

**“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

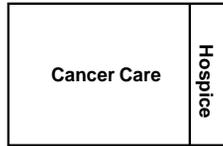
- 88 year old woman on PACE program.
 - Frail, CCF, Diabetes, COPD
- Ongoing management:
 - Family ask about hospice referral.

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

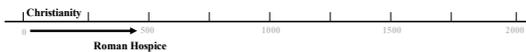
- Is palliative care new?

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

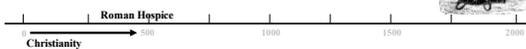
Pallium, *L. Cloak*
Wool garment worn by Catholic Bishops
Commenced in 5-6th Century



*"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 Monasteries
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.

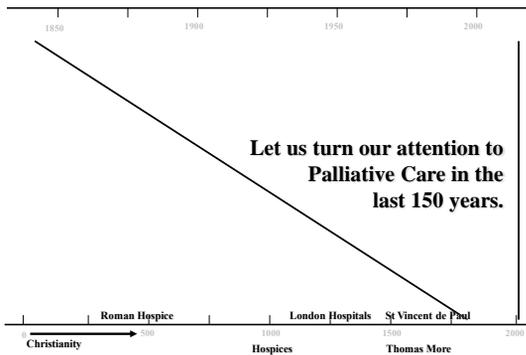


“Their moral state was worse than their physical misery.”

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



Appointed Royal Almoner of the Galleys
by Louis XIII



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.”

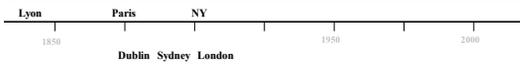


*A house for patients at the end of the lifetime
An image, too often unhoped-for, which bring comfort,
a start of happiness in the medium of the suffering.
A house where one speaks again of the life,
even if is also there to die.*

1875: Paris

1899: Calvary Hospice, New York

The First Irish Hospice



Sr. Mary Aikenhead

1845: Founded Irish Sisters of Charity
Ireland's first uncloistered religious order
Cared for the poor and dying

1879: Our Lady's Hospice, Dublin
Converted the old Noviciate house into a home
suitable for the reception of 27 dying patients.

1890: Sacred Heart, Sydney

1905: St Joseph's, London

The First English Hospice? St Patrick's



St Patrick's Hospital for Incurables, Cork - 1870

Bequest from Dr Patrick Murphy, a former Cork physician.

Bequest to the Sisters of Charity on the condition that they care for those with painful and incurable diseases, especially work among the poor.

The First English Hospice? Mary Potter



Mother Mary Potter: 1847-1913

Rheumatic fever
Bilateral Breast Cancers.

1877: The Little Company of Mary
Hyson Green, Nottingham.

1893: Chicago

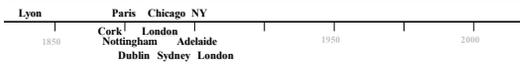
1900: Adelaide, Australia



*"Do what good we can
to those around us... There are still
so many we cannot reach
except by prayer; Let us then pray
for the dying today, those for whom
tomorrow will be too late."*

-Venerable Mary Potter
Founder, Little Company of Mary Sisters

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

1893 St Luke's Home for the Dying Poor: Regent's Park: 15 beds,



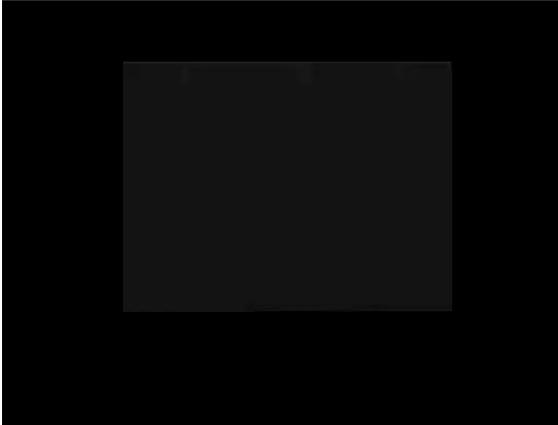
The 2nd Stage: Cecily Saunders



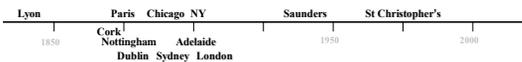
**Nurse
Social Worker
Physician**

**Documented use of
regular morphine at
St Luke's & St Joseph's**





St Christopher's



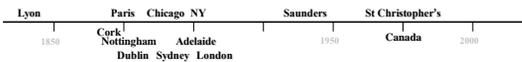
Dame Cicely met a Polish Jew in St. Thomas' Hospital David Tasma, who had fled Warsaw before the Nazi invasion was dying of cancer at age 40 without family – He was Dame Cicely's inspiration for seeking ways to help the terminally ill find comfort in their situation and relief from the agony of pain.



His bequest was foundation of St Christopher's

Birth of the Modern Hospice Movement
Hospice for Research and Education

Canada: The birth of Palliative Care



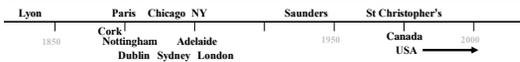
Balfour Mount MD
Uro-oncologist: visited St Christopher's
1975: Palliative Care Service
Royal Victoria Hospital, Montreal



"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



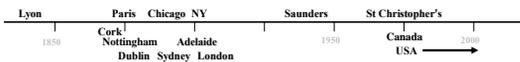
Interest in death and dying in the US was roused by Elizabeth Kubler-Ross's book, *Death and Dying*



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

- Stages of Grief**
- Denial
 - Anger
 - Bargaining
 - Depression
 - Acceptance

Death and Dying in the US



Florence Wald, Yale Dean of Nursing, Invited Cecily Saunders to Yale, 1968



1970: Home visits

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.

1983: Hospice Medicare Benefit. 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 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 hopsice 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

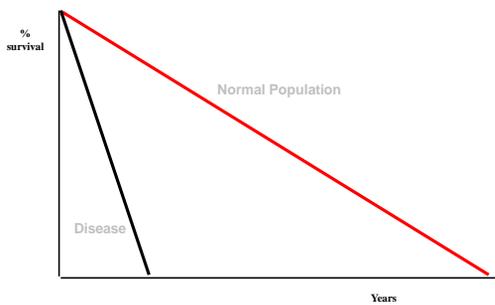
McDonald, 1990

Intentions of Treatment

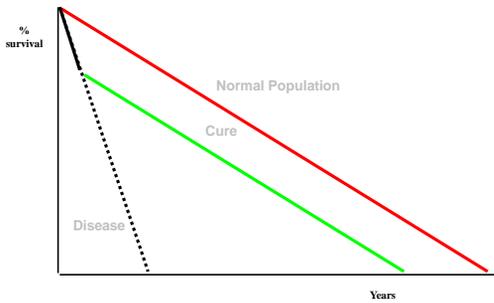
Palliative
vs
Curative

What is the big picture?

Survival Curve: Disease



Survival Curve: Cure



Curable Malignancies

Most Early Stage Disease

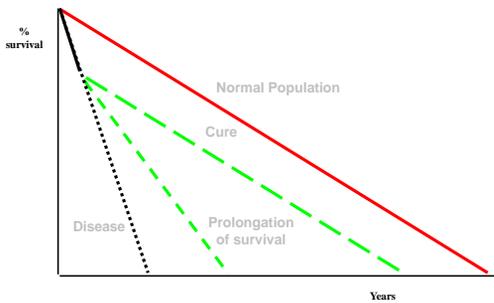
Some Advanced Stage Disease

Leukemia

Lymphoma

Testicular Cancer

Survival Curve: Prolongation of Survival

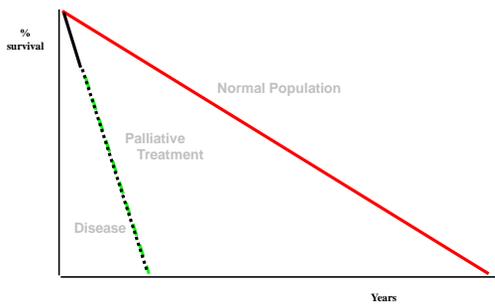


Prolongation of Survival

Many Advanced Stage Malignancies

- Prostate
- Lung
- Breast
- Colorectal

Survival Curve: Palliation

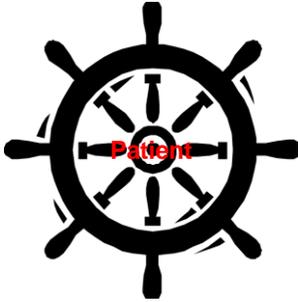


Palliative Treatment

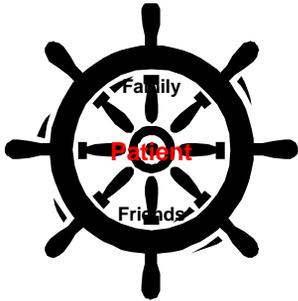
Many Patients with Metastatic Disease

Patients with Early/Advanced Disease and
Confounding Medical Problems

Hospice/Palliative Care
Patient Centered Care



Hospice/Palliative Care
Patient Centered Care



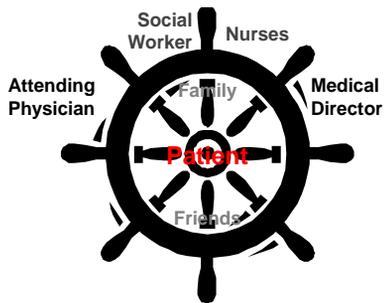
Hospice/Palliative Care
Patient Centered Care



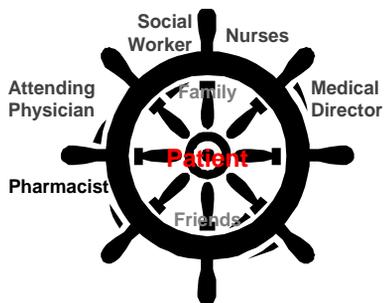
Hospice/Palliative Care
Patient Centered Care



Hospice/Palliative Care
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Hospice/Palliative Care

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Hospice/Palliative Care

Patient Centered Care

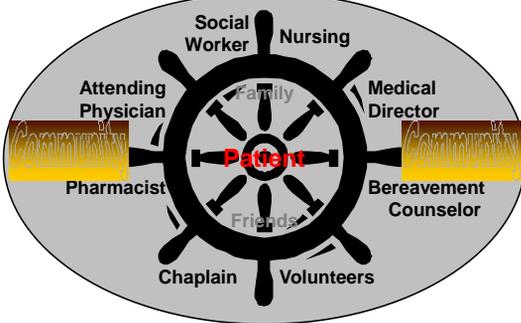


Hospice/Palliative Care

Patient Centered Care



Hospice/Palliative Care
Patient Centered Care



ASCO: Cancer Care during the Last Phase of Life
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

ASCO: Cancer Care during the Last Phase of Life
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**

ASCO: Cancer Care during the Last Phase of Life
Economic Barriers

- **Lack of universal access to care**
- **Severe under-funding of end of life care**

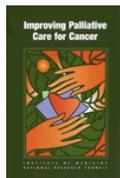
ASCO: Cancer Care during the Last Phase of Life
Educational Barriers

- **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

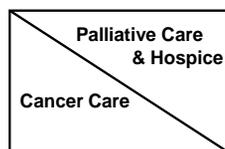
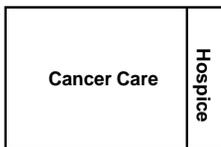
- Comprehensive multidisciplinary management of patients' physical, psychological, social, spiritual, and existential needs.
- Part of the treatment of any person with a serious or life-threatening medical condition for which a patient-centered approach, pain and symptom control, family involvement and 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





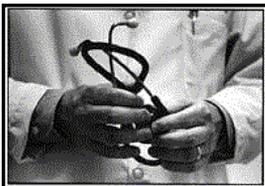
Palliative Care now



CAPC

- 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!**



University of Wisconsin
Comprehensive Cancer Center

Research. Education. Treatment. Hope.



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



University of Wisconsin
Comprehensive Cancer Center

Research. Education. Treatment. Hope.

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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.
