

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

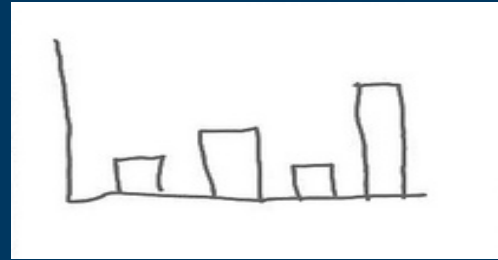
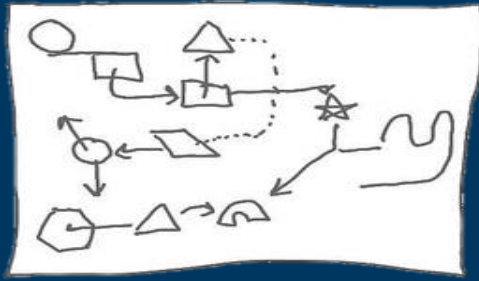
Amy Tucci

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



Making Complex Ideas Simple

 **Board
Resource
Center**
Mark Starford

Accessible training and tools
Community advocacy
Create plain language media

Inclusion | Equal Rights | 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



Learn About

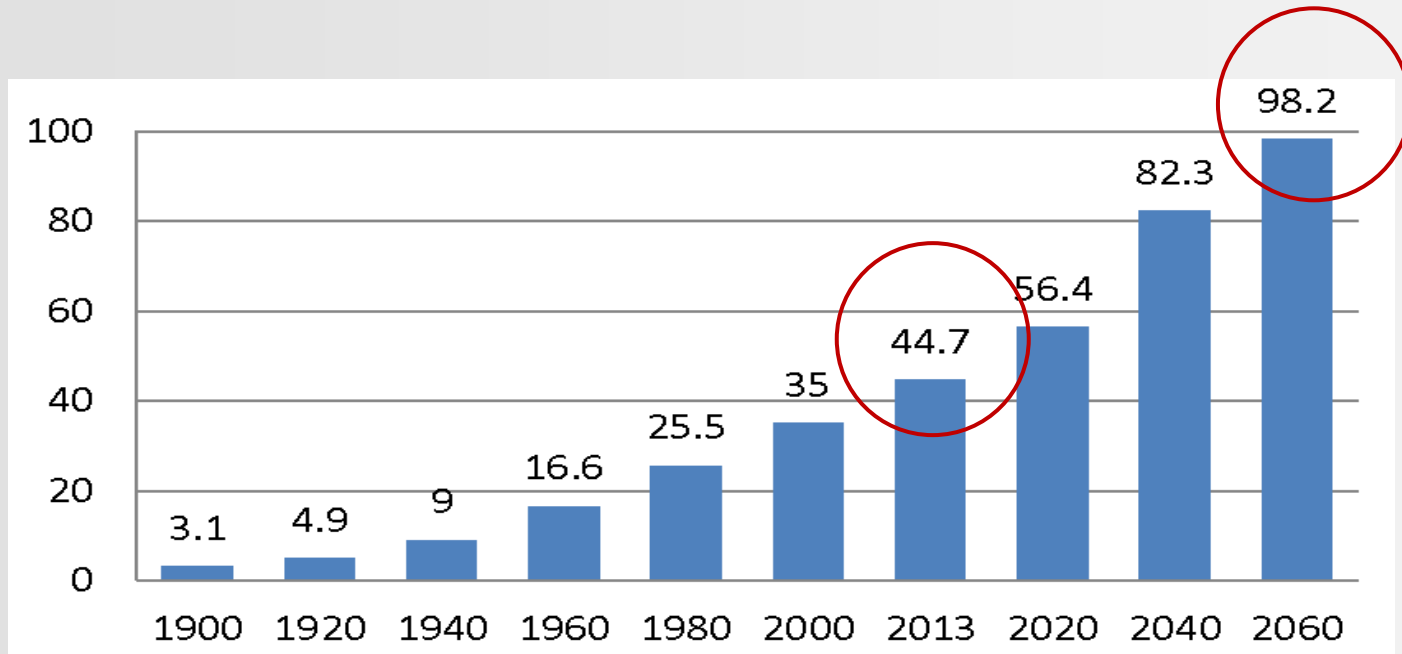
education ■ communication
planning ■ recommendations





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.



Medical Self-Determination

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



TEDMED

Leana Wen, M.D.

When Doctors Don't Listen

Patient Choice | Family Conversations



DATA



KNOWLEDGE



ACTION

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



Definitions

Palliative Care

Focus on relieving pain & symptoms, curative treatment can continue.

Hospice

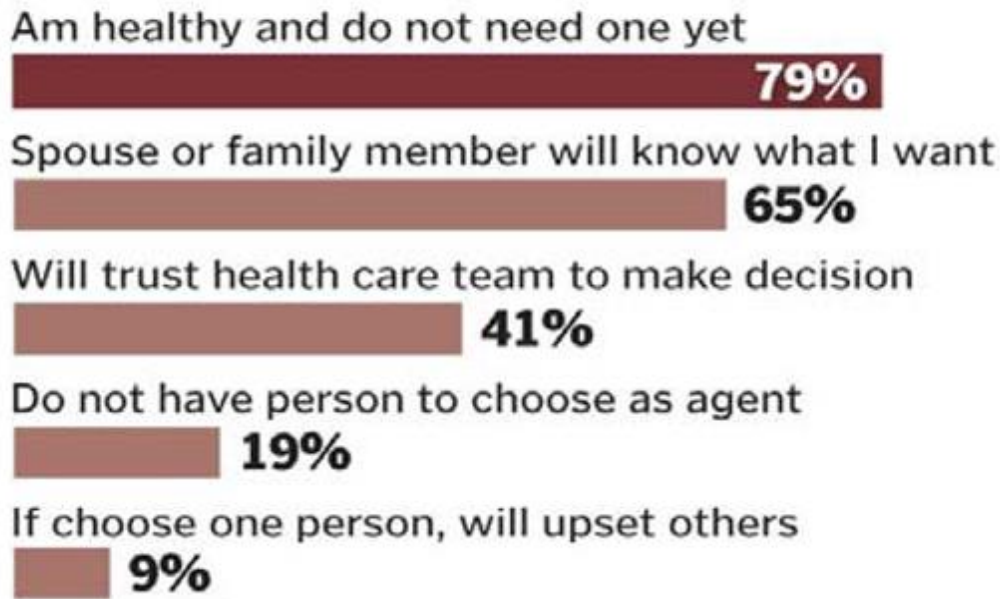
Focus on relieving pain & symptoms, providing social, spiritual supports. Generally, but with exceptions, curative care stops.



Health care Agent

Designated person to make care and treatment decisions.

Reasons for not naming a health care agent





Thinking Ahead Focus Groups



Sacramento
San Francisco
Fresno
Chico
Santa Barbara

Seniors | People with Disabilities | Providers | Adult Children



Lila's Story



Honoring Decisions



PEACE OF MIND

Video Report



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”

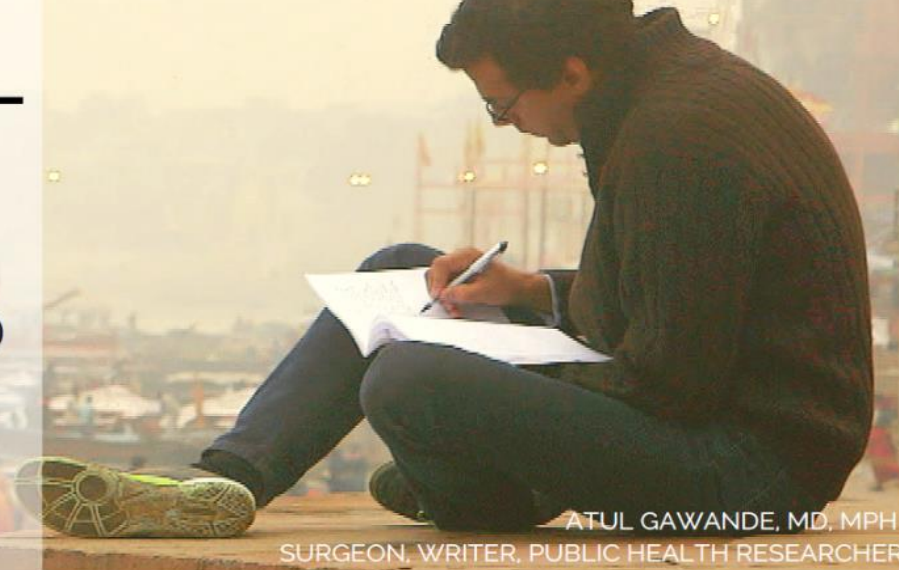
BEING MORTAL

"HOPE IS NOT A PLAN."

A PROJECT OF

HFA
HOSPICE FOUNDATION
OF AMERICA

SUPPORT FROM
THE JOHN AND
WAUNA
HARMAN
FOUNDATION



ATUL GAWANDE, MD, MPH
SURGEON, WRITER, PUBLIC HEALTH RESEARCHER

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



Project Overview

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

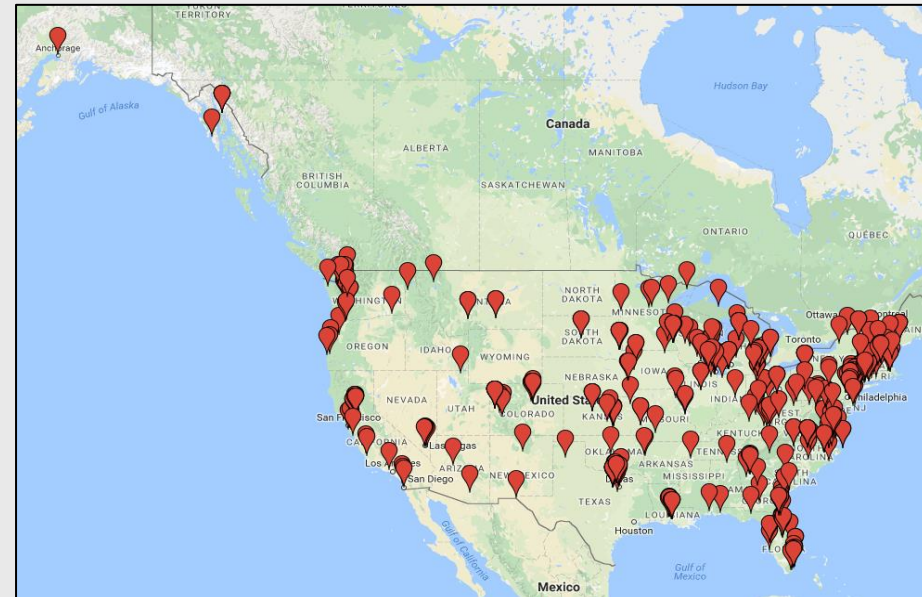
<http://www.pbs.org/video/2365349267/>



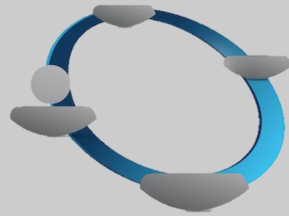
Almost **500** organizations
246 Hosts/246+ Partners

136 events held, **300** Upcoming

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



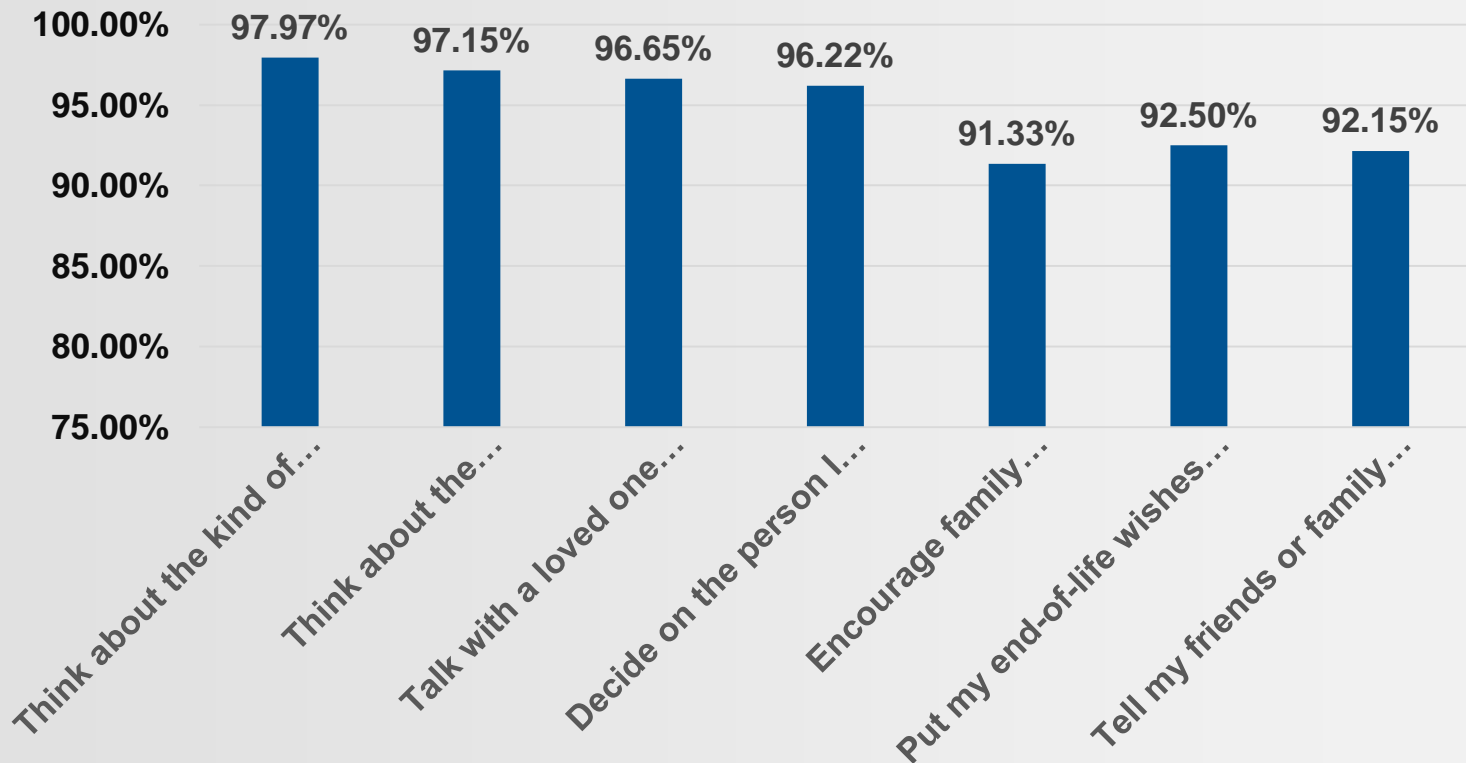
More events everyday with recent extension!



Participant Survey Results

Taking Action for First Time

of Respondents Who Have Not Previously Taken the Action





Why Host an Event?

Participant responses to survey questions

What one word best describes this experience?

Prepared
Inspired
Joy

Unprepared
Overwhelmed
Scared
Sad



Responses

Participants and Clinicians

Participants

99% Think “Everyone” should see *Being Mortal*.

85% Would attend another end-of-life focused event.

Clinicians

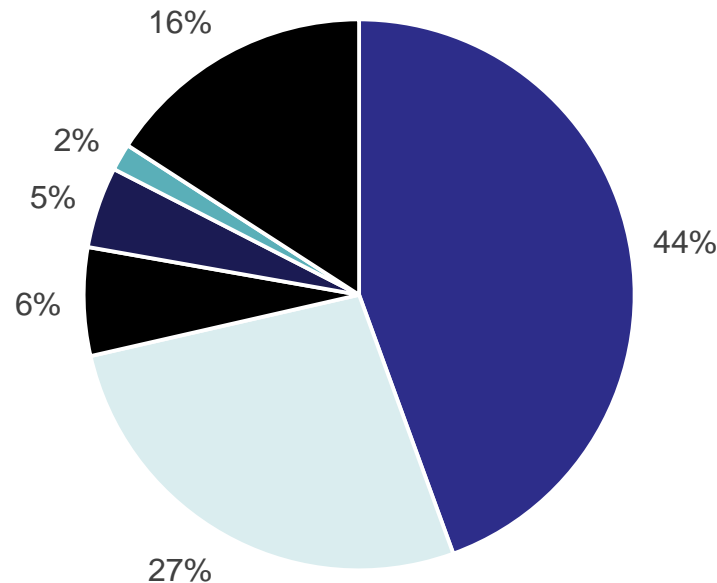
88% *Being Mortal* and discussion will be helpful in talking with patients. None felt it would not be helpful.

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%)



Medicare

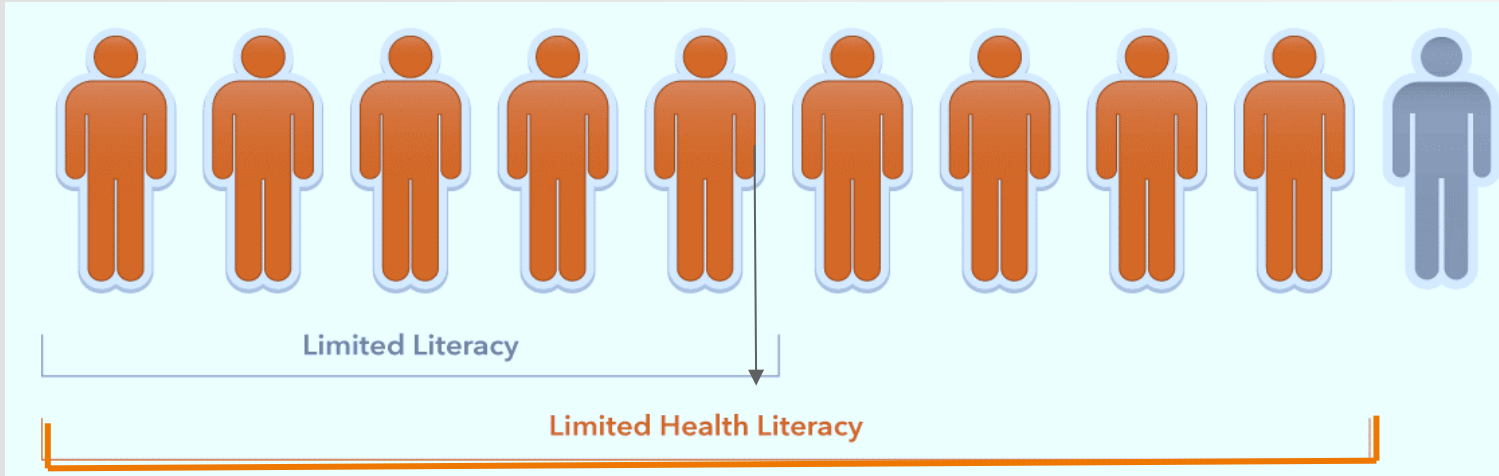
Reimbursement

Advance Care Planning

Code	Description	Amount
99497	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. <i>First 30 minutes</i>	\$86 office
	<i>Physicians, non-physician practitioners, other staff under order and medical management of the physician.</i>	\$80 hospital
99498	Each additional 30 minutes	\$75



Limited Health Literacy



Capacity to get and understand basic health information



Limited Health Literacy

Could have difficulty with

Understanding specific medical advice

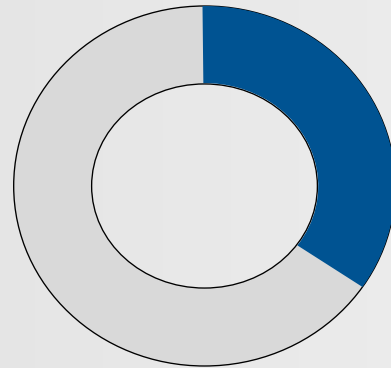
Knowing what medical terms mean in a document

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/>