



# Summary Report of National Summit on Advanced Illness Care

January 29-30, 2013

Coalition to Transform Advanced Care (C-TAC)



The C-TAC National Summit on Advanced Illness Care: A Roadmap for Transformation<sup>1</sup>, January 29-30, 2013, was a landmark event to assure compassionate, high-quality, person- and family-centered care for Americans with advanced illnesses. Over 400 participants from many disciplines and organizations, representing patients, families, policy makers, faith communities, media, and health care professionals gathered to discuss needed changes in our nation's care system to assure that people with advanced illnesses receive care consistent with their values and wishes.

The conference had two goals:

- To create a common understanding among participants of the issues, challenges, and range of possible solutions; and
- To create a shared sense of mission and action steps for achieving high-quality, advanced illness care<sup>2</sup>.

The Summit's emphasis on the social, financial and spiritual impact on patients and families, as shared through personal stories, underscored the urgency and importance of these goals. The wave of Baby Boomers reaching their middle-sixties, when serious chronic illnesses are more likely, substantially raises the stakes for society. But Americans of all ages are at risk of illness or injury that requires ongoing, complex care, and everyone may someday be a caregiver for friends or family members.

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*"I was an outsider in my own care."*

- Bruce T., featured in *A Biker's Heart*

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*"This has to be about the goals, choices and respect of the individual."*

- Kathy Greenlee,

Assistant Secretary for Aging and Administrator, Administration for Community  
Living, U.S. Department of Health and Human Services

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1 The Summit was hosted by the Coalition to Transform Advanced Care (C-TAC). Meeting sponsors were: American Heart Association (AHA); American Hospital Association (AHA); American Heart Association (AHA); American Hospital Association (AHA); American Society of Clinical Oncology (ASCO); Institute of Medicine (IOM); National Hospice and Palliative Care Organization (NHPCO); Pfizer; American Cancer Society Cancer Action Network (ACS CAN); the Schaeffer Center for Health Policy and Economics; and the Cambia Health Foundation.

2 High-quality care, as defined in past Institute of Medicine studies, is care that is safe, effective, patient-centered, timely, efficient, and equitable.

## 1. Caregiving Issues

Caregiving extracts a tremendous toll on family and friends. A financial impact arises when a family loses all or part of its income at the same time it faces high out-of-pocket health and other non-covered costs (with medical bills the biggest cause of personal bankruptcy). Caregivers' health, mental health, and well-being are frequently jeopardized, including higher incidence of chronic conditions.

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*"Caregivers want to know, 'Am I doing it right?'"*

—Susan Reinhard, AARP

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No matter how much good will and compassion are involved, even routine care, such as bathing, incontinence care, or maintaining a special diet are not easy for caregivers, and they need guidance and support. These are long-standing problems. What's different today is that families increasingly are expected to perform a range of complex medical services and deal with high-tech equipment—"medical nursing care"—with only rudimentary training, if any, and without a determination of whether they are able to do so. These high-level demands are becoming a new normal phase of life for many. In the current economy, employer-sponsored eldercare programs and other caregiver support funding have decreased, a situation that especially affects middle class individuals, who are ineligible for low-income programs and unable to pay for help out-of-pocket.

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*"Denial is nowhere near a strong enough word to describe what families are feeling.*

*We're not 'dying' people."*

– Amanda Bennett, author, *The Cost of Hope*

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Caregivers specifically would benefit from:

- Flexible workplace policies;
- New models for caregiver support and the funding to go with them;
- Treating caregivers as an essential part of the care team, and incorporating this concept in professional standards and practices and codes of ethics<sup>3</sup>; and
- Easing the paperwork burden.

The Veterans Administration's new program for caregiver support, Centers for Medicare & Medicaid Services (CMS) demonstration programs, and the Patient-Centered Outcomes Research Institute (PCORI) under the Affordable Care Act (ACA) all may produce program results especially relevant to caregiver support.

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<sup>3</sup> In addition, clarifying provisions of the Health Insurance Portability and Accountability Act that hinder the sharing of patient information with family caregivers.

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*“Having an enlightened approach is good for business.”*

– Jack Watters, M.D., Pfizer

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## 2. Employer Roles

The demands of caregiving are a growing issue for employers. Caregiving (and, ultimately, bereavement) frequently reduce employees’ productivity, contribute to absenteeism, presenteeism, stress-related health problems, and turnover. In the long run, caregiving issues and even advance care planning should become part of the normal conversation with trained human resources and employee assistance personnel, especially among health care employers. Some companies already are responding to this challenge with employee information, flexible policies, and connections to local resources<sup>4</sup>. The financial impact on employees is more difficult to resolve, though disability management programs may offer some aid. Such programs may be more acceptable to employees when part of a “plan for the future” menu that includes retirement, financial planning, and other resources.

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*“At the heart and soul of all the statistics and charts  
are individual human beings,  
spouses, siblings, parents and children.”*

— Rabbi Richard Address,  
Congregation M’Kor Shalom, Union for Reform Judaism

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## 3. Faith Community Roles

Spirituality is a vital component of care for many people with advanced illnesses and their caregivers. Clergy can help people heal, even when cure is not possible. Through partnerships with health systems, the faith community is a critical link to reaching those in society who often are underserved during serious illness. In many communities characterized by low socioeconomic status and associated disparities in access to care, institutions like the church tie the community together and often also function as the de facto provider of services that help to maintain health, stability, and spiritual welfare. Finally, a strong presence of the faith community in national and regional partnerships can provide moral authority to improve advanced illness care for the vulnerable in society, a strategy suggested by Senators attending the Summit.

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<sup>4</sup> ReACT: Respect a Caregiver’s Time: <http://reactconnection.com/>

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*“Advanced illness is as predictable as  
anything that may arise in our lives,  
but when it arrives, we are woefully unprepared.”*

— Nancy Brown, American Heart Association

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#### **4. Public Communication**

Policy and medical elites have both knowledge and a certain willingness to talk about advanced illness issues and policies, but the majority of Americans are uncomfortable doing so. The emphasis in public engagement initiatives should focus on individual/family empowerment, quality of life, and excellence of care. Focusing on the care improvements that patient will receive is more acceptable than emphasizing potential cost savings. Market research may be needed in order to find out how to talk about these issues in a way people understand. More consistent terminology would prevent confusion.

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*“People cannot do what they do not know.”*

– Sen. Blanche Lincoln (D-AR)

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In the anxiety and stress of facing illness in our medical institutions, the fact that hospice care actually provides more care and that people receiving hospice care generally live longer than those receiving aggressive treatment is frequently lost on the public. Our current medical approach deems “more care” to mean more aggressive care when in reality hospice care provides more contact, more frequent communication, and a more comprehensive team around them. The lessons learned from this hospice experience provide a blueprint for how Americans living with advanced illness should be cared for. In the end, communication with the public requires a long-term, multifaceted educational effort that must be broad-based in several respects: It should involve many types of community entities working collaboratively, including the faith community and employers; and the effort should use a full array of communications vehicles—broadcast, print, internet, social media, and interpersonal. Specific approaches must be tailored to the unique resources and population demographics of each community.

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*“Don’t you want to be there when the most important decisions  
of your life are made?”*

– Sen. Johnny Isakson (R-GA)

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*“Don’t wait for government to fix this. It’s not their job.  
It’s our job.”* – Jeff Thompson, M.D., Gunderson Health System

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## **5. Advance Care Planning**

Advance care planning and respecting patient choices should not be considered a stand-alone program, but rather integral to the entire care system. Demonstrating how pervasive this philosophy can be, Gunderson Health System (La Crosse, Wisconsin) redesigned its electronic record system to allow any provider to retrieve or add to a patient’s care plan.

Not everyone is capable of talking about what kinds of care they would want in case of serious illness. Men more than women and people who are more religious tend to want to leave care decisions to their physicians. If collaborative care planning became expected practice, some of this reticence might erode. In truth, neither families nor clinicians find these conversations easy, but ideally, they should begin far in advance of a medical crisis—around the kitchen table, rather than the ICU bed.

The content of patient/family/clinician conversations should not be built around the convenience of the health care system rather than patients and families, with yes/no choices typified by the early “living wills.” Instead, these conversations are opportunities to explore personal values. Later decisions then can be guided by those values, even in the face of unanticipated circumstances and great uncertainty. The conversation should be repeated, updated, and revised as necessary as illness progresses, in light of new information or changed life circumstances, and in an environment of “love and trust.”

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*“What we’re talking about here is self-determined care -- every individual’s inalienable right to determine, in advance, how they will be cared for near the end of their lives.”*  
-Allen S. Lichter, M.D., American Society of Clinical Oncology

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*“The system is driving behavior that serves no one.”*

—Sen. Sheldon Whitehouse (D-RI)

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## 6. New Models of Care

Acting on patient and family choices depends on having care systems in place that allow those choices to be honored. System innovations are beginning to change the health care landscape for patients with advanced illnesses, providing alternatives to the current dangerously fragmented care system<sup>5</sup>. These new models emphasize the value of care coordination and other correlates of quality and the careful alignment of services with patient values and wishes. For example:

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*“We want to end the isolation that people are going through.”*

– Don Schumacher, National Hospice and Palliative Care Organization

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- Aetna’s Compassionate Care program includes a liberalized hospice benefit, emphasizes quality of care, and trains nurse care managers to work with patients and families. One outcome has been a dramatic increase in hospice enrollment and days in hospice care<sup>6</sup>.
- Allina Health System’s LifeCourse program is focused on the development of an ongoing, personal relationship with a non-clinical Care Guide and utilizes an interdisciplinary team to address all domains of palliative care and to coordinate care across all settings and care partners. Allina views its model as a complement to existing services and to the existing strengths and assets of people with advanced illness and their caregivers.
- Amedisys’ Clinically Home and Comprehensive, Continuous Chronic Care Management (C4M) models are focused on coordinating care transitions and provide pre-acute and post-acute care that differs according to the anchors in individual communities.
- The Innovations Group, a collective of approximately 20 hospice programs across the country, has also identified best practices for leveraging the competencies of advanced illness care in hospice. Components of these models include care coordination, consultations for palliative care and new service lines, such as PACE, transitions, house calls, complementary therapy, and social programs. In addition, The Innovations Group compiles meaningful outcome measures, with multiple providers reporting standardized real-time electronic data that has been used to facilitate better clinician performance and to fast track program improvement.

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5 Bodenheimer, T. 2008. Coordinating Care — A Perilous Journey through the Health Care System. *New England Journal of Medicine* 358(March 6):1064-1071.

6 Krakauer, R., Spettell, C.M., Reisman, L. and Wade, M.J. 2009. Opportunities to improve the quality of care for advanced illness. *Health Affairs* 28(5): 1357-1359; Spettell, C.M., Rawlins, W.S., Krakauer, R., Fernandes, J., Breton, M.E.S., Gowdy, W., . . . Brennan, T.A. 2009. A comprehensive case management program to improve palliative care. *Journal of Palliative Medicine* 12(9): 827-832.

- Kaiser Permanente has tested an advanced illness care model in three randomized controlled trials. This model increases access to specialty trained palliative support, embeds specialists in high-risk settings, systematically addresses care planning, and is developing complex medical homes for the most seriously ill enrollees.
- The Sutter Medical Network through its nationally-recognized AIM program provides people more choice, overcoming fragmentation, and using telemedicine, for example, to help families provide more effective home care. Physicians participate because they see that care is better and that their patients receive services that otherwise would be uneconomical for them to offer<sup>7</sup>.

These and other models of advanced illness care have shown that it is possible to improve care in many dimensions and to align it more closely with patient and family wishes, as indicated by high satisfaction scores.

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*“It’s about creating a system of care that enables patients’ wishes to actually be honored.”*

– Diane Meier, M.D., Center to Advance Palliative Care

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Uniquely, these advanced illness models both increase the care quality and the patient/family experience and lower costs by:

- Better care coordination, which reduces repeated and unnecessary tests;
- Effective home support, which results in better symptom control and reduces the need for physician visits, 911 calls, hospital readmissions, and ICU days;
- Improved communication and exploration of choices, which leads to greater hospice utilization; and
- Increased efficiency across providers (for example, by providing data on referral facilities’ hospital readmission rates, which encourages referral to more effective providers).

Such enhanced services are ripe for greater implementation through medical homes and Accountable Care Organizations (ACOs). The testing of additional new care models also is encouraged by the ACA. Ideally, new programmatic/benefit models would incorporate robust incentives, generate data useful for program enhancement and replication, and leverage the best practices of existing clinical models to scale successful programs nationally.

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<sup>7</sup> An analysis of data from this project is near publication, according to Jeff Burnich.

Steps can be taken to strengthen the care continuum, providing a “hospice-like” interprofessional team that takes a holistic and comprehensive approach to care, supporting the medical, psychosocial, and other needs of persons with advanced illness and their families and creating a seamless transition into hospice at the appropriate time.

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*“Make the right way the easy way.”*

– Richard Payne, M.D., Duke Divinity School

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## 7. Education

Physicians and nurses are trained primarily in acute care settings, where the intense focus is on the tests or procedures to be performed next. Although an increasing number of medical residents have rotations through hospice, these may be insufficient to counter the impulse to “do something.” Patients and families, too, are inculcated with the belief that there is always something more that can be done. Understanding that the patient may derive greater benefit from pulling back on tests and interventions is an educational challenge for both patient and clinician.

Nor are clinicians generally taught enough about working effectively in multidisciplinary teams; yet team approaches are a hallmark of good palliative care and essential to managing transitions and avoiding rehospitalizations<sup>8</sup>. In the ACO environment, teamwork will be increasingly valued.

Clinicians, especially physicians, need help in learning how to communicate uncertainty. In general, they greatly overestimate a patient’s survival prospects. In addition, chaplains, other clergy, and other professional groups from whom patients and families seek advice may need special training to participate effectively in and normalize “the conversation.” In some locales, parish nurses, retired nurses, and teachers have been taught to lead discussions on end-of-life preferences.

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*“We’re the only country in the industrial world which hasn’t had this conversation”*

– Sen. Mark Warner (D-VA)

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8 McCarthy, D, Johnson, MB, and Audet, A-M. 2013. Recasting readmissions by placing the hospital role in community context. JAMA. 309(4):351-352.

## 8. Policy and Financing Reforms

Current political gridlock makes forward progress on potentially controversial issues difficult, and, while comprehensive reform of policies and financing for advanced illness care is undoubtedly desirable, what is more feasible may be incremental reforms, for example:

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*“We must act.”*

- Judith Salerno, M.D., Institute of Medicine

- Improved alignment of payment systems;
- Expansion of bundled payment approaches, which cover an episode of care rather than multiple individual providers;
- Using global budgeting and bundled payments to improve incentives for more efficient, higher quality care across the continuum of an illness;
- Change in hospice eligibility rules to allow for concurrent care and/or to decrease the focus on prognostication of 6 months or less;
- Flexible benefit design that allows for “mass customization,” in order to accommodate diverse individual circumstances; and
- Assurance that state and federal drug enforcement policies do not interfere with adequate pain management near the end of life.

If Congress eventually takes up this challenge, the U.S. Senators (Johnny Isakson (R-GA), Mark Warner (D-VA), and Sheldon Whitehouse (D-RI)) who participated in this National Summit emphasized that the discussions will have to be bipartisan, avoid demagoguery, and have “everything on the table.” Difficulties are certain to emerge, if only because many individuals and institutions benefit financially and otherwise from the current disjointed care system and are comfortable in their respective silos. Change—even change for the better—threatens entrenched interests and relationships.

## 9. Culture Change

Health professionals, much less patients and families, will be unable to change the current health system alone. What is needed—and an aim of C-TAC—is a broad cultural change in attitudes about care of advanced illnesses. Many voices need to join in efforts to develop a movement built on common interests. Specifically, C-TAC members and others can make a set of reasonable, achievable policy goals part of their regular advocacy efforts on Capitol Hill, in statehouses, and with their members and constituents. HHS has indicated interest to C-TAC for collaboration. It is now up to all of us to act.

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*“All of us here have to take personal responsibility for getting this done.”*

– Leonard Schaeffer,

USC Schaeffer Center for Health Policy & Economics

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## NEXT STEPS

Based on the Summit findings, C-TAC is reviewing its action plan for the transformation of advanced illness care in America. Members of the Coalition are taking part in this review through appropriate Workgroups and Committees (Public Engagement, Clinical Models, Professional Education, Policy Advocacy, InterFaith & Diversity, and Employer).

Organizations and individuals committed to improving care are encouraged to join C-TAC and to contact the Coalition with their comments and ideas. Once the review is completed, C-TAC will publish the learnings and refined strategies. The National Summit was a major step forward toward reform, and the goal is that all Americans with advanced illness, especially the sickest and most vulnerable, will receive comprehensive, high-quality, person-and family-centered care that is consistent with their goals and values and honors their dignity.

For additional information about C-TAC or material from the Summit, please visit <http://thectac.org/> or email [ctac@advancedcarecoalition.org](mailto:ctac@advancedcarecoalition.org). In addition, follow us on Twitter at [@CTACorg](https://twitter.com/CTACorg).

## Acknowledgement

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**FURTHER INFORMATION**

AARP. <http://aarp.org/caregiving/>

Rabbi Richard Address. *Seekers of Meaning: Baby Boomers, Judaism, and the Pursuit of Healthy Aging*. URJ Press, 2011. <http://jewishsacredaging.com>

Amanda Bennett. *The Cost of Hope: A Memoir*. Random House, 2012.

James L. Brooks. 2009. *The Unbroken Circle: A Toolkit for Congregations Around Illness End of Life and Grief*. Durham, N.C.: Duke Institute on Care at the End of Life.

Bernard J. Hammes, ed. 2012. *Having Your Own Say: Getting the Right Care When it Matters Most*. LaCrosse, Wisc.: Gunderson Lutheran. <http://havingyoursay.org/>

Center to Advance Palliative Care. *Get Palliative Care*. <http://getpalliativecare.org/>

Engage with Grace. <http://engagewithgrace.org/>

Honoring Choices Minnesota. <http://honoringchoices.org/>

Institute for Healthcare Improvement. *The Conversation Project*. <http://theconversationproject.org/>

Jewish Healthcare Foundation (Pittsburgh). *Closure Program*. <http://closure.org/>

KnowYourWishes. <http://knowyourwishes.com/>

MyDirectives. <http://mydirectives.com/>

National Alliance for Caregiving. <http://caregiving.org/>

National Healthcare Decisions Day. <http://nhdd.org/>

National Hospice and Palliative Care Organization. *Caring Connections*. <http://caringinfo.org/>

Respect a Caregiver's Time (ReACT). <http://reactconnection.com/>

Suzanne Mintz. *A Family Caregiver Speaks Up: It Doesn't Have to Be This Hard*. Capital Books, 2008. <http://caregiveraction.org/>

Susan Reinhard, Carol Levine, and Sarah Samis. *Home Alone: Family Caregivers Providing Complex Chronic Care*. AARP, 2012.