POLICY AND POLITICS OF ADVANCED ILLNESS AND END-OF-LIFE CARE:

CHALLENGES AND OPPORTUNITIES

LONG-TERM CARE DISCUSSION GROUP

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What is C-TAC?

The Coalition to Transform Advanced Care (C-TAC) is a nonpartisan, not-for-profit alliance of over 140 national healthcare stakeholders dedicated to the idea that all Americans with advanced illness, receive comprehensive, high-quality, person-centered care that is consistent with their goals and values, and honors their dignity.
What is Advanced Illness?

Advanced illness is defined as one or more conditions becoming serious enough that general health and functioning begin to decline, curative treatment loses its effectiveness, and care becomes increasingly oriented towards comfort — this process extends to the end of life.
How do we redesign our health care system to be fully responsive to one’s goals, values, and wishes – especially at the end-of-life?
**THE PROBLEM:**

**“THE BIG GAP”**

<table>
<thead>
<tr>
<th>What People Want</th>
<th>What They Get</th>
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<td>1. Be at home with family, friends</td>
<td>Recycled through the hospital</td>
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<td>2. Have pain managed</td>
<td>Often unwanted, ineffective treatment</td>
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<td>3. Have spiritual needs addressed</td>
<td>Often die in hospital, in pain and isolation</td>
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<td>4. Avoid impoverishing families/being a burden</td>
<td>At great cost to families and the nation.</td>
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THE PROBLEM: THE “CONVERSATION” AND PHYSICIAN TRAINING

• A recent study show that approximately 42% of individuals have had discussions on end-of-life issues.

• Yet only 23% put their care directives in writing and/or legal/medical (aka POLST) documentation.

• And a full 90% said that they physicians never asked about this issue.

Source: John H. Hartford Foundation
Not for copy or distribution
THE PROBLEM:
AMERICANS HIGHLY CONCERNED ABOUT TREATMENT OPTIONS

How concerned are you about not having adequate treatment options at the end-of-life?

- Concerned: 73%
- Not Concerned: 27%

Source: Cambia Health, 2014
THE PROBLEM:
WHERE DO INDIVIDUALS WISH TO DIE? AND WHERE DO THEY ACTUALLY DIE?

Where They Wish to Die
- Home: 70%
- Other/No Pref: 30%

Where They ACTUALLY Die
- Home: 68%
- Other/No Pref: 32%

Source: California Health Care Foundation, 2016
Despite Growing Average Length of Stay (25% increase over last 5 years), Short Stays Remain Very Concerning

- 36% Died within 7 days
- 64% died outside 7 days

Source: NHPCO, 2015
The (Most Obvious) Problem: Cost Implications

Source: American Academy of Actuaries
C-TAC Policy & Advocacy

C-TAC, along with our members and partners, pursues a comprehensive policy agenda at both state and federal levels focused on delivery system reform, preference driven care, caregiver and consumer support, and professional engagement involving both legislative and regulatory strategies.
C-TAC’s agenda addresses the barriers to better advanced illness care:

- Promoting **person-centered care coordination** in advanced illness
- Supporting **payment structures for innovative models**
- Establishing **best practice based care**
- Identifying **comprehensive quality measures**
- Ensuring impact and accessibility of **advance directives**
- Increasing availability of resources for **family caregivers**
- Expanding the **advanced care workforce**

Our primary goal is to establish a Medicare advanced care demonstration through CMS. Payment is the number one barrier in providing services to people with advanced illness. This shift in how we pay for healthcare is a part of the national shift from quantity to quality.
C-TAC Supported Legislation

- *The Patient Choice and Quality Care Act of 2017* (S.1334/H.R.2797)
- *The Compassionate Care Act of 2017*
- *The Removing Barriers to Person-Centered Care Act of 2017*
- *Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act* (S.870) *(Enacted)*
- *Independence at Home Act of 2017* (S. 464)
- *Medicare Choices Empowerment and Protection Act of 2017* (H.R. 3181)
- *Palliative Care and Hospice Education and Training (PCHETA) Act* (H.R. 1676)
- *Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act* (H.R. 3759) *(Enacted)*
- *Rural Access to Hospice Act* (S. 980)
Progress: Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act (S.870)

Who?
Sens. Hatch [R-UT] and Wyden [D-OR] and every member of the Senate Finance Committee.

What?
• Extends Independence at Home demonstration by 2 years
• Includes GAO study on “longitudinal care planning”
• Permanently authorizes SNPs
• Expands testing of MA Value-Based Insurance Design test model.
• Allows MA to provide additional telehealth benefits to enrollees and, to chronically ill enrollees, certain supplemental health care benefits.
• Allows prospective, voluntary assignment of Medicare fee-for-service beneficiaries to accountable care organizations (ACOs), and
• Allows ACOs to operate beneficiary incentive programs.
Progress: Bipartisan Push for Advanced Illness Care Demonstration & Quality Measure Development

Dear Secretary Azar and Administrator Verma,

We appreciate your leadership in considering innovative models for quality-oriented palliative care. Last year, we introduced the Patient Choice End-of-Life Care Act (H.R. 27576, 114th Cong.) which addresses a number of issues that threaten quality care for individuals with serious, chronic progressive or advanced illness. The legislation provides for Medicare (CMS) to develop a demonstration to test the impact of care management models that are integrated and aligned across the continuum of care to improve quality and reduce costs for Medicare beneficiaries.

We are sending you this letter to provide additional information on the model’s potential impact on quality care delivery and patient outcomes. We believe that the model can improve care for individuals with serious, chronic progressive or advanced illness by ensuring that care is more patient-centered and coordinated across the continuum of care.

Recent data show that Americans are living longer with significant changes in health status and quality of life. The Patient Choice End-of-Life Care Act would provide the flexibility and resources needed to support these changes. The Center for Medicare and Medicaid Services (CMS) is currently developing the demonstration and has issued a request for proposals to States to develop and test care management models that meet the needs of Medicare beneficiaries.

Thank you for your consideration of this important issue.

Sincerely,

Phil Roe
Representative Phil Roe

Mark P. Haxton
Representative Earl Blumenauer
Encouraging Words From Secretary Azar

Senate Finance Committee Hearing on the Nomination of Sec. Azar:

Senator Warner: An issue that Senator Isakson and I have been working on for a long time is advance care planning and end-of-life issues, and CMS obviously made a major step forward a few years back where they went ahead and put a coding in for that consult. I would just like to get you on the record in terms of [...] recognizing we don’t want to limit anyone’s choices, but we want to honor and respect peoples choices about care planning or end of life issues.

HHS Nominee Azar: I think it’s a very important part of all of our personal care management in life as we think about our life and our health care and our family members that we engage in that kind of thoughtful, directive planning of what do we desire. As you said, it’s not about imposing any one’s views on someone else it’s actually about ensuring systems respect that individual’s choices, and enabling that is very important for us.
Question: Does the Affordable Care Act allow a government panel to make decisions about end-of-life care for people on Medicare?
THANK YOU

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