“All Hospice is Palliative Care
but
all Palliative Care is not Hospice!”

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What does the topic mean to you?

“I get hospice,
but I don’t understand
this Palliative care thing!”

Hospice
Palliative Care
Clinical Situation 1

- 65 year old woman with new diagnosis of lung cancer
  Metastatic Disease
  Symptoms
  Recurrent disease after Course 1 of Chemo

Offered single agent second line chemo
  and hospice

Clinical Situation 2

- 88 year old woman on PACE program.
  – Frail, CCF, Diabetes, COPD

- Ongoing management:
  – Family ask about hospice referral.

Palliative Care

- What is it?

- "No one knows what it is!"

- "If it’s not curative, its palliative."
Hospice & Palliative Care

- Hospice:
  - Insurance Policy

- Hospice:
  - The Philosophy

- Hospice "The Philosophy"
  = Palliative Care

- Is palliative care new?

Early church and care of the Dying

Christianity: seven Acts of Mercy
  feeding the hungry, caring for the poor, etc

Fabiola, the 4th century Roman matron & disciple of St Jerome, who offered food, drink, shelter, clothing, and lodging to needy strangers just outside the gates of Rome (Source: Cecily Saunders)

Early Church and the Pallium

Pallium, L. Cloak
Wool garment worn by Catholic Bishops
Commenced in 5-6th Century

"We grant you the privilege of wearing the pallium...... whenever you celebrate the solemnities of the mass."

Bede, AD 731
A history of the English Church and People
Hospice & the Middle Ages: 1000-1200AD

Hospices
Attached to Monastaries and Convents
e.g., Hospice of St Bernard
established 1050
Resting place for travelers
Not homes for the dying.

Early Hospitals and the Terminally Ill

Hospitals established in London
Did not provide care for those with incurable cancers.
Bad for death rates.
Funding from benefactors dependent on mortality
Often cared for “lepers”

Visions of the Future: Thomas More

Thomas More wrote of care of the dying as he envisaged it.

“...and for those who are taken with fixed and incurable diseases, they use all possible ways to cherish them, and to make their lives as comfortable as possible. They visit them often, and take great pains to make their time pass off easily:”

*Utopia, 1516*
Hospice and St Vincent de Paul: 1620

Vincent de Paul cared for French Galley Convicts/Slaves. Chained in dungeons before departure or when ill.

"Their moral state was worse than their physical misery."

Established a Hospice: Home for galley slaves
Not to care for those who were dying.

Appointed Royal Almoner of the Galleys
by Louis XIII

Let us turn our attention to Palliative Care in the last 150 years.

The First Home for the Dying: Lyon 1842

1842: Jeanne Garnier, a widow
Founder of the Women of Calvary

"I started my hospice with 50 Francs; ......... providence did the rest."

A house for patients at the end of the lifetime.
An image, too often unhoped for, which bring comfort, a start of happiness in the medium of the suffering.
A house where one speaks again of the life, even if is also there to die.

1875: Paris
1899: Calvary Hospice, New York
### The First Irish Hospice

<table>
<thead>
<tr>
<th>Year</th>
<th>Hospital/Order</th>
<th>Location</th>
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<tbody>
<tr>
<td>1845</td>
<td>Founded Irish Sisters of Charity</td>
<td>Ireland's first unceloistered religious order</td>
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<tr>
<td>1845</td>
<td>Cared for the poor and dying</td>
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<tr>
<td>1879</td>
<td>Our Lady's Hospice, Dublin</td>
<td>Converted the old Noviciate house into a home suitable for the reception of 27 dying patients.</td>
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<tr>
<td>1890</td>
<td>Sacred Heart, Sydney</td>
<td></td>
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<tr>
<td>1905</td>
<td>St Joseph's, London</td>
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### The First English Hospice? St Patrick's

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<thead>
<tr>
<th>Year</th>
<th>Hospital</th>
<th>Location</th>
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<tbody>
<tr>
<td>1870</td>
<td>St Patrick's Hospital for Incurables, Cork</td>
<td>Cork, Ireland</td>
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<tr>
<td>1870</td>
<td>Bequest from Dr Patrick Murphy, a former Cork physician.</td>
<td></td>
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<tr>
<td>1913</td>
<td>Bequest to the Sisters of Charity on the condition that they care for those with painful and incurable diseases, especially work among the poor.</td>
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### The First English Hospice? Mary Potter

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<tr>
<th>Year</th>
<th>Hospital</th>
<th>Location</th>
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<tr>
<td>1847-1913</td>
<td>Mother Mary Potter:</td>
<td>Ireland</td>
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<tr>
<td>1877</td>
<td>The Little Company of Mary</td>
<td>Chicago</td>
</tr>
<tr>
<td>1893</td>
<td>Hyson Green, Nottingham</td>
<td>Nottingham, UK</td>
</tr>
<tr>
<td>1900</td>
<td>Adelaide, Australia</td>
<td>Adelaide, Australia</td>
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*“Do what good we can to those around us. There are still so many we cannot reach except in prayer. Let us then pray for the dying today, there for whom tomorrow will be too late.”* - Mother Mary Potter, Little Company of Mary Sisters
**The First English Hospice? Mary Potter**

The Sisters in Rome … caring for the terminally ill wife of a Chicago businessman. ….. he offered to sponsor any Sisters that Mary Potter could send to the U.S.

So, in 1893, three Little Company of Mary Sisters arrived in Chicago to begin their U.S. ministry.

Little Company of Mary has demonstrated excellence in health care throughout its history by performing the … offering one of the first hospice care services to the metropolitan Chicago community in the 1970s, …..

**The First English Hospice? Friendenheim**

Founder in Mildmay Park in 1885.
Frances Davidson, Scottish lady

The Home was established for "those whose hopeless condition does not justify their admission to, or retention in, ordinary hospitals, for those with no homes or having them, are not in a condition, and have not the means, to be nursed there, through the last stages of mortal illness," but was primarily intended for dying consumptive patients, for whom little provision was made in London.

**The First English Hospice? Hostel of God**

Appeal in The Times on Christmas Day 1891 by Colonel William Hoare and Clara Maria Hole, Superior of the Order of St James Servants of the Poor, an Anglican sisterhood

The idea of a home for the dying originated with Mrs Hoare who, never in strong health herself, had sympathized greatly with those whose health and strength were failing and who did not have the means to obtain the necessary comfort and alleviation.
The First English Hospice? St Luke’s

1859: Dr Howard Barrett in London’s East End exposed to the plight of large numbers of the ‘respectable’ and ‘self-respecting’ poor, who had no choice but to suffer in conditions of extreme misery and degradation.

1886: Foundation of the West London Mission, a Methodist led social & evangelical organisation.


The 2nd Stage: Cecily Saunders

Nurse
Social Worker
Physician

Documented use of regular morphine at St Luke’s & St Joseph’s
Dame Cicely met a Polish Jew in St. Thomas' Hospital
David Tasma, who had fled Warsaw before the Nazi invasion was dying of cancer at age 40 without family --
He was Dame Cicely's inspiration for seeking ways to help the terminally ill find comfort in their situation and relief from the agony of pain.

His bequest was foundation of St Christopher’s

Birth of the Modern Hospice Movement
Hospice for Research and Education

Balfour Mount MD
Uro-oncologist: visited St Christopher’s
1975: Palliative Care Service
Royal Victoria Hospital, Montreal

“Hospice” in French means “poor house”

“Although these are the sickest people in our health care system, when medical technology doesn’t know what to do, the quality and quantity of care falls away. How can we justify that?”
Death and Dying in the US

Interest in death and dying in the US was roused by Elizabeth Kubler-Ross’s book, *Death and Dying*.

Defined the stages of grief a person experienced as they approached the end of life:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

Florence Wald, Yale Dean of Nursing, invited Cecily Saunders to Yale, 1968.


1972: Hospice of Connecticut
      Hospice of Marin County (West Coast)

From the two initial modern hospices on either side of the country there are now over 3000 hospices in the USA.

Hospice in the US: Medicare

1970s: Early modern hospices: reaction to lack of medical interest in care of the dying.

1980: some 1000 US hospices
      care without reimbursement
      not covered by health insurance including Medicare.

      Congressman Leon Panetta and Senator Dole.
      Hospices could charge Medicare
      care provided to patients greater than 65
      provided required regulations were met.
Palliative Care

- Palliative Care
  - affirms life and regards dying as a normal process
  - neither hastens nor postpones death
  - provides relief for pain and other distressing symptoms
  - integrates psychological & spiritual aspects of patient care
  - offers a support system to help the family cope during the patient's illness and in their own bereavement

Palliative Care

- "Palliative Care
  - active total care of patients whose disease is not responsive to curative treatment.
  - Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount.
  - The goal of palliative care is achievement of the best possible quality of life for patients and their families.
  - Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment."

World Health Organization.

Palliative Medicine

- "the study and management of patients with active, far advanced disease for whom the prognosis is limited and the focus of care is quality of life."

The Royal College of Physicians, 1987

FACHPM
Fellow of the Australasian Chapter of Palliative Medicine
ASCO believes that provision of palliative care requires access to and availability of state-of-the-art palliative care rendered by skilled clinicians, buttressed when necessary by palliative care experts.

ASCO believes that hospice is a widely available and excellent model for managing end-of-life care and should be better utilized.

Hospice - State of Wisconsin

- Hospice
  - an organization
  - a program within an organization
  - a place

- that primarily provides palliative care and supportive care to an individual with terminal illness

No person may conduct, maintain operate or otherwise participate in conducting, maintaining or operating a hospice unless the hospice is licensed by the department.

Terminal Illness

- Wisconsin
  - Medical Prognosis that an individual's life expectancy < 12 months

- Illinois
  - Medical prognosis that an individual's life expectancy < 6 months

- Medicare
  - Medical prognosis that an individual's life expectancy < 6 months
Hospice Core Services

• Nursing
• Medical Social Services
  – under the direction of the physician
• Physician Services
• Counseling Services
  – Bereavement
  – Dietary
  – Spiritual
  – Additional

Supportive Care

• Services provided
  – during the final stages of an individual's terminal illness and dying and after the death
  – to meet the
    » psychosocial,
    » social
    » spiritual
  needs of family members of the terminally ill individual and other individuals caring for the terminally ill individual.

Hospice & Advanced Directives

• Provide
  – to the patient
    » written information about state rights
    » Hospice's policies & procedures related to state rights
  – education of staff
• Document
  – advanced directives
• Not condition provision of care based on individual execution of advanced directives
Elderly and CPR

- TV Success rate: 60-70%
- Metastatic Cancer Patients: 0%
- Elderly are influenced by data

Election Statement

- Identification of the hospice
- Acknowledgement of full understanding of palliative rather than curative nature of hospice care.
- Waiver of certain Medicare Services
- Effective date of election
- Individual’s signature

Cancer Prevention: Four Stages

- Prevention of disease
  » true prevention
- Prevention of advanced disease
  » screening
- Prevention of death
  » anticancer therapies
- Prevention of suffering
  » Palliative care

McDonald, 1990
Intentions of Treatment

Palliative vs Curative

What is the big picture?

Survival Curve: Disease
Survival Curve: Cure

Curable Malignancies

Most Early Stage Disease

Some Advanced Stage Disease
- Leukemia
- Lymphoma
- Testicular Cancer

Survival Curve: Prolongation of Survival
Prolongation of Survival

Many Advanced Stage Malignancies

Prostate
Lung
Breast
Colorectal

Survival Curve: Palliation

Palliative Treatment

Many Patients with Metastatic Disease

Patients with Early/Advanced Disease and Confounding Medical Problems
Hospice/Palliative Care
Patient Centered Care

Nurses
Medical Director
Attending Physician
Social Worker
Pharmacist
Bereavement Counselor
Family
Friends
Chaplain

Volunteers
Principles of Cancer Care:

- is centered around long standing relationship between patient, oncologist & other physician with training & interest in end of life care

- is responsive to the wishes of the patient

- is based on truthful, sensitive, empathetic communication

- Optimizes quality of life through meticulous attention to the myriad physical, spiritual and psychosocial needs of patient and family

Clinical Barriers

- Inappropriate attitudes of doctors & patients

- Ineffective communication about prognosis

- Unrealistic expectations & treatment options

- Physician failure to recognize & emphasize the importance of symptom management & psychosocial support of the dying
Economic Barriers

• Lack of universal access to care

• Severe under-funding of end of life care

Educational Barriers

• Neglected educational area

• Providing optimal end of life care requires acceptance that cure is not always possible

• ASCO believes:
  – That optimizing clinical skills of physicians in delivering end of life care is essential.
  – Students, residents, oncology trainees and oncologists

Improving Palliative Care for Cancer, 2001

http://www.nap.edu/books/0309074029/html/
Palliative Care

- Comprehensive multidisciplinary management of patients' physical, psychological, social, spiritual, and existential needs.
- Part of the treatment of any person with a serious or life-threatening medical condition for which a patient-centered approach, pain and symptom control, family involvement and compassionate care are needed.
- Palliative care is synonymous with good medical/nursing care, involving all members of health care team.

National Cancer Policy Board & Institute of Medicine

- Comprehensive Cancer Centers: palliative care.
- 6 major skill sets that comprise palliative care,
  - Communication
  - Advanced Care Planning
  - Treatment of Complications of Therapy
  - Symptom Control
  - Psychosocial issues including bereavement
  - Care of the Dying

Continuing Evolution
Palliative Care now

Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

The Bottom Line

Treat our patients as we would want ourselves or our families to be treated!
Truth Telling

“If you tell the truth, you don’t have to remember what you said.”

Hope

• 1. Trust, Reliance

• 2a. Desire accompanied by expectation of or belief in fulfillment

• 2b. Someone or something on which hopes are centered

• 2c. Something hoped for.
Hope

• 1. Trust, Reliance
  – Faith and dependence
  – Independent of outcome
  – “hopeful” person trusts that whatever the outcome, good or bad on first glance, will ultimately be for the best
  – Religious faith
  – Secular: faith in community

Hope as an expectation?

• 2a. Desire accompanied by expectation of or belief in fulfillment

• 2b. Someone or something on which hopes are centered

• 2c. Something hoped for.

Hope does not lie in a way out, but in a way through.

Robert Frost
Marginalization of US Hospice: Joe Finns

Palliative care thrived in the UK: the palliative care movement remained marginalized in America.

WHO plea for "the active total care of patients whose disease is not responsive to curative treatment:" discordant in era obsessed by either promise or the peril of medical technology.

Employing technology in the service of pain and symptom management was difficult to realize in the medical mainstream.

Hospice: set of services delivered outside of the hospital setting and within local communities.

Hospice was a reaction to the prevailing technology-driven medical culture.