



Call to Action: Transforming Advanced Illness Care

The **Coalition to Transform Advanced Care (C-TAC)** is a national non-profit, non-partisan alliance of patient and consumer advocacy groups, health care professionals and providers, private sector stakeholders, faith-based organizations, and health care payers.

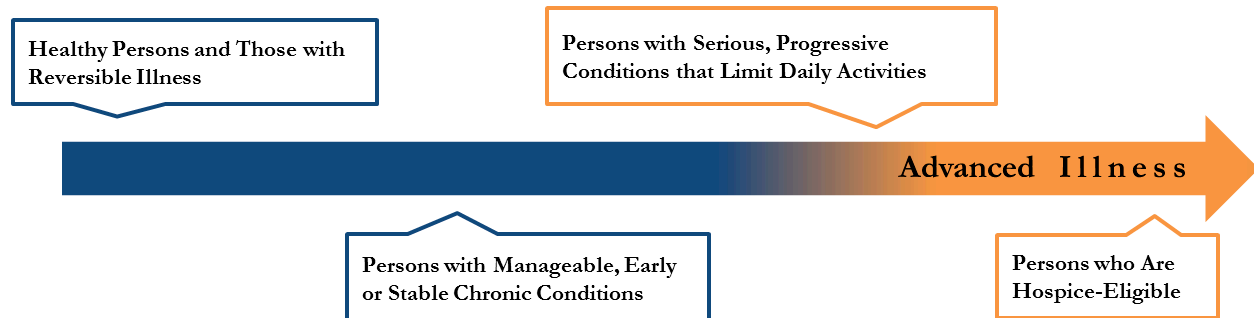
Our Vision

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.

The Challenge

Most Americans today are living longer and healthier lives than ever before. Yet at some point the great majority will face *advanced illness*, which occurs when one or more conditions become serious enough that general health and functioning decline, and treatment begins to lose its effect – a process that continues to the end of life.

Advanced Illness on the Health Continuum



What these Americans need and want is seamless, person-centered, coordinated care that helps patients live as happily, comfortably, and productively as possible. But few people, especially those who face financial hardship,¹ are lucky enough to receive it. Our health care system, despite its strengths, is ill-equipped to provide this kind of care when people are in a state of advanced illness.²

Who Needs Advanced Illness Care?

The time to prepare for advanced illness is well before serious, progressive conditions occur. **Advance planning**, including conversations among adult children, caregivers, and health providers, is an important part of eventually receiving appropriate care.

Ultimately, almost all of us will need and want advanced illness care. Over the next two decades, the number of people over 65 will nearly double to more than 72 million, or one in five Americans. The vast majority of people with advanced illness will be in this age group, though people with advanced illness exist from birth to old age. They will grapple with multiple conditions that interact in complex ways. Heart disease, stroke, cancer, diabetes, and Alzheimer's are now an increasingly common and are leading causes of disability and financial hardship. Indeed, a recent Health and Human Services



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(HHS) initiative directed at the one in four Americans that are affected by two or more chronic diseases, indicates that these individuals are at greater risk for unnecessary hospitalizations, adverse drug reactions and conflicting medical advice that may be overwhelming to patients and families.³

A number of clinical factors help identify advanced illness, including: one or more serious illnesses that are either progressively debilitating, at a late stage, or that lead to unexpected, multiple emergency hospital visits. Many of these individuals are limited in their ability to manage their personal care (bathing, grooming, dressing, etc.), placing undue stress on caregivers and providers. And just as the ranks of people with advanced illness are growing, the number of family caregivers is declining, making needed care even less available.⁴

As the health of those with advanced illness declines, they suffer increasingly frequent downturns that lead to avoidable hospital admissions. Multiple specialists further fragment their treatment. The average Medicare beneficiary with one or more chronic conditions sees eight different physicians each year, many in the hospital.⁵ For the 9 million Americans who are dually eligible for Medicare and Medicaid, the harmful effects of our fragmented system are only amplified.⁶ Remarkably, even as tests, visits and procedures multiply, studies show that providing more of this care does *not* always lead to better outcomes or reflect patients' values and preferences – in fact, quite the contrary.⁷

Reforming care is not just important for patients. Advanced illness affects everyone, imposing financial and emotional burdens on families, friends and co-workers. Each year millions of employees must navigate between caring for their loved one and their workplace responsibilities, leading to emotional distress and, as a result, billions in lost productivity.⁸

Toward a Solution

As we brace for the coming wave of older Americans with progressive chronic illness, and the growing numbers of younger people with life-limiting illnesses, we must address the fragmentation that contributes to substandard care, personal and family hardship and spiraling inefficiencies in care delivery.

Today's health care is delivered in separate, loosely affiliated silos, whether in hospitals (that provide high-tech, curative treatment), in physician offices and clinics (that address acute complaints), or long-term care facilities (that provide rehabilitation and/or skilled nursing) among others. Our weakest and most vulnerable citizens are forced to find their own way through this maze. In the process, their health, well-being, and financial stability are increasingly threatened. Adding to these challenges, there are profound shortages of all types of clinicians, especially nurses and doctors, that create additional challenges to providing care for those in need. A strategy to create and support an educated and resilient health care workforce that is able to support well-informed family caregivers is crucial.⁹



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Fortunately, high-performing systems are showing the way toward better care. Some of our nation's most innovative health care providers are proving that a coordinated, person-centered approach yields better care, greater satisfaction and, as a side benefit, lower costs.¹⁰

A new vision of care for Americans with advanced illness is becoming clearer through the efforts of these pioneers. Data from innovative programs show that when people with advanced illness get the information they need, they tend to choose less aggressive treatment and more comfort-focused care and family support. New technologies enable health care professionals to provide a customized mix of curative treatment and palliative care according to the wishes and values of the individual person and their families and caregivers.

These new models move the focus of care out of the hospital and into patients' homes and communities. No longer are the seriously ill forced to come to their providers. Their providers bring care to them; promoting teamwork, close communication, increased self-confidence, and better self-management. This care anticipates problems, avoids crises, and prevents unnecessary hospitalization. It results in better care for our most vulnerable patients and savings from treatment that patients and families do not want. In this new world of care that follows the patient's personal goals and values, everybody wins.

C-TAC: A Convener and Catalyst for Change

Our Coalition members have tested solutions to provide the right care at the right time and place, that empowers patients and their families and honors their dignity. C-TAC is striving for change in the health care system and larger environment by disseminating proven solutions, professional education, policy and advocacy, and building public demand and empowerment for quality advanced illness care.

Our mission is to transform advanced illness care by empowering consumers, changing the health delivery system, improving public and private policies and enhancing provider capacity.

We are focused on four key directives, with particular attention to faith-based and cultural perspectives:

- Analyzing and promoting **best-practice delivery models** that ensure high-quality, coordinated care across all settings.
- Disseminating innovative, inter-professional advanced care **education to clinicians** aimed at improving quality, shared decision making, and clinical care by cultivating respect, compassion and responsiveness in care delivery.



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- Developing and **advocating** for federal and state legislative, regulatory, judicial and administrative initiatives, as well as private policies, to improve care for those with advanced illness.
- Undertaking and supporting **public education and engagement** to help people make more informed decisions and to support delivery system and policy change.

Major health systems, large medical and nursing groups, consumer organizations, health insurance companies, employers and hospice and palliative care organizations are on board and involved.

How You Can Help

With over **100 organizational members**, C-TAC is the largest, most diverse, participatory Coalition of its kind. By joining C-TAC, you have the opportunity to partner with Coalition members in **shaping the way advanced illness care is provided in America**. Please join us in making this a national priority.

C-TAC hosted a National Summit on Advanced Illness Care on January 29-30, 2013. Visit <http://www.thectac.org> for findings from the Summit, a list of C-TAC members, the C-TAC action plan for transforming advanced illness care, and more information on the organization.

C-TAC is a non-profit, non-partisan organization based in Washington, D.C. The board of directors includes Tom Koutsoumpas, *Board Co-Chair and President*, Caring Foundations; Bill Novelli, *Board Co-Chair and Professor*, McDonough School of Business, Georgetown University, and former *CEO* of AARP; Alexandra Drane, *Founder, Chief Visionary Officer, and Chair of the Board*, Eliza Corporation; Bud Hammes, *Director of Medical Humanities*, Gundersen Health System; Thomas Higgins, *CEO and President*, Prosetta Corporation; Randy Krakauer, MD, *National Medical Director of Medicare*, Aetna; David Longnecker, MD, *Executive Director*, C-TAC; Ann F. Monroe, *President*, Community Health Foundation of Western and Central New York; Charlie Sabatino, *Director*, ABA Commission on Law and Aging; Leonard Schaeffer, *Judge Robert Maclay Widney Chair and Professor*, University of Southern California; Don Schumacher, *President and CEO*, National Hospice and Palliative Care Organization; and Jeff Weiss, *Founder and Director* of Center for Corporate Innovation. Nancy Brown, *CEO*, American Heart Association, and Jennie Chin Hansen, *CEO*, American Geriatrics Society, are *Co-Chairs* of C-TAC's Steering Committee.

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¹ Anderson, KO, Green, CR & Payne, R. 2009. Racial and Ethnic Disparities in Pain: Causes and Consequences of Unequal Care. *The Journal of Pain*, 10(12), 1187-1204.

² Miller, E and Mor, V., 2006. Brown University Center for Gerontology and Health Care Research.



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http://www.hhs.gov/ash/initiatives/mcc/mcc_framework.pdf

⁴ Caregiving in the USA, November, 2009. Available at:

<http://www.caregiving.org/data/CaregivingUSAllAgesExecSum.pdf>. Last Accessed, December 23, 2010.

⁵ Anderson G, Knickman, JR., *Health Affairs*, vol. 20 no. 6, (2001), pp. 146-60.

⁶ Fact Sheet: People Enrolled in Medicare and Medicaid, Centers for Medicare and Medicaid, 2011 & M. Bella, Special Committee on Aging, U.S. Senate, March 4, 2009.

⁷ Wennberg JE, Fisher ES, Goodman DC, et al.: *The Dartmouth Atlas of Health Care 2008*, Executive Summary, April 2008. Lebanon, NH: The Dartmouth Institute for Health Policy and Clinical Practice. Thorpe KE, Ogden LL, Galactionova K. *Health Affairs*. 2010;29(4):1-7. Christakis NA, Asch DA. *J Gen Intern Med*. Sep 1995; 10(9):491-494. Rucker GM, Curtis JR. *JAMA*. Aug 13 2003; 290(6):820-822. Ditto PH, Hawkins NA. *Health Psychol*. Jul 2005;24(4 Suppl):S63-70.

⁸ MetLife Mature Market Institute, National Alliance for Caregiving. *The MetLife caregiving cost study: productivity losses to U.S. business*. Westport (CT); 2006 Jul.

⁹ *Averting the Caregiving Crisis: Why We Must Act Now*. Americus, GA: Rosalynn Carter Institute for Caregiving. October, 2010.

http://www.rosalynncarter.org/UserFiles/File/RCI_Position_Paper100310_Final.pdf

¹⁰ Meyer H. Changing the conversation in California about care near the end of life. *Health Affairs* 2011;30:390-393.

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