Home is where the future is: 
*BrightFocus Foundation* consensus panel on dementia care

Constantine Lyketsos, MD, MHS  
Quincy M. Samus, PhD

Supported by the BrightFocus® Foundation

---

**Members of the Consensus Panel**

**Constantine G. Lyketsos, MD, MHS (chair)**  
Johns Hopkins School of Medicine

**Quincy M Samus, PhD, MS (co-chair)**  
Johns Hopkins School of Medicine

**Betty Smith Black, PhD EdS**  
Johns Hopkins School of Medicine

**Diane Bovenkamp, PhD**  
BrightFocus Foundation

**Michael Buckley**  
BrightFocus Foundation

**Christopher Callahan, M.D.**  
Indiana University Center for Aging Research

**Laura Gitlin, PhD**  
Johns Hopkins School of Nursing

**Nancy Hodgson, PhD, RN, FAAN**  
University of Pennsylvania School of Nursing

**Deirdre Johnston, M.B.B.Ch., M.D.**  
Johns Hopkins School of Medicine

**Helen Kales, M.D.**  
University of Michigan

**Michele Karel, PhD, ABPP**  
Veterans Administration Central Office

**John Jay Kenney, PhD**  
Montgomery Department of Health & Human Services

**Shari M. Ling, M.D.**  
Centers for Medicare and Medicaid Services

**Maï Panchal, PhD**  
LECMA, AFI, and iSAO (France)
Over two-thirds of the 6 million people with dementia in the USA live in the

Dementia at home associated with:
- Institutionalization
- High health care costs
- Reduced quality of life
- Medical and psychiatric multi-morbidity
- Family and caregiver impact: physical, emotional, social, financial

Person-centered goals of care:
- Remain at home safely for as long as possible
- Improve quality of life
- Address and support family caregiver sources of burden and strain


Current Care Situation

- Care “fragmented” rarely a comprehensive set of services
- Diagnosis is absent half the time
- Major barriers to dementia-focused care and support services
- PWD & caregivers have major needs that go unmet
- Caregiver burden, falls, acute medical problems, behavioral symptoms exacerbate poor outcomes and increase risk for costly institutionalization

We must “connect the dots” to take proper care of the 100 million+ patients and caregivers worldwide

http://www.alz.co.uk/research/statistics: Alzheimer’s Association 2012; NIH, 2004
Effective “Dementia Care across the continuum” available!

- Put in place proven, person- and family-centered interdisciplinary interventions to maximize quality of life and minimize complications
- Maintain support and guidance through the illness as needs of both the person with dementia and the caregiver change;
- Connect medical, social, and supportive care professionals, workers, and informal caregivers to achieve patient centered outcomes in care delivery and transitions between settings

Dementia Care Works

MIND at HOME delays leaving current home by 9 months, improves life quality of person with dementia, reduces weekly informal care provided by 16 hours

Samus et al, AJGP, 2014; Tanner et al, AJGP, 2015
Recommendations of the Consensus Panel

1. Home-based dementia care (HBDC) should be considered the nexus of new long term care models
2. New payment models are needed to stimulate, reward, and support home care practices
3. A skilled new workforce spanning long term care needs to be developed and equipped
4. New technologies to promote best practices must be tested, integrated and deployed
5. More effective development of value, understanding of competing local priorities and adaption, and improved communication about home-based care are needed

Samus et al, Alzheimer’s & Dementia, under revision

Specific examples

- Bridge continuum of services (e.g., medical, social) with community supports (e.g., faith based, informal)
- Make fundamental change in CMS covered benefits
- Turn to care options offered by non-medical professionals
- Embrace technologies 1) assessment; 2) monitoring; 3) assistive; 4) therapeutic, and 5) caregiver supportive
- Communicate about the need, benefits, and value of HBDC to the public and other stakeholders
Research recommendations

• Evaluate, compare models of home-based dementia care with emphasis on care outcomes, care quality, costs
• Assess the impact of linking screening and early detection to home-based dementia care
• Study the impact of non-medical professionals and new payment models on care outcomes
• Research the impact of new technologies on outcomes

Thank you!
Ευχαριστώ!