



November 20, 2017

Ms. Amy Bassano  
Acting Deputy Administrator for Innovation and Quality & Acting Director  
Center for Medicare & Medicaid Innovation  
Centers for Medicare & Medicaid Services  
7500 Security Blvd.  
Baltimore, MD 21244

***via electronic submission to [CMMI NewDirection@cms.hhs.gov](mailto:CMMI_NewDirection@cms.hhs.gov) and [amy.bassano@cms.hhs.gov](mailto:amy.bassano@cms.hhs.gov)***

Dear Acting Deputy Administrator Bassano:

Thank you for the opportunity to provide input in response to the Center for Medicare and Medicaid Innovation's Request for Information regarding the new direction for the Center. We write to offer information on exemplary evidence-based models of dementia care, which we believe are ready to be scaled for the larger population of Medicare and Medicaid beneficiaries. These models would strengthen value for taxpayers while improving quality of life both for people living with dementia and their caregivers. The Innovation Center helping to scale these dementia care models would be consistent with its own mission, the CMS vision, the HHS strategic plan, and the National Alzheimer's Plan. Scaling these dementia care models also would capitalize on recent updates to the Medicare Physician Fee Schedule that encourage dementia diagnosis and care planning, the "National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers"<sup>ii</sup> hosted in October by NIH, and the CMS "Behavioral Health Payment and Care Delivery Innovation Summit"<sup>iii</sup> held in September.

There are few more compelling or complex issues to confront our aging society, now and over the coming decades, than Alzheimer's disease and other forms of dementia. These conditions impose enormous costs to our nation's health, prosperity, and social fabric, costs that are skyrocketing.<sup>iii</sup> Based on the National Institute on Aging's Health and Retirement Study (HRS), we know that the health system costs of caring for people with dementia in the United States are comparable to, and perhaps greater than, those for heart disease and cancer.<sup>iv</sup> A recent analysis of HRS data revealed that average per-person health care spending in the last five years of life for people with dementia was more than a \$250 thousand dollars, 57 percent greater than costs associated with death from other diseases such as including cancer and heart disease.<sup>v</sup>

Today, more than 5.5 million Americans have dementia at an annual cost to our economy exceeding \$259 billion.<sup>vi</sup> Alzheimer's disease contributes to the deaths of approximately 500,000 Americans each year, and it is the only leading cause of death in the United States for which there is no proven means of prevention, disease modification or cure.<sup>vii</sup> If the current trajectory persists, at least 13 million Americans will have dementia in 2050 and total costs of care are projected to exceed \$1 trillion annually (inflation adjusted 2014 dollars).<sup>viii</sup> The federal government, through Medicare and Medicaid payments, shoulders an estimated 70 percent of all such direct care costs.

The choice before our nation is not whether to pay for dementia; already, we are paying dearly. The question is how to best invest funds to maximize value for beneficiaries and taxpayers. There are wide array of dementia care models, only some of which are listed below, that merit the Innovation Center's focus and support in bringing to scale interventions that can help lower costs while improving quality of life for people living with dementia and their caregivers.

### **Exemplary Models of Dementia Care**

The Innovation Center has extensive experience with the following four programs, each of which should be considered for further expansion: the **California Long-Term Care Education Center (CLTCEC) Care Team Integration of the Home-based Workforce Program**<sup>ix</sup>; the **Indiana University Eskenazi Healthy Aging Brain Care (ABC) Program**<sup>x</sup>; the **UCSF and UNMC Dementia Care Ecosystem: Using Innovative Technologies to Personalize and Deliver Coordinated Dementia Care**<sup>xi</sup>; and the **UCLA Alzheimer's and Dementia Care Program**<sup>xii</sup>.

Please note: the models listed in this letter appear in alphabetical order and do not represent a comprehensive or prioritized list, but rather exemplars of diverse evidence-based interventions we believe could be scaled and tested by the Innovation Center. For a more extensive list and examination of promising dementia care models worthy of Innovation Center consideration for scaling, see "Examining Models of Dementia Care: Final Report"<sup>xiii</sup> prepared for the HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE) in September of 2016. Descriptive paragraphs about each of the following programs are drawn *verbatim* from the sources identified in each endnote.

### **Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Program**<sup>xiv</sup>

Health care and community organizations collaborated with researchers to establish guidelines for quality of care for dementia patients and specific protocols for managing care. Health care and community service coordinators partnered to meet medical and support needs of people with dementia and caregivers. The program also provided dementia-related education to physicians. A web-based decision-support system was key to communication and efficiency (Lines et al., 2013; Rosalyn Carter Institute for Caregiving, 2017).<sup>xv</sup>

### **Benjamin Rose Institute (BRI) Care Consultation<sup>xvi</sup>**

Through this intervention, trained care consultants--usually social workers or nurses--provide an initial needs assessment, help the person with dementia and caregiver develop an action plan, and provide ongoing support, which includes monitoring and follow-up with reassessment, as needed. Progress is tracked through a care consultation information system. Initial contacts occur three times per month, with the frequency decreasing over time. Contacts take place via telephone, mail, and e-mail, with occasional in-person meetings (Wiener et al., 2016). Caregiver outcomes include reduced caregiver depression, increased use of support services, and reduced number of unmet needs (Bass et al., 2003, 2013).<sup>xvii</sup>

### **Care of Persons with Dementia and Their Environments (COPE)<sup>xviii</sup>**

The 4-month Care of Persons with Dementia in their Environments (COPE) intervention is designed to optimize older adults' functional independence, and to improve CG dementia management skills and health-related outcomes. COPE features 10 in-home occupational therapy visits, and 1 in-home visit and 1 telephone contact by an advanced practice nurse. COPE was deemed efficacious in a published randomized clinical trial.<sup>xix</sup>

### **Maximizing Independence (MIND) at Home<sup>xx</sup>**

In this model, non-credentialed memory care coordinators provide coordination with substantial involvement from a registered nurse and a geropsychiatrist. Beyond a comprehensive needs assessment, participants also receive dementia and skill-building training, linkage to services, and care monitoring. A key component of the program is the use of a computerized resource system that identifies needed resources to help people with dementia and caregivers cope with the illness. Most contact is by telephone, mail, and e-mail, with occasional in-person visits (Wiener et al., 2016).<sup>xxi</sup>

### **NYU Caregiver Counseling and Support Intervention<sup>xxii</sup>**

This program provides one-on-one counseling sessions to the primary caregiver and group sessions for the family. Six sessions take place over 4-6 months and address challenges that the primary caregiver or family is encountering, emphasizing communication skills and encouraging caregivers to seek support from family and friends. Outcomes include reduced caregiver depression, reduced distress with behavioral symptoms, and increased satisfaction with social support (Gaugler et al., 2016).<sup>xxiii</sup>

### **Resources for Enhancing Alzheimer's Caregiver Health (REACH II) Program<sup>xxiv</sup>**

This intervention assesses caregivers' needs and provides in-person training and counseling over a 6-month period. Training topics include self-care, healthy behaviors, and assessing and managing problem behaviors. Action steps are practiced through role-play, as are strategies for managing stress and increasing pleasant events. Caregivers are also linked with community resources and given skills related to social support and communication. Outcomes include reduced caregiver depression and burden and increase in self-care and social support (Belle et al., 2006; Nichols et al., 2008).<sup>xxv</sup>

### **Savvy Caregiver Program**<sup>xxvi</sup>

This educational and skill-building training is delivered via six weekly, 2-hour sessions in a group format. Topics include dementia basics, cognitive changes and how they impact behaviors, establishing realistic caregiving goals, gauging the care recipient's abilities, designing appropriate activities for the person with dementia, and using a problem-solving approach to manage behavioral symptoms. Outcomes include improved caregiver competence and coping and reduced depression and distress related to behavioral symptoms (Kally et al., 2014; Samia et al., 2014).<sup>xxvii</sup>

### **Skills2Care**<sup>xxviii</sup>

This intervention is designed to reduce behavioral symptoms through an environmental modification approach. In-home sessions take place over 4 or 6 months (two models exist). Occupational therapists train caregivers on reducing confusion and increasing safety for the person with dementia through changes to the living space, communication skills, simplifying tasks for the person with dementia, and engaging them in meaningful activities. They also refer caregivers to other community resources. Outcomes include reduced caregiver burden and reduced distress with behavioral symptoms (Gitlin et al., 2003, 2010).<sup>xxix</sup>

### **Veterans Affairs Partners in Dementia Care (PDC) Program**<sup>xxx</sup>

This model features a partnership between Veterans Affairs Medical Centers and local Alzheimer's Association chapters, with care coordinators at the two locations working as a team using a shared electronic information system and regular meetings. The focus is on helping people with dementia and their caregivers navigate medical and social services, with at least one contact per month. Coordinators help clients develop simple action steps, with reassessment at least every 6 months (Bass et al., 2013, 2014).<sup>xxxi</sup>

Note: there are strong similarities between the PDC Program and the **Rosalynn Carter Institute for Caregiving's (RCI's) Resources for Enhancing Alzheimer's Caregiver Health (REACH) Program**<sup>xxxii</sup>.

As noted previously, the programs detailed above do not represent a comprehensive or prioritized list, and we would encourage the Innovation Center to consider scaling and testing a wider variety of evidence-based programs. In particular, the Innovation Center also should consider the **Dementia Cal MediConnect Program**,<sup>xxxiii</sup> the **Home-Based Counseling with Family Caregivers (STAR- C) Program**<sup>xxxiv</sup>, the **Four Seasons Demonstrating the Value of Palliative Care Program**<sup>xxxv</sup>; and the **Palliative Care for Advanced Dementia (Comfort Matters) Program**<sup>xxxvi</sup>. The Physician-Focused Payment Model Technical Advisory Committee (PTAC) is reviewing several payment models, such as the **Patient and Caregiver Support for Serious Illness (PACSSI)**<sup>xxxvii</sup> model, which could improve care for patients suffering from many different types of serious illness, including dementia. Additionally, we encourage the Innovation Center to look specifically at programs and services to promote early and accurate diagnosis of Alzheimer's disease and other forms of dementia. Simply put, individuals and families are less likely to utilize strong evidence-based dementia care

and support programs if a diagnosis has not been made, is not conveyed or is delayed, or if there is a misdiagnosis.

We applaud CMS for its strong commitment to encouraging detection, diagnosis and care planning, through pathways such as the Medicare Annual Wellness Visit's cognitive assessment benefit and HCPCS 99483 (formerly G0505). We encourage the Innovation Center to seek out additional opportunities to ensure that all Americans facing dementia have the most accurate and actionable information possible at the earliest appropriate opportunity to facilitate their optimal utilization of evidence-based care and support programs.

Thank you for considering our views and for your commitment to better supporting people with dementia. Please contact Ian Kremer, executive director of Leaders Engaged on Alzheimer's Disease (LEAD Coalition)<sup>xxxviii</sup> at [ikremer@leadcoalition.org](mailto:ikremer@leadcoalition.org) or 571-383-9916 with questions or for additional information.

Sincerely,

Abe's Garden Alzheimer's Center of Excellence

Accelerate Cure/Treatments for Alzheimer's Disease (ACT-AD) Coalition

ActivistsAgainstAlzheimer's Network

African American Network Against Alzheimer's

AgeneBio

Paul S. Aisen, MD (Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute\*)

Alliance for Aging Research

Alliance for Patient Access

Alzheimer's & Dementia Alliance of Wisconsin

Alzheimer's Disease Resource Center, Inc. (ADRC)

Alzheimer's Drug Discovery Foundation

Alzheimer's Foundation of America

Alzheimer's Greater Los Angeles

Alzheimer's Mississippi

Alzheimer's Orange County

Alzheimer's San Diego

Alzheimer's Tennessee

Alzheimer's Texas

Alkermes

American Association for Geriatric Psychiatry

American Geriatrics Society

American Medical Women's Association

ARGENTUM | Expanding Senior Living

Laura D. Baker, PhD (Wake Forest University Health Sciences\*)

Banner Alzheimer's Institute

David M. Bass, PhD (Benjamin Rose Institute on Aging\*)

Beating Alzheimer's by Embracing Science

Benjamin Rose Institute on Aging

B'nai B'rith International

Soo Borson MD (Minnesota Brain Aging Research Collaborative\*)

James Brewer, M.D., Ph.D. (UC San Diego and Alzheimer's Disease Cooperative Study\*)

BrightFocus Alzheimer's Disease Research

Christopher M. Callahan, MD (Indiana University Center for Aging Research\*)

Caregiver Action Network

CaringKind, The Heart of Alzheimer's Caregiving

Center for BrainHealth at The University of Texas at Dallas

Center to Advance Palliative Care

Sandra Bond Chapman, PhD (Center for BrainHealth at The University of Texas at Dallas\*)

ClergyAgainstAlzheimer's Network

Cleveland Clinic Foundation

Coalition Against Major Diseases

CorTechs Labs

Suzanne Craft, PhD (Wake Forest School of Medicine\*)

Jeffrey Cummings, MD, ScD (Cleveland Clinic Lou Ruvo Center for Brain Health\*)

Darrell K. Royal Fund for Alzheimer's Research

Dementia Alliance International

Dementia Friendly America

Department of Neurology, Washington University School of Medicine

Duke (Alzheimer's) Family Support Program

ElevatingHOME

Gary Epstein-Lubow, MD (Alpert Medical School of Brown University\*)

Faith United Against Alzheimer's Coalition

Sam Gandy, MD, PhD (Icahn School of Medicine at Mount Sinai\*)

Joseph E. Gaugler, PhD (School of Nursing, Center on Aging, University of Minnesota\*)

Geoffrey Beene Foundation Alzheimer's Initiative

Daniel R. George, Ph.D, M.Sc (Penn State College of Medicine\*)

Georgetown University Medical Center Memory Disorders Program

Gerontological Society of America

Laura N. Gitlin, PhD (Johns Hopkins School of Nursing\*)

Lisa P. Gwyther, MSW, LCSW (Duke University Medical Center\*)

Hadassah, The Women's Zionist Organization of America, Inc.

David M. Holtzman, MD (Washington University School of Medicine, Department of Neurology\*)

Home Instead Senior Care

Huffington Center on Aging

Indiana University Center for Aging Research

Kathy Jedrzewski, PhD (University of Pennsylvania\*)

Johns Hopkins Memory and Alzheimer's Treatment Center

Johns Hopkins School of Nursing Center for Innovative Care in Aging

Katherine S. Judge, PhD (Cleveland State University\*)

Keck School of Medicine of USC, Alzheimer's Therapeutic Research Institute

Keep Memory Alive

Diana R Kerwin, MD (Texas Alzheimer's and Memory Disorders\*)

Walter A. Kukull, PhD (School of Public Health, University of Washington\*)

Janssen R&D

Latino Alzheimer's and Memory Disorders Alliance

LatinosAgainstAlzheimer's

Layton Aging and Alzheimer's Disease Center, Oregon Health & Science University

LeadingAge

Lewy Body Dementia Association

Linked Senior, Inc

Lundbeck

Kostas Lyketsos, M.D., M.H.S. (Johns Hopkins Memory and Alzheimer's Treatment Center\*)

Metropolitan Area Agency on Aging (North St. Paul, MN)

Michigan State University Alzheimer's Alliance	ResearchersAgainstAlzheimer's
Milken Institute Center for the Future of Aging	David B. Reuben, MD (David Geffen School of Medicine at UCLA*)
Minnesota Brain Aging Research Collaborative	Stephen Salloway, M.D., M.S. (The Warren Alpert Medical School of Brown University*)
David G. Morgan, PhD (Michigan State University*)	Second Wind Dreams, Inc./ Virtual Dementia Tour
National Alliance for Caregiving	Rudolph Tanzi, PhD (Department of Neurology, MGH/Harvard Medical School*)
National Asian Pacific Center on Aging	The Association for Frontotemporal Degeneration
National Association of Activity Professionals	The Evangelical Lutheran Good Samaritan Society
National Association of Area Agencies on Aging	The Michael J. Fox Foundation for Parkinson's Research
National Association of Chronic Disease Directors	The Youth Movement Against Alzheimer's
National Association of Counties (NACo)	Geoffrey Tremont, Ph.D., ABPP-CN (Alpert Medical School of Brown University*)
National Association of Nutrition and Aging Services Programs	R. Scott Turner, MD, PhD (Georgetown University Memory Disorders Program*)
National Association of States United for Aging and Disabilities	UsAgainstAlzheimer's, LEAD Coalition co-convenor
National Certification Council for Activity Professionals	USF Health Byrd Alzheimer's Institute
National Committee to Preserve Social Security and Medicare	VeteransAgainstAlzheimer's
National Council for Behavioral Health	Volunteers of America, LEAD Coalition co-convenor
National Task Group on Intellectual Disabilities and Dementia Practices	Peter J. Whitehouse, MD, PhD (Case Western Reserve University*)
Neurocern, Inc	Carol J. Whitlatch, PhD (Benjamin Rose Institute on Aging*)
Neurotechnology Industry Organization	Nancy Wilson, MA LCSW (Baylor College of Medicine*)
NYU Langone Health	Wisconsin Alzheimer's Institute
Noah Homes	WomenAgainstAlzheimer's
Piramal Imaging S.A.	
Planetree International	
Prevent Alzheimer's Disease 2020	
Eric Reiman, MD (Banner Alzheimer's Institute*)	

*\* Affiliations of individual researchers are for identification purposes only and do not necessarily represent the endorsement of affiliated institutions.*

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- ii <https://innovation.cms.gov/resources/behavioral-health-paymentcare-summit.html>
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- xxxvi [http://www.leadcoalition.org/?wpfb\\_dl=238](http://www.leadcoalition.org/?wpfb_dl=238)
- xxxvii <https://aspe.hhs.gov/system/files/pdf/255906/ProposalAAHPM.pdf>
- xxxviii <http://www.leadcoalition.org> Leaders Engaged on Alzheimer's Disease (the LEAD Coalition) is a diverse national coalition of member organizations including patient advocacy and voluntary health non-profits, philanthropies and foundations, trade and professional associations, academic research and clinical institutions, and home and residential care providers, and



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biotechnology and pharmaceutical companies. The LEAD Coalition works collaboratively to focus the nation's strategic attention on dementia in all its forms -- including Alzheimer's disease, vascular disease, Lewy body dementia, and frontotemporal degeneration -- and to accelerate transformational progress in detection and diagnosis, care and support, and research leading to prevention, effective treatment and eventual cure. One or more participants may have a financial interest in the subjects addressed.