

# The Evolution of Hospice and Palliative Care Historical Perspectives

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Back Then...



In Memory of  
JAMES HULL ALLEN,  
Son of Capt Gabriel &  
Mrs. Sarah Allen:

He departed this Life the  
6<sup>th</sup> of August, 1793. Aged  
15 Years, 3 Months & 21 Days

Young Friends regard this solemn Truth.  
Soon you may die like me in youth:  
Death is a debt to nature due,  
Which I have paid, and so must you.

# Today...

*I have nothing against  
Death... I just don't want to  
be there when it happens.*

Woody Allen



# Objectives The Learner will...

- Will come to understand the historical roots of the modern hospice/palliative care movement
- Appreciate that we are in the process of “creating” new relationships to illness and dying in response to problems in our healthcare system and culture
- Appreciate historical reasons as to why end-of-life and palliative care have been neglected

# Generalizations

*In days gone past...*

- Dying was a relatively brief affair
- “*Dying*” received little attention as compared to *death*
- Dying was a very familiar event
- *Cure* was not the major focus of Medicine
- Civilizations were organized to a large degree around what people thought happened after death – i.e. RELIGION
- Death and Dying were not principally *medical* concerns

# Historical Trends

- Increasing secularization of society (especially from the time of the Renaissance)
- Increasing attention to matters of the living (as compared to the afterlife)
- Increasing attention to the individual
- Evolution of “Scientism” (A belief in the value of objective reality as an object of study and inquiry over subjective reality)
- Progressive medicalization of dying









# *Transi* of the Middle Ages

*Reminder of the transient  
nature of this world:  
Contemptus Mundi  
(Contempt for the world)*



# Puritan New England

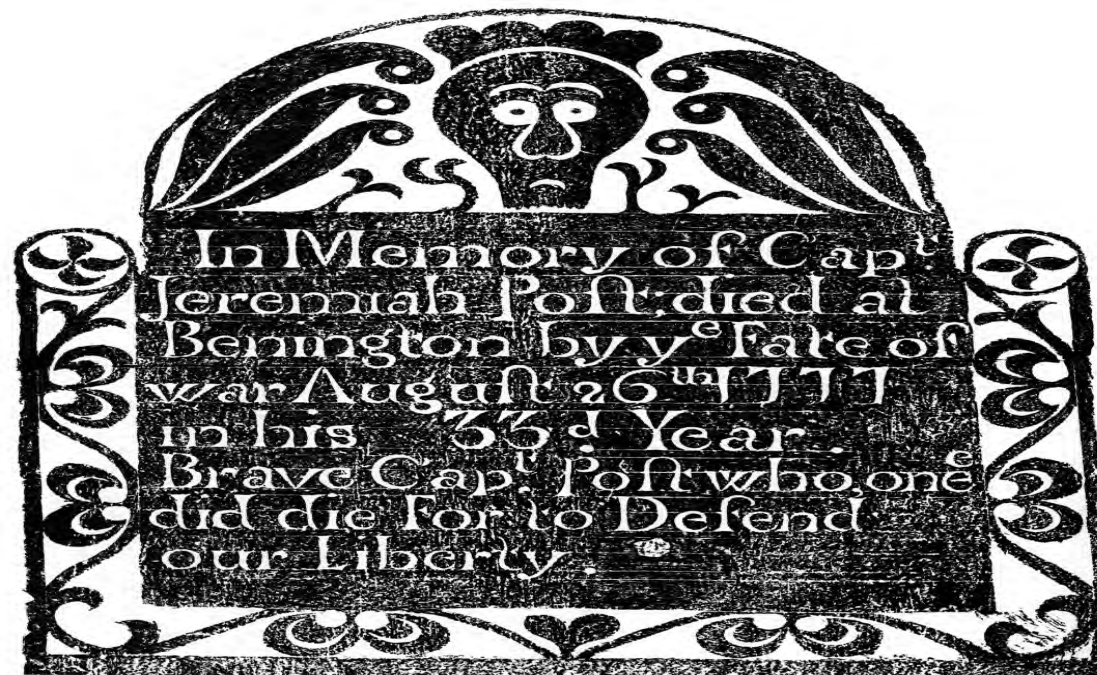
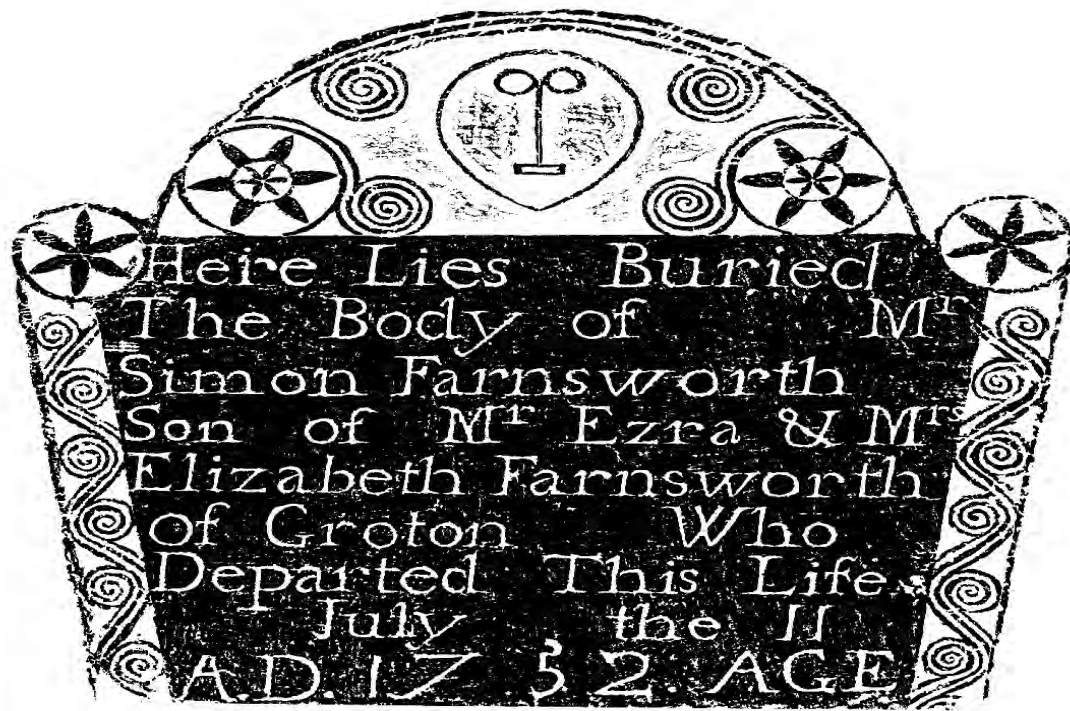
Transition from  
“Death Head” Motif  
to angels and  
cherubs. Late 1600’s  
to mid 1700’s













Progressive  
*realism* in  
portrayal of the  
dead, preceding  
the “Romantic”  
Period





# Evolving realism

Photo by David Robinson,  
Beautiful Death, Art of the  
Cemetery

Genoa, Italy





## Romanticism/Eroticism of Death

Photo by David Robinson, Beautiful  
Death, Art of the Cemetery  
Milan, Italy







# The Afterlife

Home away  
from home – an  
increasingly  
'secular' view  
of heaven

Photo by David Robinson,  
Beautiful Death, Art of the  
Cemetery

Saint-Vicent, France





# Where loved- ones meet again

Photo by David Robinson, Beautiful Death,  
Art of the Cemetery

Florence, Italy



# Modern Times

- Less about *death* than dying
- Dying moves to institutions
- Evolution of “*the cult of cure*”
  - ◆ If we can just cure everything then...
    - ◆ Death disappears
    - ◆ Suffering will be eliminated

P. Aries: the period of  
*Invisible Death*

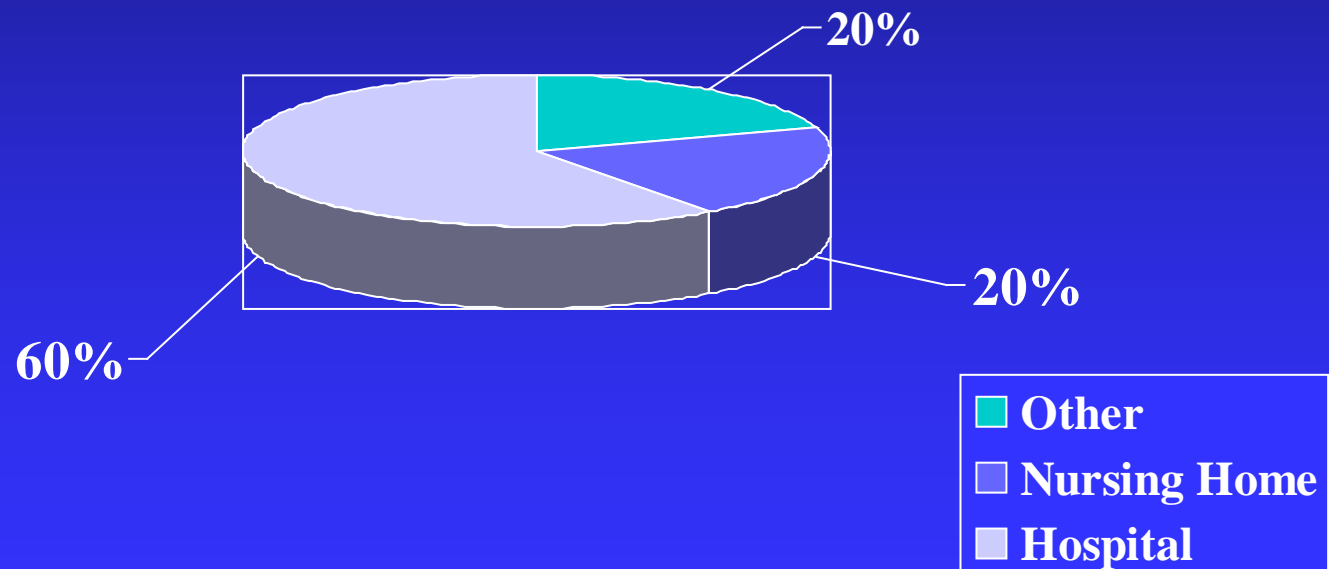
# Top 5 Causes of Death 1900

Rank	Cause of Death	Percentage
1	Influenza, Pneumonia	11.8
2	Tuberculosis	11.3
3	Gastritis, Enteritis	8.3
4	Heart Disease	8.0
5	Stroke	6.2

# Top 5 Causes of Death 1994

Rank	Cause of Death	Percentage
1	Heart Disease	32.1
2	Cancer	23.5
3	Stroke	6.8
4	COPD	4.5
5	Accidents	3.9

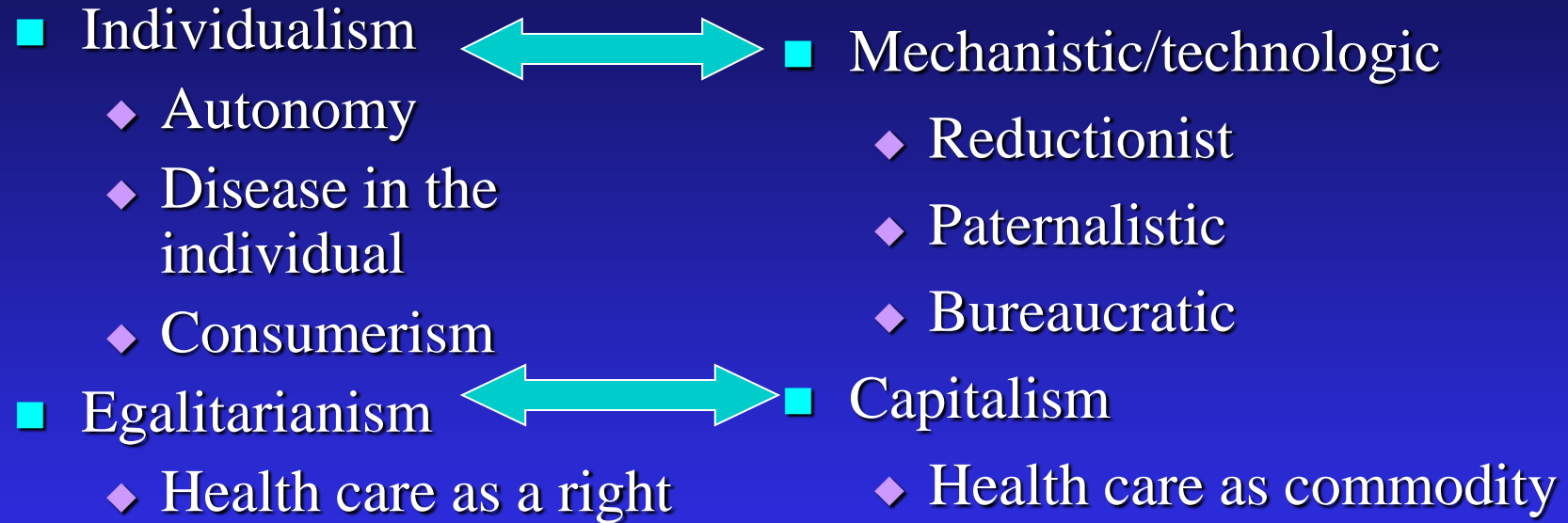
# Where Do We Die





# Culture of Biomedicine

## Tensions



### Lacking in modern biomedicine

Focus on suffering as object of medicine

Inclusion of concept of “life-force” in model

Illness as something transcending the individual

# Key Historical Events in Modern Times

- 1945 beginning wide-spread use of penicillin
  - ◆ Associated with dramatic increase in institutional deaths
- 1953 Knowsy the dog resuscitated – named because he knew ‘what was on the other side’

# Key Historical Events in Modern Times

- 1956 APA Symposium on death

→ ◆ *The Meaning of Death*, H. Feifel, 1959

- Early 1960's – CPR, ICU propagated

- 1967 Ciceley Saunders starts St. Christophers

- 1969 Kubler Ross, *On Death and Dying*

# Key Historical Events in Modern Times

- 1975 Three inpatient hospices started – New York, New Haven, Montreal
  - ◆ Balfour Mount in Montreal coins term, *Palliative Care*, as Hospice meant alms house for the poor in French-speaking Quebec
  - ◆ 1979 Marin Hospice, VA Hospice at Menlo Park

# Key Historical Events in Modern Times

- 1983 Medicare Hospice Benefit
  - ◆ Shifted focus to *home* hospice care
  - ◆ Emphasized nursing, social work care
    - ◆ De-emphasized physicians
  - ◆ Started concept of terminality (and hospice eligibility) based on 6 months prognosis

# Key Historical Events in Modern Times

- 1993 Oxford Textbook of Palliative Medicine
- 1995 SUPPORT study documents poor quality of care for dying in hospitals
- 1996 First board exam for physicians in palliative medicine
- 1997 Supreme court hears cases on physician assisted suicide

# Key Historical Events in Modern Times

## ■ 2000

- ◆ JCAHO pain/EOL mandates
- ◆ ACGME mandates all fellows in Internal Medicine have EOL training
- ◆ Decision made to push for formal palliative medicine subspecialty

## ■ 2001

- ◆ VA Interprofessional Palliative Care Fellowship approved
- ◆ California requires 22 hours pain/EOL training for all physicians in state 2002-2006

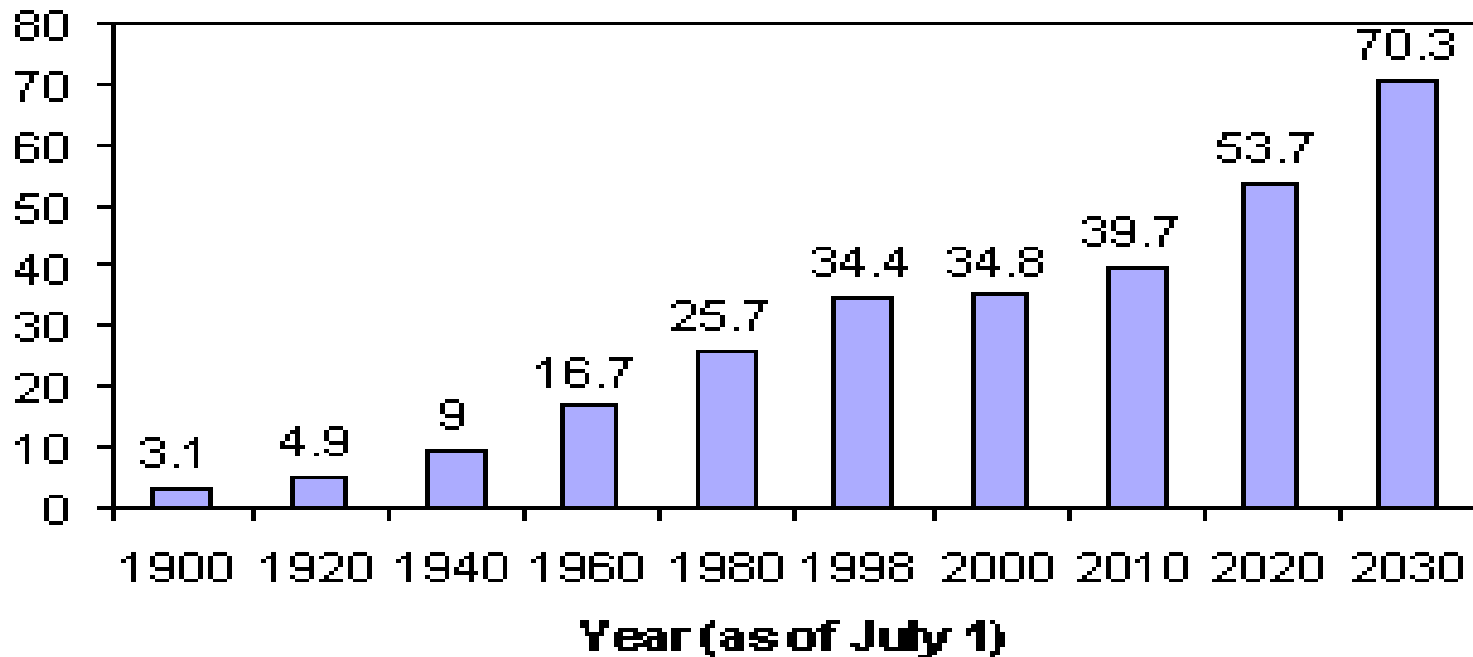


# Where are we now -

*Tensions mounting...*

- Dramatic increases in the number of elderly & chronically ill
- No coherent plan to deal with these numbers
- Passionate belief in salvation as espoused by the Cult of Cure

**Figure 1: Number of Persons 65+,  
1900 - 2030** (numbers in millions)

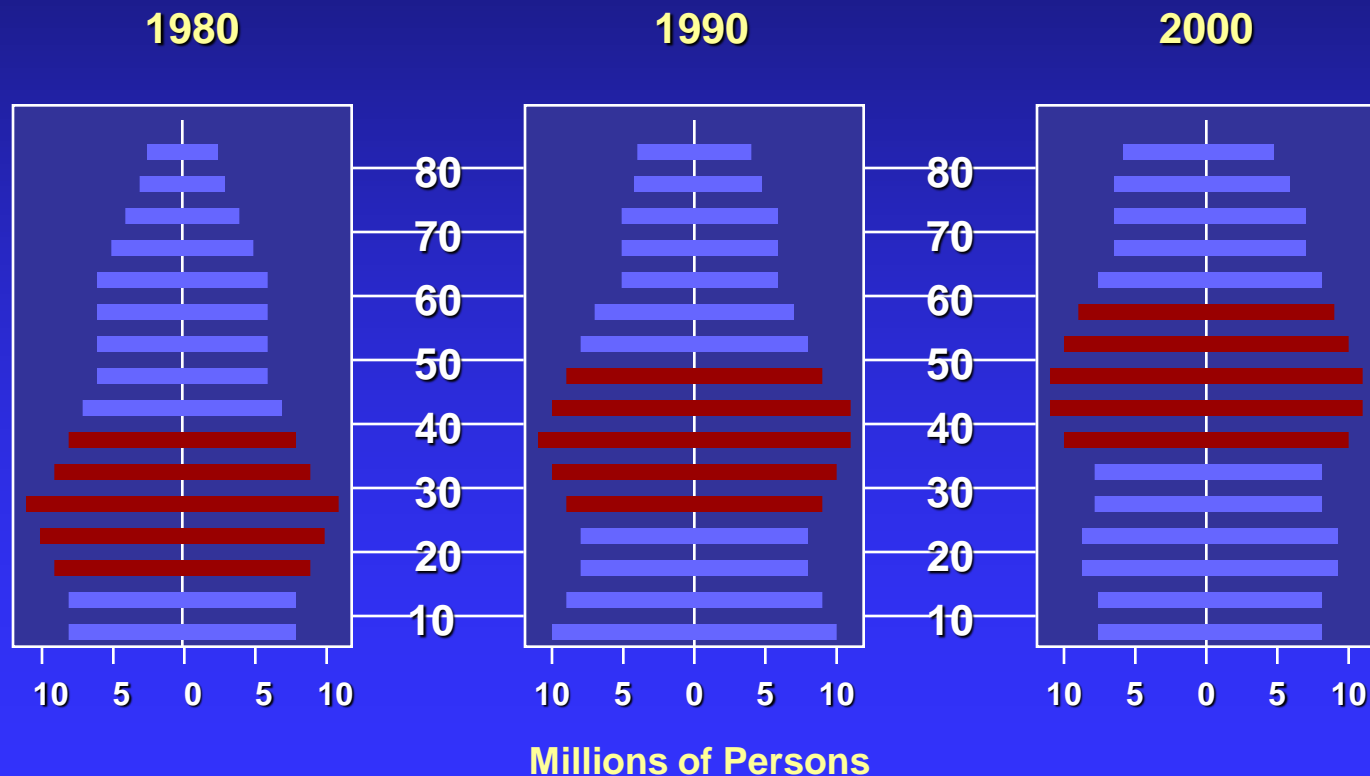


**Profile of Older Americans: 2000**  
**Fowles DG, Duncker A, Greenberg, S**  
**Administration on Aging, Department of Health and Human Services**  
**February 9, 2001** [www.aoa.gov/aoa/stats/profile](http://www.aoa.gov/aoa/stats/profile)

# The Graying of America

## Changing U.S. Age Distribution

■ Indicates the Baby-Boom Group



SOURCE: AMARA et. al., Looking Ahead at American Health Care (1988)

## Number of workers supporting each Social Security dependent:

1940 = 41

1950 = 16

1998 = 3.4

2030 = 2.1 (projected)

*The Ghost of Social Security*

Editorial, Wall Street Journal, July 12, 00 pg A26

# Implications if Prediction Accurate

- “De-medicalization” of chronic illness and dying
- A further shift in care burden to families and communities
- A caregiver crisis
  - ◆ Families unable to provide care
  - ◆ Inadequate number of professional caregivers (poor, minorities and immigrants)
- Secular romanticism -
  - ◆ The romanticism of dying

