

THE LONG TERM CARE DISCUSSION GROUP

A VOLUNTARY INDEPENDENT GROUP THAT MEETS SOLELY FOR THE PURPOSE
OF EDUCATING THE POLICY COMMUNITY ON ALL FACETS OF LONG TERM CARE

Monday, April 27, 2015
1:00 p.m. Eastern Time

America's Health Insurance Plans
601 Pennsylvania Avenue, NW – Suite 500 South Building
Washington, DC 20004

Public Perceptions of Dementia Care and the Needs of Those Living with Dementia

Speakers: Chris Perna, CEO, The Eden Alternative
and Karen Love, Founder, CCAL

People living with dementia and those who support them face many challenges. Besides managing cognitive and physical changes to their health, they deal with social-emotional isolation and stigmatization because negative information about dementia is the norm for public information. Learning that people can live fully with dementia is an antidote to misperceptions of dementia. Please take a moment (actually 7 minutes) to view [“Person-Centered Matters,”](#) an extraordinary video based in hope and possibility about living fully with dementia through meaningful engagement and person-centered dementia care and services.

Chris Perna and Karen Love will share the latest information about public perceptions of dementia care and the needs of those living with dementia based on recent studies from Rand Corporation and the University of Buffalo. These studies point to a serious disconnect between the focus of current public policy and what people living with dementia and those who support them want and need. Their discussion will highlight gaps and discuss actions to address them including the formation of the Dementia Action Alliance, where they are members of the leadership group.

They will also provide an overview of the Dementia Action Alliance, which is committed to helping people live fully with dementia and supporting those who care about them. It is a volunteer coalition engaged in changing our nation's understanding and attitude of dementia through serving as a trusted source for education, conversations, and advocacy.

Chris Perna joined The Eden Alternative, Inc. as its CEO in June, 2010. The Eden Alternative is an international non-profit organization dedicated to transforming care environments to promote quality of life and wellbeing. For the prior ten years Chris was president of MedAmerica Insurance Company, a leader in long-term care insurance. Under his leadership The Eden Alternative has developed the most complete package of person-directed tools and training resources available to support deep organizational culture change across the care continuum from skilled nursing to home and community-based services. Chris is a co-leader of the Dementia Action Alliance, a volunteer-based organization dedicated to helping individuals to live fully with dementia.

Karen Love is a gerontologist and a nationally known expert in person-centered dementia care. She spent a decade working in LTSS as an administrator for several companies and as a director of dementia services for a large national nursing home chain. Karen served as the Co-PI on four National Institute on Aging funded research projects and three Administration on Aging Alzheimer's Demonstration Grants to study, test, and evaluate a framework for person-centeredness and person-centered dementia care practices. She founded a non-profit consumer advocacy and education organization, CCAL - Advancing Person-Centered Living, in 1996 that is nationally recognized for its collaborative advocacy, public policy, and research work. CCAL is a founder of the Dementia Action Alliance. Karen was the President of the Center for Excellence in Assisted Living from 2005 – 2013.

Please RSVP to Jenifer Allen at Jenifer.allen@ltcg.com to attend in person or via phone.

**Long Term Care Discussion Group Co-Chairs:
Susan Coronel, John Cutler, Hunter McKay (ex-officio), Karl Polzer,
Jill Randolph, and Eileen J. Tell**

Long Term Care Discussion Group meetings are intended as forums for candid discussion. Dialogue and comments made during these meetings should be treated as off the record.

For more information about the Long Term Care Discussion Group, and to access materials and information relating to previous meetings, visit www.ltcdiscussiongroup.org