whether their illnesses are transitory or terminal.

The Goals that guide care at the end of life include keeping patients comfortable by addressing physical, social, emotional, spiritual, and financial pain, while maintaining their dignity, identity, and self-respect. Goals also extend to preserving the quality of life and providing support and grief counseling to family members, friends, and caregivers. Nurses are well-positioned to achieve these goals for their patients. Some experienced practitioners even develop an uncanny ability to predict imminent death, sensing the end of life in a patient's face or body.

### **Physical Changes of Dying**

No two deaths are alike. Nevertheless, as patients approach the end of life, they share common problems as physiological systems decline and their bodies begin to shut down. One of the biggest problems is physical pain and distress, which nurses can help control with the appropriate type of analgesia in sufficient quantity delivered via the right route. At the same time, nurses need to control adverse effects of nausea and vomiting, constipation, or diarrhea that often accompany the same therapeutic agents that bring relief. (The most up-to-date information is instantly available at websites, such as [www.pain.com](http://www.pain.com) or [www.NHPCO.org](http://www.NHPCO.org).)

Another problem patients face as they approach the end of life is a decline in their appetite and thirst. As an ingrained, ubiquitous social activity, this is also problematic for family and friends. Because eating is such an important activity of life, patients' inability or lack of will to eat often makes those around them uncomfortable. Nevertheless, patients should not be made feel guilty for not wanting to eat or drink. Instead, nutritionists who specialize in the dying can be consulted, and if patients are still unable to take nourishment, family members can help with comfort measures. For example, they can relieve dry mouth with good oral hygiene, humidified air, hard candies, and artificial saliva. Small ice chips, glycerin swabs, and petroleum jelly on the lips or a moist cloth for the forehead may also keep patients comfortable.

As people near death, other changes occur. The body temperature drops, and color of the skin may alter. Patients may not be as communicative as usual, and they may spend more time sleeping. However, nurses, family, and friends should continue to talk to them in normal, natural tones, because hearing is one of the last senses lost. Dying patients may hear what is being said.

Respiration alters at the end of life. The panicked or wild expressions of patients with dyspnea or air hunger can be upsetting to family and staff alike. Patients may have Cheyne-Stokes respiration, a breathing pattern punctuated by periods of apnea. They may have a death rattle-breathing that resembles snoring-the result of congestion, inadequate fluid intake, and poor expectoration.

## **Pain Management**

Most people die after a period of deterioration caused by one or more chronic progressive illnesses. The suffering that characterizes the period before death can be related, at least in part, to the experience of unrelieved symptoms.

Pain is among the most prevalent of these symptoms. When pain is unrelieved, it can be a source of great distress. This distress not only can affect the patient but also may extend to family caregivers, who may experience guilt, anger directed at medical personnel, or regret that persists long into the future. The care of patients with unrelieved pain also may adversely affect professional caregivers, potentially increasing the risk of burnout.

The proper management of pain at the end of life is imperative and the necessary analgesic interventions are well within the purview of primary care providers. All clinicians who care for the chronically ill should acquire basic skills in pain management.

### **PREVALENCE OF PAIN**

Pain is widely prevalent regardless of the setting in which patients are being managed. As an example, one estimate suggests that at least one-fifth of the million patients who die in hospitals each year experienced pain during the final admission [1]. Similarly, a survey of hospice patients in nursing homes found that about 50 percent had daily pain, which was moderate or worse in about 85 percent [2]. Similarly, in a survey of Americans with terminal illness living at home, 50 percent had moderate to severe pain

### **TYPES OF PAIN**

#### **Definitions**

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Pain is always subjective.

(International Association for the Study of Pain).

**Pain is what the patient says hurts.** It is what the patient describes and not what others think it ought to be.

### **Acute and chronic pain (persistent pain)**

#### **Acute pain**

is usually due to a definable acute injury or illness

it has a definite onset and its duration is limited and predictable

it is accompanied by anxiety and clinical signs of sympathetic over-activity

treatment is directed at the acute illness or injury causing pain, with or without the short term use of analgesics

#### **Chronic pain (Persistent pain)**

results from a chronic pathological process

it has a gradual or ill-defined onset, continues unabated and may become progressively more severe

is said to exist if the pain persists longer than the expected healing time for the injury or illness in question

the patient appears depressed and withdrawn

there may be no sympathetic over- activity and patients are frequently labeled as "not looking like somebody in pain"

requires treatment of the underlying disease where possible, regular use of analgesics to relieve pain and prevent recurrence, as well as psychosocial supportive care

#### **Incident pain**

occurs only in certain circumstances, such as after a particular movement or on standing should be regarded as chronic pain but, as it is intermittent, it is better managed with local measures where possible

#### **Breakthrough pain**

is a transitory exacerbation of pain that occurs on a background of otherwise stable and controlled pain

### **Nociceptive, neuropathic and psychogenic pain**

#### **Nociceptive pain**

nociceptive or physiological pain is produced by stimulation of specific sensory receptors or nociceptors in the tissues

the neural pathways involved are normal and intact

somatic pain from the skin and superficial structures is usually well localized

visceral pain is less well localised and there is often referred pain to cutaneous sites

### **Neuropathic pain**

is caused by peripheral or central nervous system injury

pain occurs because the injured nerves react abnormally to stimuli or discharge

spontaneously

neuropathic pain is described as

a burning stinging feeling (dysaesthesia)

a shooting pain like an electric shock (lancinating)

an aching sensation often relieved by firmly squeezing or gripping the affected area

is less responsive to non-opioid and opioid analgesics and may respond better to an adjuvant analgesics

### **Sympathetic pain**

is caused by damage to sympathetic nerves

is characterised by burning pain and increased sensitivity

there are signs of sympathetic dysfunction in the affected area

vasomotor instability (erythema, pallor, oedema)

sudomotor (sweating) abnormalities

trophic changes (thinning of the skin and atrophy of the subcutaneous tissue)

is less sensitive to non-opioid and opioid analgesics

often responds well to a regional sympathetic nerve block

### **Psychogenic pain**

is pain for which there is no physical basis in a patient who has other evidence of psychopathology

in palliative care, patients are occasionally seen with psychosocial or existential distress in whom psychological factors and not the medical condition are judged to play the major role in the onset and maintenance of the pain, and for whom primarily psychological therapies may be appropriate

however, all chronic physical pain is associated with some degree of psychological distress, for which the treatment should be primarily directed at the cause of the physical pain

# PAIN ASSESSMENT

## **Clinical Assessment**

### **Comprehensive clinical assessment is fundamental to successful treatment**

accept the patient's description

pain is always subjective and patients' pain is what they say it is and not what others think it ought to be thorough assessment of the pain patients should be asked to describe their pain, in their own words

this information is supplemented by specific questions to define the exact nature of the pain the site and radiation of the pain

the type of pain

the duration of the pain and whether it has changed

whether there are precipitating, aggravating or relieving factors

its impact on functional ability, mood and sleep

the effect of previous medications

what the pain means to the patient

physical examination, including neurological assessment, should be recorded both in writing and pictorially

further investigations should be limited to those likely to have a significant bearing on treatment decisions

assess each pain

many patients have more than one pain and each pain requires assessment

evaluate the extent of the patient's disease

the underlying disease is the most frequent cause of pain, new or worsening pain requires the extent of the patient's disease be re-evaluated

assess other factors that may influence the pain

physical, psychological, social, cultural, spiritual/existential  
reassess

repeated reviews are necessary to both assess the effect of treatment and because the underlying disease is usually progressive

## **Pain measurement**

**Pain is a subjective phenomenon and objective measurement does not always reflect the experience**

**Pain rating scales may be useful**

to follow the course of a patient's pain

to assess the effect of treatment

may be seen by the patient as indicating concern about their pain

Simple techniques should be used. Complex questionnaires may be too demanding for palliative care patients and should be reserved for research.

### **Visual Analogue Scale**

Mark on the line below how strong your pain is

No pain < \_\_\_\_\_ > Worst possible pain

### **Numerical Rating Scale**

On a scale of 0 to 10, how strong is your pain?

No pain = 0 1 2 3 4 5 6 7 8 9 10 = Worst possible pain

### **Verbal Descriptor Scale**

Which word best describes your pain?

None Mild Moderate Severe Excruciating

## **GENERAL PRINCIPLES OF TREATMENT**

### **Acute pain**

treatment of acute pain in palliative care is the same as for patients not requiring palliative care

palliative care patients may recover more slowly and require analgesics for longer periods if their general condition is poor

### **Incident pain**

occurs only in certain circumstances, such as after a particular movement or on standing where possible, it should be treated with local measures

analgesics may be used if the pain is mild and the side effects of constant administration tolerable

if the pain is severe, modification of the patient's activity may be preferable to taking strong opioid analgesics on a regular basis for pain that occurs infrequently

### **Chronic pain (Persistent pain)**

**the aim of treatment is the prompt relief of pain and prevention of its recurrence in order to prevent or minimise the subsequent development of centrally-maintained CNS pain**

**the principles involved in the treatment of chronic pain are**

- thorough assessment
- good communication reassurance about pain relief
- discourage acceptance of pain
- encourage patient participation

**the treatment of chronic pain in palliative care is**

an integrated part of the interdisciplinary plan of total care including management of psychosocial issues should be appropriate to the stage of the patient's disease treatment for an ambulant patient will differ from one confined to be employs the appropriate modality or modalities must be consistent, not variable avoid repeated changes of analgesics; titrate each drug to its optimal level requires continuity of care involves repeated reassessment

**the modalities of treatment available for chronic pain are**

- treatment of the underlying disease
- analgesics
- adjuvant analgesics
- neurostimulatory treatment
- anaesthetic, neurolytic and neurosurgical procedures
- physiotherapy
- psychological therapy
- lifestyle modification
- treatment of psychosocial issues that cause or aggravate pain

The Use of Pain Medication should varied according to the type of pain and the patients needs. Many time Pain is poorly managed and the patient unnecessarily suffers.

**What is an Advance Health Care Directive (AHCD)?**

An Advance Health Care Directive (AHCD) is a document that instructs others about your care should you be unable to make decisions on your own. It only becomes effective under the

circumstances delineated in the document. According to the Family Caregiver Alliance, an Advance Health Care Directive allows you to do either or both of the following:

1. **Appoint a health care agent.** The AHCD allows you to appoint a health care agent (also known as “Durable Power of Attorney for Health Care” or “attorney-in-fact”), who will have the legal authority to make health care decisions for you if you are no longer able to speak for yourself. This is typically a spouse, but can be another family member, close friend, or anyone else you feel will see that your wishes and expectations are met. The individual named will have authority to make decisions regarding artificial nutrition and hydration and any other measures that prolong life—or not.
2. **Prepare instructions for health care.** The AHCD allows you to make specific written instructions for your future health care in the event of any situation in which you can no longer speak for yourself.

The Advance Health Care Directive provides a clear statement of wishes about your choice to prolong your life or to withhold or withdraw treatment. You can also choose to request relief from pain even if doing so hastens death. A standard advance directive form provides room to state additional wishes and directions and allows you to leave instructions about organ donations.

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