End-of-Life Care: Do You Know Enough About Hospice and End-of-Life Care?

February 2, 2016
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Do You Know Enough About Hospice and End-of-Life Care?

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Speaker Biographies

GEORGE J. GOIKAS is Director of Palliative Care for The Community Hospice overseeing the development of inpatient and outpatient palliative care programs. He sees patients as Director of the Inpatient Palliative Care Consult Service at Ellis Hospital. Prior to joining The Community Hospice, Dr. Giokas practiced primary care internal medicine for over 25 years. He is a member of the NYS MOLST implementation team and serves on the Ellis Hospital Ethics Committee. Dr. Giokas received his undergraduate degree from Tufts University and medical degree from George Washington University School of Medicine. He completed his residency in internal medicine at Albany Medical Center and is board certified in internal medicine and hospice and palliative medicine.

BETH MAHAR is the Director of Member Services for the Hospice & Palliative Care Association of New York State. In this capacity she is responsible for overseeing the Association’s communications, educational activities, technical assistance, public engagement, marketing and implementation and maintenance of partnerships and collaborations. She has been with HPCANYS since 2006. Prior to this, Ms. Mahar was the Director of Communications for the New York State Association of Area Agencies on Aging. She holds a B.A. from Mount Holyoke College and was among the first graduating class of the Empire State Society of Association Executives’ Association Leadership Academy. She currently serves as President of the Board of Directors of the Greater Loudonville Association.

SANDRA D. RIVERA, ESQ. has over 15 years of experience counseling clients regarding legal, legislative, administrative and regulatory matters before New York State government. She represents clients before the Legislature, Executive Chamber and State agencies. Prior to opening her own law practice, Ms. Rivera worked at prominent Albany firms representing clients before New York State government. Most recently she was Counsel in the Government & Regulatory practice of a national law firm’s Albany office where she worked on a variety of matters related to technology, economic development, healthcare and criminal and social justice. Ms. Rivera started her career in the New York State Assembly Majority Leader’s Office and went on to work at the
New York State United Teachers (NYSUT) to advance their agenda before the Legislature and Executive Chamber. Ms. Rivera received her J. D. (*cum laude*) from Albany Law School in 2002. She received her M.A. in Political Communication (*magna cum laude*) and B.A. in Anthropology (*magna cum laude*) from the University at Albany in 1994 and 1992, respectively.

**PATRICIA SPREITZER, RN** is a registered nurse with over 35 years of nursing experience. Ms. Spreitzer joined the staff of The Community Hospice in 2004 and in her current position of Provider Relations Specialist / Community Nurse Liaison she focuses on providing information about Hospice philosophy of care and program services to both the healthcare provider community and community members at large. Ms. Spreitzer is personally and professionally dedicated to increasing community awareness about the importance of the advance care planning process and has been an active member of the NYS National Health Care Decision Day Coalition since 2008. She is also a Faith Community Nurse, working collaboratively with the nurses of St. Peter’s Health Partners Faith Community Nurse Program providing information and resources on the Advance Care Planning process, palliative care, hospice services and other End of Life issues.
End of Life Care:
Current State & Opportunities for Improvement

Albany Law School

Feb 2, 2016

George J. Giokas, M.D.
Director of Palliative Care, The Community Hospice
Deaths by all ages, by age, United States 2007

Approximately 2 million die in the US each year.
<table>
<thead>
<tr>
<th>Rank</th>
<th>Cause</th>
<th>Percentage</th>
<th>Gender</th>
<th>Cause</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Ischemic heart disease</td>
<td>20.3%</td>
<td>Male</td>
<td>Ischemic heart disease</td>
<td>20.3%</td>
</tr>
<tr>
<td>2</td>
<td>Alzheimer disease</td>
<td>8.3%</td>
<td>Female</td>
<td>Alzheimer disease</td>
<td>12.7%</td>
</tr>
<tr>
<td>3</td>
<td>Lung cancer</td>
<td>7.4%</td>
<td>Male</td>
<td>Cerebrovascular disease</td>
<td>7.3%</td>
</tr>
<tr>
<td>4</td>
<td>COPD*</td>
<td>5.8%</td>
<td>Male</td>
<td>Lung cancer</td>
<td>5.7%</td>
</tr>
<tr>
<td>5</td>
<td>Cerebrovascular disease</td>
<td>5.0%</td>
<td>Male</td>
<td>COPD*</td>
<td>5.6%</td>
</tr>
<tr>
<td>6</td>
<td>Lower respiratory infections</td>
<td>3.0%</td>
<td>Male</td>
<td>Lower respiratory infections</td>
<td>3.4%</td>
</tr>
<tr>
<td>7</td>
<td>Diabetes</td>
<td>2.8%</td>
<td>Male</td>
<td>Breast cancer</td>
<td>3.4%</td>
</tr>
<tr>
<td>8</td>
<td>Prostate cancer</td>
<td>2.8%</td>
<td>Male</td>
<td>Diabetes</td>
<td>2.8%</td>
</tr>
<tr>
<td>9</td>
<td>Chronic kidney disease</td>
<td>2.7%</td>
<td>Male</td>
<td>Chronic kidney disease</td>
<td>2.6%</td>
</tr>
<tr>
<td>10</td>
<td>Colorectal cancer</td>
<td>2.6%</td>
<td>Male</td>
<td>Colorectal cancer</td>
<td>2.5%</td>
</tr>
</tbody>
</table>
Figure 4. Percent distribution of five leading causes of death, by age group: United States, preliminary 2011

**Aged 1–24 years**
Number of deaths = 39,213
- Accidents (38%)
- Homicide (13%)
- Suicide (13%)
- Cancer (7%)
- Heart disease (3%)
- All other causes (26%)

**Aged 25–44 years**
Number of deaths = 113,341
- Accidents (26%)
- Cancer (13%)
- Heart disease (12%)
- Suicide (11%)
- Homicide (6%)
- All other causes (32%)

**Aged 45–64 years**
Number of deaths = 505,730
- Cancer (32%)
- Heart disease (21%)
- Accidents (7%)
- Chronic lower respiratory diseases (4%)
- Chronic liver disease and cirrhosis (4%)
- All other causes (32%)

**Aged 65 and over**
Number of deaths = 1,830,553
- Heart disease (26%)
- Cancer (22%)
- Chronic lower respiratory diseases (7%)
- Stroke (6%)
- Alzheimer's disease (5%)
- All other causes (34%)

## How Americans Die: A Century of Change

<table>
<thead>
<tr>
<th></th>
<th>1900</th>
<th>2000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at death</td>
<td>46 years</td>
<td>78 years</td>
</tr>
<tr>
<td>Top Causes</td>
<td>Infection</td>
<td>Cancer</td>
</tr>
<tr>
<td></td>
<td>Injury/Occupation</td>
<td>Organ system failure</td>
</tr>
<tr>
<td></td>
<td>Childbirth</td>
<td>Stroke/Dementia</td>
</tr>
<tr>
<td>Disability</td>
<td>Not much</td>
<td>2-4 yrs ave. before death</td>
</tr>
<tr>
<td>Financing</td>
<td>Private, modest</td>
<td>Public, substantial-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>in US - 83% in Medicare</td>
</tr>
<tr>
<td></td>
<td></td>
<td>~½ of women die in Medicaid</td>
</tr>
</tbody>
</table>

1960’s  Approx 50% accessed Medicare, And frail elders, likely not in hospital

Joanne Lynn, MD
Life Expectancy

the median number of years at birth that a population born in a particular year is expected to survive.

Life Span
Change in Life Expectancy for Males and Females, 1990-2013
Figure 1. Life expectancy at birth, by selected characteristics: United States, 1980–2010

The graph shows the trend of life expectancy at birth for different racial and gender groups from 1980 to 2010.

- **White female**: The life expectancy for white females has increased from around 75 years in 1980 to about 82 years in 2010.
- **Black female**: The life expectancy for black females has increased from around 70 years in 1980 to about 76 years in 2010.
- **White male**: The life expectancy for white males has increased from around 70 years in 1980 to about 78 years in 2010.
- **Black male**: The life expectancy for black males has increased from around 65 years in 1980 to about 71 years in 2010.

The bar chart on the right shows the life expectancy at birth for 2010:

- **Male**
  - Black, not Hispanic: 71 years
  - White, not Hispanic: 76 years
  - Hispanic: 79 years

- **Female**
  - Black, not Hispanic: 78 years
  - White, not Hispanic: 81 years
  - Hispanic: 84 years
Percent of U.S. Population in Selected Age Groups, 1970 to 2050

- **1970**:
  - Under Age 18: 34%
  - Ages 18-64: 56%
  - Ages 65+: 10%

- **2009**:
  - Under Age 18: 24%
  - Ages 18-64: 63%
  - Ages 65+: 13%

- **2030**:
  - Under Age 18: 24%
  - Ages 18-64: 57%
  - Ages 65+: 19%

- **2050**:
  - Under Age 18: 23%
  - Ages 18-64: 57%
  - Ages 65+: 20%

**Source:** PRB analysis of data from U.S. Census Bureau.
Figure 33. Place of death, over time: United States, 1989, 1997, and 2007

Decedents under 65 years

- Nursing home: 3% (1989), 5% (1997), 5% (2007)

Decedents 65 years and over

- Hospital inpatient: 49% (1989), 41% (1997), 35% (2007)
Slide Alert
20% of all deaths in the US occur in the ICU or shortly after an ICU stay

40% of COPD pts in ICU w/in 1 month of death

22% of dementia patients in ICU w/in 1 month of death

40% of patients referred to Hospice w/in 3 days of death had ICU stay that preceded referral

Teno JAMA 2013
Lunney, Lynn, & Hogan as cited CanMedAssocJrnl Aug 2013
Lunney, Lynn, & Hogan as cited CanMedAssocJrnl Aug 2013
Some day, we will all die, Snoopy!

True, but on all the other days, we will not.
What Do Patients with Serious Illness Want?

To get good medical care
Relief from physical suffering
To not be a burden on their family
To be with family
To have their affairs in order
To be at peace

D. Rosielle & L. Marr 17th ICPP Montreal 2008
Vital Signs
Core Metrics for Health and Health Care Progress

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Advising the nation • Improving health

April 2015
Vital Signs
Core Metrics for Health and Health Care Progress

1. Life expectancy
   - Infant mortality
   - Maternal mortality
   - Violence and injury mortality

2. Well-being
   - Multiple chronic conditions
   - Depression

3. Overweight and obesity
   - Activity levels
   - Healthy eating patterns

4. Addictive behavior
   - Tobacco use
   - Drug dependence/illicit use
   - Alcohol dependence/misuse

5. Unintended pregnancy
   - Contraceptive use

6. Healthy communities
   - Childhood poverty rate
   - Childhood asthma
   - Air quality index
   - Drinking water quality index

7. Preventive services
   - Influenza immunization
   - Colorectal cancer screening
   - Breast cancer screening

8. Care access
   - Usual source of care
   - Delay of needed care

9. Patient safety
   - Wrong-site surgery
   - Pressure ulcers
   - Medication reconciliation

10. Evidence-based care
    - Cardiovascular risk reduction
    - Hypertension control
    - Diabetes control composite
    - Heart attack therapy protocol
    - Stroke therapy protocol
    - Unnecessary care composite

11. Care match with patient goals
    - Patient experience
    - Shared decision making
    - End-of-life/advanced care planning

12. Personal spending burden
    - Health care-related bankruptcies

13. Population spending burden
    - Total cost of care
    - Health care spending growth

14. Individual engagement
    - Involvement in health initiatives

15. Community engagement
    - Availability of healthy food
    - Walkability
    - Community health benefit agenda
11. Care match with patient goals
Patient experience
Shared decision making
End-of-life/advanced care planning
<table>
<thead>
<tr>
<th>Medical Event</th>
<th>2010</th>
<th>2003-07</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dying in Hospital</td>
<td>25%</td>
<td>29%</td>
</tr>
<tr>
<td>Enrolled in Hospice last month of life</td>
<td>61%</td>
<td>55%</td>
</tr>
<tr>
<td>Seeing 10 or more MDs last 6 months</td>
<td>58%</td>
<td>46%</td>
</tr>
<tr>
<td>ICU Admission last month of life</td>
<td>29%</td>
<td>24%</td>
</tr>
<tr>
<td>Hospice Referral last 3 days of life</td>
<td>11%</td>
<td>8%</td>
</tr>
<tr>
<td>Chemo last 2 weeks of life</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>LST (vent, FT, CPR) last month of life</td>
<td>9%</td>
<td>9%</td>
</tr>
</tbody>
</table>

Medicare patients; Analyses controlled for pt age, sex, race, tumor type and non-cancer chronic conditions
Sept 2013
1146 patients Medicare (2003-2011)
Lung or colon cancer  Most dx’d at Stage 4

Patient Characteristics
- 80% White  7% Black  5% Hispanic
- 4% Asian/Pacific Islander  3% Other

Preferred course of treatment during last month of life
- 29% extend life as much as possible
- 68% relieve pain/discomfort as much as possible
- 3% do not know or refused to answer
Family Perspectives on Aggressive Cancer Care Near the End of Life

Alexi A.Wright, MD, MPH et al. JAMA January 2016

Family members reports of:

Quality of End of Life Care
- 51% excellent
- 28% very good
- 21% good, fair, or poor

Care “followed patients wishes a great deal”
- 81% a “great deal,”
- 19% “somewhat” or “not at all”

57% of patients died in their preferred location.
Higher ratings of quality of care and Care congruent with patient preferences were associated with 3 measures:

1. > 3 days of Hospice services
2. No ICU admission w/in 30 days of death
3. Death not occurring in the hospital
“Our findings suggest that efforts to increase earlier hospice enrollment and avoidance of ICU admissions and hospital deaths might improve the quality of end-of-life care.”
EOL Care for MDs, JDs and the general population


Retrospective  Medicare 2004-11  MA, MI, UT, VT

MDs and JDs more likely to be male and better educated

Compared to general population MDs were less likely to
die in hospital (28% vs 32%)
have surgery w/in last 6 months  (25% vs 27%)
be admitted to ICU last 6 months (26% vs 27%)

Compared to lawyers,
MDs were less likely to die in a hospital (28% vs 33%)
but did not differ in other measures
What Do Patients with Serious Illness Want?

- To get good medical care
- Relief from physical suffering
- To not be a burden on their family
- To be with family
- To have their affairs in order
- To be at peace

D. Rosielle & L. Marr    17th ICPP    Montreal 2008
Cancer Patients’ Symptoms

ESAS score 4-10:
- Pain
- Shortness of breath
- Appetite
- Anxiety
- Depression
- Drowsy
- Nausea

Proportion of cohort

Time before death (weeks)
Frequency of Symptoms in Advanced Illness

Kelley & Morrison, NEJM 2015

![Bar chart showing the frequency of symptoms in advanced illness for different conditions and symptoms.](chart.png)
I POOPED TODAY!
Seeing the **person** beyond the disease
What Do Patients with Serious Illness Want?

To get good medical care
Relief from physical suffering
To not be a burden on their family
To be with family
To have their affairs in order
To be at peace

D. Rosielle & L. Marr 17th ICPP Montreal 2008
Where have all the caregivers gone?

![Graph showing the caregiver support ratio, United States, from 1990 to 2050. The graph indicates a decrease in the ratio with the labels "Boomers turn 45," "Boomers turn 65," and "Boomers turn 80." The source is AARP Public Policy Institute calculations based on REMI (Regional Economic Models, Inc.) 2013 baseline demographic projections. Note: The caregiver support ratio is the ratio of the population aged 45–64 to the population aged 80-plus.]
U.S. Family Caregivers

78%  Caregivers regularly administering drugs (average 5-9 medications per day)

69%  Caregivers not assisted with home visits by a health professional

73%  Caregivers employed at some time while caregiving

55%  Employed workers serving as caregivers 3 years or longer

6.6 days  Average annual number of days of employed work lost as a result of caregiving

Institute of Medicine  Dying In America  Oct 2014
PALLIATIVE CARE

Specialized Care for Serious Illness
Added level of support – patient & family
Team of MD, nurses, social workers, pastoral care

Quality of life along with curative treatments
Understanding of illness
Goals of care – patient & family
Management of distressing symptoms
Plan of Care / Advance Directives
Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Newly dx’d ambulatory metastatic non-small cell lung cancer

MGH

Standard treatment vs. Standard treatment + palliative care

Intervention group
  better Quality of Life scores
  Lower rates of depression
  2.7 month survival benefit
  less chemotherapy

Temel, et al  NEJM  Aug. 2010
Palliative Care Continuum

- **Point of Crisis**
  - Hospital Based Palliative Care

- **Bridging the Gap**

- **End of Life**
  - Hospice

  - Office
  - Home
  - Long Term Care

Adapted from Diane Meier, MD
CAPC Seminar 2014
88 year old female

Dementia, hypertension, osteoporosis, hyperlipidemia, anemia, arthritis, impaired nutrition

Needs assistance feeding, bathing, transferring, toileting

Residing in an Assisted living facility
3 hospitalizations within 6 months
Infections – UTIs and pneumonia
Internal bleeding
Pleural Effusions
GI, Pulmonary, Neurology consultants

Now with 4 major pressures sores, bedbound, non-communicative

Levafloxacin, Omeprazole, Amlodipine, Simvastatin, Folic Acid, Iron, Donepezil, Alendronate, Aspirin
Family contacted
HC Proxy and Living Will reviewed
Comfort and staying at “home”
Streamlined medication list
Started RTC pain medicine
Wound care
Allowed to eat as tolerated
DNR/DNI
Hospice referral
THE CASE FOR KILLING GRANNY

CURBING EXCESSIVE END-OF-LIFE CARE IS GOOD FOR AMERICA
BY EVAN THOMAS

I WAS A TEENAGE DEATH PANELIST
BY JON MEACHAM

PLUS
THE WAY OUT OF AFGHANISTAN
BY FAREED ZAKARIA

THE ROOTS OF THE NEXT CRASH
BY NIALL FERGUSON

OBAMA'S CREDIBILITY GAP
BY GEORGE F. WILL
What happened to Grammy?

1. Did not survive to return home
2. Returned to E.D. with next crisis
3. Died comfortably at Assisted Living Facility shortly thereafter
4. Lived happily ever after
3 months after discharge from the hospital
Improving Care for ALL patients  4 C’s

CONVERSATIONS
patient- family
patient - doctor    doctor - patient

COMPETENCIES
conversations, prognosis, quality of life

COORDINATION
multiple providers & interdisciplinary

CARE-GIVER SUPPORT
• Get Palliative care  
https://getpalliativecare.org/resources/caregivers

• National Hospice and Palliative Care Organization  
http://www.caringinfo.org

• National Institute on Aging, National Institutes of Health, US Department of Health and Human  

• The Community Hospice  (518) 724-0242 or 1-800-678-0711  
http://www.communityhospice.org
Hospice Care

*It’s About How You Live*

Beth Mahar, Director of Member Services
Hospice & Palliative Care Association of NYS
Mission Statement

To promote the availability and accessibility of quality hospice and palliative care for all persons in New York State confronted with life-limiting illness.
True or False?

- Hospice is where you go when there is nothing more that a doctor can do.
About Hospice

- Hospice is a program of services, not a place
- Services are provided by an interdisciplinary team under the direction of the patient’s primary care physician
The Hospice Philosophy: Hospice Affirms Life

- Hospice provides support and care for persons in the final stages of life so that they may live in *comfort and dignity*, surrounded by family, friends, and caregivers.
“What you don’t want to do is put people on the shelf to endure the passage of time. Anything you can do to enrich the quality of a single day is all to the good.”

Robert Milch, MD, FACS
Former Medical Director
Hospice Buffalo
Comfort Care

- Hospice includes medical care with an emphasis on pain management and symptom relief
- Hospice teams of professionals and volunteers address the physical, emotional, social and spiritual needs of the patient & family
Services

- In order to meet the full range of needs, hospice care is delivered by an interdisciplinary team of professionals & volunteers

- An individualized “plan of care” is developed based on the needs of the patient and family
Unique to Hospice: Interdisciplinary Team

- Medical Director
- Nurse
- Social Worker
- Chaplain
- Home health aide
- Volunteer
Other Services

- Medical Equipment
- Medications
- Supplies
- Complementary Therapies
- Bereavement Counseling
- On-Call Nurse
Counseling: For the Patient

- To cope with illness
- Depression, grief, anxiety
- Spiritual issues
- Loss of meaning, fear of death
Counseling: For the Family

- Caregiver stress
- Role changes
- Depression and anxiety
- Family conflict
- Spiritual concerns
- Grief and bereavement
Caregiver Stress

- Loss of “the way things were”
- Increased responsibilities
- No advance directive
- Socially isolating
- Physical effects of illness & medication
Eligibility

- Terminal diagnosis of 6 months or less if the disease runs its “normal” course.
- Hospice services are available to all persons, regardless of race, religion, age, ancestry, citizenship, veteran status, marital status, handicap, sexual preference or ability to pay.
Cultural Competency

- Cultural sensitivity
- Considerations of communication
- Interpreters
- Role of the family
- Beliefs regarding death and dying
- Specialized programs
- Access for underserved populations
Diagnosis

- 40% - 50% of hospice care is provided to cancer patients; hospice is also for patients with HIV/AIDS; advanced respiratory, cardiac, liver and kidney diseases; Alzheimer’s disease; Parkinson’s disease; Multiple Sclerosis; or Amyotrophic Lateral Sclerosis (ALS)
Routine Home Care

- Most medical care for patient comfort can be provided at home
- Services are provided in the home of the patient or caregiver
- The goal is to enable the patient to remain at home in the care of loved ones
Hospital Care

- *Short-term* hospital care is provided in hospitals affiliated with hospice.
- Hospital care is for the control of symptoms that temporarily cannot be managed at home and for short-term periods in the final days of life.
Nursing Home

- Nursing home residents may elect for hospice care in affiliated nursing homes
- Hospice works collaboratively with nursing home staff to enhance residents’ quality of life
Adult Home

- Residents of adult group homes may elect for hospice care
- Hospice provides services in an adult home in the same way it provides services in private homes
- Hospice works collaboratively with the staff of the home to enhance the quality of life for the resident
Who Pays for Hospice?

- All services are covered by Medicare and Medicaid, as well as by many private insurance companies and HMO’s
- No one is refused care because of inability to pay
- Hospice handles the necessary paperwork regarding your hospice insurance reimbursement
What does Hospice not cover?

- Room and board
- Drugs and therapies unrelated to the terminal illness (ex. glaucoma medication)
- Expenses incurred without IDT approval
- Curative treatment
Bereavement

- Counseling is offered to all family members during the illness & for about a year after the death
- Hospice offers bereavement support groups which are open to the community
- The hospice bereavement team also works with schools, employers & religious organizations
How to Enroll

- You or your family can begin by calling Hospice directly. Hospice will contact your doctor concerning your medical appropriateness for hospice care.
- Many times, the doctor or hospital discharge planner will contact Hospice after they have discussed it with you.
- You actually become a patient of Hospice by signing a consent form electing hospice care.
When is the “Right Time”?

- If a disease is far enough advanced that curative treatments are being stopped, then it is time to contact hospice.

- A person is considered eligible for hospice care if the physician estimates a life expectancy of six months or less, should the disease run its normal course.
While a patient must have an expected prognosis of six months or less, hospice care can be provided for six months or longer, depending on the course of the illness. Many people do not understand this and wait unnecessarily before seeking care.
Barriers to Hospice

- Large number of Academic Medical Centers
- NYS’s rich Medicaid home care program
- “Giving up hope”
- Fee-for-service model may be an incentive for futile treatment
- Cultural perceptions
- Families unable to provide needed support at home
What Is Palliative Care?

- a. Care that provides symptom relief and other supports for people with serious illness
- b. Another term for hospice
- c. The default care choice when it is no longer possible to cure an illness
- d. Care that comes only when people are dying
Palliative Care

- Palliative Care is defined in NYS law as “health care treatment, including interdisciplinary end-of-life-care, and consultation with patients and family members, to prevent or relieve pain and suffering and enhance the patient’s quality of life, including hospice care.”
- Should be part of chronic illness management
- Should be available from time of diagnosis
Palliative Care

- Many hospitals have palliative care programs
- Greater need for community-based palliative care programs – advocacy focus for HPCANYS and the Center to Advance Palliative Care (CAPC)
Palliative Care

- Specialist-level palliative care is provided by practitioners who have advanced training and/or certification, and whose care is informed by an interdisciplinary approach to care.

- Generalist-level palliative care includes interventions by any professional that may reduce the illness burden of the patient with a serious illness.
NYS Recognizes the Importance of Palliative Care

- Palliative Care Information Act: Requires physicians and nurse practitioners to *offer* terminally-ill patients information and counselling concerning palliative care and end-of-life options.
- Palliative Care Access Act: Requires hospitals, nursing homes, home care agencies and enhanced and special-needs assisted living programs to facilitate access to palliative care.
When Should Advance Care Planning Begin?

- a. 6 months before death
- b. Upon diagnosis with a serious illness
- c. It is never too early
- d. At age 50
Learn More About Hospice

- Contact your local Hospice office
- Additional information about hospice and palliative care, is available at:
  - The Hospice and Palliative Care Association of New York State, [www.hpcanys.org](http://www.hpcanys.org), 518/446-1483; after hours toll-free number 800/431-8988.
  - [www.caringinfo.org](http://www.caringinfo.org), or call the NHPCO HelpLine at 1-800-658-8898.
  - National Hospice and Palliative Care Organization [www.nhpco.org](http://www.nhpco.org)
Contact Information

Beth Mahar
Director of Member Services
Hospice & Palliative Care Association of NYS
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Albany, NY 12205
518-446-1483
bmahar@hpcanys.org
ADVANCE CARE PLANNING

Planning for the “What Ifs” that may occur across the entire life span.

Joanne Lynn MD
Where are we now???

• **90%** of people say that talking with their loved ones about end-of-life care is important.
  The Conversation Project National Survey (2013)

• **27%** have actually done so.

• **80%** of people say that if seriously ill, they would want to talk to their doctor about wishes for medical treatment toward the end of their life.
  Survey of Californians by the California HealthCare Foundation (2012)

• **7%** report having had this conversation with their doctor.
  Survey of Californians by the California HealthCare Foundation (2012)

• **82%** of people say it’s important to put their wishes in writing.
  Survey of Californians by the California HealthCare Foundation (2012)

• **23%** have actually done it.

• **64%** of “boomers” — those born between 1946 and 1964 — say they don't have a health care proxy or living will.
  Associated Press-LifeGoesStrong.com poll, 2011
The Experts look at...
Committee on Approaching Death: Addressing Key End-of-Life Issue

Philip A. Pizzo (Co-Chair), Stanford Univ
David M. Walker (Co-Chair), Former U.S. Comptroller General
Patricia Bomba, Excellus BlueCrossBlueShield
Eduardo Bruera. MD Anderson Cancer Center
Charles J. Fahey, Fordham University
Pamela S. Hinds Children’s National Health System
Karla F. C. Holloway, Duke University
Naomi Karp, Consumer Financial Protection Bureau
Jean S. Kutner, Univ of Colorado School of Medicine
Bernard Lo, Greenwall Foundation
Salimah H. Meghani, University of Pennsylvania School of Nursing
Diane E. Meier, Center to Advance Palliative Care; Icahn School of Medicine
William D. Novelli, Georgetown University
Stephen G. Pauker, Tufts University School of Medicine
Judith R. Peres, Chevy Chase, MD
Leonard D. Schaeffer, University of Southern California
W. June Simmons, Partners in Care Foundation
Christian T. Sinclair, Gentiva Hospice
Joan M. Teno, Brown University
Fernando Torres-Gil, University of California
James A. Tulsky, Duke University Medical Center
• Delivery of Care – seamless-comprehensive-accessible
• Clinician-Patient Communication and
  **ADVANCE CARE PLANNING**
  • Professional Education and Development
  • Policies and Payments systems
  • Public Education and Engagement
A Shot in the ARM
According to the IOM Committee....

the advance care planning process can begin at any age or state of health and should center on frequent conversations with individuals, family members and care providers.

IOM Report Brief September 2014
Advance Care Planning is.....a process of planning for future medical care in case you are unable to make your own medical decisions. It is a continual process and not merely a document or an isolated event. Advance Care Planning assists you in preparing for a sudden unexpected illness, from which you expect to recover, as well as the dying process and ultimately death.

Dr. Patricia Bomba

Community Conversations on Compassionate Care
Advance Care Planning

Compassion, Support and Education along the Continuum

Advancing chronic illness

Chronic disease or functional decline

Multiple co-morbidities, with increasing frailty

Healthy and independent

Maintain & maximize health and independence

Death with dignity

P. Bomba, MD
CompassionandSupport.org
Who would speak for you
If you couldn't speak for yourself?
Who would Speak for you  If you couldn’t Speak for Yourself? Five Steps of Advance Care Planning

https://www.youtube.com/watch?v=mPtu-FpY1Kw
The ACP PROCESS

• **Examine** your values, beliefs and hopes

• **Become educated** about your own medical conditions and options for your care and other life sustaining treatments

• **Choose** your spokesperson

• **Have the Conversations**

• **Document** your wishes
What’s taken so long?

Patients and families:

• “Death denial” – if we talk about it ....it will happen
• Not a priority to me or on my “to do” list
• I’m too young
• I am not sick
• Don’t have the time
• Don’t know who to choose as my spokesperson
• Don’t know enough about it
Provider Community Challenges

- Lack of resources
- Provider discomfort with the conversations
- Inadequate education and skills training for providers
- Substantial time requirement for the conversations
- Scheduling issues
- Communication barriers/electronic systems incompatibility
- Reimbursement concerns – CY2015
Barriers in the Community

- Resource availability
- Lack of awareness
- Topic avoidance
- Questionable personal value
- Lack of Community support/champions
- Marketing challenges
- NO “DRESS REHEARSAL”

It’s always too early until it’s too late!!!!
Advance Directive Documents

Health Care Proxy: “WHO”
form for documenting a person(s) you appoint to make health care decisions for you anytime you are unable to make your own medical decisions, not only at the end of life. (Everyone over 18yrs.)

Living Will: “WHAT”
indicates your wishes about types of medical care you would want if you were in an incurable or irreversible mental or physical condition with no reasonable expectation for recovery. Difficult to predict specific future situations

MOLST: Medical Orders for Life Sustaining Treatment - ACTIONABLE MEDICAL ORDERS (appropriate for individuals with a life expectancy of one year or less)
Examine values, beliefs and hopes...

YOUR GOALS for CARE

- Cure disease
- Prolong life
- Maintain quality of life
- Retain control – be involved in decision-making
- Achieve maximum relief of pain and suffering
- Receive care where you want and from whom
- Have support for loved ones and family members
### What If You...?

<table>
<thead>
<tr>
<th></th>
<th>Definitely Want Treatment</th>
<th>Definitely Do Not Want Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>a.</td>
<td>No longer can recognize or interact with family or friends.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Comment:</td>
<td></td>
</tr>
<tr>
<td>b.</td>
<td>No longer can think or talk clearly.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Comment:</td>
<td></td>
</tr>
<tr>
<td>c.</td>
<td>No longer can respond to commands or requests.</td>
<td>1 2 3 4 5</td>
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<tr>
<td></td>
<td>Comment:</td>
<td></td>
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<tr>
<td>d.</td>
<td>No longer can walk but get around in a wheelchair.</td>
<td>1 2 3 4 5</td>
</tr>
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<td></td>
<td>Comment:</td>
<td></td>
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<tr>
<td>e.</td>
<td>No longer can get outside and must spend all day at home.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Comment:</td>
<td></td>
</tr>
<tr>
<td>f.</td>
<td>Are in severe untreatable pain most of the time.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Definitely Want Treatment</td>
<td>Definitely Do Not Want Treatment</td>
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<td>---------------------------------</td>
</tr>
<tr>
<td>g.</td>
<td>Are in severe discomfort most of the time (such as nausea, diarrhea).</td>
<td>1 2 3 4 5</td>
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<td></td>
<td>Comment</td>
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<tr>
<td>h.</td>
<td>Are on a feeding tube to keep you alive.</td>
<td>1 2 3 4 5</td>
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<tr>
<td></td>
<td>Comment</td>
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</tr>
<tr>
<td>i.</td>
<td>Are on a kidney dialysis machine to keep you alive.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Comment</td>
<td></td>
</tr>
<tr>
<td>j.</td>
<td>Are on a breathing machine to keep you alive.</td>
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<td></td>
<td>Comment</td>
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<tr>
<td>k.</td>
<td>Need someone to take care of you 24 hours a day.</td>
<td>1 2 3 4 5</td>
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<td></td>
<td>Comment</td>
<td></td>
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<tr>
<td>l.</td>
<td>No longer can control your bladder.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td></td>
<td>Comment</td>
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<tr>
<td>m.</td>
<td>No longer can control your bowels.</td>
<td>1 2 3 4 5</td>
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<td></td>
<td>Comment</td>
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</tr>
<tr>
<td>n.</td>
<td>Live in a nursing home permanently.</td>
<td>1 2 3 4 5</td>
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<tr>
<td></td>
<td>Comment</td>
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</tr>
<tr>
<td>o.</td>
<td>Other:</td>
<td>1 2 3 4 5</td>
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<tr>
<td></td>
<td>Explain</td>
<td></td>
</tr>
</tbody>
</table>
LEARN:

• Discuss your current health conditions with your provider and ask about specific clinical issues and treatment options you may need to consider in the future. Review your overall goals for care with your health care providers.

• Educate yourself about other life sustaining treatments
Choosing your Healthcare Agent
Who should you consider as your agent?

Someone who:

• you would trust with your life
• understands the responsibilities of the designation and says “yes” when asked
• meets legal criteria in your state
• knows and understands what is important to you
• can separate his/her own feelings and wishes from yours
• is able to think clearly in emotional situations
• can be a strong advocate in the face of conflicting opinions or resistance from family members, friends, providers or an institution
NYS Family Health Care Decisions Act

1. Court-appointed guardian
2. Spouse (if not legally separated) or domestic partner
3. Son or daughter 18 or older
4. Parent
5. Adult sibling
6. Close friend
The Conversations
“It’s always too early until it’s too late”

• 40% of all adult medical patients lack decision making capacity

• 44-69% of LTC residents lack decision making capacity

• The “vast majority” of critically ill patients lack decision making capacity

Most hospitalized patients will receive care from MDs who do not know them
It is time to move the CONVERSATIONS UPSTREAM Conversations before the CRISIS
Conversation Catalysts - Opportunities to “Talk”

- Birth
- Death
- Divorce
- Decline
- Diagnosis of serious illness
- Someone else’s experience
- Article/Book/Movie
- Presentation/event
Who should you be talking to?

• Your healthcare agent
• Your family
• Your healthcare provider(s)
• Your spiritual advisor
• Close friend
• Your attorney

***Those who might be present and able to support your healthcare agent should he/she need to speak on your behalf
Conversation Resources and Tools

• The Conversation Project
  www.theconversationproject.org

• The ABA Consumer Tool Kit of Advance Health Care Planning
  www.americanbar.org

• National Healthcare Decision Day Initiative
  www.NHDD.org

• Community Conversations on Compassionate Care
  www.compassionandsupport.org
Ellen Goodman, Director

Don Berwick, MD
Ira Byock, MD
Susan Block, MD
Atu Gwande, MD

http://theconversationproject.org/
The Conversation Project

• began in 2010, when Ellen Goodman and a group of colleagues and concerned media, clergy, and medical professionals gathered to share stories of “good deaths” and “bad deaths” within their own circle of loved ones.

• is dedicated to helping people talk about their wishes for end-of-life care. It’s time to transform our culture so we shift from not talking about dying to talking about it.
Online “Starter Kit”
http://theconversationproject.org/starter-kit/intro/

1) Get Ready – Consider the Facts
2) Get Set – questions to examine your values and goals and determine what matters most
3) GO – have the conversation, think about the basics. Who to talk to? When is a good time? Where would you feel comfortable? What do you want to be sure to say?
Consumer’s Tool Kit for Health Care Advance Planning

- **Complete Tool Kit**
- **Tool #1** How to Select Your Health Care Agent or Proxy
- **Tool #2** Are Some Conditions Worse than Death?
- **Tool #3** How Do You Weigh Odds of Survival?
- **Tool #4** Personal Priorities and Spiritual Values Important to Your Medical Decisions
- **Tool #5** After Death Decisions to Think About Now
- **Tool #6** Conversation Scripts: Getting Past the Resistance
- **Tool #7** The Proxy Quiz for Family & Physician
- **Tool #8** What to Do After Signing Your Health Care Advance Directive
- **Tool #9** Guide for Health Care Proxies
- **Tool #10** Resources: Advance Planning for Health Care (updated March ‘15)

[www.americanbar.org](http://www.americanbar.org)
April 16th

2016 Theme: "It Always Seems Too Early, Until It’s Too Late."

National Healthcare Decisions Day exists to inspire, educate and empower the public and providers about the importance of advance care planning.

http://www.nhdd.org/#welcome
• Participation by at least 110 national organizations
• Participation by at least 1,200 state/local organizations
• Participation at US military at bases throughout the world
• Over 3.5 million facility/organization staff members received NHDD/advance directive information or training
• At least 2.0 million members of the general public participated in NHDD events and/or were known to have received advance directive information
• Over 12 million people were exposed to NHDD via various social media outlets: Facebook, Twitter, and LinkedIn
• Over 30,000 advance directives were completed on the seven NHDDs alone
• In 2008 (NHDD’s inaugural year): NHDD was formally recognized by both houses of Congress (S.Con.Res.73 & H.Con.Res.323)
Starting the conversation

• Key is to normalize the conversation
• Try starting it after family history
• “Can you tell me about the supports in your life?”
• “Who should speak for you if you cannot speak for yourself?”
• “Have you ever thought about your end-of-life wishes?”
  • or... “about the kind of care you’d want if you got really sick someday?”
The conversation (continued)

• If they already have an advance directive (AD)
  • “May I see it? What does it say?”

• If they do not have an AD
  • “Can I offer you some tools to start thinking about it?”
    • Conversation Project Starter Kit
    • State Durable Power of Attorney for Health Care form

• Regardless of AD
  • “It is important that your surrogate know what your wishes are”
  • “A lot can happen beyond what is written in your AD”
  • The Conversation can be more powerful than the paper

• “Would it be ok if we talk about this at your next visit?”
  • Consider delegating follow up to another member of your team

January 2016
It’s Time to Start the Conversation

https://www.youtube.com/watch?v=Bar0qZTUGdw
Tricia’s Story
Tony’s Story
You Tube video link to:
Tricia’s story
Joanne’s story and
Tony’s story

www.compassionandsupport.org
The Health Care Proxy

(1) I hereby appoint

(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) Optional: Alternate Agent

This person I appoint to make health care decisions if the person I first appoint is unable or unavailable to act as my health care agent. I hereby appoint

(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Delete 1 clause (or more expansion(s) of a clause or both, in which it will expire, this proxy shall remain in effect indefinitely. (Optional). If you want this proxy to expire, state the date or conditions here. This proxy shall expire (specify date or conditions):

(4) Optional: I direct my health care agent to make health care decisions in accordance with my wishes and restrictions, as be or she know or is instructed below. (If you want to limit your agent’s authority to make health care decisions for you or give specific instructions, you may state your wishes or limitations below. I direct my health care agent to make health care decisions in accordance with the following limitations and instructions (attach additional pages as necessary):

In order for your agent to make health care decisions for you about artificial nutrition and hydration (by mouth or tube and intravenous line), your agent must reasonably know your wishes. You can either tell your agent, when you are competent and capable of making such decisions, your wishes about artificial nutrition and hydration.

(6) Optional: Organ and/or Tissue Donation

I hereby make an anatomical gift, to be effective upon my death, of (check one that apply): any needed organs or tissues. (Optional). If you want to limit your agent’s authority to make decisions about organ or tissue donation, state the date or conditions here.

(7) Limitations

If you do not state your wishes concerning your organ or tissue donation or your limits on your agent’s authority to make decisions about organ or tissue donation, it will not be unlawful for your agent to make decisions about organ or tissue donation on your behalf. (Optional). If you want to limit your agent’s authority to make decisions about organ or tissue donation, state the date or limits here.

(8) Statement for Witnesses

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. If the person signed was asked another to sign for him or her, this document is not in my possession.

Date

(9) Signature

Address

Name of Witness 1

Address

Name of Witness 2

Signature

Address

[Healthcare provider’s information]

[The Community Hospice]

[Information on how to contact The Community Hospice]
NYS Living Will

http://www.compassionandsupport.org/pdfs/about/Living_Will_Form.pdf
When should you review your Advance Directives?

- At least every 1-2 years
- Upon the death of a loved one
- If you experience a major life event – birth, adoption, marriage, divorce, separation or physical relocation
- If you are diagnosed with a serious illness
- If you experience a decline in your health status especially if it diminishes your ability to live independently
MOLST
Medical Orders for Life Sustaining Treatment

• [http://www.compassionandsupport.org/pdfs/professionals/molst/DOH-5003_06.10_.FINAL_.pdf](http://www.compassionandsupport.org/pdfs/professionals/molst/DOH-5003_06.10_.FINAL_.pdf)
MOLST

• Actionable Medical Orders
• Must be signed by a physician
• For individuals with serious health conditions that might die within 1 year
• Can indicate an individual wants to avoid or receive any or all life-sustaining treatment
• Transportable with patient across levels of care
• Requires review and signature by MD each time there is a change in patient’s condition or level of care
8-Step MOLST Protocol*

1. Prepare for discussion
   • Understand the patient and family
   • Understand the patient’s condition and prognosis
   • Retrieve completed Advance Care Directives
   • Determine “Agent” (Spokesperson) or responsible party

2. Determine what the patient and family know
   • re: condition, prognosis

3. Explore goals, hopes and expectations

4. Suggest realistic goals

5. Respond empathetically

6. Use MOLST to guide choices and have patient/family share wishes
   • Shared medical decision-making
   • Conflict resolution

7. Complete and sign MOLST

8. Review and revise periodically

*Developed for NYS MOLST, Bomba, 2005
Advance Care Directives

For All Adults

Health Care Proxy Form
Living Will
Organ Donation (optional)

For Those Who Are Chronically Ill or Near the End of Their Lives

Nonhospital Do Not Resuscitate (DNR) Order
Medical Orders for Life Sustaining Treatment (MOLST) form
Why complete Advance Directives?

- Enhances autonomy and self-determination
- Reflects value of life
- Retain Control
- Identifies quality of life choices
- Preserves dignity
- Identifies spokesperson
- Avoids unwanted and burdensome treatments
- Affirms religious beliefs
- Provides direction for and lessens the burden on family members
Facilitating the ACP Process

• LEAD BY EXAMPLE – PRACTICE WHAT YOU PREACH
• Provide quiet comfortable space
• Schedule ample (uninterrupted) time for the conversations
• Identify individual’s readiness – What do they know/understand/expect
• Ask if there is anyone else who should be present
• Encourage the individual to talk
• Listen attentively – clarify information and validate what was said
• Be prepared to respond to emotions
• As appropriate have informational materials and ACP documents available and assist in completion
It's time to start the conversation
Bibliography

Prepared by Janel Kaufman

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Deanna Cucharale

Deanna is a third year law student at Albany Law School. Her concentrations are in the areas of Trusts and Estates and Elder Law.


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