

The Hidden Financial Dimensions of Cognitive Decline and Caregiving



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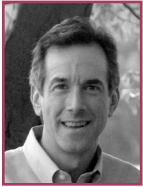
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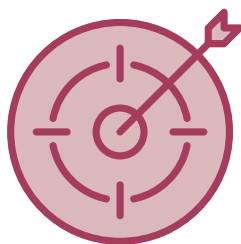
About The Gerontological Society of America and National Academy on an Aging Society

The Gerontological Society of America (GSA) is the oldest and largest international, interdisciplinary scientific organization devoted to research, education, and practice in the field of aging. The principal mission of the Society—and its 5,500+ members—is to cultivate excellence in interdisciplinary aging research and education to advance innovations in practice and policy.

GSA's policy institute, the National Academy on an Aging Society, conducts and compiles research on issues related to population aging and provides information to the public, the press, policymakers, and the academic community. It publishes the quarterly *Public Policy & Aging Report* as well as a public policy e-newsletter.



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GOALS

Using the individual, interpersonal, organizational, community, and public policy framework of the socio-ecological model, this report:

1. Explores the direct, indirect, and hidden costs associated with cognitive decline and related caregiving through a selective literature review.
2. Differentiates among cognitive decline, dementia, and Alzheimer's disease.
3. Explains the impact of cognitive decline on individuals, families, care partners, and caregivers.
4. Illustrates how cognitive decline results in a multifaceted set of financial burdens (many unseen) that change as disease progresses through mild-to-moderate and severe stages.
5. Demonstrates the impact on caregivers' and care partners' health and well-being over time and the outsized impact on women and diverse communities.
6. Identifies best practices for employers to integrate into employment policies, practices, and programs along with beneficial programmatic and policy actions that can be taken by communities, institutions, organizations, and governments at the local, state, and federal levels.

CAREGIVERS AND CARE PARTNERS:

Defining the Terms as Used in This Report

The word “caregiver” is generally used to describe people who take care of others, either through their profession or occupation or because of a special relationship with someone with special needs, such as a child or dependent adult. For some topics in this report, differentiation is needed between those providing paid and unpaid care. In those sections, “caregivers” is used to refer to those being paid for services, whereas “care partners” is used in referring to family members, friends, neighbors, or groups of individuals providing unpaid care.

As explained in a recent National Academies of Sciences, Engineering, and Medicine report (2021), “care partner” refers to someone with whom a person with mild cognitive impairment or dementia has a reciprocal relationship in managing the demands of their condition. Important elements in this relationship are the provision of emotional support and participating in decision making.

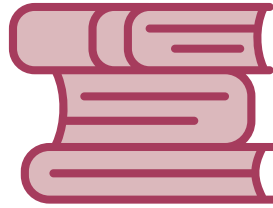


TABLE OF CONTENTS

1 INTRODUCTION

2 THE INDIVIDUAL:
The Science of Cognitive Decline

**8 FAMILIES, EMPLOYERS,
AND ADVISORS:**
The Costs of Cognitive Decline

**12 INSTITUTIONS AND
ORGANIZATIONS:**
*Sources of Help for Care Partners
and Caregivers*

18 COMMUNITIES:
*Addressing the Challenges
of Cognitive Decline*

**22 CHANGE AT THE
SYSTEMS LEVEL:**
*Insights Into Solutions
for Aging Populations*

25 CONCLUSION

26 RESOURCES

27 REFERENCES



INTRODUCTION



“What do you want to be when you grow up?”

It's a question every kindergartner has heard. Like much of what is learned in life's early years, the question itself plants the seed of an important lesson: Knowing where you want to end up helps in planning a better journey.

That is certainly true for older adulthood, a time in life when years of healthy living and planning for the future come together to provide the health, wealth, and social connections needed in older adulthood.

Historic numbers of people will reach older adulthood in this and future decades, and this large cohort of experienced people with years of remaining life has much to contribute to the world. By 2030, all the Baby Boomers will have turned 65, and

later generations—some even larger than the Boomers—will begin reaching older adulthood. Once there, older adults have several options: continue their careers in jobs they love or need, move into an encore occupation or take a part-time job, engage in volunteer or other unpaid activities in their community, or pursue hobbies.

In planning for older adulthood using a life-course approach, many people both fear and consistently underestimate the risk of an important variable and its tremendous impact on their finances: Alzheimer's disease and related dementias (ADRD). Across all generations now in or approaching older adulthood, ADRD is the condition described as “scariest” by more than 50% of respondents in a recent survey. Other threats to health and life—cancers, strokes, and heart disease in particular—can often be managed or eliminated with modern medicines, surgeries, and other interventions; Alzheimer's disease and many other forms of dementia are at this time incurable, progressive, and terminal (Merrill Lynch, 2014).

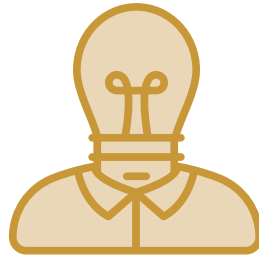
Thus, while people comprehend the threat of ADRD, the costs are usually underestimated—partly because of the hidden nature of some of these expenses. There are the obvious costs of caring for a loved one with ADRD such as the number of years of care needed in expensive long-term care facilities. Not so easy to estimate and anticipate are the lost wages of both



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affected people and their care partners, careers ended early, and lost retirement funds spent on hidden out-of-pocket expenses (Merrill Lynch, 2017).

In this report, *The Hidden Financial Dimensions of Cognitive Decline and Caregiving*, the literature on age- and disease-related cognitive decline is reviewed through the lens of the socio-ecological model (individual, interpersonal, organizational, community, and public policy levels). Topics include the science of cognitive function, what happens when mental abilities decline, actions for preventing or slowing mental decline, and ways that individuals, families, employers, financial and legal advisors, organizations and institutions, communities, and policymakers can plan for the hidden financial impact of an increasing prevalence of ADRD. Vignettes are used to illustrate challenges and options at each level of the socio-ecological framework.



THE INDIVIDUAL:

The Science of Cognitive Decline

For people who grew up in rural Alabama, Peggy and Sal felt lucky at age 62. After moving to Birmingham and finding hourly jobs at the university, they had made enough money to buy and almost pay off a cute little home. Their two kids had enjoyed their childhoods, made it to college, and graduated into better-paying careers than Peggy and Sal could have imagined. Retirement income was going to be almost all Social Security, but if they could pay off their house before leaving their jobs, they figured they would be all right financially. That was the plan until the day the past-due notice came for their mortgage. Sal prided himself on making every payment on time. He couldn't explain what happened, and he angrily blamed

the mortgage company, the bank, and even Peggy for the omission. This pattern of missed payments continued, and Sal also made a few inexplicable purchasing decisions. When their children, Sally and William, traveled back home for the holidays, they encouraged their father to see his doctor. It turned out Sal was developing dementia; 7 years later, he would die of complications of Alzheimer's disease. For 6 of those years, Peggy provided most of Sal's care, at the cost of her job, her close relationships with friends, and the little money the couple had saved. She had to claim Social Security when she began providing care, reducing the monthly income that could have helped her later in life.

The impact of ADRD on the roadmap to financial health for the older adult is tremendous in the long run, and it begins in some cases before identifiable clinical symptoms emerge. In addition, as in the vignette about Peggy and Sal, the initial indication that ADRDs are developing can be a decline in ability to manage one's finances. Payments are missed as early as 6 years before a clinical diagnosis of ADRD, and subprime credit scores are evident 2.5 years earlier (Nicholas et al., 2021).

Understanding the hidden financial costs of ADRD starts by looking deep inside the human brain and finding ways to stop, delay, or cope with the detrimental changes in this complex organ. Because of the limited number of years of expected life in older adults, a delay of a few months or a year or two in onset of Alzheimer's disease can make the difference in being able to live out life in one's home and take care of oneself (Zissimopoulos et al., 2014).

Just as the brain itself is complex, changes in cognitive and emotional processes during aging are equally complicated. Current definitions and concepts presented in this section show how researchers are helping people understand the brain and how it can change, giving them more tools for developing their own personal roadmaps in aging and understanding the hidden financial costs of cognitive decline.

Cognition Across the Lifespan: Definitions and Risk Factors

"Senior moment," "senility," and other ageist terms reflect a stereotype and assumption that cognition begins to decline when people reach older adulthood. While cognitive disorders are more likely to become clinically evident in later decades of life, the process of age-related decline actually begins in healthy educated adults when they are in their 20s or 30s (Salthouse, 2009).

Understanding age-related changes in brain function and health starts with knowing how the mind works. The brain comprises the cerebrum, cerebellum, and brain stem. Using nutrients and oxygen supplied by the



About 15% of adults aged 65 years or older are living with symptoms of mild cognitive impairment.

blood, the parts of the brain are involved in distinct functions such as memory, problem solving, movement, coordination, balance, and automatic functions such as heart rate and breathing. About 100 billion nerve cells, or neurons, are connected by branches that connect with each other at some 100 trillion gaps called synapses. The release of chemicals, or neurotransmitters, into the synapse results when a branch is activated, allowing neurons to signal other neurons. This process is responsible for memories, emotions, and problem-solving abilities in ways that are not yet entirely understood (Alzheimer's Association, 2021a).

Throughout life, people can take a number of actions to increase their chances of maintaining their mental health over the lifespan (Figure 1). While about 60% of risk results from genetics or unknown factors, the other 40% of risk can be affected through education, healthy living, and avoiding causative factors such as alcohol, smoking, and air pollution.

In discussing the health and normal function of the brain, several terms should be used carefully. As shown in Figure 1, cognition, fluid and crystallized intelligence, cognitive impairment, and dementia have specific definitions. Fluid intelligence is thought to peak at age 25 and decline over time, while crystallized intelligence remains relatively stable or increases slightly in older adulthood (Santucci, 2019). Along with institutional knowledge, it is this crystallized intelligence that makes experienced workers so valuable to companies, even as their fluid intelligence declines.

The age-related declines in cognition that began decades earlier can cause



In a given year, about 15% of people living with mild cognitive impairment progress to dementia.

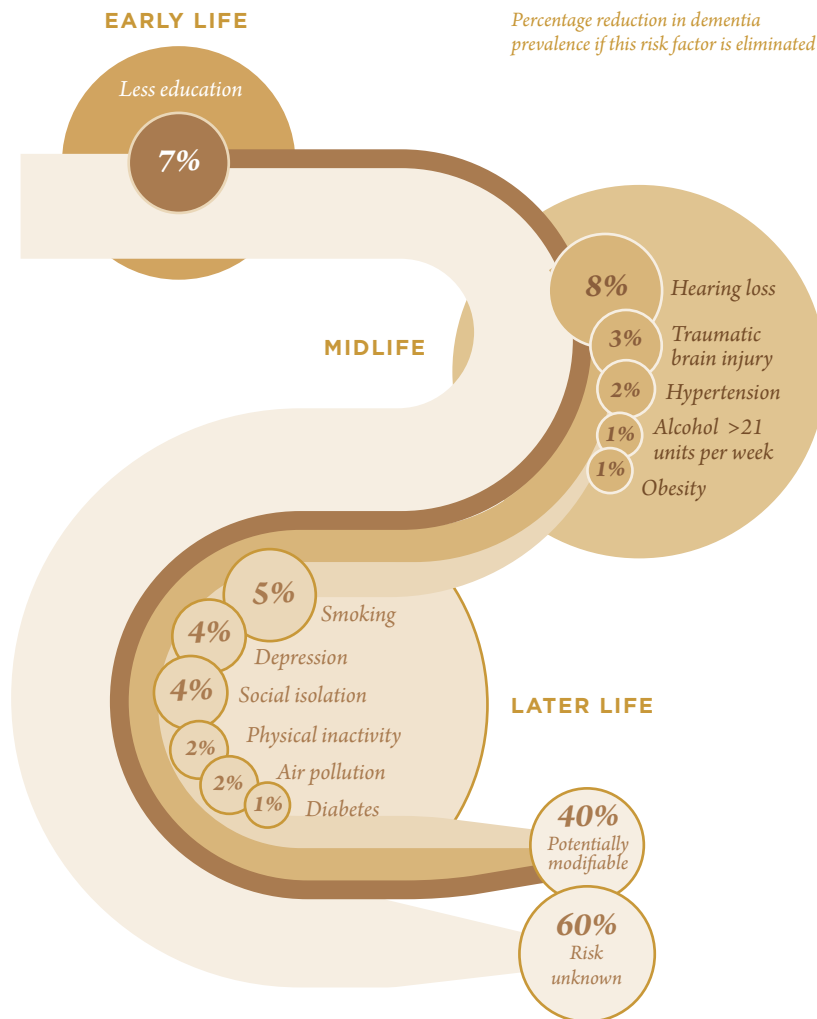
older adults to misplace their car keys occasionally, forget words or people's names, or have trouble remembering recent events. These are common and do not necessarily mean that the person is developing more serious conditions (Centers for Disease Control and Prevention, 2019).

About 15% of adults aged 65 years or older are living with symptoms of *mild cognitive impairment*. Based on clinical histories or examinations, deficiencies can be identified in one or more cognitive domains (learning and memory, language, visuospatial skills, executive function, psychomotor ability) that are beyond what is expected based on the person's age and educational background. These may affect the person's ability to manage money, prepare meals, shop, or complete tasks efficiently. These individuals continue to be able to live independently and in many ways do everything as they always have. However, mild cognitive impairment is associated with higher risks of further mental decline (Knopman & Petersen, 2014; Alzheimer's Association, 2021c; Reuben et al., 2021).

In a given year, about 15% of people living with mild cognitive impairment progress to *dementia*. In contrast to mild cognitive impairment, dementia produces a decline severe enough to interfere with activities of daily living (eating, transferring, toileting, dressing, bathing, walking across a room) or instrumental activities of daily living (preparing meals, grocery shopping, making telephone calls, taking medications, managing money). The first stage, *mild dementia*, involves a change in thinking, ability to recall words, ability to quickly change emotions, or manual skills that require mental coordination of body motion (Knopman & Petersen, 2014).

FIGURE 1.

Cognition and Dementia: Definitions and Potentially Modifiable Factors Over the Lifespan



Cognition: The general ability of a person to acquire knowledge and understand new information through thought, experience, and the senses. Measured using tasks that require:

- **Fluid intelligence:** Processing of new information or solving new problems without relying on past intelligence.
- **Crystallized intelligence:** Processing that relies on past experience such as recall of geographic locations or historical dates.

Mild cognitive impairment:

Deficiencies in one or more cognitive domains (learning and memory, language, visuospatial skills, executive function, psychomotor ability) beyond what is expected based on a person's age and educational background. May affect a person's ability to manage money, prepare meals, shop, or complete such tasks efficiently. Occurs in approximately 15% of older adults.

Dementia: Decline affects multiple cognitive domains that affect a person's ability to function at home or work. Follows mild cognitive impairment in 15% of affected older adults.

Source: Adapted from Livingston et al., 2020. Used under a Creative Commons license with permission.

As dementia worsens, symptoms lead people to consult medical professionals, who assess for the presence of specific changes in the brain. *Alzheimer's disease* is the most common cause of cognitive impairment and dementia. Clinical trials indicate that 60% to 80% of people with dementia have Alzheimer's disease, however in community-based samples, this figure is closer to 50% (Alzheimer's Association, 2021a; Drabo et al., 2019).

Alzheimer's disease is associated with specific pathological changes in the brain,

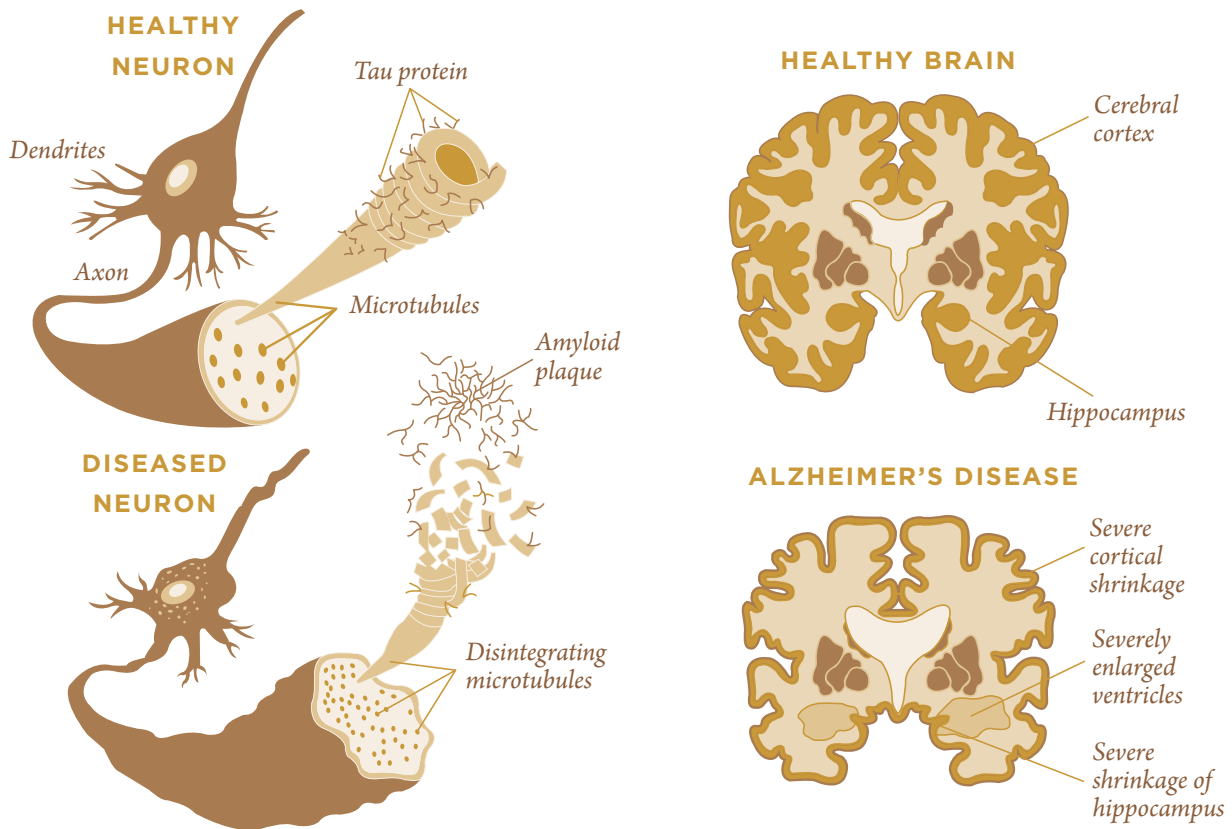
but the cause of the cognitive decline is not completely clear. As illustrated in Figure 2, the brains of people with advanced Alzheimer's disease show death of neurons and loss of tissue, resulting in a shrinkage compared with normal brains. Amyloid- β protein, present in normal brain tissue, has formed amyloid plaques between neurons, and another protein, tau, forms tangles inside cells. These abnormalities are thought to cause cell death that, in turn, interferes with brain function. These changes may begin in the brain as much as 20 years before clinical diagnosis. The

abnormalities then multiply and spread in mild-to-moderate Alzheimer's disease (lasting for 2 to 10 years) and then throughout the brain in the severe phase of the disease (lasting for 1 to 5 years) (Alzheimer's Association, 2021a).

In addition to Alzheimer's disease, ADRDs can be caused by Lewy body disease, frontotemporal lobar degeneration, or cerebrovascular disease (strokes). It has recently been recognized that many individuals suffer from a combination of factors. Genetics is a

FIGURE 2.

Pathophysiologic Changes in Alzheimer's Disease



Source: Shutterstock.

major risk factor for ADRD, contributing about 60% of a person's odds of developing dementia (Figure 1). Other causes of cognitive impairment include Parkinson's disease and other neurological disorders, normal pressure hydrocephalus, and many other factors (Livingston et al., 2020; Thunell et al., 2021).

Early Indications of Cognitive Decline

Much has been learned through basic research and medical investigations about the reasons for cognitive decline and the pathophysiology behind ADRDs that occur during the aging process. While preventives and cures that are reliably effective are the ultimate goal in this search, tremendous advantages result from drugs and other interventions that delay the onset of ADRD and reduce the

effects of cognitive decline on a person's functionality and activities of daily living (Thunell et al., 2021).

Researchers have known for decades that certain abnormal anatomical features are associated with neurodegeneration and found on autopsy in brains of people who died of Alzheimer's disease. These include amyloid- β and tau protein, physical structures detectable on positron emission tomography (PET), and through biomarkers in cerebrospinal fluid and blood (Figure 2). However, some of these features are not diagnostic; people with the biomarkers are at increased risk of developing ADRD, but they do not always do so in a clinically relevant timeframe (Livingston et al., 2020).

The lack of a reliable means of detecting with certainty that ADRD is present



While preventives and cures that are reliably effective are the ultimate goal in this search, tremendous advantages result from drugs and other interventions that delay the onset of ADRD and reduce the effects of cognitive decline on a person's functionality and activities of daily living.

is particularly frustrating since these conditions are thought to begin to develop as many as two decades before clinical symptoms are evident. In addition, self-reports and information shared by family members and other care partners are not reliable in detecting deficits in patients' financial abilities (Okonkwo et al., 2008).

Development of chemical, biologic, behavioral, or psychologic tests useful for detecting ADRD at an early point is an active area of research. With lifestyle choices and therapeutic interventions (Figure 1) potentially useful for changing the course of the diseases, early detection is recognized as an important research objective (Livingston et al., 2020). Scientists have looked for biomarkers in accessible body tissues such as the blood in an effort to identify at-risk patients. Detection of amyloid- β peptides is possible as is identification of some mutations that have been linked to development of ADRD. Imaging techniques such as PET scans have

revealed amyloid- β accumulations in the brains of patients with ADRD (Masters et al., 2015).

Problems with financial tasks in daily life are often the first noticeable indication of cognitive decline (Figure 3). Some of these tasks are simple, such as recognizing and counting money, while tasks such as paying bills and balancing a checkbook are complex. Some deficits may be noted during normal age-related cognitive declines, and by the time a person develops mild cognitive impairment, complex tasks are often compromised. Deficits in financial judgment can follow, leaving an older adult with mild cognitive impairment or ADRD susceptible to financial elder abuse (Widera et al., 2011).

In a study that linked credit scores with ADRD diagnoses in Medicare claims data, ADRD diagnoses were linked to adverse financial events years before clinical diagnosis, and the events became more prevalent after clinicians made diagnoses. These events were more common among

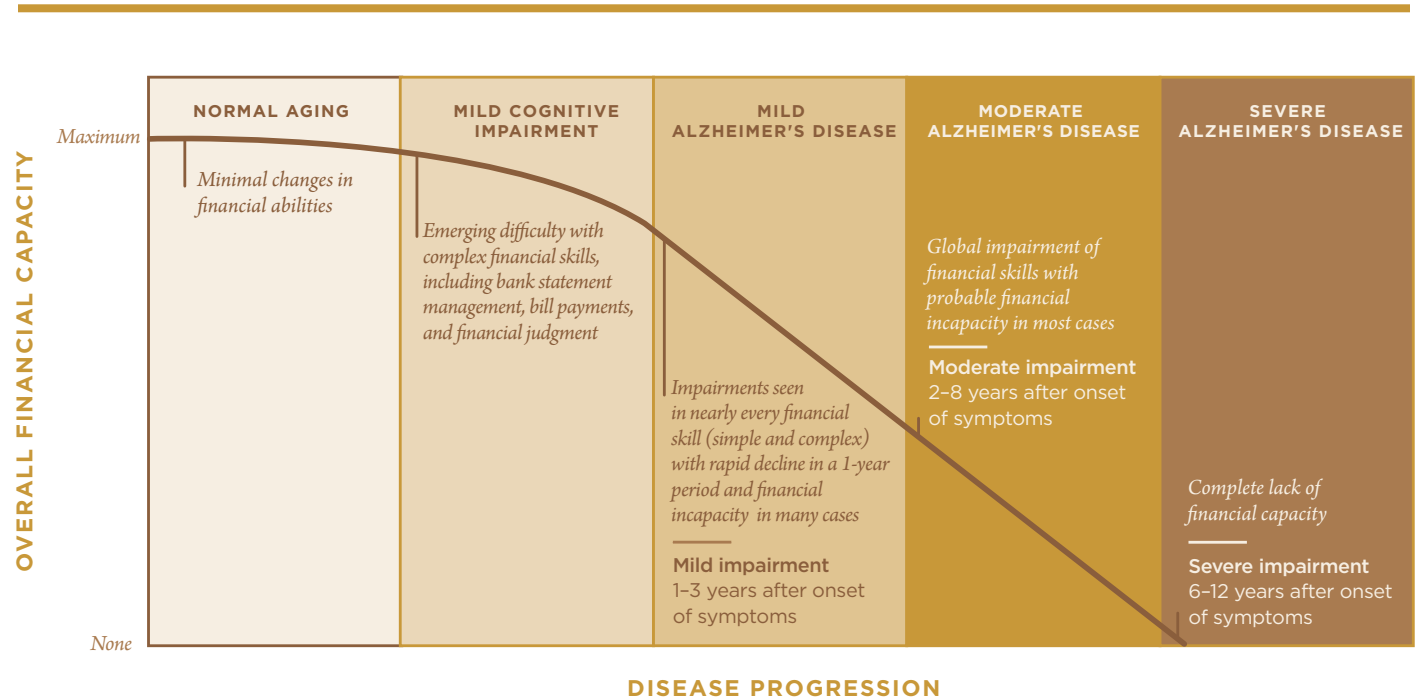
people living in census tracts with lower educational attainment, highlighting the importance of social determinants of health in examining who is at greatest financial risk (Nicholas et al., 2021).

Driving ability is another complex task that can point to possible mild cognitive impairment and dementia. In a study of nearly 3,000 drivers with in-vehicle monitoring devices, applying both demographic characteristics and driving behaviors showed an overall predictive validity of 88%. Given the importance of driving for many people in daily life—including traveling to and from work and driving as a necessary task on the job for some people—monitoring driving ability could prove an important screening tool (Di et al., 2021).

The hidden financial impacts of cognitive decline create challenges for older adults around the world, but these are particularly severe in individualistic societies such as the one in the United States, where risk and responsibility are

FIGURE 3.

Timeline of Effects of Alzheimer's Disease on Financial Skills



Source: Reuben et al., *Geriatrics at your fingertips* (23rd ed.), American Geriatrics Society, 2021, reproduced with permission of American Geriatrics Society; Widera et al., 2011.

increasingly shifted to the individual and safety nets are not available for everyone. People with preclinical ADRD are more susceptible to financial fraud and abuse and poor financial self-management. Financial institutions have a role to play when unusual activity is detected and cognitive decline is suspected, but policy and legal changes are needed to increase available options in such situations (Nicholas et al., 2021).

In addition, people who manage their own investments can get to a point in life when cognitive impairment leads them to shift to risky investments. As described in the *The Wall Street Journal*, financial firms have set up alert systems and processes for investigating such changes to protect investors. Firms are also gathering information on “trusted contacts” who can be reached when unusual transactions raise questions. However, these programs rely on clients voluntarily opting in, naming someone who is still available to help with financial decisions at the time of contact, and do not transfer information across banks and brokerage firms (Smith, 2021).

Older adults who are cognitively intact can develop age-associated financial vulnerability, putting them at risk for financial exploitation or poor decision regarding their wealth. These individuals often want to talk with someone about their perceived financial risk but can also be concerned about losing their financial freedom (Lichtenberg et al., 2020b).

The Lichtenberg Financial Decision Rating Scale (LFDRS-SF) is a tool for assessing financial decision-making abilities. The 34-item scale, available at [Older Adult Nest Egg](#) with training materials, has been validated for predicting financial abilities and fraud susceptibility (Lichtenberg et al., 2017; Lichtenberg et al., 2020a).

“Turning Back the Clock” on Cognition Decline

The media tend to focus on the failures of medications or interventions that can “cure” Alzheimer’s disease. Just as important are medications that can “turn back the clock” on cognition decline. Since older adults have relatively few years of

expected life remaining, a delay in onset of ADRD can mean people live on their own (with reduced or no need for unpaid care) or with family members (with less cost of institutionalized care) until dying of other causes. These options also provide a higher quality of living than is possible during later stages of ADRD (Peron et al., 2020; Zissimopoulos et al., 2014).

As with most aspects of life in the United States and to some degree in other industrialized countries, socioeconomic disparities limit the choices of people with limited income and wealth. Many of the modifiable risk factors shown in Figure 1 are difficult to change when neighborhoods lack quality schools for education in younger years, have no sidewalks and parks that facilitate exercise, lack access to healthy foods and medicines, and expose residents to an unhealthy environment. The financial impact of such factors leads to greater cognitive decline and dementia in those least able to afford the costs of these conditions.

In a longitudinal study, exposure of Black participants to racially segregated neighborhoods during young adulthood was associated with increased risk of cognitive decline as early as midlife (Caunca et al., 2020). Similarly, analysis of data from the Health and Retirement Study (HRS) showed greater cognitive decline among Hispanic participants who were segregated from Whites. Each increase of 20 percentage points in a neighborhood’s Hispanic composition or segregation from Whites was associated with 1 or 1.25 additional years of cognitive aging over 10 years, respectively. In this HRS investigation, neighborhood Black composition and Black–White segregation were not associated with differences in cognitive decline (Kovalchik et al., 2015).

Over the past quarter century, pharmaceutical manufacturers have been searching assiduously for drugs that affect cognitive decline. Research has produced five therapeutic agents that have been approved by the U.S. Food and Drug Administration (FDA).

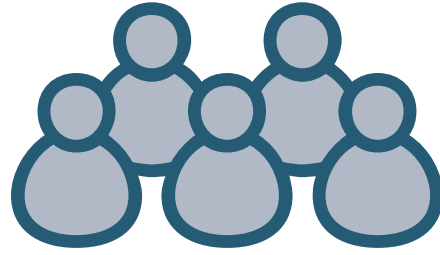
Three older FDA-approved agents are cholinesterase inhibitors that target symptoms of Alzheimer’s disease. Donepezil is indicated for patients with

mild, moderate, or severe Alzheimer’s disease; galantamine is approved for use in those with mild-to-moderate Alzheimer’s disease; and rivastigmine is indicated for mild-to-moderate Alzheimer’s disease and dementia associated with Parkinson’s disease (U.S. Food and Drug Administration, 2021a).

Memantine targets two different neuronal pathways in the brain, and it is indicated for patients with moderate or severe Alzheimer’s disease (but not mild disease). It is available as a single agent or with donepezil in the combination product Namzaric, which has the same approved use as memantine (U.S. Food and Drug Administration, 2021a).

Usage of these older agents has been limited, with only about one third of people with ADRD having used any of them in a recent study of the 2008–2016 time period (Barthold et al., 2020). Newer agents are being studied for their role in preventing or reversing ADRD changes in the brain. These include drugs that target amyloid- β and tau protein accumulation in the brain, degeneration of dendrites, lipoproteins involved in glucose and lipid metabolism, and a protein involved in glycogen synthesis (Agarwal et al., 2021; Selkoe & Hardy, 2016). According to FDA, aducanumab is an amyloid- β -directed antibody indicated to treat Alzheimer’s disease. Aducanumab is approved under the accelerated approval pathway, which provides patients with a serious disease earlier access to drugs when there is an expectation of clinical benefit despite some uncertainty about the clinical benefit.

Accelerated approval is based on the drug’s effect on a surrogate endpoint—an endpoint that reflects the effect of the drug on an important aspect of the disease—where the drug’s effect on the surrogate endpoint is expected, but not established, to predict clinical benefit. In the case of aducanumab, the surrogate endpoint is the reduction of amyloid- β plaque. The accelerated approval pathway requires the company to verify clinical benefit in a post-approval trial. If the sponsor cannot verify clinical benefit, FDA may initiate proceedings to withdraw approval of the drug (U.S. Food and Drug Administration, 2021b).



FAMILIES, EMPLOYERS, AND ADVISORS: *The Costs of Cognitive Decline*

Alan, Maurice, and Wayne were friends of Sal in high school. It was thus both ironic and fortuitous that Peggy would call on Alan as their banker, Maurice as the lawyer who prepared their wills, and Wayne as the local sheriff when Sal almost lost \$3,000 in a financial scam a year after his Alzheimer's

diagnosis. Alan and Maurice worked with the family to place controls on what Sal could do on his own, and Wayne notified federal authorities of how the fraudsters were in the process of getting Sal to transfer the money needed to hold a “free trip” to California when the scam was detected.

Life and the outlook on the future are changed precipitously for the person who is confronted by a diagnosis of Alzheimer’s disease or another type of dementia. The same is true for everyone in that person’s life: immediate and extended family, friends and neighbors, business colleagues and coworkers, health providers, and financial and legal advisors. The emotional impact on the person and the family comes first, followed by disruptions in daily routines, and often lead to financial costs not previously evident or imagined.

When the signs and symptoms of cognitive impairment or ADRD begin to emerge, family members, employers, and nonmedical professionals in the affected person’s life have much to learn and do in preparing for the coming years. Conversations will be needed early in the course of ADRD, and legal papers may

need to be prepared or reviewed. Bankers, stockbrokers, and financial advisors must be brought into the conversation so that limits and roles can be put into place for activation when needed.

**Communicating the ADRD
Diagnosis: The KAER Model**

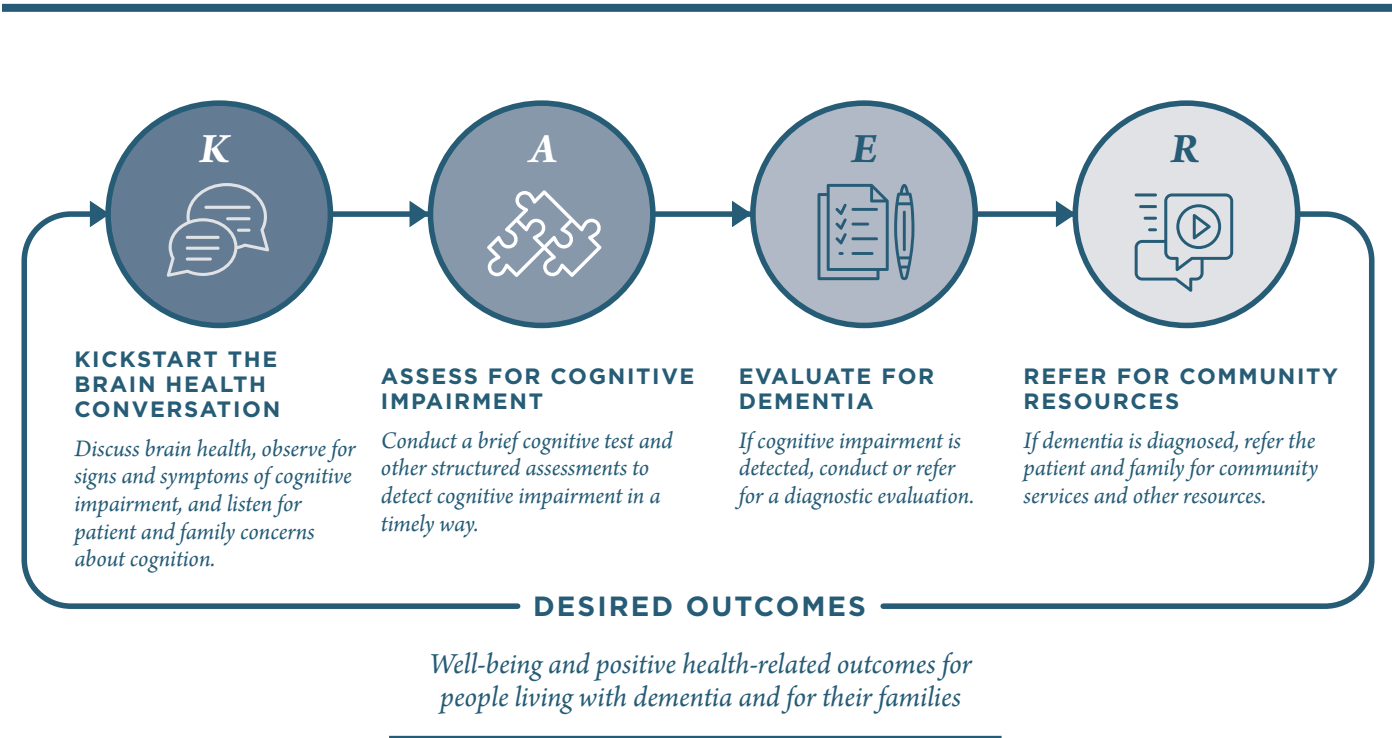
Developed for a report of The Gerontological Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis, the KAER (Kickstart, Assess, Evaluate, and Refer) model—shown in Figure 4—is useful for organizing the thought process needed for conversations about cognitive impairment and guiding the presentation of information during sessions with family, other caregivers, and legal and financial colleagues. Discussion of the affected person’s signs and symptoms of cognitive impairment, results of

tests and what those mean, how the formal diagnosis was reached, and the community services that are available provides a complete picture of what is needed for protection of the individual from elder financial abuse, the person’s safety, and the medical decisions on the horizon. Motivated family members and people diagnosed or at risk for ADRD will also find much useful information in the original report (Gerontological Society of America, 2017) and in a recently revised KAER toolkit targeted to the needs of primary care teams (Gerontological Society of America, 2020), including resources and pointers on how to initiate conversations and communicate effectively during this journey.

During such conversations, family and others in the lives of people with ADRD need to comprehend the hard reality of the direct and indirect financial costs that

FIGURE 4.

KAER Model Developed by The Gerontological Society of America



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Source: Gerontological Society of America, 2020.

are likely following an ADRD diagnosis. These can include medical bills for the individual and/or family, hidden costs for employers who lose key workers, partners whose career velocity slows as they care for their loved one, middle-aged people who must concurrently care for both their children and their own parents, and children who delay college or a career while they are helping with parents or grandparents. Many older adults are aging into dementia-prone times of life, but few are planning adequately for it despite the obvious impact of medical, respite, or residential care of people with ADRD. Sometimes these conversations are initiated by motivated care teams; other times, people affected by an ADRD diagnosis in a loved one, employee, or client may need to drive this process.

Viewed on a macroeconomic level, the monetary outlays for ADRD in the United States reached an estimated \$305 billion in 2020, up from \$157 billion to \$215 billion a decade earlier. These costs are similar to those of cardiovascular disease and cancer. Medicare and Medicaid paid approximately \$206 billion of the 2020 costs of dementia. The remainder came from the health care marketplace—employer-funded insurance policies and other insurers—and out of the pockets and savings accounts of affected individuals and their family, neighbors, friends, and colleagues (Alzheimer's Association, 2020; Hurd et al., 2013).

These trends in aging portend a large increase in spending on people living with ADRD in coming decades. Projected increased spending when a person has Alzheimer's disease is in the \$70,000 range based on current dollars. By 2050, total formal costs per person with Alzheimer's disease is projected to increase to \$106,639. In contrast, total costs in 2050 per person without Alzheimer's disease would be \$37,670. With the number of Americans with ADRD projected to climb from 7.2 million in 2020 to 11.7 million in 2040, the cost of caring for people with ADRD is just as much a concern for policymakers as for the individual planning for an expanded lifespan (Zissimopoulos et al., 2014; Zissimopoulos et al., 2018).

The burden of ADRD is not shared evenly, and the risks are higher among those who are disproportionately in lower socioeconomic groups. Even though Whites and Asians live longer, Alzheimer's disease occurs more commonly in Blacks (2-fold increased risk compared with Whites) and Hispanics (1- to 1.5-fold increased risk). Lower educational attainment contributes to an increased risk of Alzheimer's disease in these groups, as do diabetes and stroke. Genetics could also be a factor, with higher frequencies of the detrimental ε4 variant of the apolipoprotein E gene in Blacks and Hispanics (Chen & Zissimopoulos, 2018; Steenland et al., 2016; Gurland et al., 1999; Haan et al., 2003).



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groups.*

In the Workplace: Hidden Costs for Employers

Beyond the obvious medical and related costs of ADRD are many financial aspects evident in the individual and family stories of the millions of people with ADRD—the employee whose symptoms affect workplace performance, the care partner who is unable to maintain a full workload and misses out on employer contributions to retirement accounts, an employee who has to decline a promotion to create the time needed for caregiving, the person living with ADRD who makes exorbitant online purchases but does not remember doing so when the products arrive, and those who fall for the many

financial scams directed at people with mild symptoms and full access to their bank accounts and credit cards. These hidden costs add a dimension to the human tragedy that is ADRD.



*About 200,000 Americans are
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or other forms of dementia.*

As increased longevity allows people to work further into older adulthood, employers are encountering more workers with cognitive impairment and ADRD. In addition, both older and younger workers often have care roles with family members (including grandparents, parents, partners, adult children, and younger children and grandchildren), neighbors, or friends, which can affect flexibility and attendance at work as well as their attention, energy, and focus while on the job. The greatest risk for ADRD is after a person turns 80 years of age, but the larger numbers of older adults in the workforce during their 60s and 70s translates into many workers in those age ranges who are affected by these conditions. In addition, about 200,000 Americans are diagnosed each year with early-onset Alzheimer's disease or other forms of dementia (before age 65).

These realities translate into several responsibilities for employers: To recognize the onset of cognitive deficits in employees and have procedures for dealing with those shortfalls, help workers balance their employee and caring roles, and educate all employees about the need for disability and long-term care insurance.

As workers age, the inability to recall a name or term is usually written off as “normal aging,” and it often is. Combined with sensitivities with asking about the health of others in the workplace, the employee with emerging mild cognitive impairment presents a conundrum for colleagues and supervisors. Further, the

legal obligations of the employer to treat memory loss as a covered condition under the Americans With Disabilities Act can be difficult to determine, depending on the nature of the employee's position description and responsibilities (Babcock, 2009; Gurchiek, 2018).

Minimizing the hidden costs of ADRD for employers begins with well-developed human resources policies and procedures. For managers with budgetary responsibilities, inability to perform financial tasks can be the first clear indication of cognitive decline. Depending on how integral these tasks are to the employee's overall job, the employer could be unable to provide accommodations that would enable continued working, and federal courts have upheld terminations in such situations (*Stern v. St. Anthony's Health Center*, 2015).

When duties of a position make accommodations feasible, employees expect support from employers. People can often continue functioning in many aspects of their jobs if reasonable support systems are in place or problematic responsibilities can be reassigned. Employers should monitor performance and/or productivity using objective criteria for all workers; if the progressive nature of cognitive decline reaches a point where the individual can no longer meet the expectations of the position, the employer can take action as it would with any employee (Babcock, 2009).

A common situation in the workplace is the need to support workers who become care partners for parents, spouses, and others in their lives with ADRD. Flexible work schedules and time off to provide care—including paid time off—are increasingly recognized as necessary by employers and required in some state laws and federal initiatives, including the proposed national comprehensive paid family and medical leave program in the Biden administration's American Families Plan (White House, 2021).

In the Home: Hidden Costs for Families and Friends

The economic cost of unpaid caring of people living with ADRD is staggering. In a 2018 study of data from 2015 and 2016

for 38 states, the District of Columbia, and Puerto Rico, researchers estimated that 3.2 million care partners provided more than 4.1 billion hours of care—1,278 hours per care partner per year. The median economic value of this care was \$41.5 billion annually, or an average of \$13,069, based on a median hourly value of \$10.28 (Rabarison et al., 2018).

Not only do care partners pay the price in terms of lost wages and terminated careers, they find themselves responsible for paying medical and other bills for the loved one with ADRD, including out of their own accounts. They may eat less or less healthfully while they maintain the nutrition for the person with ADRD. Care partners are also often in poor physical or mental health themselves, with conditions such as depression, anger, stress, and guilt particularly common (Caputo, 2021).

In addition, since the majority of those providing unpaid care are women—who also have more years of expected life remaining—the effects on retirement funds are compounded. Women earn less in the income-generating years and therefore accrue less retirement monies. This gender-related gap is exacerbated when funds are pulled to cover the expenses during time spent providing unpaid care, and these care partners encounter retirement insecurity when they need those funds for themselves in later years. This leaves them dependent on Social Security income for community living and Medicaid if they need paid care during later years (Weller & Tolson, 2018).

Hidden costs are also higher for employed workers who are providing unpaid care in rural areas. Workplace supports are less

common, and employees are more likely affected by financial costs of caregiving; they are also more likely to miss work because of these caregiving responsibilities (Henning-Smith & Lahr, 2019).

The reality of stretching limited funds is striking at the individual and family level, but the experience is not limited to small groups of people. The Alzheimer's Association estimates that 11.2 million people were providing care for people with ADRD in 2020. About two-thirds of these care partners are women, and nearly one-third are aged 65 years or older. The racial makeup is 67% White, 10% Black, 8% Hispanic, 5% Asian American/Pacific Islander, and 10% other groups. About 40% of care partners have a college degree (Alzheimer's Association, 2021a).

The financial expense of health emergencies such as ADRD and the resulting unemployment for the patient and oftentimes the partner are simply unaffordable for many Americans. The lack of financial security cuts across all racial and ethnic lines, but it is particularly severe for Black and Hispanic households. In an analysis of major policy options for addressing the wealth gap between Blacks and Whites—specifically debt-free college, baby bonds (providing children with start-up capital), civil rights enforcement in housing markets, credit market regulations enforcement, and a national retirement savings plan—baby bonds had the single largest effect, the authors concluded. But only targeted cash or liquid asset transfers to Blacks could “overcome the persistent wealth differences with White households” (Weller et al., 2021).





INSTITUTIONS AND ORGANIZATIONS:

Sources of Help for Care Partners and Caregivers

When the COVID-19 pandemic began soon after Sal's death, the children encouraged Peggy to move closer to them. But with the problems of traditional long-term care facilities laid bare during the pandemic, the family sought an option that would increase Peggy's chances of living on her own for as long as possible. Sally lived in Tennessee, near where an

innovative housing option for older adults was being planned on the grounds of an existing long-term care facility. Sidewalks, parks, and other outdoor activities were promised for these small, age-friendly homes where people would be able to age in place while knowing and socializing with their neighbors.

All unpaid care partners need their own support systems, whether for work or just to decompress from the 24/7/365 attention needed to help people as ADRD progresses. Given the timeline involved in Alzheimer's disease and the severity of symptoms toward the end of life, the care process almost always involves some amount of paid care or institutional services later in the disease course.

Support systems form the connection between community members, the care partner, and the individual with ADRD. These can be friends and neighbors, and they often include institutions and organizations that can help with activities of daily living such as meal preparation, bathing, and daily hygiene or provision of respite care that allows care partners to focus on their own needs.

Important to remember also are the people with ADRD who lack reliable support in the form of unpaid care. Many older adults today have no children at all, and other families are widely dispersed thus limiting what relatives can do for one another. Cultural practices, sexual orientations, and gender identities can create special needs in care for individuals with ADRD. Institutions and organizations serving older adults must be adept at meeting their needs as unique persons and helping them remain in the community as long as they can safely do so.

Melding Paid Caregiving With Unpaid Care Partners

At whatever point community services or paid caregiving is needed, individuals living with ADRD and their care community move to the next phase of the dementia journey. As illustrated in Figure 5, the process of transition is a complex one; it is also likely to generate unexpected reactions by the person with ADRD as well as out-of-pocket costs (Ashbourne et al., 2021). Given the complex biopsychosocial needs of families living with ADRD, alternate payment models would be useful for speeding up the development, testing, and adoption of collaborative dementia care models (Boustani et al., 2019).

The transition process can involve areas in which needs and services are aligned and other aspects in which conflict occurs. Various factors can help this process feel continuous and logical rather than disruptive and abrupt. Sudden events such as falls or strokes can catalyze the process, but preparation for the possibility of a



Given the complex biopsychosocial needs of families living with ADRD, alternate payment models would be useful for speeding up the development, testing, and adoption of collaborative dementia care models.

transition of care can provide emotional and physical buffers. Compassionate health providers facilitate these processes; any number of obstacles can make transitions difficult (Ashbourne et al., 2021).

On this journey, several models of care have accumulated sufficient evidence of their benefits—but not their costs or cost-effectiveness—for both people with ADRD and their care partners. Chief among these are the collaborative care and the REACH II (Resources for Enhancing Alzheimer's Caregiver Health II) models, according to a 2021 report from the National Academies of Sciences, Engineering, and Medicine.

These two models of care are recommended based on a growing body of evidence showing that they make a difference in the health of the heterogeneous group of care partners in a wide variety of communities and settings and for people with a wide range of disease severity. A systematic review conducted by the Agency for Healthcare Research and Quality (AHRQ) describes these models as multifaceted and ready for dissemination and implementation. While the evidence is low strength and much more research is needed, the collaborative care models—ones that use truly multidisciplinary teams to integrate medical and psychosocial care—have improved quality of life for persons living with dementia and improve system-level markers such as guideline-based quality indicators and reduction in emergency department visits. In REACH II studies, care partner and caregiver depression have been reduced within 6 months of implementation (National Academies of Sciences, Engineering, and Medicine, 2021).

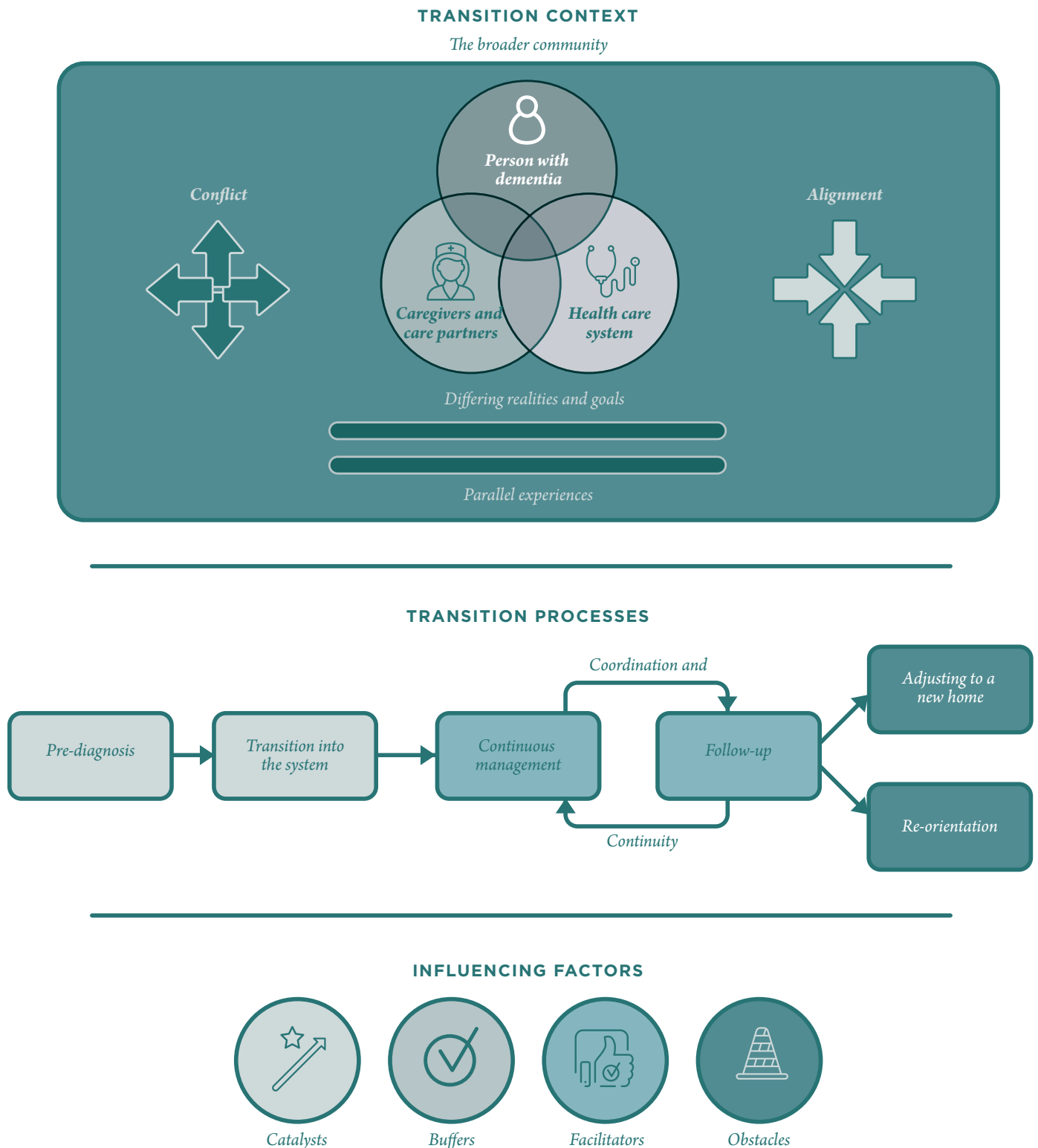
Collaborative care models operationalize many core components of care, often leverage existing resources and partnerships, and have been used for other chronic diseases. Examples of collaborative care models are ACCESS (Alzheimer's Disease Coordinated Care for San Diego Seniors), Dementia Care Management, Care Ecosystem, and the Indiana University/Purdue University Model. These all share several components, including coordination of psychosocial interventions, medical management, and other services through a care manager; the development of care plans; case tracking; and collaboration with care. The AHRQ systematic review found collaborative care models are effective for improving quality of life and quality indicators as well as reducing emergency department visits. Individual studies have shown other benefits such as reducing neuropsychiatric symptoms and long-term care facility placement for people living with ADRD and reducing caregiver strain and depression (National Academies of Sciences, Engineering, and Medicine, 2021).

The REACH II model and its derivatives share seven common components: problem solving, skills training, stress management, support groups, provision of information, didactic instruction, and role playing. Studies have shown reduced caregiver strain with the REACH II model, and it has been implemented in a wide range of real-world settings. Caregiver strain, stress, and depression have been reduced, as have challenging behaviors, caregiver frustration or bother, and physical symptoms. Outcomes have also been improved, including self-reported social support, self-reported caregiver health, caregiver reactions to challenging behaviors, positive aspects of caregiving, and safety of persons living with dementia. The model is being used in the Veterans Affairs system and by local chapters of the Alzheimer's Association (National Academies of Sciences, Engineering, and Medicine, 2021).

Other care interventions are useful for people living with ADRD and their caregivers, but evidence supporting their effectiveness is lacking. As more studies of other approaches provide greater insights, additional care interventions could be recommended in addition to collaborative care and REACH II (Butler et al., 2020).

FIGURE 5.

Health Care Transitions for Persons Living With Dementia and Their Care Partners and Caregivers



Source: Ashbourne et al., 2021. Reprinted with changes under a Creative Commons Attribution 4.0 International License.

Sources of Financial Advice and Assistance

For people living with ADRD and their care partners, financial challenges are evident in several key areas: having enough money to pay routine and medical bills, managing funds as the affected person gradually loses cognitive abilities, and avoiding financial scams often targeted at this patient population. Numerous institutions and organizations can help overcome these challenges by matching a person's needs with helpful financial services. The Centers for Medicare and Medicaid Services and other agencies of the federal government focus on health care fraud and scams that employ telemarketing, text and email messages, social media, and door-to-door visits (Centers for Medicare and Medicaid Services, 2021; U.S. Department of Health and Human Services Office of Inspector General, 2021).

For the financial leg of the ADRD journey, the first step should be to retain an attorney to prepare several legal documents: a durable power of attorney for financial matters and health care decisions, a living trust (for managing assets, including money, while the person living with ADRD is not able to do so and for how property and funds are to be distributed at death), a living will (for medical directives in end-of-life care, including the person's preferences regarding "do not resuscitate" orders), and if needed, a will for distribution of remaining assets at the end of life. The [National Academy of](#)

[Elder Law Attorneys](#) has a "find a lawyer" service for finding legal practitioners who specialize in this field. By focusing on the intersection between law, aging, and policy, the [American Bar Association Commission on Law and Aging website](#) is also useful in helping everyone age with dignity (National Institute on Aging, 2020a; National Academy of Elder Law Attorneys, 2021; American Bar Association Commission on Law and Aging, 2021).

Having advance directives in place means that a loved ones receive the care they want but are not subjected to unwanted interventions at the end of life. In addition to being ethical and loving, this can also have financial impacts as medical expenses—including some out-of-pocket expenses—at the end of life are reduced (Nicholas et al., 2011; Nicholas et al., 2014). Important to note is that patients may not have deep-seated opinions about the end-of-life care they want to receive and their choices can depend on how these are presented to them. Furthermore, this is a sensitive topic, one requiring people to think about situations they may prefer to ignore or not talk about (Halpern et al., 2013).

Legal and financial planning resources for low-income families can be identified by searching on the [Eldercare Locator website](#) of the Administration for Community Living and the Administration on Aging. Samples of state's advance directives can be downloaded on the [National Hospice and Palliative Care Organization website](#) (Administration for Community Living & Administration on Aging,

2021; National Hospice and Palliative Care Organization, 2021).

Regardless of a person's specific financial situation, everyone needs these legal documents so that trusted care partners can take care of financial matters—such as accessing accounts where Social Security funds are paid—when the person living with ADRD is no longer able to handle such tasks independently. Health care professionals can provide valuable input about the types of medical directives they find most useful and advise on when the cognitive skills of the person with ADRD have declined to the point that living trusts or wills should be invoked (National Institute on Aging, 2020a).

The next step is to meet or talk with trusted financial advisors and institutions. Five principles define the innovative steps that financial institutions can take in an aging society to protect people living with ADRD (Nedopil & Schurman, 2014):

1. Protect older people from financial abuse.
2. Customize financial products and services for older people.
3. Offer affordable financial management.
4. Guarantee access to banking products for older people with critical incomes and facilitate aging in the community.
5. Improve the accessibility of branches and services, including for people living alone with restricted mobility or in remote areas.

Stockbrokers and other financial advisors can advise the family on how the assets of the person with ADRD can be managed during the course of the disease. The components of the living trust can be reviewed and confirmed. Bankers and other representatives of financial institutions can provide information on their legal obligations and any limits on suspicious activity in financial accounts that they can suggest based on state laws and corporate policies.

If the person living with ADRD will be participating in conversations about finances or continuing to control accounts while cognitively intact, a nonverbal signal is sometimes established for use during in-person meetings so that the care partner and financial advisor can let each other know when they think the person with ADRD is not comprehending the discussion. If the person with ADRD is legally competent and cognitively able to understand these transactions, the institution may be limited in what it can do even if the family disagrees with an action; such situations make it important to set up financial powers of attorney beforehand with conditions that, once met, will transfer control of the accounts to a trustee.

“We believe that banks will continue to innovate and offer more accessible and age-friendly services to aging consumers,” Nedopil & Schurman (2014) wrote. “However, banks also need to think more about creating products and services that help and protect the growing number of consumers with Alzheimer’s and dementia.” AARP International highlighted how such principles are being applied more broadly in development

of small, innovative economies in Australia, Chile, Costa Rica, Lebanon, Mauritius, Netherlands, New Zealand, Norway, Singapore, and Taiwan (AARP International, 2018).

In addition to providing information on the above-mentioned financial services, the [Eldercare Locator service](#) helps people living with ADRD and their families in identifying local agencies that can provide food, medical or legal services, insurance advice, and assistance if elder abuse is suspected. A toll-free number (800-677-1116) is available for those wanting to talk directly with information specialists, and online chats and email messages can be initiated from the website (Administration for Community Living & Administration on Aging, 2021).

Assistance with the money-saving aspects of care of people living with ADRD is available through many other organizations. Some of these are well known such as the local Area Agency on Aging and its nutritional, housing, transportation, counseling, educational, ombudsman, and Alzheimer’s disease-specific services, including day programs and caregiver support groups. [Meals on Wheels America](#) serves older adults through more than 5,000 community-based programs that are dedicated to addressing isolation and hunger. Local food banks can help when funds are low, and state Medicaid and nutritional support programs can be accessed when income is insufficient. The [local chapter of the Alzheimer’s Association](#) is an important source of educational programs and support groups for care partners (Meals on Wheels America, 2021; Alzheimer’s Association, 2021b).

Options for Institutional Care

Scrutiny is nothing new for the long-term care industry in the United States. The quality of care provided and the oversight of employees’ treatment of residents have been areas of concern for decades. Yet for many people with ADRD, skilled-nursing services in a long-term care facility are the only option at the end of life—if they can afford it. Everyone who is aging—that is *all people*—should look into the cost of care in areas where they might require long-term care services. The [genworth.com](#) site allows users to enter their location and see the costs of care ranging from homemaker services or in-home health aide assistance to adult day care, assisted-living residences, and long-term care facilities. For example, the average cost of a private room in a nursing home in 2020 was \$105,850, although this figure varies greatly by location (Genworth, 2021).

A number of factors are currently leading to wholesale re-examination of the long-term care sector and proposals for new and better options in coming years. The COVID-19 pandemic exposed the deficiencies in infection control in long-term care facilities and lack of options once viral spread created the need for lockdown on facilities. With about half of current residents of skilled-nursing facilities having some form of dementia, many residents could not understand why schedules were disrupted, congregate dining facilities were closed and recreational and social activities were cancelled, family members no longer visited or did so by tapping on the outside windows of their rooms, and staff members were wearing masks and other protective equipment (Roubein, 2021).

Despite the efforts to control the pandemic coronavirus, thousands of deaths of residents of long-term care facilities ensued. Fewer than 1 in 200 Americans lives in long-term care facilities, but one-third or more of COVID-19 deaths occurred in this population. The deaths of upwards of 10% of these residents reduced the census of many facilities, and families have moved many loved ones into other settings when



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possible. Added to income reductions as the flow of subacute patients from hospitals subsided, many long-term care facilities found themselves in financial difficulty (Grabowski & Mor, 2020; Eaton, 2020; Christ, 2020). Data from before COVID-19 vaccines became available show that long-term care facilities with relatively high percentages of Black or Hispanic residents were more likely to have at least one death associated with the disease (Chidambaram et al., 2020).

All this comes as millions of Americans are entering older adulthood. Given the longer lifespans of the Baby Boomer generation—and the expected years of life for other large generations following it—millions more Americans are projected to require care for ADRD in coming decades. If that becomes a reality, providing care using currently available facilities and systems will not be possible.

Thus, it is not surprising that innovators such as geriatrician Bill Thomas believe that now is the time to, as one news report put it, “really blow up the nursing home.” Describing his vision for a project called Canopy, Thomas told *Politico*, “I’m saying, let’s go beyond, let’s move past the era of mass institutionalization. Let’s create a model that’s actually based on one of the oldest ideas we have, which is people living in their own homes” (Roubein, 2021).

Thomas envisions a group of small rental homes of 400 to 600 square feet each clustered together on the grounds of Signature HealthCare facilities. The clusters will have sidewalks and other

amenities appropriate for neighbors to know one another. Nursing care and daily support services will be provided by long-term care facility staff as people require those services. Changes in the ways state and federal governments support such developments began under the Trump administration, and Thomas and his partners expect those to accelerate in coming years (Roubein, 2021).

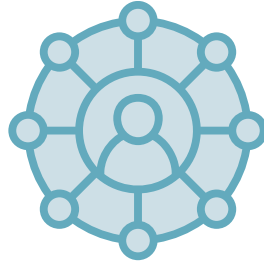
Older adults have always wanted to age with dignity in their own homes, and many were able to do so when lifespans were shorter. However, with chronic diseases creating functional deficits for many older adults, retrofitting the older homes in which they have lived is rarely financially feasible. Family sizes are smaller and members are more dispersed. Larger percentages of people enter older adulthood with no children or relatives living nearby. Divorces in which one or both parties are aged 50 years or older leave more women living alone and more often in poverty or with fewer sources of retirement income (Butrica & Smith, 2012).

Investment in innovations will be needed to care for older adults in coming decades, but so will improvements in facility-based services. Like many aspects of life in a postpandemic world, care of older adults and those with ADRD will need to be reimagined in a new long-term care system and scaled to meet the demands of a world with greater proportions of people of advanced age (Grabowski, 2021).



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COMMUNITIES:

Addressing the Challenges of Cognitive Decline

Peggy's son, William, had settled in the Atlanta suburb of Decatur. In that area, planning by the Atlanta Regional Commission has addressed numerous issues facing older adults, all with knowledge that keeping older adults and their retirement incomes in the area is smart from an economic standpoint. For Peggy, a great option is to live in a smaller "cottage court" unit that can be built in William's backyard under updated zoning ordinances. Through its **CATLYST program**, the Commission has also led education in the 10-county

area it serves about the need for affordable, accessible homes for older adults, improvements such as walkable and safe neighborhoods with parks that go beyond children's playscapes, walking and biking paths, transportation to get people to shopping and medical appointments, and the need for senior centers and other services to help people live independently for as long as possible. Peggy decided that being close to William was important to her—and it helped that her three grandchildren lived there!

Communities around the world—in countries with low, middle, and high income levels—are looking for cost-efficient ways of meeting the needs of the many people soon entering ages of high risk for ADRD. For the first time in human history, the number of older adults already exceeds the number of young children, and the financial impact of this reality goes far beyond the number of active workers needed to maintain programs such as Social Security in the United States. The number of people aged 60 years or older will double between 2019 and 2050, and 80% of older adults will be living in middle- and lower-income countries (World Health Organization, 2021).

The existing long-term care infrastructure falls far short of being able to take care of the number of older adults who are likely to experience cognitive impairment and dementias in the coming decades, and the current cost of caring for people living with ADRD is simply not sustainable. Communities will need to build more capacity, and those that are most competitive in doing so will find better and lower-cost options; moreover, older adults and the families who love them will grow and prosper as this scenario plays out. This requires innovations and outside-the-box thinking, with economic efficiency at the core.

In the search for solutions, success will help people:

- Age in properly designed homes that maximize their ability to work in rewarding careers for as long as they wish.
- Meet the needs of an increasingly diverse population accustomed to different lifestyles and cultures.
- Maintain activities of daily living by making medical and healthy living options available and accessible.
- Thrive in a social environment where they can interact with friends and family.
- Conserve precious retirement funds so they can live within their means.
- Deal with declining cognitive function, if that day comes.

Consider the following examples of innovative programs of communities and countries that are creating opportunities for success in the coming world with growing numbers of older adults. Each example provides insights into how societies around the world are trying to incorporate the burgeoning population of older adults on a financially feasible basis.

Aging-Friendly Communities

Recognizing that much of the work in building aging- and dementia-friendly communities happens below the national level, the World Health Organization has established a Global Network for Age-Friendly Cities and Communities that comprises 1,114 cities and communities, 14 network affiliates, and 44 countries that cover 262 million people. In the United States, the AARP Network of Age-Friendly States and Communities serves as a catalyst for local champions to implement needed changes (World Health Organization, 2018; AARP, 2019).

Age-friendly initiatives operate within specified geographic areas such as an apartment building, neighborhood, zip code, municipality, or region, with specific programs offered using defined methods by identified partners. Community-planning, support-focused, and cross-sector partnership approaches can have multiple and diverse goals in the who, where, what, how, and why of age-friendly initiatives (AARP, 2019).

The Lifelong Communities Initiative in Atlanta, Georgia, is an example of a community-planning approach. Through this consortium of local governments, community partners, and residents, more inclusive lifelong communities have been developed that offer multiple housing types and enhanced transportation options, increased opportunities for healthy living, and convenient access to shopping, services, and transit. The Atlanta Regional Commission “develops plans with the goal of better enabling people of all ages and abilities to remain in their homes and communities,” according to the organization’s website. “People who stay in their communities generally experience a better quality of life, with improved physical and mental health.

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14 network affiliates



44 countries



262 million people

These plans convey a framework for the region that identifies priority focus areas as well as goals and strategies to collectively achieve well-designed well-being” (Atlanta Regional Commission, 2021).

The Villages and Naturally Occurring Retirement Community Supportive Service Programs (NORC programs) are examples of support-focused approaches to age-friendly communities in the United States. The villages are self-governing and funded through member fees and private donations. NORC programs are administered through social service agencies. They both seek to maintain and promote the access of older adults to needed services and reduce social isolation (Greenfield et al., 2015).

Cross-sector partnership approaches leverage the activities of entities from a wide range of sectors to develop and implement locally based action plans concerning aging, which can lead to a



These feelings of fear and isolation are aspects of the social exclusion older adults with cognitive impairment or dementias have long endured.

variety of proximal objectives under this category. Examples include the Robert Wood Johnson Foundation's Community Partnerships for Older Adults program and several grantees as part of Community Innovations for Aging in Place (Greenfield et al., 2015).

Dementia-Friendly Communities

As with many aspects of modern life, the COVID-19 pandemic exposed and compounded the pressures older adults feel. Those older adults who live by themselves felt isolated and alone before the pandemic; as the scope and severity of COVID-19 became clear in spring 2020, many were frightened with concern that they or their loved ones would get the virus and possibly die from it. News programs and social media were troubling, not just with the pandemic but also racial unrest and a turbulent presidential election. Transportation options were reduced, and stores, medical offices, and churches were closed. Deliveries of batteries for medical equipment were delayed. As a result, older adults experienced fear and isolation, and some were prone to believe much of the misinformation they heard from others or through mass and social media (Portacolone et al., 2021).

These feelings of fear and isolation are aspects of the social exclusion older adults with cognitive impairment or dementias have long endured. Even when living in the home, other family members and occupants may avoid conversations with people with ADRD or leave them out of social activities. Social exclusion is a serious problem for people with ADRD, and it worsens their symptoms, behaviors, and prognosis (Hung, 2020).

Digital technology promises to add positive dimensions to life for people with ADRD. Pedestrian safety is a key feature being built into the software for autonomous vehicles, and facial recognition could help locate those who wander off from homes or facilities. Such innovations could enable older adults to exercise and have more opportunities for social interactions with friends and neighbors, particularly when combined with better infrastructure such as even sidewalks and increased time for walk signals at intersections (U.S. Environmental Protection Agency, 2013; Hamblen, 2021a; Hamblen, 2021b).

While few could have imagined the disruption created by the pandemic, the underlying problems of fear, isolation, lack of coping skills, and need for accessing essential resources can be addressed. Building on the concept of aging-friendly communities, planners have been working to create new environments that address these needs, including innovations in the home that can help involve loved ones with ADRD in the activity of the family.



Dementia Friends USA has chapters in most states and has trained nearly 100,000 people to drive the creation of dementia-friendly communities.

Dementia-friendly communities empower people at the local level through education, collaboration, and contributions. Reduction of stigma and lack of understanding is a first step, one that can be addressed through public education and health promotions campaigns. Another important goal is to help people with ADRD feel that they can make contributions to the home and community, and educate caregivers as to how they can include people with ADRD in daily tasks and activities. In the words of the Dementia Alliance International, "If it's *about us without us*, it is not friendly" (Hung et al., 2020; Dementia Alliance International, 2018).

Dementia Friends USA has chapters in most states and has trained nearly 100,000 people to drive the creation of dementia-friendly communities. These "Dementia Friends" work to create informed, safe, and respectful communities for people with dementia by raising awareness of Alzheimer's and other cognitive diseases, transforming attitudes, and moving people to action. Part of a worldwide movement developed by the Alzheimer's Society in the United Kingdom, Dementia Friends USA defines a dementia-friendly community as one where the options for a person's individualized roadmap includes these opportunities (Dementia Friends USA, 2021):

- Businesses with dementia-informed services and environments for customers and employee caregivers.
- Health care that promotes early diagnosis and uses dementia care best practices along the care continuum.
- Residential settings that offer memory-loss services and supports.
- Dementia-aware and responsive legal and financial planning.
- Welcoming and supportive faith communities.
- Supportive options for independent living and meaningful community engagement.

- Dementia-aware local government services, planning, and emergency responses.
- Dementia-friendly public environments and accessible transportation.



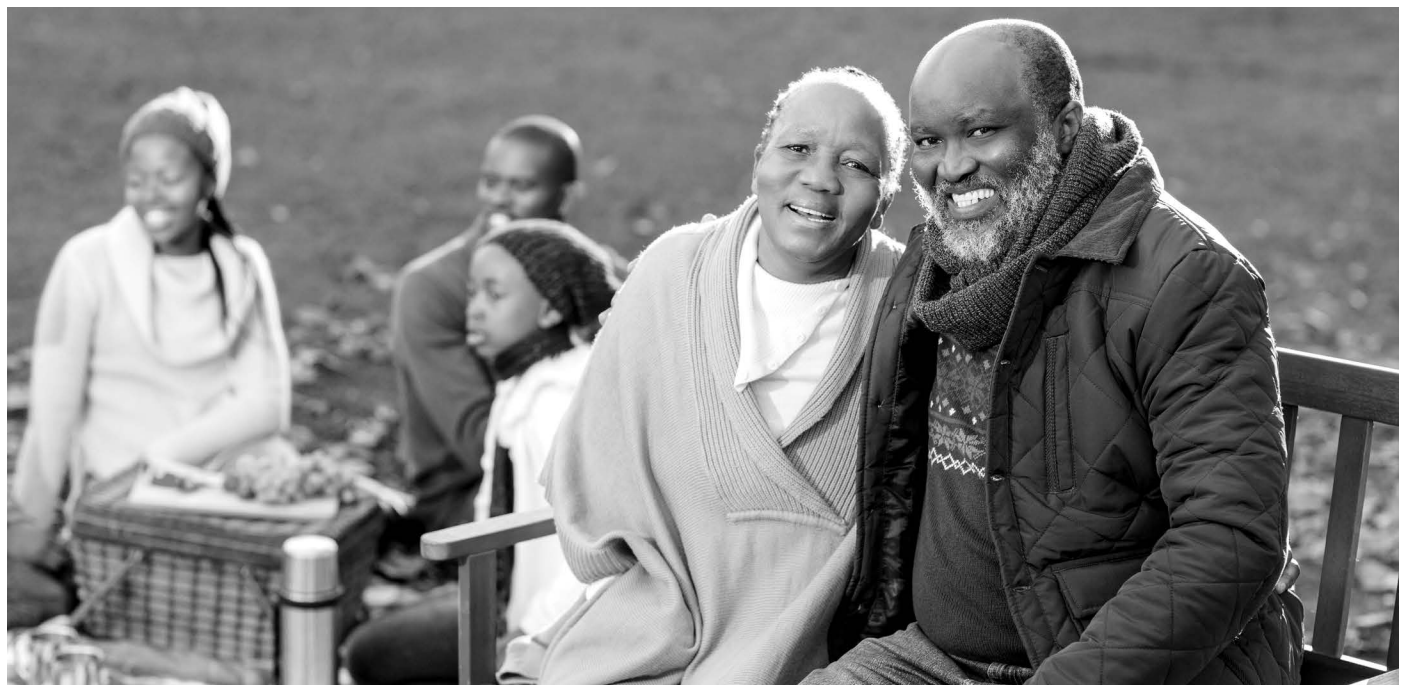
In institutional settings, meeting the needs of diverse groups of residents requires an equitable set of rules that guide the community in respecting each person's individuality.

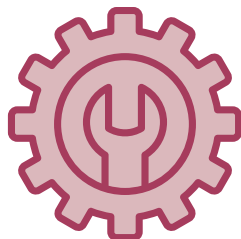
people akin to those they have known throughout life. In institutional settings, meeting the needs of diverse groups of residents requires an equitable set of rules that guide the community in respecting each person's individuality.

Translated into the real world, such options include communities that cater to people of specific cultural backgrounds or those in the LGBTQ community. But to be truly inclusive, cities, towns, institutions, and long-term care facilities must be welcoming of everyone. As defined in the Community Toolbox on a University of Kansas website, this means (Center for Community Health and Development, 2021):

- Doing everything possible to respect all citizens, give them full access to resources, and promote equal treatment and opportunity.
- Working to eliminate all forms of discrimination.
- Engaging all citizens in decision-making processes that affect their lives.
- Valuing diversity.
- Responding quickly to racist and other discriminating incidents.

In the Canadian province of British Columbia, PlanH of the BC Healthy Communities Society emphasizes the importance of inclusivity in developing and planning for healthier communities. By welcoming diverse groups of people—older adults, youth, children, Aboriginal peoples, immigrants and newcomers, persons with disabilities, people experiencing mental health challenges, and low-income populations—inclusive communities can improve the physical and mental health of community members, including their longevity, infant mortality rates, and mental health. In such communities, people with ADRD are able to live independently far into their clinical course and get the services they need to function at their highest possible level (BC Healthy Communities Society, 2021).





CHANGE AT THE SYSTEMS LEVEL: *Insights Into Solutions for Aging Populations*

The COVID-19 pandemic taught America many lessons. One of them was the overwhelmingly positive effect of relieving financial stress through direct payments to individuals and families with children, something that could have changed life for Sal and Peggy had they been able to sock away a portion of the income for retirement or the health expenses of older adulthood. In proposing the [American Families Plan](#), the Biden administration has outlined a national comprehensive paid family and medical leave program that, if enacted, could change life for those currently living paycheck to paycheck. As proposed, the plan guarantees 12 weeks of paid parental, family, and personal illness or safety-related leave within 10 years and ensures

3 paid days of bereavement leave starting in year 1. The proposed program provides for up to \$4,000 per month, with a minimum of 80% for the lowest-wage workers. The cost to the federal government over a decade is \$225 billion according to the White House estimate. The proposal also calls for employers to provide 7 paid days per year for sick leave that can be used to get an influenza vaccination, recover from short-term illness, or care for a sick child or family member or a family member with disability-related needs. With these or other similar benefits and direct payments, the worker has some hope of balancing gainful employment with the time devoted to care of loved ones with ADRD.

When developing a roadmap for those at increased risk for or with ADRD, perhaps it is the policy arena where beneficial actions could yield immediate relief and better options for millions of people and their families. After all, to have the requisite social and financial resources for coping with ADRD, a person would need to plan early in life to save extra funds for an early retirement prompted by ADRD or an extended retirement into the years when these conditions are highly likely. Those now turning 65 have a high probability of requiring long-term care services later in life, but few have insurance or savings sufficient to cover those costs.

Federal and state governments can take action to assist people with ADRD, their paid caregivers and unpaid care partners, and other family members through existing social support systems such as unemployment benefits, Social Security (disability and retirement benefits for the individual, partner, and dependent), the Affordable Care Act, and Medicaid and Medicare. With more flexibility, funding, and recognition of the needs of people with ADRD, these support systems could help people develop a viable roadmap for navigating a difficult journey and help younger people develop their plans and expectations for later in life. Investments and incentives for building and repairing the long-term care infrastructure are also needed to prepare the expected increase in people with ADRD.

Recognizing, Educating, and Supporting Unpaid Care Partners

The unpaid care partner is central to helping most people with ADRD handle home care and activities of daily living. Yet this is the person in the ADRD picture who is mostly overlooked. The care partner frequently has to cut back on work hours or leave the workforce completely; the average financial toll on the unpaid care partner was estimated to exceed \$300,000 in a 2011 study (Arno et al., 2011). As discussed further in this section, health insurance and

other benefits generally provided in U.S. society by employers are often lost as a result, and replacement policies are often unaffordable—especially given the high costs of care for the person with ADRD (Reyes et al., 2021).

Care partners often must perform health-related tasks for which they are unprepared, including medication management, preparation of specialized diets, and assisting with physical therapy and other exercises. A patchwork of federal and state policies leave many gaps in the support for increasingly diverse care partners. Most care partners are women (65%), partners/spouses (21%), or daughters (30%), and aged 50 years or older (85%). Care partners can be caught in the “sandwich” generation, taking care of both young children and older parents. They are often in their years of greatest expected income when employment becomes difficult or impossible to manage. The physical, mental, and emotional toll on care partners is immense (Dawson et al., 2020; Reyes et al., 2021).

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2018 takes an important step toward recognizing care partners and addressing their needs at the federal level. Caregiver Advise, Record, Enable (CARE) Acts have been enacted in 40 states, requiring recognition of care partners in patients’ records and provision of discharge dates and instructions following hospitalizations of those to whom they provide care. Future statute

and policy advances can build on the platform provided by these important laws (Reyes et al., 2021).

The National Institute on Aging (NIA) is working to make telehealth available and common for patients with ADRD. NIA is also funding demonstration and pilot projects such as the Care Ecosystem, Tele-Savvy, and Moving Together, which are reaching out to care partners and patients in communities that lack access to specialized dementia care and support. The Centers for Medicare and Medicaid Services is increasingly supportive of telehealth, as reflected in temporary expansions of payments in 2019 and during the COVID-19 pandemic (Reyes et al., 2021; National Institute on Aging, 2020b). The Care Ecosystem has demonstrated that effective care management, including education related to health care tasks, can be provided by interprofessional care teams from central hubs to people with ADRD and their care partners in remote areas (Possin et al., 2019).

Many policy-related gaps remain in meeting the needs of care partners of people with ADRD. Better flextime work arrangements and maintenance of insurance coverage during times when an employee must reduce hours or take leave can best be addressed by employers, but state and federal governments should continue looking for cost-effective ways of helping unpaid care partners to assist people with ADRD.

Gaps in Health Care Services and Coverage

In addition to the ADRD-related financial stressors discussed in the previous section, loss of employer-provided health care and other benefits can jeopardize a family’s finances, health, and ultimately longevity. While the person living with ADRD and care partners qualify for continuation of employer’s insurance under COBRA (Consolidated Omnibus Budget Reconciliation Act), they may not be able to afford this option, given



The average financial toll on the unpaid care partner was estimated to exceed \$300,000 in a 2011 study.

its cost. Yet this is exactly the time when a family needs coverage for immediate health care needs and later for long-term care, hospice, and palliative care. Social Security and Medicare may offer options, depending on age and disability status.

The Affordable Care Act, signed into law in 2010, offers assistance to families in situations like this, with options better in some states than in others. Families with very low incomes can qualify for assistance with premiums and Medicaid for children and some other dependents. As with many social programs in the United States, families in the middle income ranges have fewer supports to call on, yet their jobs may not provide health insurance and their salaries are too low to afford even the least expensive (but high-deductible) policies through the Affordable Care Act (Reyes et al., 2021).

States have begun to address the need for long-term care coverage. In Washington State, employee contributions under the Long-Term Care Trust Act of 2019 will allow participants to receive up to \$36,500 for long-term services and supports (LTSS) over their lifetimes. This new model of social insurance begins paying benefits in 2025. Hawaii implemented the Kupuna (Elders) Caregivers Program in 2017; it pays up to \$210 per week to family care partners who provide up to 30 hours per week of LTSS for residents aged 60 years or older. Hawaii also has the Kupuna Care Program, implemented in 2008 to make limited LTSS available for residents aged 60 years or older who need LTSS and do not qualify for Medicaid (Veghte et al., 2019).

Both social insurance models and services provided through general state revenues are needed by people in all states. Among high-income countries, the United States stands alone as the only one without plans and programs for citizens to rely on during times of life when LTSS are needed for chronic conditions, including ADRD.

New and Better Options for Long-Term Care

A third policy focus should be on the need for new, different, and higher quality services provided in the long-term care facilities necessary to care for people living with ADRD in future decades—and better ways of paying for them. As expressed during the COVID-19 pandemic by Ouslander and Grabowski (2020), society and the long-term care industry have an opportunity to “improve nursing homes to protect residents and their caregivers” in the future and to reimagine the ways in which these facilities are paid for and regulated.

The congregate nature of these facilities, combined with the compromised immune systems of older adults and lax regulatory attention to requirements such as infection control, enables pathogens to take hold and spread rampantly. These and other aspects of long-term care are the focus of recommendations for improvements (Kohn, 2021; Vipperman et al., 2021).

As millions of additional people reach older adulthood, new models of care will

be needed for providing for the needs of chronic diseases in general and ADRD in particular. That is a policy challenge that must be prioritized in coming months and years. As identified by an Urban Institute roundtable, key areas must be addressed, including the following (Gleckman & Favreault, 2021):

- Redesigning Medicaid.
- Creating a strong foundation for home- and community-based services.
- Integrating medical care and LTSS.
- Enhancing pay, benefits, and training for direct-care workers.
- Focusing on the quality of life for frail older adults and younger people with severe disabilities, not just medical treatment or service delivery.
- Reimagining long-term care facilities.
- Supporting adults with disabilities along the full continuum of care.
- Recognizing profound disparities in need for and access to high-quality care.
- Improving data collection.

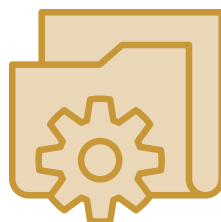




CONCLUSION

Mapping out a life course that leads to better health and quality of life in older adulthood is a challenging task, and the hidden financial costs of ADRD create situations that can be catastrophic for people with ADRD and their families. Americans are at particular risk of these obstacles given the individualistic society in the United States. As research provides more solutions to early detection of

cognitive decline and more therapies to prevent and treat ADRD, and as better systems are developed to care for people with dementia, Americans and millions of others around the world will be able to mitigate the financial challenges that have put strains on people with dementia, their caregivers and care partners, employers, and the public and private systems that support them.



RESOURCES

Apps for Smartphones and Tablets and Digital Resources

Alz Calls: A chatbot for patients who repeatedly ask for their family or loved ones

Alzheimer's Life Therapy: Light, sound, and cognitive therapy

BetterHelp: Website with online services and information on online counseling apps that connect people with professional therapists

GreyMatters: Portable scrapbook for preserving memories and reaching out to noncommunicative patients

Lumosity: Brain-training app for improving memory, increasing focus, and making the mind feel sharper

MEternally: Reminiscence therapy videos that use "collections" such as the outdoors or the 1950s along with other tools to stimulate memory

Word Search Colorful Puzzle: Word search games with adaptations for completing a story, competing with others, or working against time

Books and Multimedia

Recently Published Books

A Farewell to Gabo and Mercedes: A Son's Memoir of Gabriel García Márquez and Mercedes Barcha, by Rodrigo Garcia

Bridging the Family Care Gap, by Joseph Gaugler

Remember: The Science of Memory and the Art of Forgetting, by Lisa Genova

TED Talks

How Your Memory Works—and Why Forgetting Is Totally OK, by Lisa Genova

What You Can Do to Prevent Alzheimer's, by Lisa Genova

Groups and Organizations

AARP Fraud Watch Network
877-908-3360
aarp.org/money/scams-fraud/

Administration for Community Living
Administration on Aging
acl.gov/about-acl/administration-aging
Eldercare Locator
800-677-1116
eldercare.acl.gov

National Center on Elder Abuse
855-500-3537
ncea.acl.gov/About-Us/History.aspx

Preventing Falls for Older Adults and Caregivers
202-401-4634
acl.gov/FallsPrevention/

Alzheimer's Association
800-272-3900
alz.org

American Bar Association Commission on Law and Aging
312-988-5000
americanbar.org/groups/law_aging/

American Geriatrics Society
Health in Aging
800-563-4916
healthinaging.org

Centers for Disease Control and Prevention
Alzheimer's Disease and Healthy Aging
cdc.gov/aging

Consumer Financial Protection Bureau
855-411-2372
consumerfinance.gov

Council of State Governments
csg.org

Family Caregiver Alliance
caregiver.org

Legal Services Corporation
202-295-1500
lsc.gov

Meals on Wheels America
888-998-6325
mealsonwheelsamerica.org/find-meals

National Academy of Elder Law Attorneys
703-942-5711
naela.org

National Adult Protective Services Association
202-370-6292
napsa-now.org/get-help/how-aps-helps/

National Alliance for Caregiving
caregiving.org

National Association of Area Agencies on Aging
n4a.org

National Council on Aging
BenefitsCheckUp
benefitscheckup.org
COVID-19 Resources for Older Adults
571-527-3900
ncoa.org/ncoa_acf/covid-19-resources-for-older-adults/

National Institute on Aging
nia.nih.gov

U.S. Department of Justice
Senior Scam Alert
justice.gov/elderjustice/senior-scam-alert



REFERENCES

- AARP. (2019). AARP Network of Age-Friendly States and Communities: Introducing the Age-Friendly Network. <https://www.aarp.org/livable-communities/network-age-friendly-communities/info-2014/an-introduction.html>
- AARP International. (2018). *The aging readiness & competitiveness report: Small innovative economies*. <https://arc2018.aarpinternational.org/home>
- Administration for Community Living & Administration on Aging. (2021). Eldercare locator. <https://eldercare.acl.gov/Public/Index.aspx>
- Agarwal, M., Alam, M. R., Haider, M. K., Malik, M. Z., & Kim, D-K. (2021). Alzheimer's disease: An overview of major hypotheses and therapeutic options in nanotechnology. *Nanomaterials (Basel)*, 11(1), 59. Published online December 29, 2020. doi: 10.3390/nano11010059
- Alzheimer's Association. (2020). Fact sheet: Costs of Alzheimer's to Medicare and Medicaid. https://act.alz.org/site/DocServer/2012_Costs_Fact_Sheet_version_2.pdf?docID=7161
- Alzheimer's Association. (2021a). 2021 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 17(3), 327–406. doi: 10.1002/alz.12328
- Alzheimer's Association. (2021b). Get involved with your local chapter. https://www.alz.org/local_resources/find_your_local_chapter
- Alzheimer's Association. (2021c). Mild cognitive impairment. https://www.alz.org/alzheimers-dementia/what-is-dementia/related_conditions/mild-cognitive-impairment
- American Bar Association Commission on Law and Aging. (2021). About the Commission. https://www.americanbar.org/groups/law_aging/
- Arno, P. S., Viola, D., & Shi, Q. (2011). *The MetLife study of caregiving costs to working caregivers: Double jeopardy for Baby Boomers caring for their parents*. MetLife Mature Market Institute; Center for Long-Term Care Research and Policy, New York Medical College; and National Alliance for Caregiving. <http://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf>
- Ashbourne, J., Boscart, V., Meyer, S., Tong, C. E., & Stolee, P. (2021). Health care transitions for persons living with dementia and their caregivers. *BMC Geriatrics*, 21(1), 285. doi: 10.1186/s12877-021-02235-5
- Atlanta Regional Commission. (2021). Planning for lifelong communities: Working across disciplines to help people age in place. <https://atlantaregional.org/aging-health/aging-health-planning/aging-health-planning/>
- Babcock, P. (2009, October 28). Avoid assumptions about Alzheimer's. Society for Human Resource Management. <https://www.shrm.org/resourcesandtools/hr-topics/behavioral-competencies/global-and-cultural-effectiveness/pages/avoidassumptionsabout.aspx>
- Barthold, D., Joyce, G., Ferido, P., et al. (2020). Pharmaceutical treatment for Alzheimer's disease and related dementias: Utilization and disparities. *Journal of Alzheimer's Disease*, 76(2), 579–589. doi: 10.3233/JAD-200133
- BC Healthy Communities Society. (2021). PlanH: Inclusive communities. <https://planh.ca/take-action/healthy-society/page/inclusive-communities>
- Boustani, M., Alder, C. A., Solid, C. A., & Reuben, D. (2019). An alternative payment model to support widespread use of collaborative dementia care models. *Health Affairs*, 38(1), 54–59. doi: 10.1377/hlthaff.2018.05154
- Butler, M., Gaugler, J. E., Talley, K. M. C., Abdi, H. I., Desai, P. J., Duval, S., ... Yeshi, L. (2020). *Care interventions for people living with dementia and their caregivers*. Agency for Healthcare Quality and Research Comparative Effectiveness Review No. 231. doi: 10.23970/AHRQEPCCER231
- Butrica, B. A., & Smith, K. (2012). The retirement prospects of divorced women. *Social Security Bulletin*, 72(1), 11–22. <https://www.ssa.gov/policy/docs/ssb/v72n1/ssb-v72n1.pdf>
- Caputo, A. (2021, February 3). The emotional experience of caregiving in dementia: Feelings of guilt and ambivalence underlying narratives of family caregivers. *Dementia (London)*. Advance online publication. doi: 10.1177/1471301221989604

- Caunca, M. R., Odden, M. C., Glymour, M. M., Elfassy, T., Kershaw, K. N., Sidney, S., ... Zeki Al Hazzouri, A. (2020). Association of racial residential segregation throughout young adulthood and cognitive performance in middle-aged participants in the CARDIA study. *JAMA Neurology*, 77(8), 1000–1007. doi: 10.1001/jamaneurol.2020.0860
- Center for Community Health and Development. (2021). *Community toolbox: Tools to change our world* (chapter 27, section 11: Building inclusive communities). University of Kansas. <https://ctb.ku.edu/en/table-of-contents/culture/cultural-competence/inclusive-communities/main>
- Centers for Disease Control and Prevention. (2019, April 5). What is dementia? <https://www.cdc.gov/aging/dementia/index.html>
- Centers for Medicare and Medicaid Services. (2021). *Medicare fraud & abuse: Prevent, detect, report*. <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/Fraud-Abuse-MLN4649244.pdf>
- Chen, C., & Zissimopoulos, J. (2018). Racial and ethnic disparities in dementia prevalence and risk factors from 2000 to 2012 in the United States. *Alzheimer's and Dementia Translational Research*, 4, 510–520. doi: 10.1016/j.trci.2018.8.009.
- Chidambaram, P., Neuman, T., & Garfield, R. (2020, October 27). Racial and ethnic disparities in COVID-19 cases and deaths in nursing homes. Kaiser Family Foundation. <https://www.kff.org/coronavirus-covid-19/issue-brief/racial-and-ethnic-disparities-in-covid-19-cases-and-deaths-in-nursing-homes/>
- Christ, G. (2020, December 16). Two-thirds of nursing homes risk closure in 2021, survey shows. *Modern Healthcare*. <https://www.modernhealthcare.com/post-acute-care/two-thirds-nursing-homes-risk-closure-2021-survey-shows>
- Dawson, W. D., Bangerter, L. R., & Splaine, M. (2020). The politics of caregiving: Taking stock of state-level policies to support family caregivers. *Public Policy & Aging Report*, 30(2), 62–66. doi: 10.1093/ppar/praa005
- Dementia Alliance International. (2018). Inclusive communities: See the person, not the dementia. <https://www.dementiaallianceinternational.org/dementia-friendly-communities/>
- Dementia Friends USA. (2021). What is a dementia-friendly community? <https://dementiafriendsusa.org/what-dementia-friendly-community>
- Di, X., Shi, R., DiGuseppi, C., Eby, D. W., Hill, L. L., Mielenz, T. J., ... Li, G. (2021). Using naturalistic driving data to predict mild cognitive impairment and dementia: Preliminary findings from the Longitudinal Research on Aging Drivers (LongROAD) Study. *Geriatrics*, 6(2), 45. doi: 10.3390/geriatrics6020045
- Drabo, E. F., Barthold, D., Joyce, G., Ferido, P., Chui, H. C., & Zissimopoulos, J. (2019). Longitudinal analysis of dementia diagnosis and specialty care among racially diverse Medicare beneficiaries. *Alzheimer's & Dementia*, 15(11), 1402–1411. doi: 10.1016/j.jalz.2019.07.005
- Eaton, J. (2020, December 3). Who's to blame for the 100,000 COVID dead in long-term care? AARP. <https://www.aarp.org/caregiving/health/info-2020/covid-19-nursing-homes-who-is-to-blame.html?intcmp=AE-HP-BB-LL2>
- Genworth. (2021). Cost of care trends & insights. <https://www.genworth.com/aging-and-you/finances/cost-of-care/cost-of-care-trends-and-insights.html>
- Gerontological Society of America. (2017). *KAER toolkit: A 4-step process to detecting cognitive impairment and earlier diagnosis of dementia—approaches and tools for primary care providers*. <https://www.geron.org/publications/kaer-toolkit?start=1>
- Gerontological Society of America. (2020). *The GSA KAER toolkit for primary care teams: Supporting conversations about brain health, timely detection of cognitive impairment, and accurate diagnosis of dementia*. <https://www.geron.org/publications/kaer-toolkit>
- Gleckman, H., & Favreault, M. M. (2021). *Reforming long-term care with lessons from the COVID-19 pandemic: Proceedings of an Urban Institute roundtable*. Urban Institute. https://www.urban.org/sites/default/files/publication/103758/reforming-long-term-care-with-lessons-from-the-covid-19-pandemic_0.pdf
- Grabowski, D. C. (2021). The future of long-term care requires an investment in both facility- and home-based services. *Nature Aging*, 1, 10–11. doi: 10.1038/s43587-020-00018-y
- Grabowski, D. C., & Mor, V. (2020). Nursing home care in crisis in the wake of COVID-19. *Journal of the American Medical Association*, 324(1), 23–24. doi: 10.1001/jama.2020.8524
- Greenfield, E. A., Oberlink, M., Scharlach, A. E., Neal, M. B., & Stafford, P. B. (2015). Age-friendly community initiatives: Conceptual issues and key questions. *The Gerontologist*, 55(2), 191–198. doi: 10.1093/geront/gnv005
- Gurchiek, K. (2018, July 26). Former executive shares Alzheimer's story. Society for Human Resource Management. <https://www.shrm.org/hr-today/news/hr-news/pages/former-executive-shares-alzheimers-story.aspx>
- Gurland, B. J., Wilder, D. E., Lantigua, R., Stern, Y., Chen, J., Killeffer, E. H., & Mayeux, R. (1999). Rates of dementia in three ethnoracial groups. *International Journal of Geriatric Psychiatry*, 14(6), 481–493. doi: 10.1002/(SICI)1099-1166(199906)14:6<481::AID-GPS959>3.0.CO;2-5
- Haan, M. N., Mungas, D. M., Gonzalez, H. M., Ortiz, T. A., Acharya, A., & Jagust, W. J. (2003). Prevalence of dementia in older Latinos: The influence of type 2 diabetes mellitus, stroke and genetic factors. *Journal of the American Geriatrics Society*, 51(2), 169–177. doi: 10.1046/j.1532-5415.2003.51054.x
- Halpern, S. D., Loewenstein, G., Volpp, K. G., Cooney, E., Vranas, K., Quill, C. M., ... Bryce, C. (2013). Default options in advance directives influence how patients set goals for end-of-life care. *Health Affairs*, 32(2), 408–417. doi: 10.1377/hlthaff.2012.0895

- Hamblen, M. (2021a). Peachtree Corners, Georgia, deploys C-V2X with Qualcomm for safety, traffic flow. Fierce Electronics. <https://www.fierceelectronics.com/electronics/peachtree-corners-georgia-deploys-c-v2x-qualcomm-for-safety-traffic-flow>
- Hamblen, M. (2021b). Smart cities: What works/what doesn't? Fierce Electronics. <https://www.fierceelectronics.com/electronics/smart-cities-what-works-what-doesn-t>
- Henning-Smith, C., & Lahr, M. (2019). Rural-urban difference in workplace supports and impacts for employed caregivers. *The Journal of Rural Health*, 35(1), 49–57. doi: 10.1111/jrh.12309
- Hung, L. (2020). Creating dementia friendly community for social inclusion: A scoping review. *Alzheimer's & Dementia*, 16(S10), e047147. doi: 10.1002/alz.047147
- Hung, L., Leitch, S., Hung, R., & Phinney, A. (2020). Creating dementia-friendly and inclusive communities for social inclusion: A scoping review protocol. *BMJ Open*, 10(6), e035028. doi: 10.1136/bmjopen-2019-035028
- Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J., & Langa, K. M. (2013). Monetary costs of dementia in the United States. *New England Journal of Medicine*, 368(14), 1326–1334. doi: 10.1056/NEJMsa204629
- Knopman, D. S., & Petersen, R. C. (2014). Mild cognitive impairment and mild dementia: A clinical perspective. *Mayo Clinic Proceedings*, 89(10), 1452–1459. doi: 10.1016/j.mayocp.2014.06.019
- Kohn, N. A. (2021). Nursing homes, COVID-19, and the consequences of regulatory failure. *The Georgetown Law Journal Online*, 110, 1–18. https://www.law.georgetown.edu/georgetown-law-journal/wp-content/uploads/sites/26/2021/04/Kohn_Nursing-Homes-COVID-19-and-the-Consequences-of-Regulatory-Failure.pdf
- Kovalchik, S. A., Slaughter, M. E., Miles, J., Friedman, E. M., & Shih, R. A. (2015). Neighbourhood racial/ethnic composition and segregation and trajectories of cognitive decline among US older adults. *Journal of Epidemiology and Community Health*, 69, 978–984. doi: 10.1136/jech-2015-205600
- Lichtenberg, P. A., Gross, E., & Campbell, R. (2020a). A short form of the Lichtenberg Financial Decision Rating Scale. *Clinical Gerontologist*, 43(3), 256–265. doi: 10.1080/07317115.2018.1527424
- Lichtenberg, P. A., Paulson, D., & Han, S. D. (2020b). Examining health and wealth correlates of perceived financial vulnerability. *Innovation in Aging*, 4(4), igaa039. doi: 10.1093/geroni/igaa039
- Lichtenberg, P. A., Teresi, J. A., Ocepek-Welikson, K., & Eimicke, J. P. (2017). Reliability and validity of the Lichtenberg Financial Decision Screening Scale. *Innovation in Aging*, 1(1), igx003. doi: 10.1093/geroni/igx003
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., ... Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*, 396(10248), 413–446. doi: 10.1016/S0140-6736(20)30367-6
- Masters, C. L., Bateman, R., Blennow, K., Rowe, C. C., Sperling, R. A., & Cummings, J. (2015). Alzheimer's disease. *Nature Reviews Disease Primers*, 1, 15056. doi: 10.1038/nrdp.2015.56
- Meals on Wheels America. (2021). Find a Meals on Wheels provider near you. <https://www.mealsonwheelsamerica.org/find-meals>
- Merrill Lynch. (2014). *Health and retirement: Planning for the great unknown*. Age Wave. https://agewave.com/wp-content/uploads/2016/07/2014-ML-AW-Health-and-Retirement_Planning-for-the-Great-Unknown.pdf
- Merrill Lynch. (2017). *The journey of caregiving: Honor, responsibility, and financial complexity*. Age Wave. <https://agewave.com/what-we-do/landmark-research-and-consulting/research-studies/the-journey-of-caregiving/>
- National Academies of Sciences, Engineering, and Medicine. (2021). *Meeting the challenge of caring for persons living with dementia and their care partners and caregivers: A way forward*. The National Academies Press. doi: 10.17226/26026
- National Academy of Elder Law Attorneys. (2021). Find a lawyer. <https://www.naela.org/FindALawyer?>
- National Hospice and Palliative Care Organization. (2021). Advance directives. <https://www.nhpc.org/patients-and-caregivers/advance-care-planning/advance-directives/>
- National Institute on Aging. (2020a, October 29). Legal and financial planning for people with dementia. <https://www.nia.nih.gov/health/legal-and-financial-planning-people-alzheimers>
- National Institute on Aging. (2020b, September 23). Telehealth: Improving dementia care. <https://www.nia.nih.gov/news/telehealth-improving-dementia-care>
- Nedopil, C., & Schurman, B. (2014). Financial institutions innovate for aging society. *The Journal (AARP International)*. <https://journal-archive.aarpinternational.org/a/b/2014/06/financial-institutions-innovate-for-aging-society>
- Nicholas, L. H., Bynum, J. P. W., Iwashyna, T. J., Weir, D. R., & Langa, K. M. (2014). Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. *Health Affairs*, 33(4), 667–674. doi: 10.1377/hlthaff.2013.1258

- Nicholas, L. H., Langa, K. M., Bynum, J. P. W., & Hsu, J. W. (2021). Financial presentation of Alzheimer disease and related dementias. *JAMA Internal Medicine*, 181(2), 220–227. doi: 10.1001/jamainternmed.2020.6432
- Nicholas, L. H., Langa, K. M., Iwashyna, T. J., & Weir, D. R. (2011). Regional variation in the association between advance directives and end-of-life Medicare expenditures. *Journal of the American Medical Association*, 306(13), 1447–1453. doi: 10.1001/jama.2011.1410
- Okonkwo, O. C., Wadley, V. G., Griffith, H. R., Belue, K., Lanza, S., Zamrini, E. Y., ... Marson, D. C. (2008). Awareness of deficits in financial abilities in patients with mild cognitive impairment: Going beyond self-informant discrepancy. *The American Journal of Geriatric Psychiatry*, 16(8), 650–659. doi: 10.1097/JGP.0b013e31817e8a9d
- Ouslander, J. G., & Grabowski, D. C. (2020). COVID-19 in nursing homes: Calming the perfect storm. *Journal of the American Geriatrics Society*, 68(10), 2153–2162. doi: 10.1111/jgs.16784
- Peron, E. P., Zimmerman, K. M., Crouse, E. L., Slattum, P. W., & Hobgood, S. E. (2020). Alzheimer disease. In J. T. DiPiro, G. C. Yee, L. M. Posey, S. T. Haines, T. D. Nolin, & V. L. Ellingrod (Eds.), *Pharmacotherapy: A pathophysiologic approach* (11th ed., pp. 835–852). McGraw-Hill.
- Portacolone, E., Chodos, A., Halpern, J., Covinsky, K. E., Keiser, S., Fung, J., ... Johnson, J. K. (2021). The effects of the COVID-19 pandemic on the lived experience of diverse older adults living alone with cognitive impairment. *The Gerontologist*, 61(2), 251–261. doi: 10.1093/geront/gnaa201
- Possin, K. L., Merrilees, J. J., Dulaney, S., Bonasera, S. J., Chiong, W., Lee, K., ... Miller, B. L. (2019). Effect of collaborative dementia care via telephone and internet on quality of life, caregiver well-being, and health care use: The care ecosystem randomized clinical trial. *JAMA Internal Medicine*, 179(12), 1658–1667. doi: 10.1001/jamainternmed.2019.4101
- Rabarison, K. M., Bouldin, E. D., Bish, C. L., McGuire, L. C., Taylor, C. A., & Greenlund, K. J. (2018). The economic value of informal caregiving for persons with dementia: Results from 38 states, the District of Columbia, and Puerto Rico, 2015 and 2016 BRFSS. *American Journal of Public Health*, 108(10), 1370–1377. doi: 10.2105/AJPH.2018.304573
- Reuben, D. B., Herr, K. A., Pacala, J. T., Pollock, B. G., Potter, J. F., & Semla, T. P. (2021). *Geriatrics at your fingertips* (23rd ed.). American Geriatrics Society. <https://geriatricscareonline.org/toc/geriatrics-at-your-fingertips/B055>
- Reyes, A. M., Thunell, J., & Zissimopoulos, J. (2021). Addressing the diverse needs of unpaid caregivers through new health-care policy opportunities. *Public Policy & Aging Report*, 31(1), 19–23. doi: 10.1093/ppar/praa039
- Roubein, R. (2021, April 30). Will the nursing home of the future be an actual home? *Politico*. <https://www.politico.com/news/agenda/2021/04/30/nursing-home-future-483460>
- Salthouse, T. A. (2009). When does age-related cognitive decline begin? *Neurobiology of Aging*, 30(4), 507–514. doi: 10.1016/j.neurobiolaging.2008.09.023
- Santucci, L. (Ed.). (2019). *Aging, cognition, and financial health: Building a robust system for older Americans*. Consumer Finance Institute conference summaries: Federal Reserve Bank of Philadelphia. <https://www.philadelphiafed.org/-/media/frbp/assets/consumer-finance/conference-summaries/conference-summary-aging-cognition-and-financial-health.pdf>
- Selkoe, D. J., & Hardy, J. (2016). The amyloid hypothesis of Alzheimer's disease at 25 years. *EMBO Molecular Medicine*, 8(6), 595–608. doi: 10.15252/emmm.201606210
- Smith, R. (2021, June 6). Baby Boomers' biggest financial risk: Cognitive decline. *The Wall Street Journal*. <https://www.wsj.com/articles/baby-boomers-biggest-financial-risk-cognitive-decline-11622942343>
- Steenland, K., Goldstein, F. C., Levey, A., & Wharton, W. (2016). A meta-analysis of Alzheimer's disease incidence and prevalence comparing African-Americans and Caucasians. *Journal of Alzheimer's Disease*, 50(1), 71–76. doi: 10.3233/JAD-150778
- Stern v. St. Anthony's Health Center*, 788 F.3d 276 (2015). <https://www.leagle.com/decision/infco20150604148>
- Thunell, J., Chen, Y., Joyce, G., Barthold, D., Shekelle, P. G., Brinton, R. D., & Zissimopoulos, J. (2021). Drug therapies for chronic conditions and risk of Alzheimer's disease and related dementias: A scoping review. *Alzheimer's & Dementia*, 17, 41–48. doi: 10.1002/alz.12175
- U.S. Department of Health and Human Services Office of Inspector General. (2021, March 25). Fraud alert: COVID-19 scams. <https://oig.hhs.gov/fraud/consumer-alerts/fraud-alert-covid-19-scams/>
- U.S. Environmental Protection Agency. (2013). *Creating equitable, healthy, and sustainable communities: Strategies for advancing smart growth, environmental justice, and equitable development*. <https://www.epa.gov/smartgrowth/creating-equitable-healthy-and-sustainable-communities>
- U.S. Food and Drug Administration. (2021a). Drugs@FDA: FDA-approved drugs. <https://www.accessdata.fda.gov/scripts/cder/daf/>
- U.S. Food and Drug Administration. (2021b). Aducanumab (marketed as Aduhelm) information. <https://www.fda.gov/drugs/postmarket-drug-safety-information-patients-and-providers/aducanumab-marketed-aduhelm-information>
- Veghte, B. W., Bradley, A. L., Cohen, M., & Hartmann, H. (Eds.). (2019). *Designing universal family care: State-based social insurance programs for early child care and education, paid family and medical leave, and long-term services and supports*. National Academy of Social Insurance. <https://www.nasi.org/research/2019/designing-universal-family-care-state-based-social-insurance>

- Viperman, A., Zimmerman, S., & Sloane, P. D. (2021). COVID-19 recommendations for assisted living: Implications for the future. *Journal of the American Medical Directors Association*, 22(5), 933–938.e5. doi: 10.1016/j.jamda.2021.02.021
- Weller, C. E., Maxwell, C., & Solomon, D. (2021). Simulating how large policy proposals affect the Black-White wealth gap. *Journal of Economics, Race, and Policy*. Published online January 25, 2021. doi: 10.1007/s41996-020-00077-8
- Weller, C. E., & Tolson, M. E. (2018). Do unpaid caregivers save less for retirement? *The Journal of Retirement*, 6(2), 61–73. doi: 10.3905/jor.2018.6.2.061
- White House. (2021, April 28). Fact sheet: The American Families Plan. <https://www.whitehouse.gov/briefing-room/statements-releases/2021/04/28/fact-sheet-the-american-families-plan>
- Widera, E., Steenpass, V., Marson, D., & Sudore, R. (2011). Finances in the older patient with cognitive impairment: “He didn’t want me to take over.” *Journal of the American Medical Association*, 305(7), 698–706. doi: 10.1001/jama.2011.164
- World Health Organization. (2018). *The Global Network for Age-Friendly Cities and Communities: Looking back over the last decade, looking forward to the next*. <https://www.who.int/publications/i/item/WHO-FWC-ALC-18.4>
- World Health Organization. (2021). Ageing. https://www.who.int/health-topics/ageing#tab=tab_1
- Zissimopoulos, J., Crimmins, E., & St. Clair, P. (2014). The value of delaying Alzheimer’s disease onset. *Forum for Health Economics and Policy*, 18(1), 25–39. doi: 10.1515/fhep-2014-0013
- Zissimopoulos, J. M., Tysinger, B. C., St. Clair, P. A., Crimmins, E. M. (2018). The impact of changes in population health and mortality on future prevalence of Alzheimer’s disease and other dementias in the United States. *The Journals of Gerontology: Series B*, 73, supplement 1, S38–S47. doi: 10.1093/geronb/gbx147



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