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INSTITUTE

# Reducing the Cost and Risk of Dementia

Recommendations to Improve Brain Health  
and Decrease Disparities

AN EXECUTIVE SUMMARY BY NORA SUPER, RAJIV AHUJA, AND KEVIN PROFF

## ABOUT THE MILKEN INSTITUTE

The Milken Institute is a nonprofit, nonpartisan think tank.

For the past three decades, the Milken Institute has served as a catalyst for practical, scalable solutions to global challenges by connecting human, financial, and educational resources to those who need them. Guided by a conviction that the best ideas, under-resourced, cannot succeed, we conduct research and analysis and convene top experts, innovators, and influencers from different backgrounds and competing viewpoints. We leverage this expertise and insight to construct programs and policy initiatives.

These activities are designed to help people build meaningful lives, in which they can experience health and well-being, pursue effective education and gainful employment, and access the resources required to create ever-expanding opportunities for themselves and their broader communities.

## ABOUT THE CENTER FOR THE FUTURE OF AGING

The Milken Institute Center for the Future of Aging is nonpartisan, independent, collaborative, and solutions-focused. The Center promotes healthy, productive, and purposeful aging to improve lives and strengthen societies. Through its Healthy Longevity program, the Center for the Future of Aging seeks to increase awareness of developing knowledge, evidence-based programs, and strategies to promote prevention and wellness for longer, healthier lives. Recognizing the growing prevalence of Alzheimer's disease and related dementias, the Center seeks to develop and promote optimal strategies to maintain and improve brain health for all ages, genders, and across diverse populations. The Center also works to find innovative solutions to finance long-term care support services and keep people independent and healthy as long as possible.

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## EXECUTIVE SUMMARY

People around the globe are living longer than ever thanks to major medical and public health advances and greater access to health care. And while longer lifespans are a huge success story, they also create new challenges to healthy aging—our risk of developing dementia doubles every five years after we turn 65. According to the Milken Institute, the number of people living with Alzheimer’s disease and related dementias in the US will nearly double over the next 20 years, with women being disproportionately impacted (Figure 1).

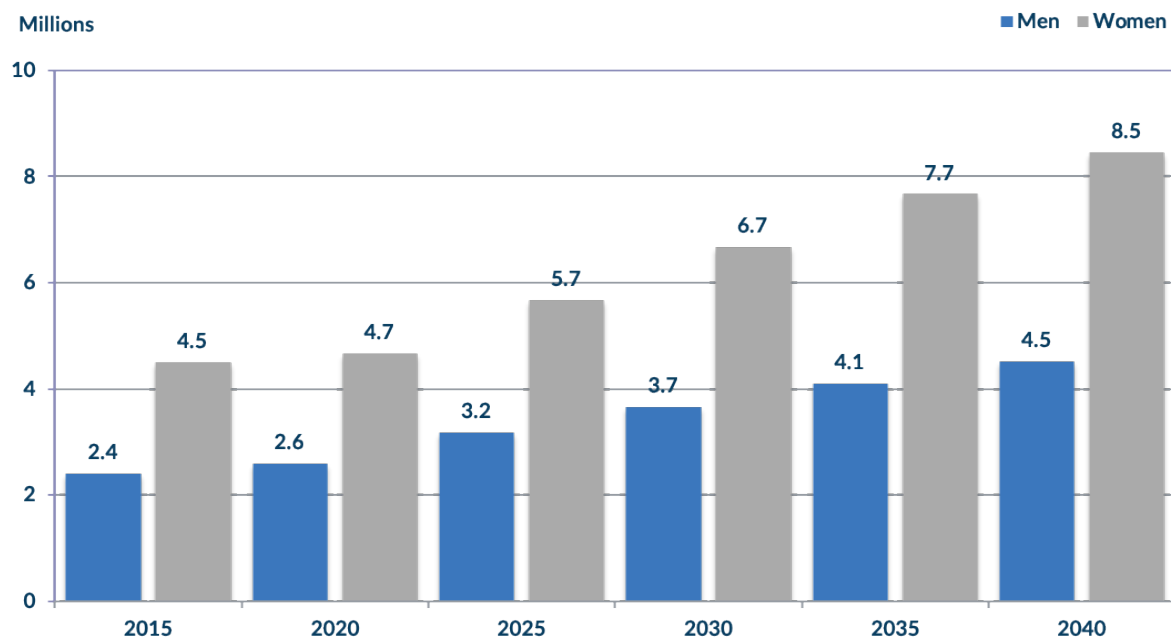
Alzheimer’s disease is already the most expensive disease in the US.<sup>1</sup> The Milken Institute estimates the total cumulative economic impact of treating dementia will reach \$368 billion by 2040. More than 70 percent of these costs will be attributed to the treatment of women, even though women are less likely than men to be treated for the disease. Because most people living with dementia and their caregivers are women, the economic loss associated with women alone will total \$2.1 trillion, representing over 80 percent of the cumulative costs from 2012 to 2040.

Minority populations, especially African Americans and Latinos, are also disproportionately impacted by Alzheimer’s disease and related dementias—both as patients and caregivers. With no cure in sight, we must double down on efforts to reduce risk, maintain cognitive function, and preserve brain health.

At the Milken Institute, we strive to catalyze practical solutions to global challenges. That is why we are putting forward new ideas to reduce the cost and risk of dementia. This report updates previously published data from our 2016 report, “The Price Women Pay for Dementia: Strategies to Ease Gender Disparity and Economic Costs,” and expands our analysis to include the value of brain health and the effects of dementia on diverse communities.

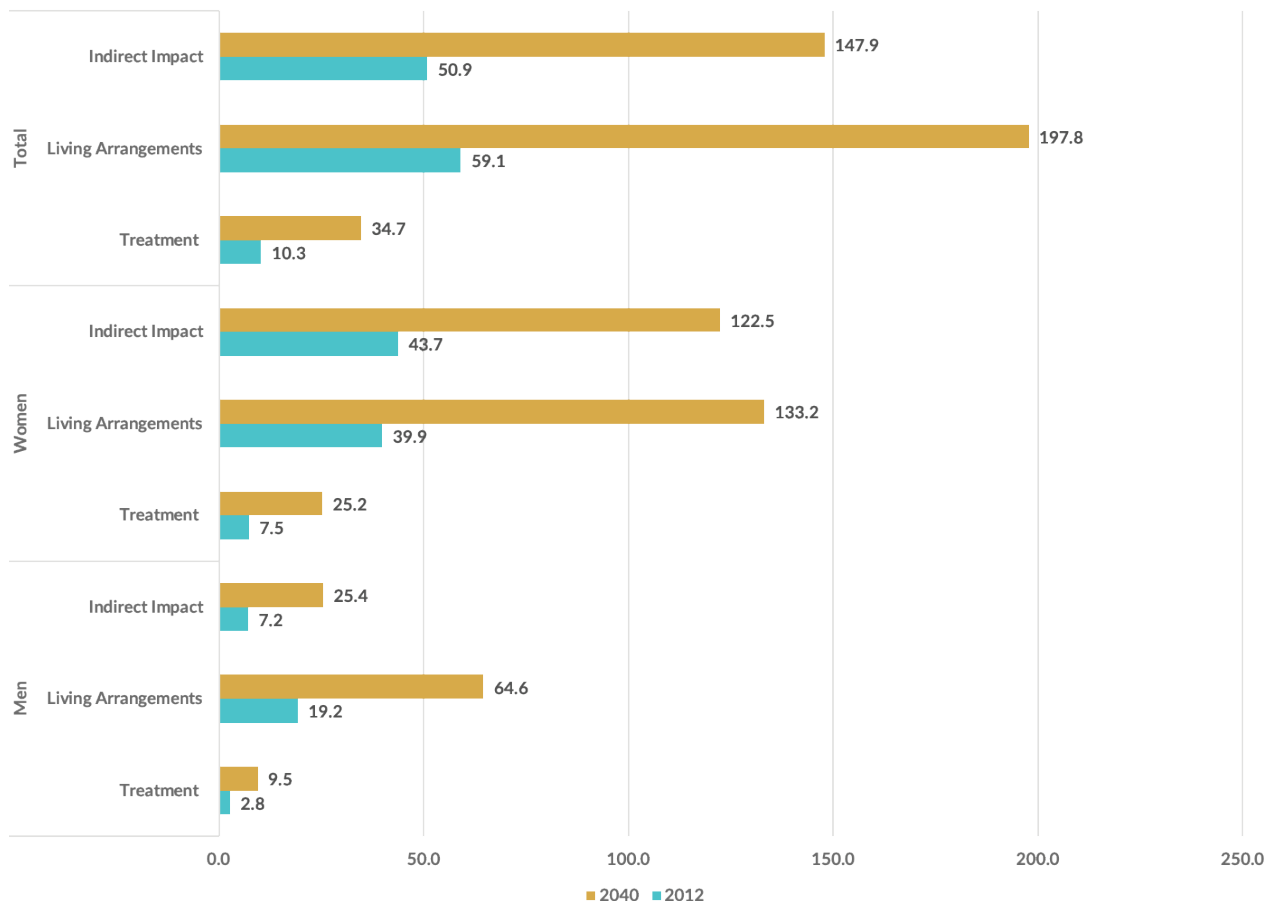
Based on new evidence and a better understanding of the underlying causes of dementia, the Milken Institute analyzed data, conducted interviews, and hosted consensus-building sessions with thought leaders, experts, industry stakeholders, and advocates.

**Figure 1: Increasing Dementia Prevalence by Gender (2015-2040)**



Source: Milken Institute, 2019.<sup>2</sup>

**Figure 2: Economic Impact of Dementia (in 2012 US\$ Billions)**



Source: Milken Institute, 2019.<sup>9</sup>

In this report, we have developed actionable recommendations to improve brain health, reduce disparities, and ultimately change the trajectory of this disease. These recommendations center around five overarching goals.

Years of investment and research in dementia are now sowing seeds of hope. As evidence emerges, we are in a prime position to act, but time is of the essence. In a field that can often look grim, there is hope. **To build upon this momentum, we must act now.**

**Goal #1:** Promote Strategies to Maintain and Improve Brain Health for All Ages, Genders, and Across Diverse Populations

**Goal #2:** Increase Access to Cognitive Testing and Early Diagnosis

**Goal #3:** Increase Opportunities for Diverse Participation in Research and Prioritize Funding to Address Health Disparities

**Goal #4:** Build a Dementia-Capable Workforce Across the Care Continuum

**Goal #5:** Establish Services and Policies that Promote Supportive Communities and Workplaces for People with Dementia and Their Caregivers

## Goal #1: Promote Strategies to Maintain and Improve Brain Health for All Ages, Genders, and Across Diverse Populations

Scientists, health professionals, scholars, and policy experts are rapidly building the evidence base to understand how to reduce dementia risk and enhance cognitive function as we age. As the science advances, we must spread awareness of the steps that individuals, communities, and health professionals can take to prevent or reverse mild cognitive impairment and improve cognitive function, performance, and brain health for all ages.

*“Focusing on brain health can improve people’s lives and ... save health-care costs in a really immediate and tangible way as we look for a cure. Even if we can delay the onset of dementia in people by only five years, we can cut the incidence rate in half.”<sup>4</sup>*

SARAH LENZ LOCK

SENIOR VICE PRESIDENT FOR POLICY AT AARP;  
EXECUTIVE DIRECTOR OF THE GLOBAL COUNCIL  
ON BRAIN HEALTH

To promote strategies to improve brain health, we recommend the following:

**1. Raise awareness of modifiable risk factors associated with cognitive decline (e.g., hypertension, diabetes, diet, exercise, sleep, obesity, depression, and social engagement) through public awareness campaigns.** Organizations like the Lancet Commission, Alzheimer’s Association, and World Health Organization have identified modifiable health and lifestyle factors across our lifetime that, if properly addressed, could potentially prevent one-third of future dementia cases.<sup>5</sup> These

factors include, among others, poor education, hypertension, obesity, smoking, depression, physical inactivity, social isolation, hearing loss, and diabetes. Integrating the best available evidence on these risk factors into existing health communications and public health campaigns will reinforce the importance of lifestyle choices at every age.

**2. Develop tools and resources for physicians and other health professionals to promote healthy brains for patients of all ages before and after symptoms of cognitive impairment present.** Primary care providers are often the first level of care for patients. They are in an ideal position to leverage cognitive screening tools and assessment resources to promote the importance of brain health. They can also provide reliable information, guidelines, and action steps that integrate brain health strategies into their overall discussion of prevention and wellness. These efforts should extend to all settings of care, including specialist offices, pharmacies, emergency departments, and community health clinics. Tools and resources that help clinicians facilitate these discussions within the context of other age-related chronic diseases will go a long way to promote the importance of brain health.

**3. Tailor and disseminate culturally sensitive messages with a particular focus on underserved populations, including women and minorities.** Women make up two-thirds of all Americans living with Alzheimer’s disease and are further impacted because they represent 60 percent of all caregivers of people living with dementia.<sup>6</sup> Latinos and African Americans are more likely to have certain chronic diseases, including heart disease and diabetes, which increases their risk of dementia. Culturally tailored health communication techniques can help raise awareness about specific changes in cognition that merit a conversation with a health professional, shift mindsets, and normalize discussions about cognitive health in the routine delivery of health care. This approach can also improve access to care planning and community services and reduce stigmas surrounding the disease.<sup>7</sup> Leveraging communication

techniques and information that health plans, clinicians, and public health agencies already use for conditions like diabetes, hypertension, and cardiovascular disease would elevate the importance of brain health to all body systems.

**4. Increase community capacity to promote brain health messages and to support interventions at state and local levels.** Local communities play a significant role in promoting brain health and supporting people with dementia and their caregivers. State and local agencies provide needed training, policies, education, information, and support services. Community-led efforts also account for the socioeconomic issues and challenges that underserved communities face. A public health approach that bridges scientific discovery with community-based interventions can accelerate action towards promoting brain health.

*“Brain health broadens the fight against Alzheimer’s to include everyone. It’s the key to defeating stigma, increasing early detection, speeding up research—and ending this disease. It offers us hope—and points us to the actions we can all take. This new look by the Milken Institute offers important recommendations and actions to help move us to an optimal system of brain health care in this country.”<sup>8</sup>*

**JILL LESSER**

BOARD MEMBER, USAGAINSTALZHEIMER’S;  
PRESIDENT, WOMENAGAINSTALZHEIMER’S

## **Goal #2: Increase Access to Cognitive Testing and Early Diagnosis**

Regular cognitive assessments are important to determine baselines, identify changes in cognition, and guide people at risk or showing signs of dementia to appropriate treatments, interventions, and services and supports. While Medicare covers cognitive assessments, they are not being utilized on a widespread basis. Diagnostic tests, such as PET scans that detect beta-amyloid buildup, may reveal symptoms of dementia years before they appear. However, these tests are expensive and often only covered for limited populations (e.g., those participating in clinical trials). To increase access to cognitive screening and early diagnosis, we recommend the following:

**5. Identify and address the stigma surrounding dementia and cultural barriers that inhibit screenings and early diagnosis among diverse populations.** The stigma surrounding dementia often prevents people from seeking help when symptoms arise. Overcoming this stigma requires a multi-pronged effort, including educational and awareness campaigns, dissemination of reliable information, positive media coverage, and tools that make it easier to assess individuals. Providing information about how we can improve our brain health and the differences between healthy aging and dementia, as well as the different ways that dementia symptoms present based on gender, race, ethnicity, and disability, can also encourage people to seek early cognitive screenings.

**6. Develop a national Medicare dementia prevention and detection strategy to spread awareness of risk reduction strategies, increase regular cognitive assessments, and improve early detection rates.** The Brain Health Partnership, an initiative convened by UsAgainstAlzheimer’s, calls for a National Medicare Dementia Prevention Strategy that aligns business incentives for payers and health systems to promote better brain health.<sup>9</sup> This partnership (of which the Milken Institute belongs)

recommends strategies that include a review of payment systems, demonstration programs, measure development, benefit flexibility, and lifetime risk reduction activities. These strategies will encourage providers and payers to address brain health proactively and strengthen early detection and interventions.

**7. Optimize cognitive testing tools, referral pathways, and workflows for health-care providers (e.g., cardiologists, OB/GYNs, and community health workers), making sure to focus on those who serve women and minorities.** The primary care setting is well positioned to identify memory impairment and other early signs of cognitive impairment. However, early symptoms are not always apparent during a routine office visit, and patients and caregivers may not voice their concerns. Cognitive testing should be made available in multiple settings where individuals receive their health care. Additional research on testing methods outside of medical settings as well as population-based approaches to increase access to cognitive testing for all communities is warranted.

**8. Conduct more research on screening and treatment for mild cognitive impairment. Develop an evidence base to demonstrate links between cognitive screenings, early diagnosis, and improved outcomes for people diagnosed with dementia early.** Despite Medicare coverage for cognitive assessments, some clinicians are reluctant to perform screenings for their patients because the US Preventive Services Task Force has not endorsed them. Other professional societies, like the American Academy of Neurology, do recommend annual cognitive screenings for everyone over 65 years old.<sup>10</sup>

*“Improving the system of care through better case management is necessary to increase routine cognitive screenings. It’s important to determine*

*who to screen, when to screen, what kind of instruments to use, and then define good quality of care.”<sup>11</sup>*

**HOWARD FILLIT**

FOUNDING EXECUTIVE DIRECTOR AND CHIEF SCIENCE OFFICER, ALZHEIMER'S DRUG DISCOVERY FOUNDATION (ADDF)

**9. Develop more reliable, affordable, and minimally invasive diagnostic tests to improve rates of early diagnosis and more accurately monitor responses to services, supports, and treatments.** Scientists and clinicians must be able to identify those at greatest risk for developing dementia to understand how the disease progresses and develop treatments. Recognizing the importance of developing easier and more accurate ways to diagnose dementia, Bill Gates and ADDF Co-Founder Leonard Lauder have launched the Diagnostics Accelerator program. This program commits more than \$50 million to develop cutting-edge biomarkers and diagnostic technologies to improve diagnoses.

### **Goal #3: Increase Opportunities for Diverse Participation in Research and Prioritize Funding to Address Health Disparities**

Given that women, African Americans, and Latinos are disproportionately affected by dementia, efforts need to be made to facilitate their participation in clinical research studies where they are traditionally underrepresented. Furthermore, research funding must be directed towards identifying promising new treatments earlier in clinical trials and understanding the underlying factors that create health disparities. To engage more diverse participants in dementia research, we recommend the following:

**10. Ensure that gender- and sex-based differences are integrated into the design, analysis, and reporting of biomedical research, and more emphasis is placed on understanding why women are more**

likely than men to develop dementia. Despite our progress in understanding the disease, we still do not have answers to fundamental questions, like who develops the disease, why two-thirds of those who do are women, and most importantly, how to cure it.<sup>12</sup> Researchers are now questioning whether these sex-based disparities are due to biological or genetic variations or differences in life experiences. Adopting an approach that integrates sex- and gender-based differences in dementia research from the outset will help create a body of data to understand and narrow these differences.

**11. Increase culturally sensitive recruitment and retention efforts of women, communities of color, and people with intellectual and developmental disabilities (IDD) in clinical trial research through tailored awareness and engagement strategies. Explore strategies to bring clinical trials into underrepresented communities, including the utilization of mobile technologies.** The National Institutes of Health (NIH) developed a National Strategy for Recruitment and Participation in Alzheimer’s and Related Dementias Clinical Research that addresses the challenges of recruiting and retaining participants. NIH also developed the *All of Us* program, which will significantly oversample African American, Latino, rural, and lower socioeconomic status participants, and prioritizes trust and transparency in clinical research methods.

*“It is important to improve current communication messages and focus on the benefits of participating in dementia clinical trials more clearly. One message [that works] over and over, is hope ... [Participants say] ‘if I participate in this, there’s some nugget that’s going to come out that’s*

*either going to help myself or going to help my family or help my community.’ And that’s the sense of hope that is needed when it comes to clinical study messaging.”<sup>13</sup>*

**HOLLY MASSETT**  
SENIOR ADVISOR ON CLINICAL RESEARCH  
RECRUITMENT AND ENGAGEMENT, NATIONAL  
INSTITUTE ON AGING

Because many communities are not located near research centers or lack the resources to support large-scale clinical trials, we should also leverage new mobile technologies to help recruit, enroll, and retain participants.

**12. Build research capacity and a recruitment infrastructure in study sites that are conducting clinical trials on dementia, including workforce development.** Increasing enrollment of participants from underrepresented communities requires improving recruitment infrastructure and study site capacity. Information technology, like electronic health records, can help identify potential dementia trial participants across various clinical settings. And consumer mobile applications can gather data to identify volunteers outside of clinical settings. A diverse and capable workforce also ensures that researchers and study site personnel are representative of the people they are trying to recruit and helps build trust with potential participants.

**13. Ensure data collection and sharing across subgroups of racial and ethnic minorities as well as people with IDD and stratified by gender to promote a more precise understanding of Alzheimer’s pathologies among high-risk populations.** Clinical trial data are often inaccessible to the broader research community. Sharing de-identified clinical trial data is beneficial because



it allows researchers to build upon each other's work, deters inaccurate result reporting, and quickens potential findings and treatments. Data generated from diverse volunteers may also lead to more tailored findings that increase the safety and effectiveness of medical products for specific communities. Appropriate safeguards assuring proper use and storage of data will protect consumers and make them more comfortable sharing data.

**14. Increase investment in prevention and risk reduction research.** The importance of finding a cure should not overshadow research efforts to prevent and reduce the risk of dementia. This research not only helps delay the onset, slow the progression, and improve symptoms of dementia, but also can decrease costs for people living with dementia, their caregivers, and the overall health system. We must increase the study of lifestyle factors that can reduce the risk of cognitive decline.

#### **Goal #4: Build a Dementia-Capable Workforce Across the Care Continuum**

A culturally competent, dementia-capable workforce is required to effectively identify people with dementia, tailor services to meet their needs and those of their caregivers, and ensure those living with dementia get the right care at the right time. To promote strategies to build a dementia-capable workforce, we recommend the following:

**15. Reauthorize and increase funding for the Geriatrics Workforce Enhancement Program (GWEP) to improve health outcomes for older adults by developing a health-care workforce that maximizes patient and family engagement and integrates geriatrics with primary care. Prioritize communities that have growing populations of older Americans and a particular shortage of geriatric specialists.** The GWEP is a highly effective model for incorporating best practices for geriatric and dementia care training, and we support its reauthorization. GWEP educates and trains patients,

families, caregivers, direct care workers, and health professions' students, faculty, and practitioners. The Geriatric Workforce Improvement Act would reauthorize the GWEP for an additional five years and increase funding to \$45 million per year.

*“Expanding GWEP would promote geriatric education for our current workforce, while optimizing resources to bolster academic careers in geriatrics, helping to attract the best and the brightest into the field. This bipartisan bill is necessary to develop a high quality geriatric workforce ready to provide care for Americans as we grow older.”<sup>14</sup>*

SENATOR SUSAN COLLINS (R-ME)  
CHAIRMAN, SENATE SPECIAL COMMITTEE ON AGING

**16. Spread Age-Friendly Health Systems for older adults with dementia.** A large portion of the costs associated with caring for Medicare beneficiaries with dementia can be attributed to avoidable or preventable hospitalizations, poor coordination and communication across care teams, and ineffective care transitions.<sup>15</sup> To better prepare for an aging population, the John A. Hartford Foundation and its partners launched the Age-Friendly Health Systems (AFHS) initiative. AFHS employ a systematic approach to information sharing and coordination across care settings to reduce unnecessary costs and inefficient care. They also train interdisciplinary teams to work with and support caregivers to best meet the needs of older adults and should also be applied to dementia care to provide evidence-based, coordinated, person- and family-centered care across the care continuum.

**17. Develop and train workers to provide high-quality care to people living with dementia.** As the disease progresses, people living with dementia typically require extensive care—either from unpaid, family caregivers or direct care workers. By 2030, the US will need an estimated 3.4 million direct care workers to provide long-term services and supports (LTSS), a 1.1 million increase over the 2.3 million who filled these jobs in 2015.<sup>16</sup> To attract and retain this workforce, we need to ensure these jobs are of high quality and well paid. We must also ensure direct care workers, including personal care aides, home care aides, and certified nursing aides, have access to dementia-specific training.

**18. Increase the cultural competency of the existing dementia workforce to ensure they provide culturally sensitive care, services, and research opportunities to high-risk populations.** Cultural competency in health-care settings can improve health outcomes for people with dementia. While geriatric and dementia-focused training across interdisciplinary teams should be ubiquitous, training for cultural sensitivity requires regional specificity, based on the racial, ethnic, and cultural characteristics of each community. Cultural sensitivity training for dementia care staff will create opportunities to engage and recruit diverse individuals into health and LTSS professions.

**19. Provide paid and unpaid caregivers with the tools, information resource centers, and training to meet the unique challenges of caring for people living with dementia.** Many family caregivers are on their own when it comes to managing complex medical and nursing tasks for individuals with challenges to physical, cognitive, and behavioral health. Dementia caregivers report higher levels of stress than other caregivers, mainly due to the progressive and complex nature of the disease. The Health Resources and Services Administration created a caregiving-specific curriculum to address their unique needs. The training helps caregivers take care of their own health and better understand

the unique challenges of caring for a person with dementia. It also helps health-care professionals engage the caregiver as a member of the inter-professional care team.

**20. Pilot new payment and delivery models to provide comprehensive, coordinated, and person-centered care for people living with dementia and provide services in the home and out of more costly settings of care, where possible.** The Affordable Care Act created the Center for Medicare & Medicaid Innovation (CMMI) to develop and test new payment and delivery models for providing value-based care to Medicare and Medicaid beneficiaries. While several models are designed to improve care for a host of chronic conditions, new models specific to dementia care do not exist. We could fill this gap through a CMMI demonstration project aimed at Medicare beneficiaries with dementia who need progressive interventions to avert or delay institutional care and enrollment into Medicaid. Implementing new dementia care models across settings, coupled with new Medicare billing codes and increased opportunities for Medicare Advantage plans to treat people with dementia, will help deliver cost-effective, coordinated, and high-quality care.

### **Goal #5: Establish Services and Policies that Promote Supportive Communities and Workplaces for People with Dementia and Their Caregivers**

To meet the needs of the growing population living with dementia, communities and workplaces must provide support for people living with dementia and their caregivers. Caregivers of people living with dementia are impacted more severely by challenges than non-dementia caregivers and seek out resources more frequently for assistance.<sup>17</sup> Dementia-friendly communities and workplaces foster the ability of people living with dementia and their caregivers to remain active and engaged in their communities. To encourage communities and workplaces to establish the necessary services and supportive policies, we recommend the following:

**21. Reduce the stigma associated with dementia through increased community engagement between people living with dementia and those who are less familiar with the condition. Include people with dementia in discussions about how to improve their lives and increase funding for community-based services to support them.** We can reduce stigma by creating opportunities for people in the community to interact with individuals with dementia. As people personalize the experience, the anxieties and misconceptions that create stigma will lessen. Community-based programs can provide services and support for people living with dementia and their caregivers like home-delivered meals, housekeeping, transportation, and respite care.

**22. Educate individuals, family members, and financial services professionals about early warning signs of dementia and implement safeguards to protect against financial exploitation.** The first area that older adults show signs of cognitive decline and dementia is often money management.<sup>18</sup> Some of the earliest signs can include difficulty balancing a checkbook, forgetting to pay bills, unusual charges on a credit card, and increased susceptibility to scams.<sup>19</sup> Recognizing this risk, leading financial institutions and consumer organizations have supported research and created consumer-friendly materials to help individuals, family members, and financial advisers be more aware of warning signs that an individual may be a victim of fraud or financial exploitation.

*“In our study, ‘Women and Financial Wellness,’ we learned that women on average live five years longer than men. By age 85 they outnumber men two-to-one, and the majority (81 percent) of centenarians are women.*”

*This means that women are more likely to be alone and financially self-reliant in their later years. Given that women also have a higher prevalence of dementia, their need to factor in longevity and the potential impact of this disease later in life is critically important.”<sup>20</sup>*

LORNA SABBIA  
HEAD OF RETIREMENT AND PERSONAL WEALTH  
SOLUTIONS, BANK OF AMERICA

**23. Expand Dementia Friendly America’s national network of communities, organizations, and individuals to foster the ability of people living with dementia to remain in communities and engage and thrive in day-to-day living.** Dementia Friendly America (DFA) networks include cross-sector community stakeholders, like transportation, housing, businesses, faith-based organizations, and emergency responders. DFA networks not only bring a wide variety of care services into a community, but they also amplify local resources, maximize independent living, and help sustain meaningful community engagement. As dementia-friendly communities mature, efforts are needed to measure their effectiveness and develop metrics to help them scale.

**24. Support and promote bipartisan federal and state policy efforts to expand paid family and medical leave for elder care.** Many dementia caregivers are forced to take leave from their jobs without pay or leave the workforce altogether. The US is one of the few developed countries without guaranteed paid leave to care for children or older relatives. This forces far too many family caregivers to choose between work and caring for their loved ones—often putting themselves in financial jeopardy

to do so. Employed caregivers also need time to care for aging relatives. Given the projections of those who will need care in the future, we must develop more protections and benefits for these essential family caregivers.

**25. Create a national employer task force on elder care to explore innovative caregiver support strategies. Encourage employers to provide benefits such as flexible work schedules, respite care, and paid family and medical leave.** Existing programs for employees have shown positive impacts on flexibility for medical appointments, providing care, and emotional and physical well-being.<sup>21</sup> Adding additional programs supporting caregiver needs could be instrumental in helping employees navigate existing paid family and medical leave benefits given the barriers to utilization that exist, particularly for caregivers of color. Access to employer-sponsored benefits for workers can help caregivers meet the needs of the people they care for without having to leave their jobs.

*To read the full report  
and learn more about the  
Milken Institute's work in  
the field, please visit  
[aging.milkeninstitute.org](https://aging.milkeninstitute.org).*



## ENDNOTES

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## ACKNOWLEDGMENTS

Our work depends on the efforts of many colleagues who share our aspirations. A special thanks to our sponsors and collaborators, AARP, Bank of America, Biogen, BrightFocus Foundation, Home Instead Senior Care, The John A. Hartford Foundation, and UsAgainstAlzheimer's.

Thank you to our colleague, Ken Sagynbekov from the health economics research team, for analyzing data and updating projections on the prevalence and economic impact of dementia. We especially appreciate our Center for the Future of Aging colleague, Cara Levy, for her valuable research assistance. We also appreciate our colleagues Jill Posnick, Karen Rogers, Emily Ball, Kelsey Biggins, and Bridget Wiegman for their editing and design help.

To our friends in the field—Matthew Baumgart, Ellen Blackwell, Jisella Dolan, Robert Egge, Howard Fillit, Molly French, Terry Fulmer, Carolyn Jones, Melinda Kelley, Brooks Kenny, Surya Kolluri, Ian Kremer, Jill Lesser, Sarah Lock, Erin Long, Holly Massett, Lisa McGuire, Kelly O'Brien, Jason Resendez, Mark Roithmayr, Robyn Stone, George Vradenburg, Joan Weiss, Grace Whiting, and Jennifer Ann Zimmer—we greatly appreciate your insights and feedback during our review process. Your comments helped make our report a much better product.

To the many experts from government, the private sector, and academia with whom we consulted, we appreciate your time and valuable input in helping us develop our recommendations for action. We thank Norma Coe for her contributions to helping us better understand the economic value of caregiving. Finally we thank, as always, our Chairman Paul Irving, the members of our Center for the Future of Aging Business Council and Academic and Policy Advisory Board. Their support, ideas, and shared commitment to a better future motivate our work in many ways.



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