



Summary of the C-TAC National Summit on Advanced Illness Care: Building Bridges to Success, Sept. 20-21, 2016

Hundreds of C-TAC members and other professionals gathered at the National Academy of Sciences building in Washington, D.C. to share experiences, learn and define the way forward to achieve the goal that all Americans with advanced illness receive comprehensive, high-quality, person-and family-centered care that is consistent with their goals and values and honors their dignity.

SUMMIT THEMES

A number of strong themes emerged during the Summit:

Patients and families must be at the center of decision-making and care.

Virtually every session reflected this tenet. This belief is clearly at our core.

Advanced illness care is uniquely unifying.

We know that we, or a loved one will be faced with serious illness and need help one day. BJ Miller, MD famously referred to this as a "cosmic spanking" when we realize that no one is immune. This unity was evident in discussions of care delivery and caregiving, in community action, and in policy making. The four members of Congress present—U.S. Senator Sheldon Whitehouse (D-RI), U.S. Representative Diane Black (R-TN), U.S. Representative Earl Blumenauer (D-OR), and U.S. Representative Phil Roe (R-TN)—spoke of this unifying theme. Senator Whitehouse called the experience of advanced illness "the most human issue of all."

Storytelling and faith are powerful assets for our movement.

They bring us together. Personal stories help people deal with this complex, difficult issue and weather the storms of serious illness. We can summon the power of stories to change and support the actions of patients, families and clinicians alike. There is no better evidence of a story's strength than the late Dr. Paul Kalanithi's best-selling memoir of his journey through advanced illness, *When Breath Becomes Air*. It was vividly described at the Summit by his wife, Lucy Kalanithi, MD, who wrote the book's epilogue. Spirituality is also a powerful human asset. The Rev. Yvonne Delk and Bishop Jerry Macklin brought this home for all of us and urged us to consider faith leaders as part of the care team. Panelist William Richards, Ph.D., Johns Hopkins University, spoke of science and medicine "encountering the sacred" as we consider new ways to provide psychological support to those living with advanced illness.

We can do this—together. This theme was everywhere at the Summit: in panels, workshops, networking and conversations. As Victor Dzau, MD, president of the National



Academy of Medicine reminded us, "The time is now." Why now? Medicare is now paying clinicians for advance planning counseling; the media are covering this issue more and better than ever; and the movement is gaining momentum. As Joseph Milano, MD, medical director at Northwell Health's Housecalls program said, "We're at the beginning, but the beginning is beginning to end." Our challenge now is to build on what is already working and to create new avenues for change.

EMERGING NEEDS HIGHLIGHTED AT THE SUMMIT

Accelerating and scaling up. The need for advanced illness care is growing rapidly as the Baby Boomers age. In a session on lessons from the field, C-TAC Innovations COO Khue Nguyen asked: "How do we move our knowledge, experience and tools into our systems and our culture?" To take effective programs and multiply their effect, we need a national, coordinated framework for delivering and measuring effective, person-centered advanced illness care.

Addressing cost. The need to contain costs is important and must be addressed, but in the context of the treatment that ill persons want and value. As we reform and improve payment structures, we must keep the patient and family at the center of care.

Measuring effectiveness. Arif Kamal, MD noted, "There are no measures for coping and rapport building. There is a misalignment between where we think we should focus and where quality measures actually are." Nonetheless, it appears from Summit discussions that thinking is beginning to mature on the difficult subject of metrics to assess progress and success, both in clinical settings and in the broader public arena. We need to seize this opportunity.

Continuing and strengthening policy/advocacy. We are the voice for the sickest and most vulnerable. While political partisanship continues among our law makers, there is clearly substantial opportunity for policy reform both at national and state levels. As Senator Sheldon Whitehouse (D-RI) noted, "When somebody who is holding the hand of the mom who gave them birth and raised them as she dies, what they want more than anything else is to know that they've done everything they can for her. And that is something we should support."

Capitalizing on technology. Former U.S. Senator Tom Daschle spoke of the twin drivers of policy and technology. In both a workshop (Adopting Technology Applications) and in a panel session (Technology-Enabled Innovations) it was clear that major advances in technology can help us achieve personalized care and decision-making at a scale needed to serve the rapidly aging U.S. population. Follow up is urgently required.



Initiating Partnerships. Many Summit attendees stressed the importance of working together, and new partnerships are being formed. Rick Pollack, CEO of the American Hospital Association, called for "redefining the H" (hospitals) in response to the twin forces of chronic disease and consumerism. His charge to "move beyond the four walls" of hospitals was a clear invitation to Summit participants to work together. There are many opportunities for new alliances.

NEXT STEPS TO ADVANCE DISCUSSION AND ACTION

We were all clearly energized to build on the Summit and accelerate momentum. We can all help by:

- **Incorporating what we learned at the Summit into strategic planning in our settings.**
- **Sharing lessons to ensure Summit meetings continue to grow in reach and value.** Please send suggestions to C-TAC Communications Coordinator Zach Barehmi (ZBarehmi@TheCTAC.org).
- **Spreading clinical models and shared and informed decision interventions that have proven valuable. For C-TAC, this means ramping up our new affiliate, C-TAC Innovations,** for health systems, hospitals, and others. To learn more, contact C-TAC C Innovations COO, Dr. Khue Nguyen, PharmD (KhueN@TheCTAC.org).
- **Taking action in our communities,** including involvement in C-TAC's Community Action programs, that connect community services with clinical care to improve outcomes for people with advanced illness, reduce caregiver burdens, and reinforce community support, contact Shelia Snoddy, Ph.D. Director of Community Action (SSnoddy@TheCTAC.org).
- **Help develop metrics to measure the progress** by establishing an agreed upon national framework of quality measures (working with NQF and others). To participate, contact David Longnecker, MD (DEL@TheCTAC.org) C-TAC's Secretary-Treasurer of the Board and Chief Clinical Innovations Officer.
- **Continue to develop and support bi-partisan, bi-cameral legislation** designed to support key aspects of person-centered care. For more information, please contact Leslie Brady (LBrady@TheCTAC.org), C-TAC's Policy Manager.

THE FINAL WORD

Nancy Brown, CEO of the American Heart Association, closed the Summit by saying: "Each one of us is a voice, a partner and a key player in the change we all seek. If you are a C-TAC member, let's do even more together. If not, please join the team."