End-of-Life Planning & Communication
Your Right to Self-Determination

Amy Tucci, President & CEO, Hospice Foundation of America
Mark Starford, Executive Director, Board Resource Center
Hospice Foundation of America

Amy Tucci

501 c-3, founded in 1982
Information for the public
Professional education for clinicians

leadership in the development and application of hospice and its philosophy of care
Board Resource Center

Making Complex Ideas Simple

Accessible training and tools
Community advocacy
Create plain language media

Inclusion I Equal Rights I Leadership
“I want to have a voice in deciding what the last few weeks of my life will be like. I want my wishes to be honored.”

Self-Determination at the End-of-Life
Population Change 65 years +

Number of Persons 1900 to 2060 (millions)
Self-Determination

1991 - Congress passed the Self-Determination Act

Requires facilities that receive Medicare and Medicaid to inform patients about their right to complete an advance directive.
1996 American Medical Association Code of Ethics revised to emphasize importance of autonomy.

“Physicians have an obligation to relieve pain and suffering and promote the dignity and autonomy of dying patients in their care.”

**Autonomy:** Make informed treatment decisions consistent with culture, values, and belief systems.

Rooted in medical ethic of autonomy
Leana Wen, M.D.

*When Doctors Don’t Listen*

Patient Choice | Family Conversations
Survey

85% Doctors should discuss wishes with patients
15% Had discussion with a doctor
25% Patients with serious illness talked about wishes
55% Failed to name a healthcare agent

University of Massachusetts Medical School
<table>
<thead>
<tr>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Palliative Care</strong></td>
</tr>
<tr>
<td><strong>Hospice</strong></td>
</tr>
</tbody>
</table>
Health care Agent
Designated person to make care and treatment decisions.

Reasons for not naming a health care agent

- Am healthy and do not need one yet: 79%
- Spouse or family member will know what I want: 65%
- Will trust health care team to make decision: 41%
- Do not have person to choose as agent: 19%
- If choose one person, will upset others: 9%
Thinking Ahead Focus Groups

Sacramento
San Francisco
Fresno
Chico
Santa Barbara
Lila’s Story

Honoring Decisions
Video Report

PEACE OF MIND
Worries

Preferences ignored by medical staff/family
Family disagrees with personal choices
Healthcare agent authority
Treatments and care options available

“It’s my life, let me decide”
Want to learn more about

Responsibilities of the Healthcare Agent
How to talk with my family
Meaning of specific documents
Hospice care

“I want to remain in control”
Recommendations

Everyday “Plain” language
Short booklets - single topic
Short videos - personal stories
Large type

“Include us in the development of materials”
Being Mortal Project
Underwritten by the John and Wauna Harman Foundation

Americans are not having the conversations that would allow them to die according to their preferences.

Amy Tucci, President & CEO, Hospice Foundation of America
Nationwide public awareness campaign.
PBS FRONTLINE film, “Being Mortal,”
Educate and encourage people.
End-of-life preferences and goals with loved ones and medical professionals.

Extended through March 31, 2017
PBS FRONTLINE film

Being Mortal

Trailer

http://www.pbs.org/video/2365349267/
Almost **500** organizations
246 Hosts/246+ Partners

**136** events held, **300** Upcoming

**7,750** (approx) have/will attend events by Sept. 1.

More events everyday with recent extension!
Participant Survey Results

Taking Action for First Time
of Respondents Who Have Not Previously Taken the Action

- Think about the kind of... 97.97%
- Talk with a loved one... 97.15%
- Decide on the person I... 96.65%
- Encourage family... 96.22%
- Put my end-of-life wishes... 91.33%
- Tell my friends or family... 92.50%
- 92.15%
Why Host an Event?
Participant responses to survey questions

What one word best describes this experience?

- Prepared
- Inspired
- Joy
- Unprepared
- Overwhelmed
- Scared
- Sad
Participants
99%  Think “Everyone” should see *Being Mortal*.
85%  Would attend another end-of-life focused event.

Clinicians
88%  *Being Mortal* and discussion will be helpful in talking with patients. None felt it would not be helpful.
89%  Would encourage colleagues to watch *Being Mortal*.
72%  Pursue education/training on how to talk with patients.
Clinician Responses

- I've received some education or training, but having more would increase my skill and comfort with these conversations (44%)
- I've received sufficient education or training to feel confident and at ease with these conversations (27%)
- I've received no education or training in this area, but feel comfortable and confident having these conversations anyway (6%)
- I've received no education or training in this area and would benefit from it (5%)
- This type of education/training would not apply to my professional role (2%)
- N/A - Blank (16%)
## Reimbursement

### Advance Care Planning

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Amount</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>99497</td>
<td>Explanation and discussion of advance directive forms with or without completing forms, by a qualified health care professional with the patient, family member(s), and/or surrogate. <em>First 30 minutes</em></td>
<td>$86</td>
<td>office</td>
</tr>
<tr>
<td></td>
<td><em>Physicians, non-physician practitioners, other staff under order and medical management of the physician.</em></td>
<td>$80</td>
<td>hospital</td>
</tr>
<tr>
<td>99498</td>
<td>Each additional 30 minutes</td>
<td>$75</td>
<td></td>
</tr>
</tbody>
</table>

California Coalition of Compassionate Care  
Jan 2016
Limited Health Literacy

Capacity to get and understand basic health information
Limited Health Literacy

Could have difficulty with

Understanding specific medical advice
Knowing what medical terms mean in a document
Which document applies to a situation
Physicians

End-of-life conversations with families

29% Received training
Physicians who talked with their medical provider (their own end-of-life wishes)

Yes 48%
No 52%
Successful Meetings

Healthcare Professional –

- Speaks in everyday (Plain) language
- Willing to listen
- Provides easy-to-understand forms (if needed)
- Provides easy read resource materials (if needed)
- Is sensitive to culture and family relationships

“I have to understand to make an informed choice and be self-determined”
Lessons Learned

Information makes a difference
Join community conversation groups
Demand accessible resources
Choose health care agent wisely
Physicians and other medical professionals want education
Resource Materials

- Presentation
- Video clips
- Reports/Surveys
- Articles
HFA  https://hospicefoundation.org/

BRC  http://brcenter.org/
    http://www.you-determine.org/