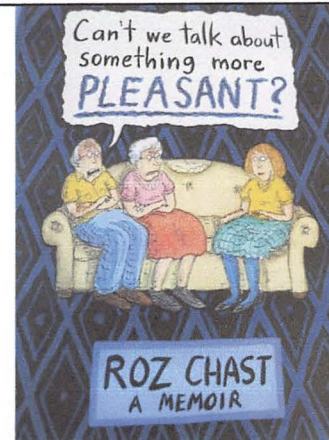


All's Well That Ends Well

SPHEX 2015
Ellen Nygaard



A Brief History of Dying in America

- Societal norm was dying at home, this persisted even in the wake of immigration and urbanization.
- Exceptions; Indigents died in almshouses, consumption victims in sanitariums, soldiers on the battlefields.
- A shift emerged as the focus of scientific medicine became the hospital in 20th century

A Brief History of Dying in America

- 1949, 40% >65 years died in a hospital
- 1970's-early 80's more than half of Americans died in the hospital, proportion of home deaths was 15%
- Within the hospital and with the increase of medical technology, the dying were increasingly separated from routine care into ICU's, and the process of death and dying was often rendered invisible.

A Brief History of Dying in America

- There was a to reaction to this isolating, segregating experience of death:
- Dame Cicely Saunders pioneered the hospice movement in Britain.
- Elizabeth Kubler-Ross renewed the case for dying at home.
- Palliative Care became recognized and widely practiced.

A Brief History of Dying in America

- CDC reported that between 1989-2007 the proportion of home deaths rose from 15-24%
- CDC reported the number of those dying in a hospital dropped from 49-35%
- The incidents of ICU stays in last 6 months of life has increased.

Are these contradictory statements?

Pew Research Center Religion and Public Life

- New survey, released November 2013 examines public's views of end-of-life medical treatments.
- Landline telephone survey completed March and April 2013, among a nationally representative sample of 1,994 adults.

Pew Survey Many Americans have faced end-of-life situations with family and friends.

- 47% have have family or friend in a terminal illness or coma in the past 5 years.
- This experience cuts across most social and demographic groups, including age, gender, education and religious affiliation.

Pew Survey Prepared for end-of-life issues

- 37% have given a great deal of thought
- 35% have given some thought
- 27% have given no thought
- >75 years, 1 in 5 neither talked to someone about nor written down their wishes, 3 in 10 describe their health as fair or poor

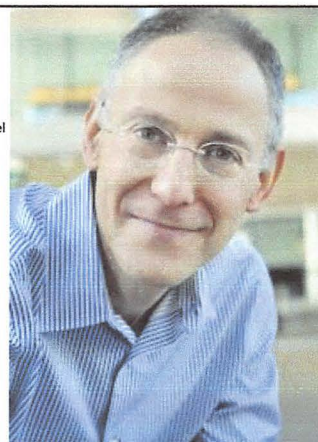
Death Panels

- Institute of Medicine; a research and policy advising group affiliated with the National Academies of Science has published a comprehensive report September 2014 entitled "Dying in America" in response to the evolving medical system, public perceptions and the predicted changing demographics in the US.

A Modern Parable

- "Why I hope to Die at 75"
- An argument that society and families-and you-will be better off if nature takes its course swiftly and promptly.
- The Atlantic, Sept., 2014
- By Ezekiel J. Emanuel, MD, PhD – Oncologist, bioethicist, author, health policy advisor

Ezekiel Emanuel

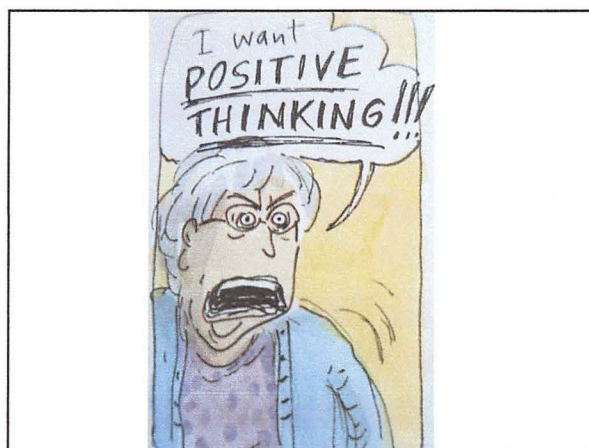
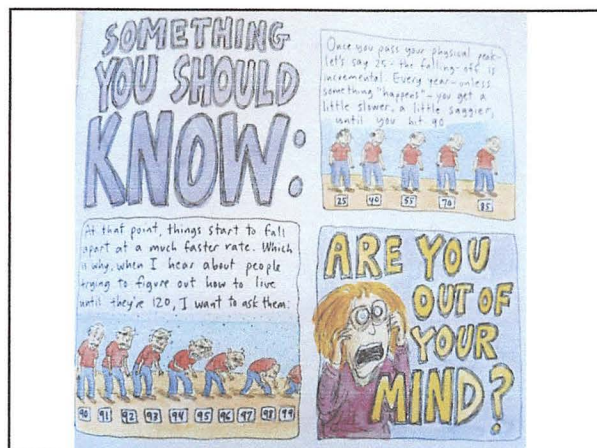


Ezekiel J. Emanuel

- "I think this manic desperation to endlessly extend life is misguided and potentially destructive."
- The American Immortal (a cultural type)
- James F. Fries of Stanford, Compression of Morbidity Theory postulates that as we extend life spans we will be living healthier lives.

Life Expectancy

- 1900 average life expectancy of an American was 47 years.
- 1930 it was 59.7 years
- 1960 it was 69.7 years
- 1990 it was 75.4 years
- Today women 81.1 and men 76.3 years
- 2050 > 20% of the population will be > 65 years old. IOM



**A Long Bright Future
Happiness, Health and Financial
Security in an Age of Increased
Longevity.**

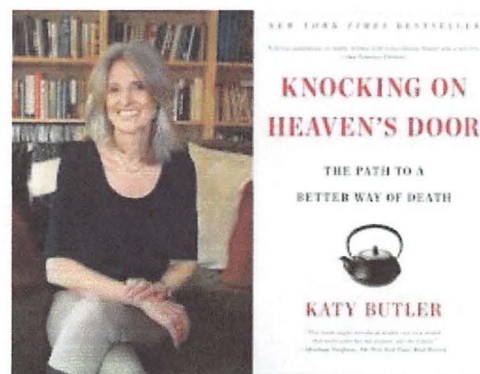
Laura Carstensen, PhD.

Extended Life Expectancy

- Be prepared. What gives your life meaning and purpose throughout your years?
- Will the next generation be more able to manage the later years?
- What must we as a society do to accommodate our older generation in their later years?

**Extended Life Expectancy
Financial**

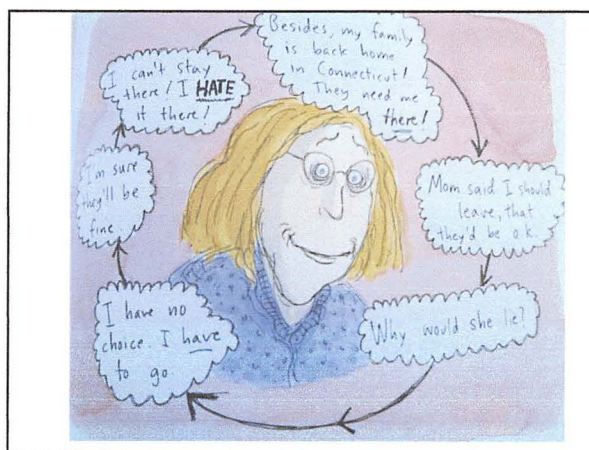
- One quarter of Medicare's 560 billion in annual costs covers medical care in the last year of life. Butler
- 34% of our population will utilize 46% of US health care dollars as chronic conditions increase with age. IOM*
- These figures do not include other insurances or out-of-pocket costs.





Extended Life Expectancy Caregiving

- 29 million, 9% of the US population, are unpaid caregivers of someone over 74 years. Butler, pg 29
- 3 in 10 adults; 2 in 10 workforce members are functioning in a caregiving role. IOM "Dying in America"
- 2/3 are female contributing 20 hours a week to care





Why have an Advanced Directive?

- To ensure desired care for the patient and minimize family burdens during a time of crisis.

Advanced Care Planning

- "It's always too early, unless it's too late."
- Advanced Directives identify surrogate health care decision maker and patient wishes for medical care in the situation when patient is not able to decide for themselves.
- Presently all 50 states have laws supporting advanced directives and power of attorney for health care decisions.

Power of Attorney for Health Care

- Who should you choose?
- What should you discuss with them before they agree to be your POA?
- People who discuss these issues with POA have 3X the likelihood that their wishes will be carried out, experience less family stress and anxiety and less depression after death occurs. IOM "Dying in America"

Medical Treatment

- What kind of medical treatments do you want at the end of your life? For how long?
- All possible treatments
- Some specific treatments
- DNR
- Palliative Care
- Hospice Care



Palliative Care

- Palliative Care provides relief from pain and other symptoms and supports desired quality of life. It focuses on patients and their families instead of only disease. IOM "Dying in America"

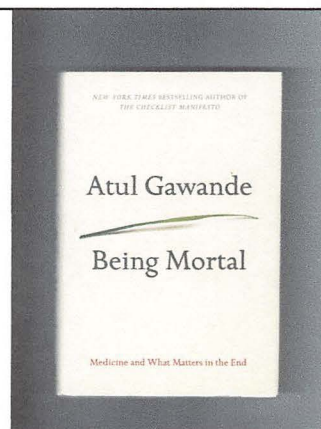
Challenges to Advanced Directives

- AD document is not available to all of the team involved in health care of patient.
- Family does not agree with patient wishes expressed in AD.
- Lack of continuity in communication of care between all health care providers, a systemic issue in many places.

AD Understanding

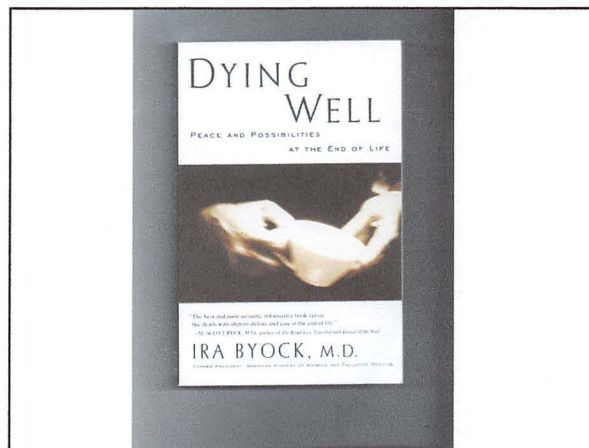
- AD has an 12th grade literacy level. IOM
- 14% US population and 25% of those > 65 years old read below basic prose level. IOM
- 90% of US population has a health literacy (more than just reading level) level that is not conducive to making fully informed complicated health care decision. IOM
- During illness, though legally competent, many people have difficulty fully understanding the scope of an important medical decision.

Atul Gawande



Physician Challenges to Advanced Care Planning

- Fear of malpractice lawsuits often hinders physicians from less intervention. Trend is to default to treatment.
- Physician culture is to cure and fix problems
- Intervention pays
- Physician goals, roles, and communication styles are not consistent, ever-evolving, and very personal. (Paternalistic, Informative, Interpretive)



What Next?

- "The Four Things that Matter Most" By Ira Byock, M.D. Hospice and Palliative Care physician.
- "Please forgive me"
- "I forgive you"
- "Thank you"
- "I love you"



Patricia Burns Gebhardt
b.1928 – d.2014

Ellen Gebhardt Nygaard
b.1952



“All’s Well That Ends Well”
Bibliography

Butler, Katy. Knocking on Heaven’s Door. The Path to a Better Way of Death
NY, NY: Scribner 2013.

Byock, Ira. Dying Well. Peace and Possibilities at the End of Life. NY, NY: Riverhead
Books. 1998.

Carstensen, Laura L. PhD. A Long Bright Future. Happiness, Health, and Financial
Security in an Age of Increased Longevity. NY, NY: Random House Inc. 2009.

Chasts, Roz. Can’t We Talk About Something More Pleasant?. A Memoir. NY, NY
Bloomsbury USA

Emanuel, Ezekiel, M.D., PhD. Why I Hope to Die at 75.
13oct2014<<http://www.theatlantic.com/features/archives/2014/09/why-i-hope-to-die-at-75/379329/>

Gawande, Atul, M.D. Being Mortal. Medicine and What Matters in the End. NY, NY:
Metropolitan Books, Henry Holt and Co. 2014

IOM.edu Dying in America: 17sept2014. Improving Quality and Honoring Individual
Preferences Near the End of Life.

Pew Research Center. Religion and the Public Life Project “Survey to Examine Public
View on End-of-Life Medical Treatment.”
6feb2014<<http://www.pewforum.org/2013/11/21/new-survey-examines-public-views-on-the-end-of-life-medical-treatments>

Rothman, David J. PhD. “Where We Die” NEJM 370;26 June 26, 2014 p.2506-2514.