Back to the Future: Palliative Care in the 21st Century
“I didn’t set out to change the world, I set out to do something about pain. It wasn’t long before I realized that pain wasn’t only physical, but it was psychological and spiritual”

-Dame Cicely Saunders
Dame Cicely Saunders: Founder of Hospice - 1967

- The name was first applied to specialized care for dying patients which began in England during the 1960’s
- Saunders began her work with the terminally ill in 1948 and created the first modern hospice—St. Christopher’s Hospice—in a residential suburb of London
- Saunders introduced the idea of specialized care for the dying to the US during a 1963 visit with Yale University
Dame Cicely Saunders: Founder of Hospice - 1967

- Her lecture, given to medical students, nurses, social workers, and chaplains about the concept of holistic hospice care, included photos of terminally ill cancer patients and their families, showing the dramatic differences before and after the symptom control care.

- This lecture launched the following chain of events, which resulted in the development of hospice care as we know it today.
History of Hospice

- **1963** – Dr. Saunders introduced the idea of specialized care for the dying to the United States.

- **1965** – Florence Wald, then Dean of the Yale School of Nursing, invites Saunders to become a visiting faculty member of the school.

- **1967** – The first modern hospice, St. Christopher’s was founded in England.

- **1969** – Elizabeth Kubler-Ross, wrote “On Death and Dying” and gave impetus to the movement in the U.S.


- **1983** – Medicare began offering a hospice benefit.

- **1986** – Hospice benefit offered to terminally ill patients in Nursing Homes.
Hospice Philosophy

- Hospice focuses on caring, not curing
- Hospice neither hastens nor postpones death
- Patient and family are the unit of care
- Care is holistic
- Hospice affirms life
End of Life Care in the Past

- Prior to antibiotics, people died quickly from infectious disease or accidents.
- Medical care was focused on caring, and comfort.
- The sick were cared for at the home with cultural variations and preferences.
- People saw death as a normal part of life—a transition from this life to the next.
Medicine’s Shift in Focus

- With improved sanitation, public health, antibiotics and other new therapies, life expectancy greatly increased
- In 2012, the average American lived 78.8 years
- With modern medicine and health care, only some illnesses can be completely cured
- Because of modern advances in technology and medicine, individuals can live much longer and more comfortably with chronic illness
<table>
<thead>
<tr>
<th></th>
<th>1900</th>
<th>2012</th>
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<tbody>
<tr>
<td><strong>AGE AT DEATH</strong></td>
<td>- 46 Years</td>
<td>- 78.8 Years</td>
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<tr>
<td><strong>CAUSES</strong></td>
<td>- Infection</td>
<td>- Cancer</td>
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<tr>
<td></td>
<td>- Accident</td>
<td>- Heart Disease</td>
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<tr>
<td></td>
<td>- Childbirth</td>
<td>- Chronic Lower</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Respiratory Disease</td>
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<tr>
<td></td>
<td></td>
<td>- Stroke</td>
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<tr>
<td><strong>DISABILITY</strong></td>
<td>- Not much</td>
<td>- Median &gt;4 years before death</td>
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<tr>
<td><strong>FINANCING</strong></td>
<td>- Private, modest</td>
<td>- Public and substantial</td>
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<tr>
<td></td>
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<td>- 84.1% in Medicare</td>
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<td>- (2012) 1,971,260= Total Medicare</td>
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<td></td>
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<td>Beneficiaries in OH</td>
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<td>- (2012) 49,435,610= Total US Medicare</td>
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<td>Beneficiaries</td>
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<td>~1,151,358 Total Persons Served with</td>
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<td></td>
<td></td>
<td>Hospice Services</td>
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<tr>
<td></td>
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<td>- 5.2% Medicaid</td>
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Short-Term Predictions are Difficult

- Physicians tend to **underestimate** (by months) survival for heart and lung disease.

- We tend to **overestimate** (by weeks to months) for cancer.

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**Trajectory for Dying of Lung Cancer or CHF**

![Graph showing the trajectory of dying for Lung Cancer and Congestive Heart Failure.](image-url)
Inflated Expectations?

Statistics on survival following successful resuscitation after cardiac arrest:

- 85% according to the lay public
- 67% on television
- 30% overall
- 0-5% in the elderly, debilitated, chronically ill
Shift in Focus...

- Shift in location of dying had an impact on the nature of dying
- Increased focus on science, technology, and curative treatment
- Marked shift in values
  - Our society became “death denying”
  - Increased value on productivity, youth, and independence
- Fragmentation of care
- Minimal psychosocial and spiritual support for patients
Perverse Incentives: How we finance health care

- We like things that are **NEW**
  - A 2% increase in survival with a 2000% increase in cost is all that’s needed for a new treatment to become the “standard of care”

- We like **PROCEDURES**
  - Much, much easier to get a hip replacement or bypass then to get someone to help Mrs. Brown with a bath
The Tradeoff...

- No money left for basic care
  - Home care
  - Aides
  - Simple medicines to provide comfort
  - Simple equipment in the home

- Our medical-industrial complex is much more in love with high tech solutions and not necessarily what is best for the patient
Poor Communication about Death & Dying

- We do not share our fear and desires with our loved ones or our doctors
- We have no real agenda for discussion
- Advance directives are inadequate in Ohio
Consequences of Denial & Poor Communication

- Lost opportunities:
  - Goodbyes
  - Reconciliation
  - Affairs not in order
  - Spiritual reconciliation
- Inappropriate care
- Spiritual concerns are not addressed
Current: Cure vs. Care Model

- Aggressive Medical Care
- Hospice
- Death

Treatment

Time
Proposed: Integrated Model

- Curative Care
- Palliative Care
- Hospice
- Bereavement

Time

Death
“End-stage chronically ill patients do NOT need intensive care...”
“...they need intensive caring”
So, What is Hospice?

- Hospice care is a type of palliative medicine. It is a *concept of care, not a place*
- A system of care for terminally ill patients who meet Medicare’s criteria of a six-month or less (approximate) prognosis.
- Care is holistic and is delivered by an interdisciplinary team that are available 24 hours a day.
So, What is Hospice?

- Provides compassion and support to patients and their loved ones both during the illness and following the death.
- Do not prolong suffering or hasten the end of life.
- Focuses on living life to its fullest in the patient’s final days.
What is Palliative Care?

- Palliative medicine focuses on care, NOT cure
- Beneficial for any patient at any stage of an advanced illness and can be provided simultaneously with other treatments.
- Provides relief from pain and other symptoms.
- Uses a team approach which integrates the psychological and spiritual aspects of patient care with medical treatment.
What is Palliative Care?

- Palliative care is available for any patient who needs and desires it at any course in their illness.
- Offers a support system to help patients live as actively as possible for as long as possible.
- Enhances the quality of life for both patients and their families.
# Palliative Care VS. Hospice

<table>
<thead>
<tr>
<th>PALLIATIVE CARE</th>
<th>HOSPICE</th>
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<tbody>
<tr>
<td><strong>PLACE</strong></td>
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<tr>
<td>- Hospital</td>
<td>- Home</td>
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<tr>
<td>- Extended Care Facility (ECF)</td>
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<tr>
<td>- Home</td>
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<tr>
<td><strong>TIMING</strong></td>
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<tr>
<td>- No time restrictions</td>
<td>- Within 6 months of death</td>
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<tr>
<td><strong>PAYMENT</strong></td>
<td></td>
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<tr>
<td>- Regular medical insurance</td>
<td>- Medicare Hospice Benefit 100% Covered</td>
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<tr>
<td>- Specialist visit</td>
<td>- Private Insurance varies</td>
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<tr>
<td><strong>TREATMENT</strong></td>
<td></td>
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<tr>
<td>- Comfort-oriented</td>
<td>- Comfort-oriented</td>
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<tr>
<td>- Curative treatment allowed</td>
<td>- Curative treatment NOT allowed</td>
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In simpler terms, remember...

All Hospice is Palliative Care

But...

Not all Palliative Care is Hospice
Did you Know...

- In 2011, an estimated 1.65 million patients received services from Hospice.
- In 2011, the National Hospice and Palliative Care Organization estimated that approximately 44.6% of all deaths in the US were under the care of a hospice program.
- Mean survival was 29 days longer for hospice patients than non-hospice patients.
Did You Know...

- 90% of Americans wish to die in the comfort of their own home.
- In 2011, 66.4% of patients died in their home:
  - 18.3% in Nursing Homes
  - 26.1% in Hospice Inpatient Facilities
  - 7.4% in Acute Care Hospitals
- More than half of hospice patients are female:
  - 56.4% of Female Patients in 2011
  - 43.6% of Male Patients in 2011
- In 2011, 83.3% of Hospice patients were 65 years of age or older:
  - More than 1/3 of all hospice patients were 85 years of age or older.
Did You Know...

- When Hospice care in the U.S. was established in the 1970’s, cancer patients made up the majority of hospice patients.

- Today, cancer diagnoses account for less than ½ of all hospice patients, 37.7%.

- The top 4 non-cancer primary diagnoses for patients admitted to Hospice in 2011 were:
  - 13.9% Debility Unspecified
  - 12.5% Dementia
  - 11.4% Heart Disease
  - 8.5% Lung Disease
Medicare Hospice Benefit

- In 2011, 84.1% of Hospice patients are covered by the Medicare Hospice Benefit
- 7.7% Managed Care or Private Insurance
- 5.2% Medicaid Hospice Benefit
- 1.1% Self Pay

- Patient may revoke the benefit at any time
- May resume at any time with recertification
- Currently recertified regularly while on the benefit
- Most private insurances now offer some form of Hospice Benefit
Medicare Hospice Benefit: Levels of Care

- **Routine Home Care** per day reimbursement rate for following:
  - Home visits by RNs, social workers, spiritual care coordinators, hospice aides and volunteers
  - Medications – specifically identified in the Plan of Care as being related to the Palliation and management of symptoms related to the patients’ terminal illness
  - Durable Medical Equipment and supplies
  - Physical Therapy, Nutritional Therapy, Speech Therapy, Occupational Therapy, Massage Therapy
Medicare Hospice Benefit: Levels of Care

- **Respite Care**: For up to 5 days at a time in an in-patient unit or ECF

- **Continuous Home Care**: Crisis management of acute symptoms; a minimum of 8 hours of nursing care in the home each day

- **General Inpatient Care**: Pain and symptom management in an in-patient hospice or in contracted hospital beds
Medicare Hospice Benefit: Summa at Home Interdisciplinary Team (IDT)
Hospice Admission Diagnoses

- Cancer
- Cardiovascular Diseases
- Congestive Heart Failure
- Chronic Obstructive Pulmonary Disease (COPD)
- Renal Disease
- Dementia or Alzheimer’s Disease
- Neurological Disease (Parkinson’s, ALS, etc.)
- Acquired Immune Deficiency Syndrome (AIDS)
- Liver Disease
History: Summa at Home Hospice

- In October, 1998 program development started.
- In July, 1999, the program was Medicare-certified and JCAHO-accredited.
- In December 2002, Summa’s Palliative Care Consult Service was established.
- In August, 2006, new Acute Palliative Care Unit at Akron City Hospital opened.
- In 2010, Summa’s Palliative Care and Hospice Services received the American Hospital Association’s prestigious Circle of Life Citation of Honor Award.
- Hospice of Summa is under the umbrella of “Summa’s Palliative Care and Hospice Services.”
- In October, 2012, new Acute Palliative Care Unit at Barberton Hospital opened.
- 2013, Hospice of Summa joined with Home Care and Home Care Infusion to become Summa at Home Hospice and Palliative Care.
Summa at Home Hospice: Vision & Values

- **Vision**
  - To be the premiere regional provider of Palliative Care & Hospice Services

- **Values**
  - Uncompromising, interdisciplinary, team-based, quality care is provided to our patients and those who love and care for them.
  - Supportive services are delivered through cost-effective means promoting comfort, dignity and the opportunity to live each day to the fullest.
  - Education and support are provided to team members and other professionals in recognition of the challenging and unique nature of this work.
Acute Palliative Care Unit (APCU)

- 12 Bed Inpatient Unit- Akron City Hospital and 8 Bed Inpatient Unit- Barberton Hospital:
  - Rooms all private
  - 24-hr visitation
  - Family rooms
  - Kitchen and shower for family

- Patients Served:
  - Patients with progressive neurologic, renal, cardiac, respiratory and oncologic illness
  - Actively dying patients
  - Hospice in-patients for pain and symptom management
Volunteer Involvement in Hospice

Volunteers and Hospice Medicare Conditions of Participation:

- Under Medicare Hospice law, Conditions of Participation (COP) Regulation 418.70, 5% of total patient care hours must be provided by volunteers

- Early hospice efforts were almost entirely from a voluntary source and the writers of the Medicare regulations realized the importance of the volunteer role in providing quality hospice care

I feel privileged to be a hospice volunteer. I learn so much about living from my patients and their families.
Volunteer Involvement in Hospice

- The U.S. Hospice movement was founded by volunteers and there is continued commitment to volunteer service.

- NHPCO estimated that in 2011, 450,000 Hospice volunteers provided 21 million hours of service.

- In 2011, 60.0% of volunteers were assisting with direct support.

- Hospice volunteers provide service in three general areas:
  - Spending time with patients and families (Direct)
  - Providing clerical and other services that support patient care and clinical services (Clinical)
  - Helping with fundraising efforts and/or the board of directors (General)
One Final Note...

“You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die.”

Dame Cicely Saunders (1918-2005)