

BETTER MEDICARE
ALLIANCE

Putting Patients and Families at the Center of Care

C. Grace Whiting, J.D.
President and CEO
National Alliance for Caregiving



May 17, 2018

**Mini Summit II:
Family Caregivers
and Patient
Engagement**

**Medicare
Advantage Summit**

Washington, D.C.

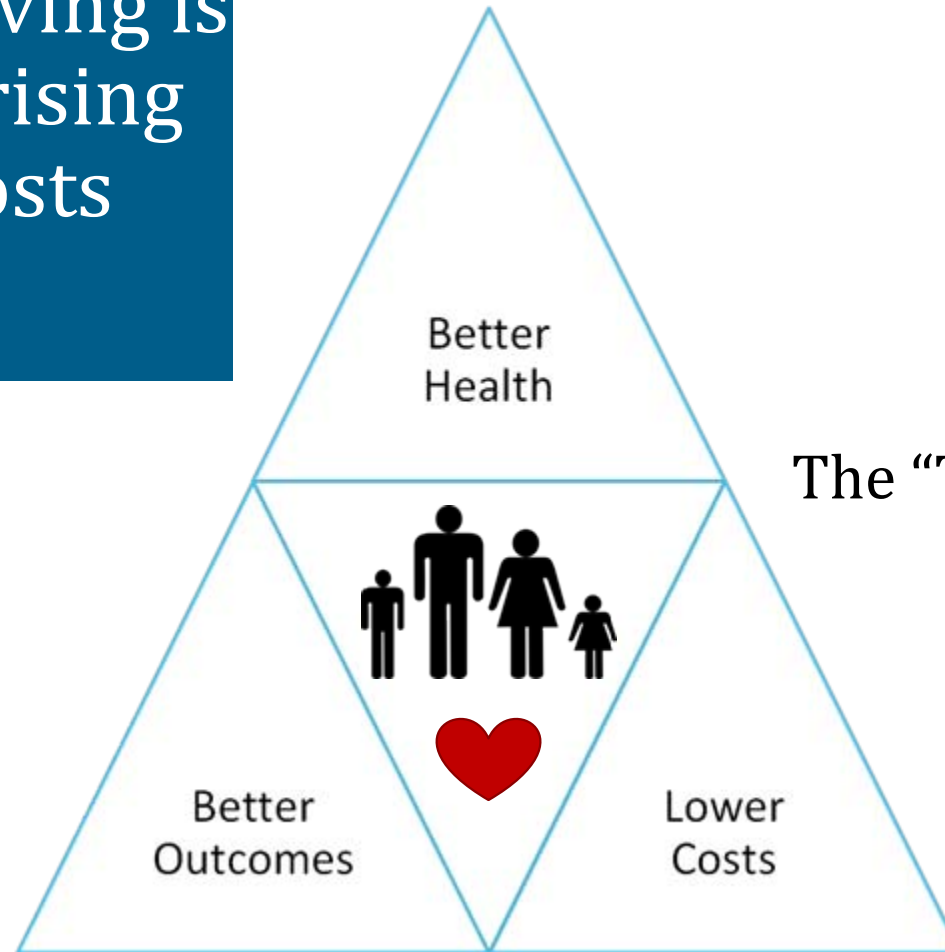


There are **43.5 million family caregivers in the U.S.**, providing an estimated economic value of **\$470 billion** in care.

Data from Caregiving in the U.S., AARP & National Alliance for Caregiving (2015) and Valuing the Invaluable, AARP (2015 Update). Learn more at www.caregiving.org/research.

Value:

Family caregiving is a solution to rising health care costs



The “Triple Aim”

Donald M. Berwick, Thomas W. Nolan, and John Whittington. “The Triple Aim: Care, Health, and Cost.” *Health Affairs* (May 2008). Available online: <http://content.healthaffairs.org/content/27/3/759.full>. See also, the Institute for Healthcare Improvement, <http://www.ihl.org/Engage/Initiatives/TripleAim/Pages/default.aspx>.

Caregivers are the “Voice of Care”

Caregiving Activity	All Caregivers (n=1,248)	Cancer Caregivers (n=111)	Dementia Caregivers (n=372)
Communicating with healthcare professionals (doctors, nurses, social workers) about his/her care	66%	82%*	80%*
Monitoring severity of recipient’s condition to adjust care accordingly	63%	76%*	79%*
Advocating for him/her with health care providers, community services, government agencies	50%	62%*	65%*

**Indicates statistically significant difference when compared to all caregivers.*

National Alliance for Caregiving & AARP, Caregiving in the U.S. (2015), caregiving.org/caregiving2015 and see also, Cancer Caregiving in the U.S. (2016) and Dementia Caregiving in the U.S. (2017), caregiving.org/research/condition-specific.

Patient advocacy is especially important for complex diseases

Figure 27: Caregiving Support Activities in Rare Disease Caregiving

(n=1,406)

		Child CR (n=871)	Adult CR (n=535)
Monitoring condition severity	94%	97%^	91%
Advocating	94%	98%^	89%
Communicating w/ professionals	94%	97%^	90%
Educating professionals	89%	92%^	83%

CR = Care Recipient

^ significantly higher than comparison group

National Alliance for Caregiving & Global Genes, Rare Disease Caregiving in America (February 2016), www.caregiving.org/rare

Caregivers support the healthy aging of populations, reducing system costs

- Caregivers can reduce avoidable hospital readmissions in discharges to the home.
 - By 25% at 90 days and by 24% at 180 days
- Sometimes, caregivers can help an older adult or person with a disability to live in the community longer, delaying institutionalization.

Rodakowski, et al. "Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Metaanalysis," *Journal of the American Geriatric Society* (April 2017), <http://onlinelibrary.wiley.com/doi/10.1111/jgs.14873/full>
Mittleman, et al. "An intervention that delays institutionalization of Alzheimer's disease patients: treatment of spouse-caregivers," *Gerontologist* (1993), <https://www.ncbi.nlm.nih.gov/pubmed/8314099>