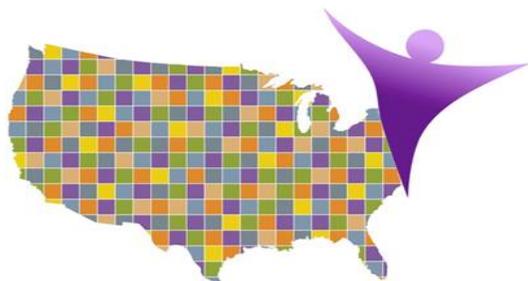




**Karen Love  
DEMENTIA ACTION ALLIANCE  
July 21, 2014 NAPA Advisory Council Meeting**



**karenlove4@verizon.net**

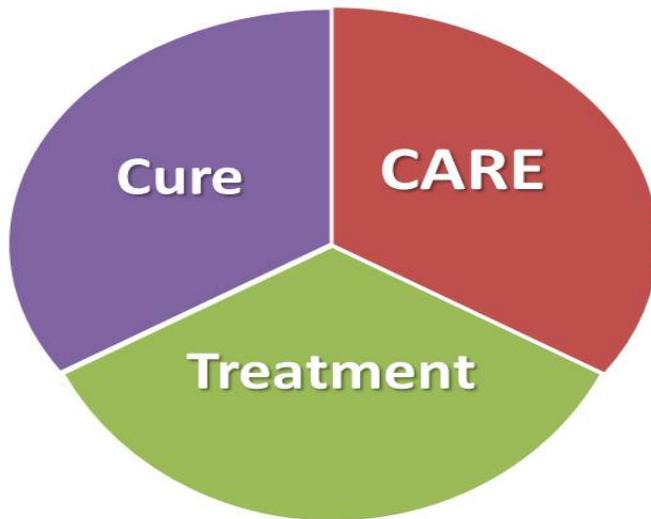


**Dementia Action Alliance**

**A national initiative to coalesce and connect people, organizations, and communities for collective impact to improve dementia care in the U.S..**

**The Alliance Leadership Team includes CCAL-Advancing Person-Centered Living, Planetree, The Eden Alternative, and AMDA: The Society for Post-Acute and Long-Term Care Medicine.**

## COMPONENTS OF DEMENTIA



### DEMENTIA CARE

The daily, social, health care, and supportive services for people who are living with dementia and for those caring for them.

## Dementia Thought Leaders Summit

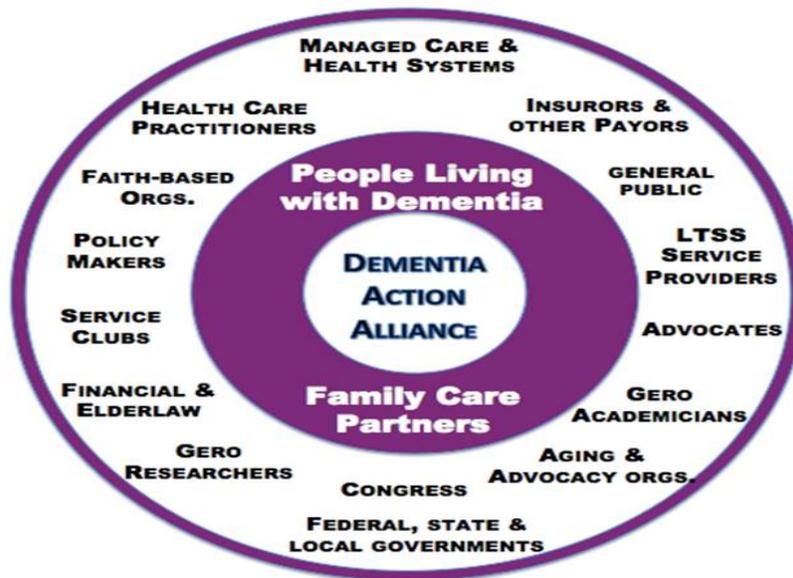
June 30, 2014 ~ Washington, DC

### Objective –

Form consensus agreement on what is needed to improve dementia care in this country.



# Dementia Stakeholders



## LANGUAGE MATTERS

➤ Preferred: **Dementia, including Alzheimer's – More Inclusive**

➤ Preferred: **Person living with dementia**



“Patient” stigmatizes the individual. “Living” underscores that people continue to live with dementia.

## Definition of Person-Centered Care

Person-centered dementia care is based on the fundamental premise that every individual has a unique background, human experience, and the right to determine how to live his/her own life.

Person-centered dementia care is relationship-based and focused on supporting the individual's emotional, social, physical, and spiritual well-being (e.g., belonging, experiencing a continuation of self and normality, purpose, meaning, enjoyment, comfort, and opportunities for growth).



**DEMENTIA SUMMIT - GOAL TO IMPROVE  
DEMENTIA CARE IN THE U.S.**

**HELP PEOPLE WITH DEMENTIA  
LIVE FULLY**



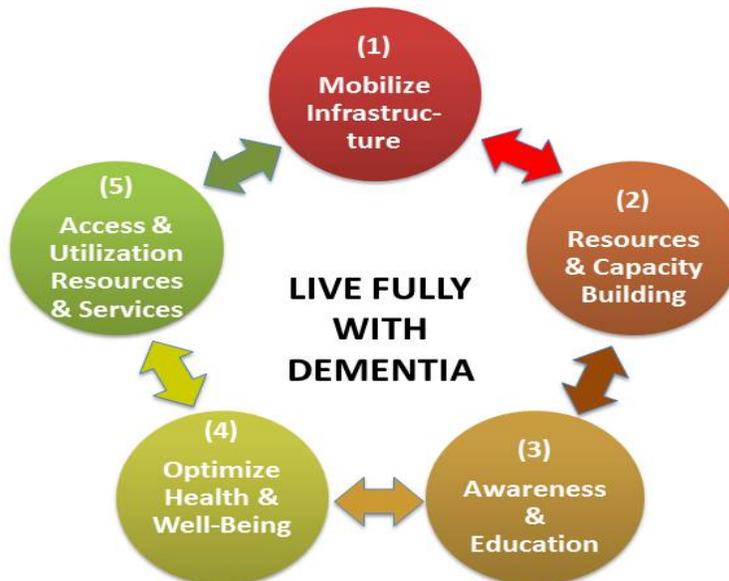
## Summit Participant

While the U.S. Constitution provides certain inalienable rights to its citizens, this doesn't including specific rights for those who are ill, old, or disabled – but perhaps should. The treatment, stigmatization, and lack of national will to provide the complement of resources needed for people living with dementia and those who care for them is a civil and human rights issue.



Val Halamandaris – CEO, National Association of Home Care & Hospice

## Consensus Summit Goal and Strategies



## **Short-Term Objectives To Achieve “Helping people live well with dementia”**

- **Establish a Planning Team and four Workgroups;**
- **Have agreed-upon consistent standards and expectations for dementia services and supports across all settings;**
- **Have agreed-upon an optimal education and skills curriculum for each stakeholder group; and**
- **Have a national Clearinghouse that aggregates national and international information about dementia care including curated resources, dementia-friendly communities/stores/neighborhood efforts, social and behavioral science research, etc.**

## **Mid-Term Objectives To Achieve “Helping people live well with dementia”**

- **Dementia is included as a priority for the White House Conference on Aging;**
- **Criteria established for person- and family-centered assessments, resources, and settings that meet individual needs and choices; and**
- **There are national initiatives that coordinate the implementation of person-centered planning for everyone and ensure person-centered care is the standard of care.**

## Long-Term Objectives To Achieve “Helping people live well with dementia”

- Have national policy that fosters system change;
- Have system to ensure dementia-capable care by all those providing services and support;
- Have system to ensure there is care coordination and management;
- Have a system to incentivize, empower, and retain quality workforce needed for dementia care;
- Scale practice models that offer best solutions;
- Have system to ensure people are getting and using the resources they need in a timely manner; and
- Have system to ensure people are as fully integrated and included in the community as they want.

### Proposed Organizational & Operating Infrastructure



## Summit Participant

“We don’t always agree on the ideal solution, but passion on all sides will get us to a different place as we try to deal with the realities of dementia care.”



Jack York - CEO, It's Never 2 Late

<http://vimeo.com/pasternakmedia/personcenteredmatters>

Password: ARDRAF



Public service video announcement ~ Funded by the Commonwealth of Virginia's Alzheimer's and Related Diseases Research Award Fund ~ 2014