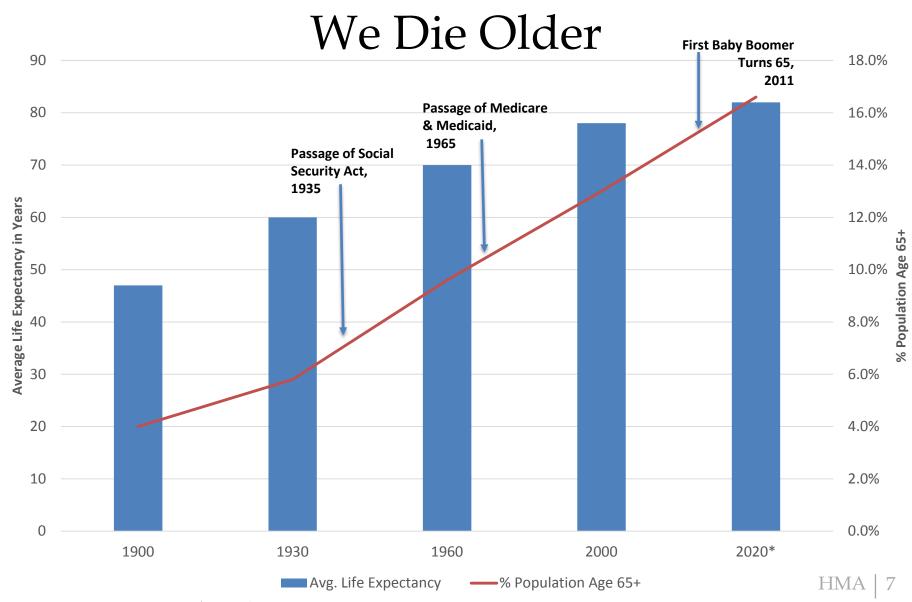


Value Based End-of-Life Care and Planning

PROBLEM STATEMENT

The way people die has, in large part, changed significantly over time; and our systems for dealing with dying and death have not evolved to respond to new and forthcoming realities and to result in quality end of life planning and care.



We Die More Slowly

	1900	2000
Age at Death	46	78
Top Causes of Death	Infection Accident Childbirth	Cancer Organ System Failure Stroke Dementia
Disability	Not much	Average 2-4 years before death
Financing	Private, Modest	Public, Substantial

Source: J. Lynn, 2015

Systems

- Healthcare payers pay for curative care
- Healthcare education focuses on curative care
 - Survey of 122 medical schools and 34 nursing schools to obtain information regarding coursework training in the areas of palliative, emotional, and spiritual care to the dying (Cowgill and Cowgill, 2013)
 - 8 medical schools and 0 nursing schools had mandatory course work
 - 16 medical school offered elective course work
- We are culturally focused on curative care

Discomfort and Fear: EOL Conversations

Individuals

- Difficulty accepting diagnosis
- Fear about care that will or won't be provided
- · Worry about family members' burden or perspective

Families

- Lack of clear decision tree
- Fear of guilt
- Lack of knowledge/understanding of individual's preference

Providers

- Reluctant to deliver bad news
- Admission of defeat
- Change in relationship with individual
- Fear of offense

Barriers to Conducting Effective EOL Conversations

- Language and medical interpretation issues
- Patient/family religious and spiritual beliefs about death and dying
- Doctor's ignorance of patients' cultural beliefs, values, and practices
- Cultural differences in truth handling and decision making
- Patient/family's limited health literacy
- Patient/family's mistrust of doctors and the healthcare system

Source: Periyakoil VS, Neri E, Kraemer H (2015) No Easy Talk: A Mixed Methods Study of Doctor Reported Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients. PLoS ONE 10(4): e0122321. doi:10.1371/journal.pone.0122321

Value Based End-of-Life Care and Planning

SYSTEM AND CULTURAL CHANGE

Medicare and EOL

- January 1, 2016, Medicare begins paying for end-of-life discussions
- Medicare Care Choices Model

Medicare Care Choices Model



Through the Medicare Care Choices Model, the Centers for Medicare & Medicaid Services (CMS) will provide a new option for Medicare beneficiaries to receive hospice-like support services from certain hospice providers while concurrently receiving services provided by their curative care providers. CMS will evaluate whether providing these supportive services can improve the quality of life and care received by Medicare beneficiaries, increase patient satisfaction, and reduce Medicare expenditures.

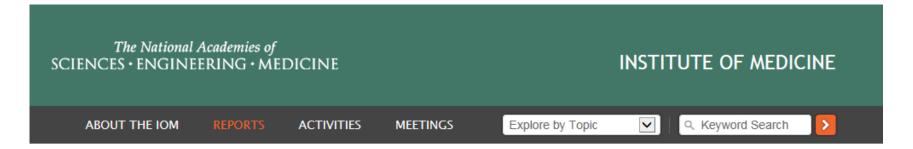
Under current payment rules, Medicare and dually eligible beneficiaries are required to forgo curative care in order to receive services under the Medicare or Medicaid Hospice Benefit.

Fewer than half of eligible Medicare beneficiaries use hospice care and most only for a short period of time.

The model is designed to:

- Increase access to supportive care services provided by hospice;
- Improve quality of life and patient/family satisfaction;
- Inform new payment systems for the Medicare and Medicaid programs.

"...to receive hospicelike support services.... while concurrently receiving...curative care..."



Report



Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life

Released: September 17, 2014

REPORT AT A GLANCE

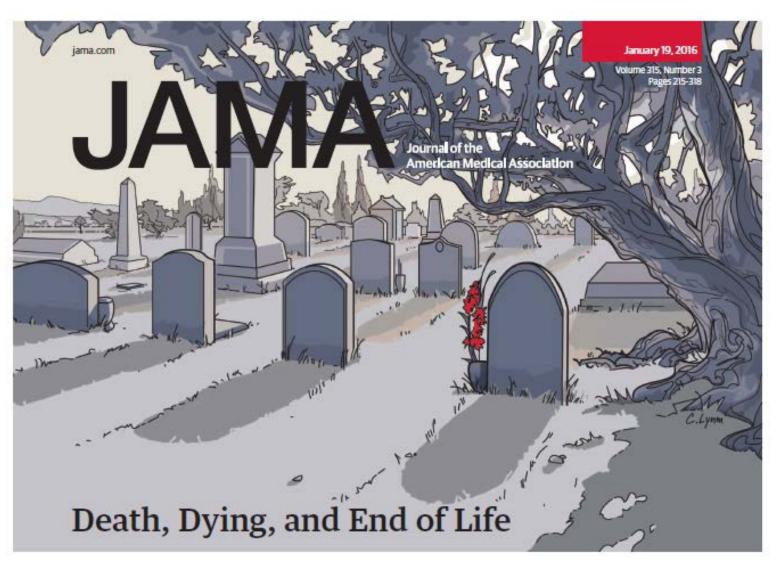
- The Conversation (HTML)
- Introductory Slides (HTML)
- Organizational Commitment Statements (HTML)
- Report Brief (PDF, HTML)
- Stakeholder Webinar Recording (HTML)
- Stakeholder Webinar Slides (HTML)
- · Key Findings and Recommendations (PDF)
- · Core Components of Quality End-of-Life Care (PDF)
- Infographic (PDF)
- Palliative Care Graphic (PDF, HTML)
- Palliative Care Graphic (Spanish) (PDF, HTML)
- Palliative Care Graphic (Portuguese) (PDF, HTML)

Get this Report



Details

Activity:	Committee on Approaching Death: Addressing Key End of Life Issues
Type:	Consensus Report
Topics:	Aging, Health Care Workforce, Health Services, Coverage, and Access, Public Health, Quality and Patient Safety





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'Right to Try' Legislation Tracker

Posted 24 June 2015

By Alexander Gaffney, RAC

Since early 2014, more than 20 states have introduced so-called "Right to Try" bills in the hopes of allowing terminally ill patients to access experimental—and potentially life-saving—treatments more easily. These bills are modeled off a federal policy known as " Compassionate Use," but contain several key changes meant to make it faster and easier for patients to obtain experimental therapies.

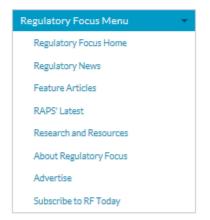
This Right to Try Legislation Tracker is meant to be a resource for regulatory professionals and patients to keep track of legislation as it moves through various state legislative bodies.

Last updated 25 June 2015: Legislation awaiting Governor's signature in North Carolina. Fixed error indicating Maine had passed a RTT law (it has not).



Regulatory Tracker





States With Right to Try Laws

State	Link to Legislation
Alabama	Text of Legislation
Arizona	Ballot Measure
Arkansas	Text of Legislation
Colorado	Text of Legislation
Florida	Text of Legislation
Indiana	Text of Legislation

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THE BRITTANY MAYNARD FUND



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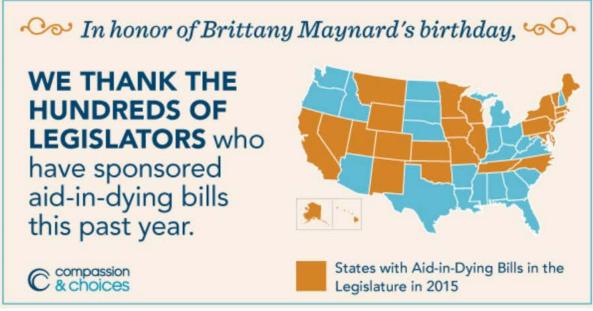
"My dream is that every terminally ill American has access to the choice to die on their own te with dignity. Please take an active role to make this a reality." – Brittany Maynard

Send a note to Brittany's Husband Dan Diaz

C&C Observes Day of Gratitude



have joined in bringing acces



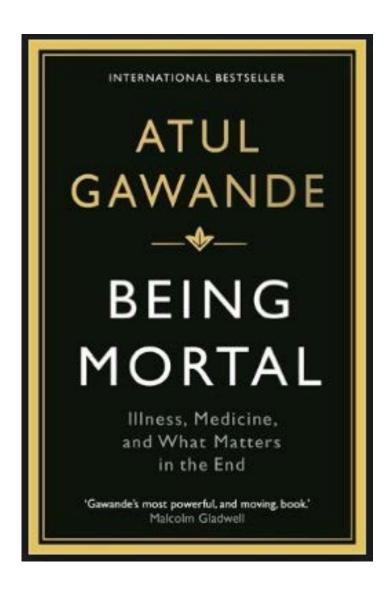
November 19, 2015, is our first ever Day of Gratitude, in honor of Brittany Maynard's birthday. Because Brittany shared her story and touched the lives of millions of people, more than half of the states and the District of Columbia introduced aid in dying legislation in 2015.



LEGEND 01.31.16 12:15 AM ET

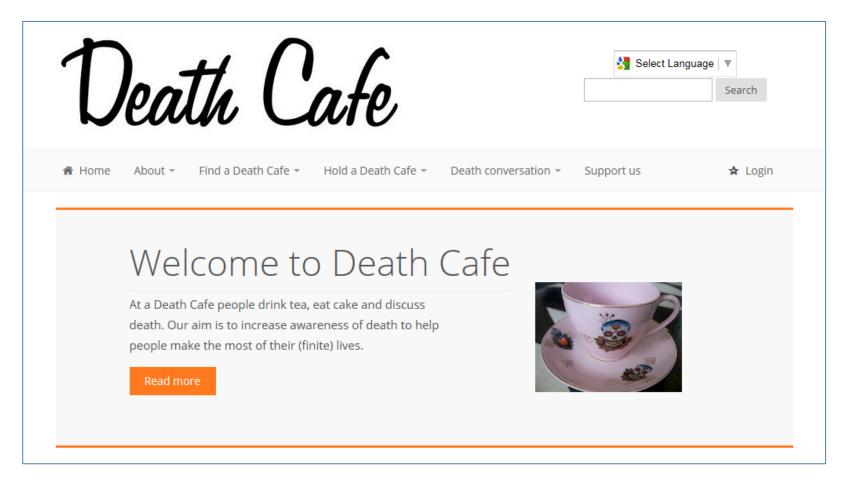


Diane Rehm On Living—And Dying—With Dignity



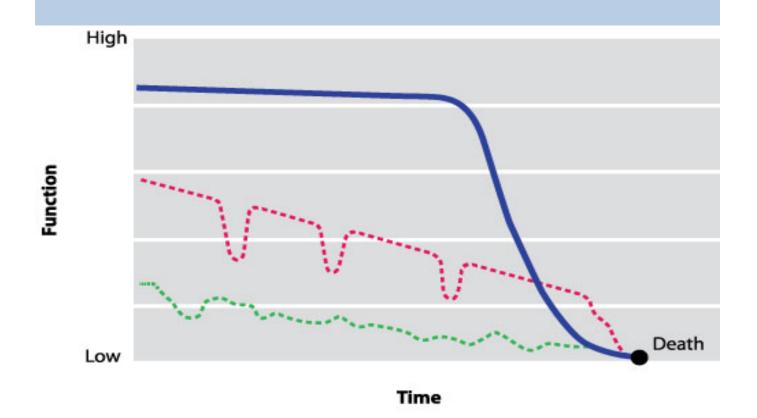
"If your problem is fixable, we know just what to do. But if it's not? The fact that we have had no adequate answers to this question is troubling and has caused callousness, inhumanity and extraordinary suffering."

Death Cafe



What is End of Life Care?

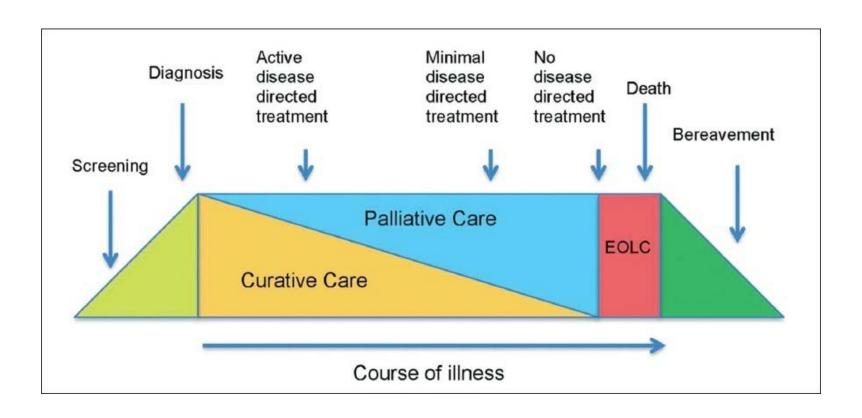
Uncertainty in Late Stage Illness



Palliative Care vs Hospice

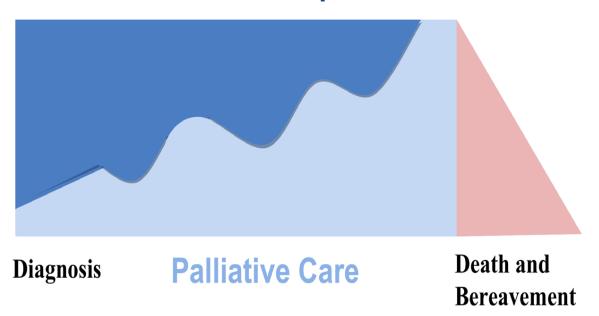
- Palliative care focuses on the best-possible QoL based on patient/family needs and goals, independent of prognosis or care setting.
- Addresses symptom burden, complex medical decision making, mobilize practical aid.
- **Hospice** provides palliative care in the <u>last six</u> months of a terminal illness & bereavement.
- When hospice care is chosen, a beneficiary is no longer eligible to receive curative care.
- Both are interdisciplinary.

Medical Care In Late Stage and Serious Illness



Concurrent Care = Palliative + Curative

Disease-Directed Therapies





Value Based End-of-Life Care

THE BUSINESS CASE

Value in Palliative & EoL Care



Palliative care programs increase value by both improving quality and reducing costs of care.

(Anderson and Horvath 2002; Back, Li, and Sales 2005; Brumley et al. 2007; Elsayem et al. 2004; Kelley and Meier 2010; Morrison et al. 2008; Penrod et al. 2006; Smith et al. 2003; Temel et al. 2010; Teno et al. 2004; Wright et al. 2008; Zhang et al. 2009).

Value Proposition for Palliative Care

Quality

- Be home
- Family support, care coordination, home care
- Less symptom burden
- Higher satisfaction
- May prolong life

Cost

- Fewer acute admissions
- More hospice referrals
- Direct admissions to the palliative care service
- Avoid non-beneficial or harmful services and procedures

What is Hospice Benefit?

- Formalized as a Medicare benefit in 1982.
 Covered by both Medicare and Medicaid.
- Only 47% of Medicare beneficiaries use hospice care and only for a short time.

• Low enrollment in part due to reluctance to forgo curative care.

Business Case: Palliative Care

- Average per-patient per-admission net cost saved by hospital palliative care consultation is \$2,659
- Palliative care programs should serve ~6% discharges
- In 2009, PC programs reach ~1.5% discharges with estimated savings of \$1.2B/year at 1,500 U.S. hospitals

Saving could reach ~ \$4 Billion/year if capacity were expanded

(Morrison, Meier, and Carlson 2011; Morrison et al. 2008; Siu et al. 2009).

Business Case: Hospice care

 An estimated \$2,300 is saved per hospice patient, compared with similar patients not receiving hospice services

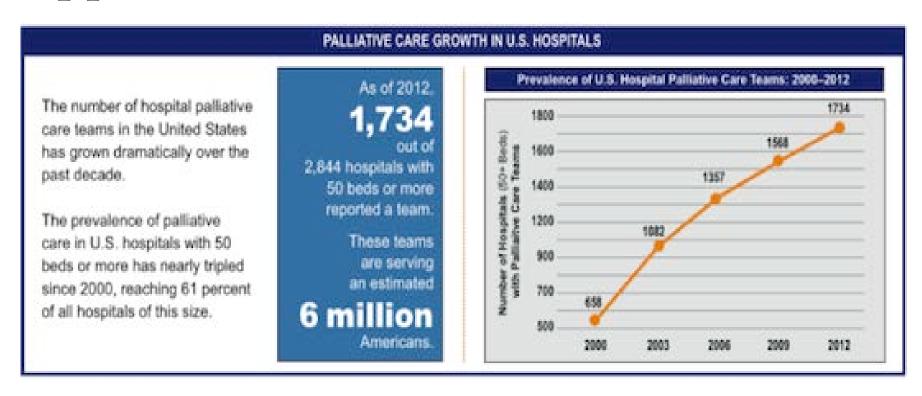
1.5M hospice patients served \times \$2,300 = \$3.5Bil/yr

(Carlson 2010) (Taylor 2009; Taylor 2007)

Barriers to Palliative Care & Hospice

- Variability in access
- Inadequate workforce
- Insurance barriers
- Lack of public knowledge of, and demand for, the benefits of palliative care and hospice
- Lack of public trust creates reluctance to engage in advance care planning

Opportunities for Value-based EOL Care



ACA law allows integration of palliative care and hospice programs in (ACOs), (PCMHs) and the bundling of payments for a single episode of health care.

Concurrent Care Model

• Medicare Care Choices Program: the option to receive supportive care services typically provided by hospice, while continuing to receive curative services.



Effective Advanced Care Planning

- Relationship-centered decision making for EOL Care
 - Engage a healthcare proxy
 - Assess past experiences
 - Meet people where they're at in acceptance
 - Don't force a DNR
 - Revisit decisions on care whenever needed
 - Avoid abandonment

The Conversation: Advance Care Planning

Assess Advance Care Planning Discussion Opportunistic informal conversations Formalised systematic What? What matters to you? What do you wish to happen? What do you do not want to happen? Who? Named spokesperson (informal) Can tell those who act in best interests what sort of person you are Lasting Power of Attorney (formal) Can make legal decisions regarding your health Where? Preferred Place of Care Carer's Preferred Place of Care Other? assess Special instructions-Organ/tissue donation framework

Using trauma-informed practices to have the conversation with your patients

A CASE STUDY: ANN

Ann's EHR Problem List

- Alcohol dependence in remission
- COPD
- Lung cancer Stage III
- Cannabis abuse
- Self-injurious behavior
- Antisocial personality disorder
- Noncompliance with medication treatment due to overuse of medication
- Ankle fracture
- Depressive disorder

- PTSD
- GAD (Generalized Anxiety Disorder)
- Bipolar disease, depressed
- Vaccine refused by patient
- Hand fracture
- Broken wrist
- Drug-seeking behavior
- Benzodiazepine abuse, continuous

Traumatic events

- Physical assault
- Sexual abuse
- Emotional or psychological abuse
- Neglect/abandonment
- Domestic violence
- Witnessing abuse/violence
- War/genocide

- Accidents
- Natural or man-made disasters
- Dangerous environment
- Witness or experience street violence
- Poverty
- Homelessness
- Historical trauma and current oppression

Impact of Trauma

- Emotional Reactions
 - Feelings-regulation
 - Alteration in consciousness
 - Hypervigilance
- Psychological and Cognitive Reactions
 - Concentration impaired, slowed thinking, difficulty with decisions, blame
- Behavioral or physical
 - Pain, sleep, illness, substance use
- Beliefs
 - Changes your sense of self, others, world
 - Relational disturbance

Trauma Informed Care

- A program, organization, or system that is trauma-informed:
 - Realizes the widespread impact of trauma and understands potential paths for recovery;
 - Recognizes the signs and symptoms of trauma in clients, families, staff, and other involved with the system;
 - Responds by fully integrating knowledge about trauma into policies, procedures, and practices; and
- Seeks to actively resist re-traumatization (SAMHSA, 2014)

Coming in to Talk with Ann

- Who should have the conversation with patients?
- Quiet, calm, unhurried time to talk
- An invitation to talk:

"Ann, I understand you just had a difficult conversation with your doctor during your recent hospitalization.

Would it be ok to talk about it?"



The Conversation with Ann

- Use short explanations; check for understanding and questions
- Give a person time to think... but long silences are not helpful
- Use non medical language
- Leave the door open for future conversations
- Trust that people will lead you and provide information

We Want to Engage People, Not Re-traumatize Them

- Develop a script for yourself. Carry it in your pocket and use it.
 - "Help me understand what the medical team told you."
 - "What do you understand about your situation?"
 - "What is most important to you?"
 - "What would help you the most to live better?"
- Listen. Provide information. Keep explanations simple and short. Check for understanding.

