

Senate Special Committee on Aging
Roundtable Discussion
Continuing the Conversation:
The Role of Health Care Providers in Advance Care Planning

Written Statement of Bill Novelli, Co-Chair, Coalition to Transform Advanced Care

Thank you Chairman Nelson and Ranking Member Collins for your leadership in the areas of aging and advanced illness. As Co-Chair of the Coalition to Transform Advanced Care (C-TAC), I would also like to thank you for the opportunity to be apart of the discussion today and promote the alignment of efforts nationwide to improve care for the seriously ill.

Over three years ago, my colleague Tom Koutsoumpas and I started C-TAC with the mission to transform advanced illness care by empowering consumers, changing the health delivery system, improving public and private policies and enhancing provider capacity. Today C-TAC is a national non-profit, non-partisan alliance of over 100 national organizations including patient and consumer advocacy groups, health care professionals and providers, private sector stakeholders, faith-based organizations, and health care payers united by this common vision to transform advanced illness care.

Though individuals of any age can experience *advanced illness*, including children, we know it usually occurs among the frail elderly, when one or more chronic conditions, such as cancer, heart or vascular disease, progress to the point where general health and function decline, response to treatment is reduced and care needs increase. In fact, beneficiaries with 5 or more chronic conditions represent the fastest growing segment of the Medicare population. In 2005, they represented 23% of Medicare beneficiaries and 68% of Medicare spending. We also know that the point at which one reaches advanced illness is often difficult to define. Aging and illness occur along a continuum; we all enter life stages in different ways at different times. Accordingly, patient preferences and goals vary and change over time.

Research shows that the majority of seriously ill patients have the following priorities: to be at home, with family and friends; to have their pain managed; to have their spiritual needs respected and honored; and to be assured that those who love them are not emotionally and financially devastated in the process. Unfortunately, too much of the time, this is not what happens. Instead, advanced illness care in the United States is often painful, isolating, and costly. Some 25% of seniors lose their entire assets during the last 5 years of life because of the cost of advanced illness care. Trips to the emergency room and hospitalizations occur frequently [with nearly 25% of seniors visiting the emergency department once per year]. Prognosis and treatment plans become uncertain, and there is stress and crisis among patients and their families. Situations like this are the result of care that is fragmented, uncoordinated, uninformed, and/or inadequate.

To improve care for this population, we need to focus on four primary areas. First, we must empower the public by engaging and educating patients and their families to make more informed decisions about advance directives and other early choices, and to make informed treatment decisions when serious illness occurs. As part of this, C-TAC is launching a consumer website – using content from our members- which will focus on care options, caregiving, and both financial and spiritual information. We have also engaged interfaith communities and organizations across the country, to form effective partnerships with health systems and promote advanced illness care.

Second, we must support and educate health professionals, including in our medical and nursing schools, to approach care services for people with advanced illness with the patient and family at the center of care, rather than focusing on clinical urgency or provider needs. We are currently examining evidence to determine which resources work best in this regard so we can promote effective models.

Third, we need to advocate for policy change -- for federal and state legislative and regulatory action, as well as private policies -- to improve care for those with advanced illness. This includes payment and regulatory reform, health information technology, research, standards of care, and other important areas. We regularly serve as resource to policymakers and engage them with our member organizations as well as experts in the field.

And finally, we must build on what already works. Some of our nation's most innovative health care providers are proving that a coordinated, person – and family – centered approach yields better care, greater satisfaction, and as a side benefit, lower costs. These innovative clinical programs and interventions, however, are often isolated along the advanced illness continuum and best practices are not widespread.

Therefore, in partnership with the AHIP Foundation's Institute for Health Systems Solutions and with initial support from the Commonwealth Fund, we have launched The Advanced Care Project. This is a collaboration among an exceptionally diverse group of health systems, health plans, faith-based groups and national innovators from around the country. Our goal is to develop a groundbreaking framework for comprehensive and patient-centered advanced illness management across care settings, for adoption throughout the United States. Our focus is on advanced illness population management not limited by diagnosis, age or mortality risk. It is based on healthcare system integration; interfacing with other care models; and leveraging the healthcare workforce.

Tackling the issue of advanced illness care requires simultaneous interventions in all of these areas and the building of unique partnerships that focus on the common good. It is through this process that we will ensure access to high quality, comprehensive, and person-centered care for all Americans that honors their dignity and is consistent with their wishes.

Thank You.

