

## Special Report

# Mapping a Better Future for Dementia Care Navigation



“Following a dementia diagnosis too many individuals and families are left on their own groping in the dark for services that can help them. I don’t want others to go through what I did. I lost two to three years searching for answers. It was time I could have spent differently.”

— Pamela, individual living with early-onset Alzheimer’s disease

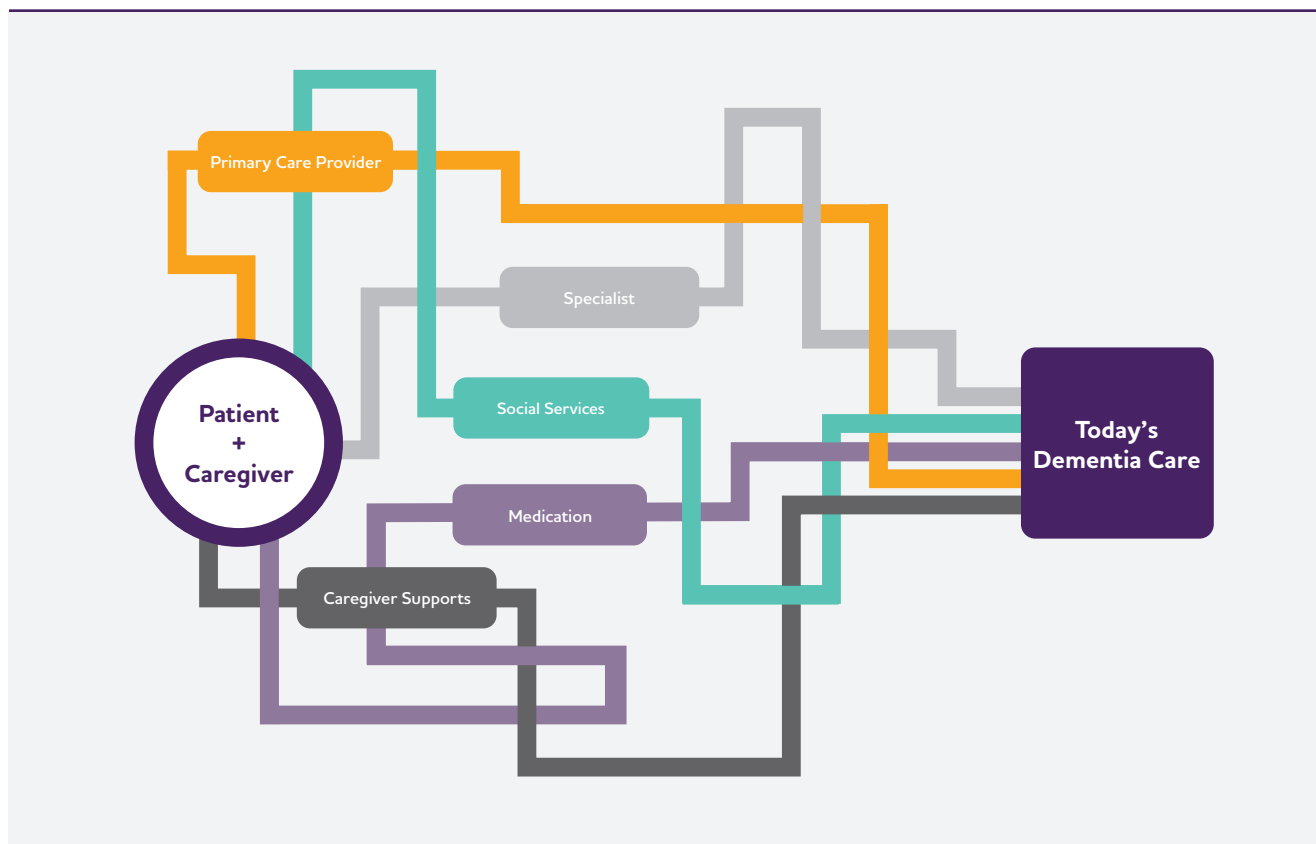
Dementia care is a complex maze encompassing interactions with primary care providers, specialists (including those involved in managing chronic conditions coexisting with cognitive issues), social services, medication management and caregiver support (Figure 17).<sup>978</sup>

Navigating this maze is difficult and often frustrating for people living with Alzheimer’s or other dementia and their caregivers. Without a clear path forward, any roadblock or detour along the way can have considerable ramifications.

This could materialize as delayed detection, diagnosis and treatment of early-stage cognitive issues or mild cognitive impairment (MCI). For caregivers, a detour could cause them to miss valuable or necessary educational opportunities, miss connections with community-based services for respite and behavioral health support or be unable to locate resources that could help reduce their stress. Breakdowns in transitions of care between health care providers and settings limit high-quality, comprehensive and/or appropriate dementia care, as evidenced by an increase in emergency room visits and hospitalizations and decreased quality of life.<sup>979</sup>

Figure 17

Today’s Dementia Care<sup>978</sup>



## Caregiver Burden and Stress Are Compounded by the Complexity of Dementia Care

Unpaid caregivers (sometimes referred to as care partners), who can be a spouse, family member or friend, provide extensive, sometimes all-encompassing care for people living with Alzheimer's or other dementia. In 2023, 11.5 million family members and other caregivers of people living with Alzheimer's or other dementia provided an estimated 18.4 billion hours of unpaid help. On average, this represents nearly 31 hours of care per caregiver per week or 1,612 hours per caregiver per year.<sup>A8</sup> Caregivers spend much of this time interacting with the health care system or learning more about dementia caregiving, and nearly 2 in 3 (63%) help with health or medical care.<sup>427, 440</sup> Daily health care activities may include scheduling appointments with health care providers, attending doctor's visits, and scheduling social and community support for themselves and the person living with dementia, such as in-home assistance, adult day programs or meal delivery. Collectively, performing these activities and the organization of care across multiple health care providers can be described as care coordination.<sup>980, 981</sup>

The effort expended trying to find their way through the health care system can add to the already high emotional and physical stress levels that caregivers experience. Caregivers need assistance to gather dementia care information, synthesize it and act upon it in a way that does not add to their stress level — support that primary care providers and health systems have historically been ill-equipped or unprepared to provide. (For more information on supporting people living with Alzheimer's or other dementia and the impact of unpaid caregiving, see the Caregiving section, page 42.)

## Nationwide Movement to Improve Care While Reducing Strain on Caregivers

For more than a decade, the National Plan to Address Alzheimer's Disease has included goals to improve health care quality and expand support for individuals living with Alzheimer's disease or other dementia and their families.<sup>982</sup> Recently, the Alzheimer's Association and the Alzheimer's Impact Movement (AIM) — a separately incorporated advocacy affiliate of the Alzheimer's Association — championed critical legislation to help unravel the health care maze.<sup>983</sup> This legislation, the bipartisan Comprehensive Care for Alzheimer's Act, proposed a new approach to dementia care management covering care coordination and navigation, caregiver education and support, and alternative payment models for physician reimbursement.<sup>983, 984</sup>

In July 2023, the Centers for Medicare & Medicaid Services (CMS) announced the culmination of policy, working group and legislative efforts like the Comprehensive Care for

Alzheimer's Act with the introduction of the Guiding an Improved Dementia Experience (GUIDE) Model.<sup>985</sup> The new model represents a pivotal opportunity to reshape and enhance dementia care in the United States.

## What is GUIDE?<sup>986</sup>

The Guiding an Improved Dementia Experience (GUIDE) Model is an eight-year pilot program in dementia care management designed to help dementia patients and caregivers better navigate health care and social support systems to improve dementia care. Three primary aims of GUIDE are to:

- Improve quality of life for people living with dementia.
- Reduce strain on their unpaid caregivers.
- Enable people living with dementia to remain in their homes and communities.

Beginning in July 2024, health care providers who participate in GUIDE will deliver supportive services to people living with dementia, including comprehensive, person-centered assessments and care plans, care coordination and 24/7 access to a support line. They will also provide access to a care navigator to help patients and caregivers access services and support.

GUIDE acknowledges that current fee-for-service payment structures prevent many practices from implementing sustainable dementia care management programs.<sup>984-986</sup> To overcome this challenge, GUIDE is testing an alternative payment model (APM) to incentivize health systems and increase the likelihood that smaller practices, rural practices and inner-city health centers that traditionally do not have the financial resources of larger entities will be able to deliver this type of program.<sup>984, 986</sup> The APM shifts payments from a fee for individual services to a monthly per-patient payment for all services under the GUIDE Model umbrella, including those not typically reimbursed by Medicare.<sup>984, 986</sup>

Recognizing that some health care providers will face resource, staffing and capability constraints, a second GUIDE Model track will engage those who do not have experience offering comprehensive dementia care services. The Centers for Medicare & Medicaid Services will offer these organizations technical assistance, learning support and a preparatory pre-implementation year to facilitate their participation in the model. (For more information about GUIDE and other national strategies to support caregivers, see the Caregiving section, page 42, and the Workforce section, page 58.)

## Navigators as Dementia Health Care Wayfinders

### What is Care Navigation?

Care navigation is a critical process that assists patients and caregivers with various aspects of obtaining health care, such as helping them understand and overcome the complex logistics of the health care system.<sup>987-989</sup> The concept originated in cancer clinics in the 1990s to address the overwhelming experience cancer patients faced trying to manage their care.<sup>989</sup> It has since expanded to support individuals with chronic diseases, including kidney disease, diabetes and dementia.<sup>987, 990-992</sup>

This assistance aims to be holistic and spans both medical and nonmedical needs. On the medical side, care navigation encompasses:<sup>988, 991</sup>

- Scheduling appointments.
- Coordinating diagnostic testing or follow-ups.
- Providing disease education.
- Facilitating communication and referrals across clinical specialties and organizations.
- Offering insurance and benefits assistance.
- Medication management.

Beyond medical support, care navigation programs may connect patients and caregivers to nonmedical resources, such as education, social services and community support.<sup>991</sup>

Providing both types of navigation services underscores the importance of a comprehensive approach to health care.<sup>991</sup> By addressing medical and nonmedical needs, care navigation programs strive to ensure better access to health care, improve health outcomes and reduce disparities in care.<sup>990-992</sup>

### What is Dementia Care Navigation?

Dementia care navigation shares many features of care navigation programs in other specialties. However, dementia care navigation emphasizes person-centered, empowered support throughout the dementia care journey.<sup>990</sup> This includes addressing nonmedical needs unique to dementia care, such as behavioral symptom management and access to community-based services and supports for individuals with dementia and their caregivers.<sup>987, 990, 992, 993</sup> The approach remains nimble to adapt to emerging treatments and diagnostic tests, disease progression, or other individual needs as they arise.

A key tenet of dementia care navigation is recognizing the importance of the “care dyad”— the partnership between people living with Alzheimer’s disease or other dementia and their caregivers — in all aspects of dementia care.<sup>987, 992</sup> As described previously, caregivers are prone to information overload and may feel lost and overwhelmed as they try to find their way to quality dementia care for the person living with dementia. Dementia care navigation programs are primed to offer assistance in this area.

**“Due to high incidence, duration and medical-social complexity, dementia is an ideal candidate for patient-centric health care delivery models such as care navigation.”<sup>990</sup>**

In 2023, an expert workgroup convened by the Alzheimer’s Association defined dementia care navigation as “a program that provides tailored, strengths-based support to persons living with dementia and their care partners across the illness continuum and settings to mitigate the impact of dementia through collaborative problem solving and coaching.”<sup>990</sup>

The workgroup outlined seven essential principles for dementia care navigation, which underscore person-centered care. According to the workgroup, dementia care navigation should:<sup>990, 993</sup>

1. Be person- and family-centered to ensure collaboration and enhance engagement.
2. Be culturally responsive and address disparities in access to health care and support services.
3. Include well-defined roles and responsibilities for all members of the dementia care navigation team.
4. Address barriers relating to medical, legal, financial, emotional and other domains facing the person living with dementia and their care partners.
5. Provide coaching, education, and coordination in a manner that is empowering, solution-focused and strengths-based.
6. Focus on the family unit as defined by the person living with dementia.
7. Ensure processes and protocols are evidence-based.

By adhering to these principles, dementia care navigation programs can achieve more coordinated care for patients. Health systems are already finding that dementia care navigation can improve health outcomes, decrease the number of emergency room visits, lower hospital readmissions, shorten hospital stays and minimize delays in long-term care placement.<sup>993</sup>

### What is a Care Navigator?

Care navigators are staff who guide patients and caregivers through the health care system and help overcome barriers that prevent them from getting the care they need.<sup>991, 995</sup> As integral members of interprofessional care teams, care navigators are connectors — liaising, communicating and facilitating medical and nonmedical needs.<sup>991, 992, 995</sup> Unlike other care team members, their work spans various settings, making them crucial touchpoints for care coordination.<sup>991, 992</sup> Common synonyms for “care navigator” include patient navigator, care consultant and care team coordinator.<sup>990, 992, 995</sup>

## Prioritizing Person-Centered Care in Dementia Care Navigation<sup>990, 992-994</sup>

Person-centered care is the foundation of quality dementia care. It challenges the traditional medical model of care that tends to focus on processes, schedules, and staff and organizational needs. Instead, person-centered care stresses knowing the person living with dementia, including their values, beliefs, interests, abilities, likes and dislikes — both past and present. A person-centered approach to care assures the individual living with dementia and their caregivers that health professionals know the person, understand the person's unique needs and circumstances, and put these needs at the forefront in making decisions and directing the person's care.

Anchoring dementia care navigation in the principles of person-centered care prioritizes the humanity of each individual living with dementia while also committing to a standard of care that elevates their dignity, autonomy and quality of life at every stage.

Qualifications, training and time dedicated to the care navigator role vary based on the care team structure and the health system. They range from paraprofessionals to licensed health care professionals, including nurses, physician assistants, social workers, community health workers or even former caregivers.<sup>991</sup> Care navigators, including dementia care navigators, frequently share the racial, ethnic or cultural background of those they assist, enhancing the delivery of culturally competent care and building stronger patient-navigator relationships.<sup>987, 991</sup>

Dementia care navigators work with care dyads, but evidence suggests that the primary recipients of navigation services are caregivers.<sup>987</sup> In addition to the typical navigation services, dementia caregivers frequently look to care navigators for emotional support.<sup>987</sup> Through these interactions, navigators and caregivers establish trusting, long-term relationships.

In summary, care navigators are pivotal in helping patients and caregivers find their way through an increasingly intricate dementia care landscape.

## Awareness and Understanding of Dementia Care Navigation: Caregiver and Health Care Workforce Surveys

This year's Special Report takes a deeper look into how dementia caregivers interact with the health care system and how the non-physician health care workforce currently employs care navigation. To better understand these aspects of dementia care, the Alzheimer's Association commissioned Versta Research to conduct surveys of (1) current or recent caregivers of adults age 50 or older with cognitive issues (referred to in this report as dementia caregivers) and (2) health care workers who are likely to assume care navigation responsibilities in their role, including nurses, social workers, and community health workers (referred to in this report as the non-physician health care workforce).

### Key Findings

#### Dementia Caregivers

Dementia caregivers experience difficulty and stress interacting with the health care system.

- Seven in 10 dementia caregivers (70%) report that coordinating care is stressful. More than half of caregivers (53%) said navigating health care is difficult. Two in 3 dementia caregivers (66%) also have difficulty finding resources and support for their needs.

Cost and care coordination are top stressors for dementia caregivers.

- Two in 5 caregivers (42%) cite cost as a stressor in getting care for their recipient. More than 1 in 3 caregivers report coordinating care with multiple doctors (36%), securing appointments (35%) and getting help taking a break (35%) as leading stressors in navigating care for their recipient.
- Despite these and other stressors, only half of the caregivers (51%) report ever talking with a health care professional to help address their challenges.

Care navigation is an unfamiliar term for most dementia caregivers, although many receive help akin to care navigation.

- Three in 4 dementia caregivers (75%) report little or no familiarity with the term "care navigator." Half of caregivers (50%) say they receive help with dementia health care, support and services for the care recipient from someone within their physician's office or hospital.
- Nurses (42%) and social workers (35%) most often provide navigation help to dementia caregivers.

Overwhelmingly, caregivers would welcome dementia care navigator support and believe it would benefit both the person living with dementia and the caregiver.

- More than 4 in 5 dementia caregivers (85%) say having access to a care navigator would influence their choice of dementia health care provider for the person they care for.
- Three in 5 dementia caregivers (61%) cite improvement in quality of life for their care recipient as a benefit of having a care navigator. Two in 5 caregivers (43%) believe access to a care navigator would improve the overall health of their care recipient.
- Three in 5 dementia caregivers say less stress (62%) and more peace of mind (62%) would be valuable outcomes of having a care navigator. More than half (56%) say having a care navigator could help them be better caregivers.

Top services that would be helpful to dementia caregivers include around-the-clock support, care coordination and help understanding their care recipient's condition.

- The vast majority of dementia caregivers (97%) say they would find navigation services helpful.
- Nearly 2 in 5 dementia caregivers (36%) say a 24/7 helpline would be valuable in helping navigate care for someone living with Alzheimer's or other dementia. Coordinating care and communication between different specialists (34%) and getting help in understanding their care recipient's condition (34%) are also viewed as valuable services.
- Almost 1 in 3 dementia caregivers say it would be helpful to have assistance with insurance or public benefits (32%), scheduling appointments (31%), caregiver training (31%), managing behavioral symptoms (31%), understanding the health care system (30%) and finding services to help with respite care (30%).
- The most helpful community-based resources cited to help dementia caregivers include local caregiver support groups (41%), respite programs (38%) and availability of financial resources in the community (37%).

### Non-Physician Health Care Workforce

The findings below reflect the views of the non-physician health care workforce currently providing navigator-type services to patients and caregivers in addition to the other responsibilities of their role. The health care workers surveyed included medical professionals (nurse practitioners, physician assistants and registered nurses) and nonmedical professionals (health care social workers, community health workers and home health aides).

Most health care workers who provide navigator-type services are familiar with the concept of care navigation, even if that is not their focus.

- Three in 4 survey respondents (77%) are familiar with the term "care navigator." They spend roughly half their time providing navigator-type services, even if they do not refer to themselves as care navigators.
- Nearly 2 in 3 survey respondents (62%, predominantly nonmedical professionals) help people living with Alzheimer's or other dementia and caregivers understand the health care system, and more than 1 in 2 health care workers (57%) say they coordinate care and communication with specialists.
- The most frequently provided navigator services are referrals to community support services and resources (75%), helping with emotional and cultural support (68%), and screening for safety needs (66%).

Most health care workers providing navigator-type services have experience in other medical specialties, with few focusing exclusively on dementia.

- Four in 5 survey respondents (80%) have navigation experience in non-dementia medical specialties, and fewer than 1 in 10 (7%) focus primarily on offering navigator-type support and services to people living with dementia.
- Most providing navigation services (93%) feel at least somewhat knowledgeable about MCI, Alzheimer's disease and other dementia but only 1 in 3 (36%) report they are very knowledgeable.
- Nearly 9 in 10 (86%) feel knowledgeable about directing patients with dementia and caregivers to appropriate health care resources, but less than 1 in 3 (30%) feel very knowledgeable. Four in 5 (82%) feel knowledgeable about directing patients with dementia and caregivers to community resources, but only 31% say they are very knowledgeable.

Training in dementia care navigation is lacking and not standardized.

- Three in 4 health care workers providing care navigation (75%) indicate they received no formal training in dementia care navigation.
- Those who did receive training were predominantly nonmedical professionals, receiving a median of 30 hours of formal training. Medical professionals who were trained received a median of 20 hours of formal training.

Nonmedical professionals are viewed as best suited to help people with dementia and their caregivers navigate care.

- Nine in 10 health care workers offering navigation support (92%) say social workers, community health workers or home health aides are best suited to help people living with dementia and their caregivers navigate health care.

Health care workers say more can be done to help patients and families navigate dementia care but point out current barriers.

- Six in 10 survey respondents (60%) believe that the U.S. health care system is not effectively helping patients and their families navigate dementia care.
- Nearly half surveyed (46%) say their organizations do not have a clearly defined process for care coordination and clinical pathways for patients with MCI, Alzheimer's disease or other dementia.
- More than 3 in 4 (77%) identified a lack of community-based resources as a barrier, and 44% viewed it as the greatest barrier. Seven in 10 (70%) called out current reimbursement as a barrier, with 41% saying this was the greatest barrier.
- Nearly 9 in 10 (87%) say developing alternative payment models is important in providing future care coordination for people diagnosed with dementia.

## Survey Design and Research Methods

The surveys were designed to elicit in-depth responses from both dementia caregivers and the non-physician health care workforce about the current state and challenges of navigation in dementia care.

The dementia caregiver survey analyzed distinct aspects of the caregiving journey, including:

- Time spent on caregiving and top stressors.
- Challenges in navigating health care services.
- Challenges in locating or accessing community supports and services.
- Awareness of dementia care navigators and/or navigation programs.
- Which health care workers help with care navigation.
- Communication preferences for care navigation.
- Value of navigation services and community-based resources.
- Anticipated benefits and outcomes of care navigation.

The non-physician health care workforce survey covered various aspects of care navigation, including:

- Familiarity with navigator terminology.
- Focus areas for care navigation services being delivered.
- Frequency and preferred method of communication.
- Perceived value of care navigation.
- Which health care workers deliver navigation services.
- Barriers to care navigation.
- Background and training in care navigation.

## Dementia Caregiver Survey

A survey of 1,533 U.S. adults who were current or recent unpaid caregivers for a relative or friend age 50 or older experiencing problems with thinking, understanding, or remembering things or who sometimes have physical problems or behavioral changes was conducted from

November 20, 2023, through December 20, 2023. The sample included White (n=629), Hispanic (n=309), Black (n=308), Asian (n=206) and Native American (n=24) caregivers and caregivers who identified as belonging to other ethnic or racial groups (n=57). While Native Americans were oversampled in an attempt to get subgroup estimates, the sample size was still insufficient; thus, Native American respondents were included in the "all caregivers" grouping. Respondents were recruited via non-probability online panels used exclusively for research, with full population screening data weighted to match U.S. Census data on age, gender, income, education and race/ethnicity to ensure accurate representation of the caregiving population and to establish weighting benchmarks for demographic oversamples. The survey was offered in both English and Spanish. Differences noted in the report between racial and ethnic groups were tested and found to be statistically significant at the  $p < .05$  level.

## Non-Physician Health Care Workforce Survey

A survey of 1,204 U.S. health care workers was conducted from November 13, 2023, through December 6, 2023.

The survey collected the views of medically-trained and nonmedically-trained professionals who perform navigation duties, regardless of whether they describe themselves as navigators or hold a formal navigator position at their organization.<sup>A17</sup> For brevity, medically-trained professionals are referred to as "medical professionals" and nonmedically-trained professionals as "nonmedical professionals" throughout the remainder of the report. The report refers to the combined group of medical and nonmedical professionals as "health care workers."

Medical professionals (n=708) included:

- Registered nurses (RN, n=526).
- Nurse practitioners (NP, n=145).
- Physician assistants (PA, n=46).

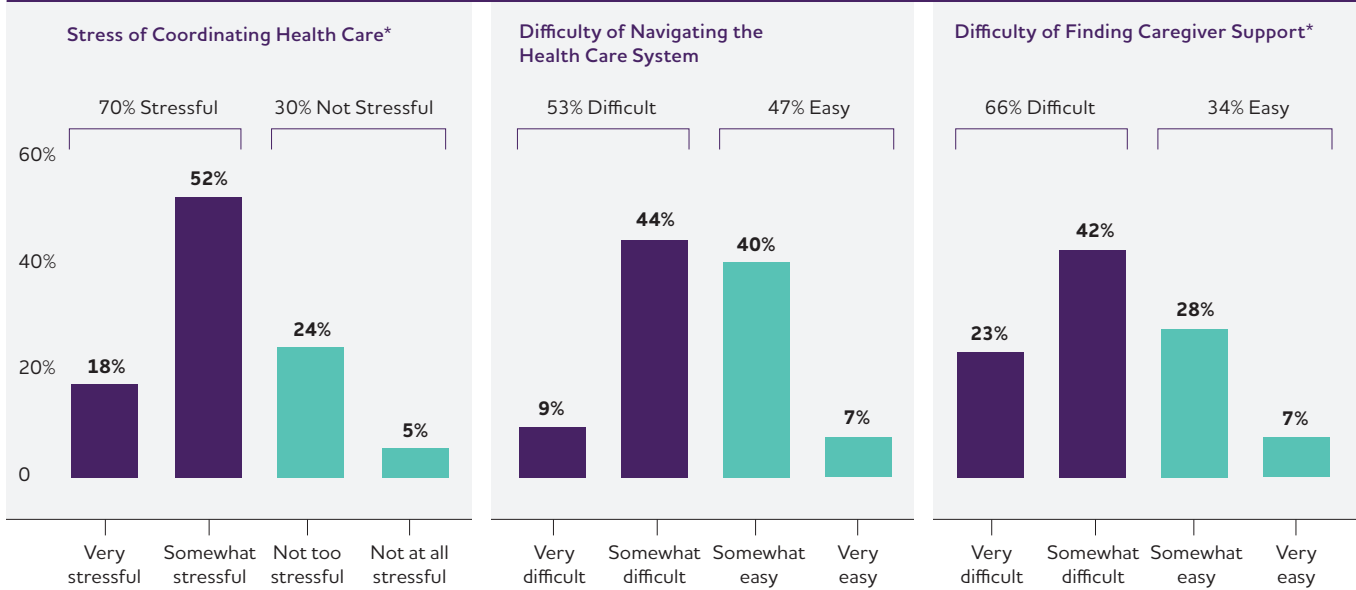
Nonmedical professionals (n=503) included:

- Social workers (MSW, n=458).
- Community health workers (CHW, n=32).
- Home health aides (HHA, n=14).

Health care workers are classified as both medical and nonmedical professionals if they indicate both types of training (e.g., RN with MSW degree). Because of this, the total of the numbers of medical and nonmedical professionals shown above exceeds 1,204. Likewise, if health care workers are classified as having more than one role in the medical or nonmedical category (e.g., community health worker and home health aide), they are included in the count for each role. As a result, the total of the specific roles in the medical and nonmedical categories exceeds the 708 and 503 shown above.

Figure 18

Difficulties and Stressors That Caregivers Experience



\*Percentages of bars may not total the percentages above due to rounding.

Dementia Caregiver Survey Results

Dementia Caregiving is a Demanding Job That Can Last for Years

People with memory and thinking problems see an average of four different doctors every year, with more than 1 in 4 (27%) seeing five or more doctors annually. Scheduling and managing doctor's visits can be time-consuming, and more than 1 in 3 dementia caregivers (35%) coordinate health care needs (communicating with doctors, taking care of insurance, getting appointments, picking up medication, etc.) at least once daily, with some caregivers saying they coordinated care several times per day.

Caregivers for people with Alzheimer's and other dementia provide approximately 26 hours of care per week. This is consistent with other reports that caregivers spend almost 31 hours per week on caregiving.<sup>AB</sup> Additionally, a large majority of dementia caregivers surveyed spend years providing care, with nearly 1 in 2 acting as a caregiver for one to three years and almost 1 in 3 spending four years or more as a caregiver.

Black Caregivers Report More Time on Caregiving Responsibilities Than Other Groups

The need to coordinate health care is common for dementia caregivers, and this is especially true for Black and Hispanic caregivers, who are more likely to coordinate health care at least once per day than White caregivers (43%, 45%, and 31%, respectively). This likely influences the

overall time spent providing care, with Black caregivers reporting the most time at 30 hours per week followed by White caregivers (27 hours), Hispanic caregivers (25 hours) and Asian caregivers (19 hours).

Dementia Caregivers Experience Difficulty and Stress Interacting With the Health Care System and Addressing Their Own Needs

A majority of caregivers surveyed (70%) indicated that coordinating care is stressful. More than half (53%) said navigating health care for the person they care for was difficult. Finding resources and support for their needs is also a challenge for 2 in 3 caregivers (66%; Figure 18).

Black Caregivers Report Less Stress and Difficulty With Dementia Care

Black caregivers find coordinating dementia care somewhat less difficult and stressful than all other groups. Three in 5 Black caregivers (58%) reported that coordinating care was somewhat or very stressful compared with Hispanic caregivers (71%), White caregivers (72%) and Asian caregivers (76%). When asked about difficulty coordinating health care, Asian caregivers expressed the greatest challenges, with 7 in 10 (68%) indicating that they found it somewhat or very difficult (vs. Black caregivers, 37%; White caregivers, 54%; and Hispanic caregivers, 57%). Additionally, Black caregivers have less difficulty finding support for their own needs as a caregiver than other groups (52% report somewhat or very difficult vs. White caregivers, 66%; Hispanic caregivers, 70%; and Asian caregivers, 77%).



Figure 19

**Stressors When Getting Health Care for Care Recipients**

Worries about cost and expenses	42%
Coordinating with multiple doctors	36%
Scheduling and helping with appointments	35%
Getting help to take a break	35%
Finding appropriate doctors	32%
Finding support services and resources	30%
Feeling unprepared to be a caregiver	29%
Transportation to doctor visits	24%
Getting care for urgent needs	22%
Contacting administrators or billing	22%
Getting prescriptions	22%
Understanding recommended treatments	20%
Lack of knowledge about the disease	18%
Finding clinical trials	6%

**Worries About Costs and Coordinating Health Care Are Top Stressors**

The most often cited worry for dementia caregivers is cost (42% of caregivers), followed by the stress of coordinating with multiple doctors (36%), securing appointments (35%) and getting help taking a break (35%; Figure 19). Finding appropriate doctors (32%) rounded out the top five stressors. When viewed together, these top five stressors underscore challenges in coordinating dementia health care without greater assistance from a care navigator.

Asian caregivers report worries about costs and expenses (51%) as the top stressor, more so than other groups (Black caregivers, 37%; Hispanic caregivers, 42%; White caregivers, 41%). Asian caregivers also are more likely to report stress in finding appropriate doctors (41%) and understanding recommended treatments (30%) than other groups. Finding respite care is the top stressor for Black caregivers (39%), and concerns about cost and expenses are top of mind for Hispanic caregivers.

Despite these current stressors, only half of the dementia caregivers surveyed (51%) have ever talked with a health care professional about challenges finding their way through the health care system or asked for help with dementia care.

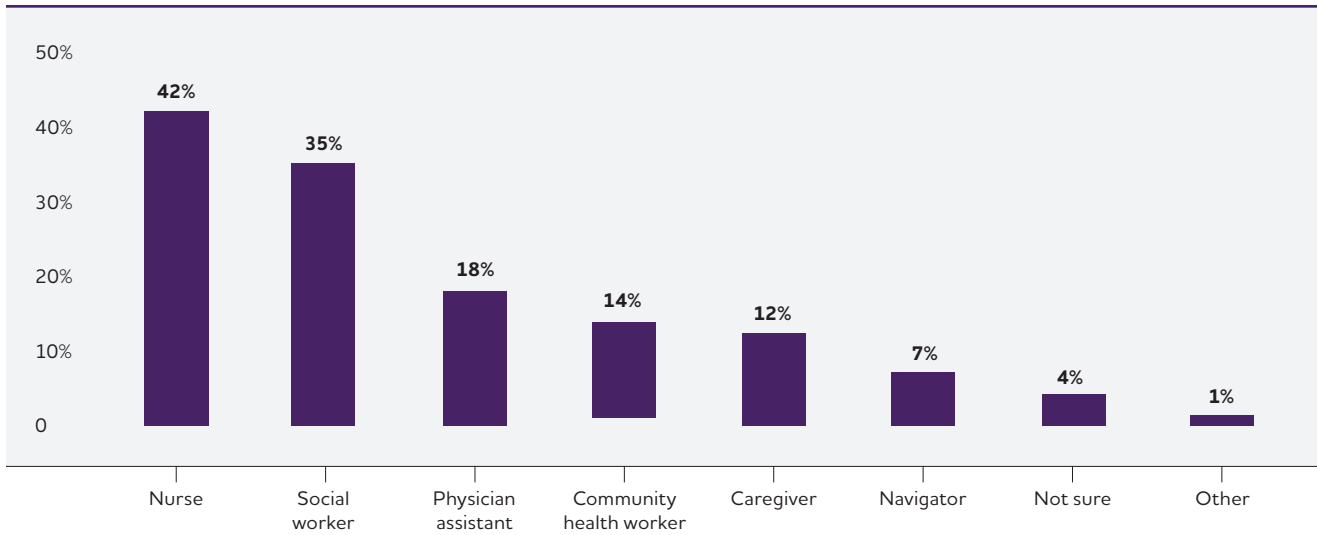
**Although Largely Unfamiliar With the Term “Care Navigator,” Dementia Caregivers Receive Help Navigating Care**

Three in 4 dementia caregivers surveyed report little or no familiarity with the term “care navigator,” with 30% saying they know very little about the term and 45% reporting they have never heard of the term. Yet half of caregivers (50%) receive help with dementia health care, support and services for the care recipient from someone within their physician’s office or hospital. These health care workers may or may not be serving in a formalized navigator role. Nurses (42%) or social workers (35%) most often provide navigation help to dementia caregivers, with physician assistants (18%), community health workers (14%), other caregivers (12%) or actual care navigators (7%) providing health care guidance to a lesser degree (Figure 20).

Nearly 7 in 10 Black caregivers (68%) report receiving help navigating care. Asian caregivers (52%), Hispanic caregivers (51%), and White caregivers (47%) also report currently receiving help navigating care.

Figure 20

### Navigator's Professional Role

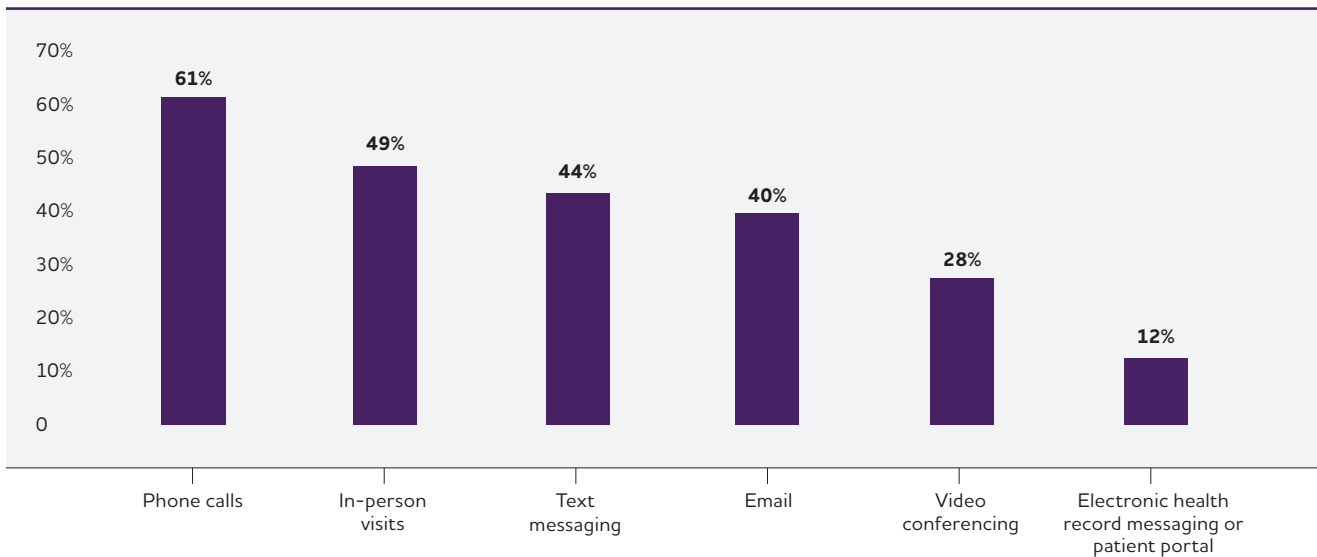


When working with staff helping with care navigation, a majority of caregivers would prefer that they communicate via more traditional channels, with nearly 2 in 3 saying a phone call was best and 1 in 2 saying they desired

in-person communication during a visit (Figure 21). Overall, very few caregivers wanted to communicate through electronic health record (EHR) messaging or a patient portal (12%).

Figure 21

### Preferred Channels for Communicating With a Care Navigator



## Cultural Competency is Fundamental for Dementia Care Navigation

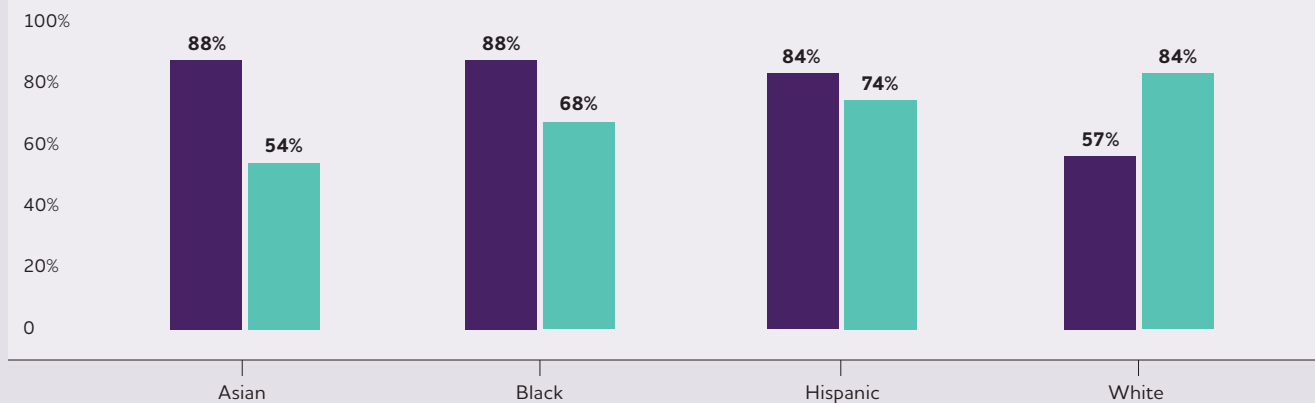
Caregivers for people living with dementia stressed that it is essential for care navigators to understand their ethnic or racial background. Significantly, 9 in 10 Asian, Black, and Hispanic caregivers felt it crucial for navigators to be aware of the background of the person they are caring for (Figure 22). In contrast, White caregivers placed less importance on this shared experience. Among White caregivers who received

navigation help, 84% believed the person helping them had a good or excellent grasp of their care recipient's background, a confidence level higher than that for other racial and ethnic groups. Confidence in the cultural competency of the person providing navigation assistance was lower for all other groups, and lowest for Asian caregivers, with only 54% rating understanding of the person helping them as "good" or "excellent."

Figure 22

### Access to Care Navigators With Cultural Competency by Race/Ethnicity of Care Recipient

- Important for care navigator to understand the ethnic or racial background of the person being cared for
- Provider of navigator-type service rated "good" or "excellent" on understanding the ethnic or racial background of the person being cared for



Health care workers surveyed echoed that empathy for racial, ethnic and cultural backgrounds and experiences is key. They overwhelmingly agreed that effective dementia care navigation requires cultural competence, with 99% saying that it is

important for navigators to understand (Figure 23). Four in 5 health care workers believe their organization has an effective understanding of the racial, ethnic, and cultural backgrounds and experiences of people with dementia and their caregivers.

Figure 23

### Health Care Professionals' Views on Cultural Competence

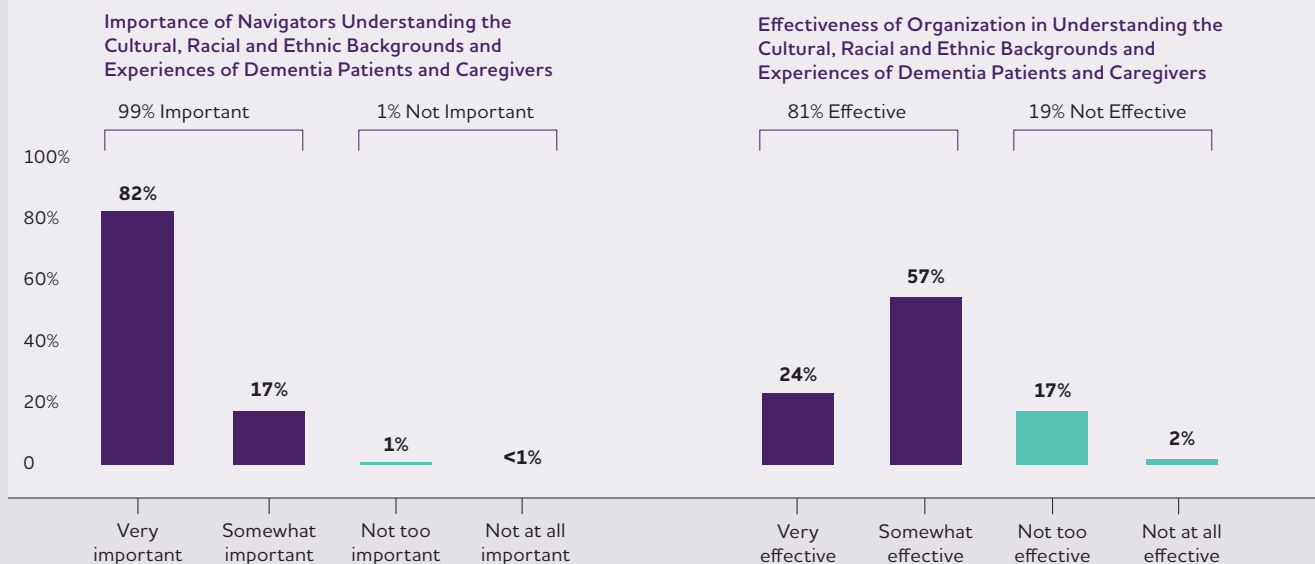
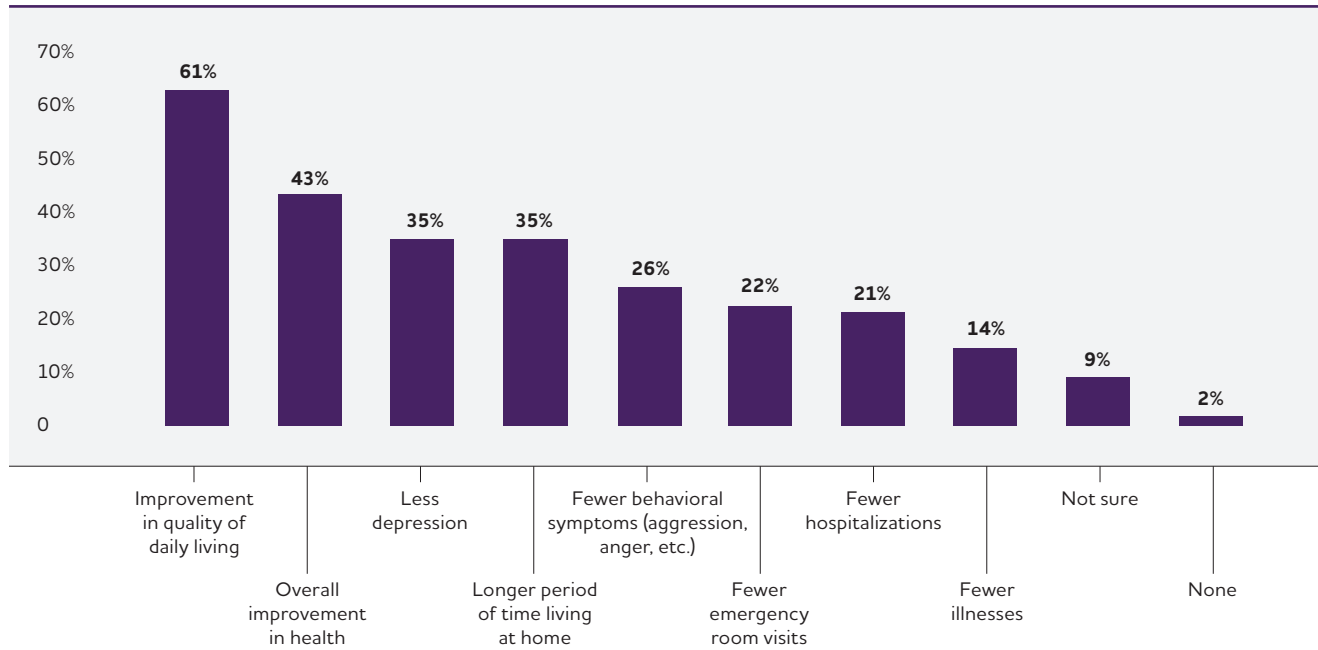


Figure 24

Anticipated Outcomes for Care Recipients of a Navigator Program



**Caregivers Welcome Dementia Navigation Support**

Overwhelmingly, dementia caregivers surveyed would welcome navigator support, with 4 in 5 caregivers (85%) indicating that having access to a care navigator would influence their choice of a dementia health care provider for the person they care for. This sentiment was strongest among Black caregivers, with 52% saying it would influence their choice a great deal, followed by Hispanic caregivers (44%), White caregivers (43%) and Asian caregivers (38%).

**Less Stress and Better Outcomes are Biggest Benefits of Working With a Dementia Care Navigator**

Caregivers see improvement in quality of life (61%) and health (43%) for the person they care for as being the greatest positives of working with a dementia care navigator (Figure 24). Other benefits for the person living with Alzheimer’s or other dementia include less depression (35%), longer period of time at home (35%) and fewer behavioral symptoms (26%).

For themselves, 2 in 5 caregivers surveyed see less stress (62%) and more peace of mind (62%) as the most valuable outcomes of having a navigator as part of the dementia care team (Figure 25). They also think a care navigator could help them be better caregivers (56%), improve their mental health (45%) and help them find opportunities to take a break from their care responsibilities (38%). Overall, very few dementia caregivers believed a care navigator would make caregiving less expensive (18%); however,

there was a clear difference in this view among caregivers from different racial and ethnic groups. Nearly twice as many Asian, Black and Hispanic caregivers thought working with a navigator could make caregiving less expensive compared with White caregivers (26%, 23% and 22%, respectively, vs. 14%)

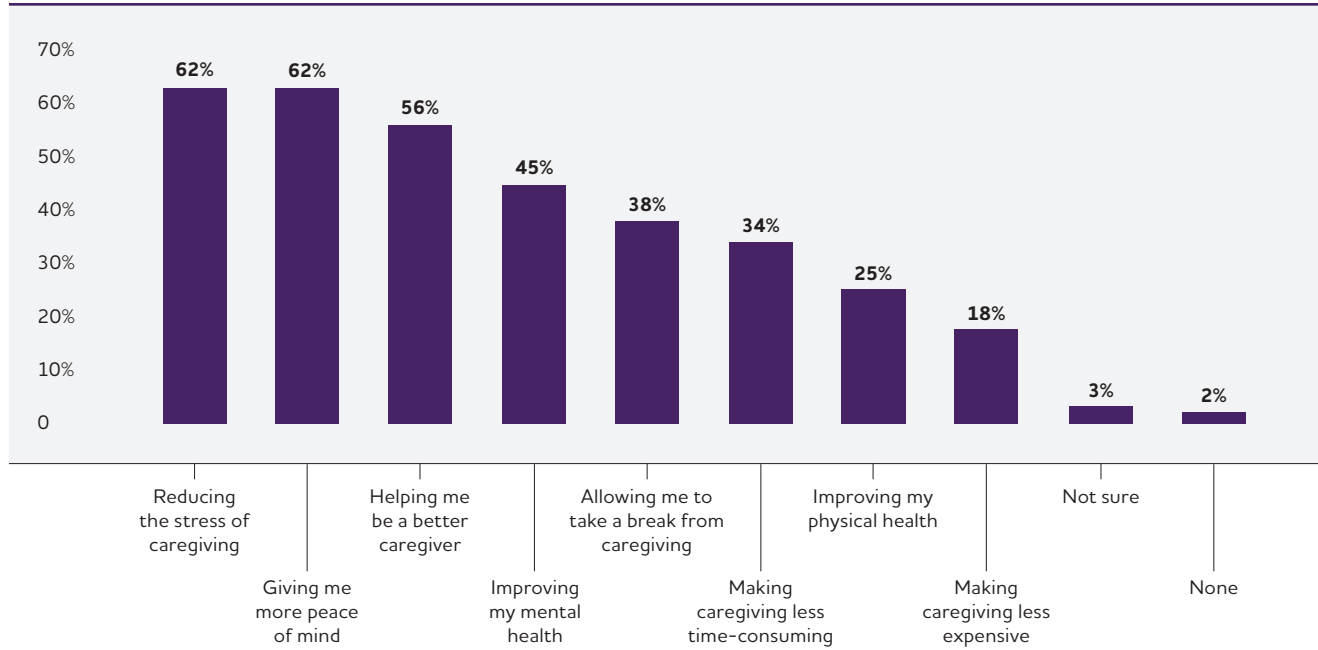
**Around-the-Clock Support, Care Coordination and Help Understanding the Care Recipient’s Condition Viewed as Most Valuable Navigation Services Overall**

Nearly all dementia caregivers (97%) say they would find navigation services helpful. Almost 2 in 5 caregivers (36%) said a 24/7 helpline to call is the top service a care navigation program should provide (Figure 26). Coordinating care and communication between different specialists (34%) and helping to understand their care recipient’s condition (34%) are also viewed as valuable services. Overall, caregivers see value in a mix of medical and nonmedical navigation services. Other helpful services, according to 1 in 3 caregivers, included:

- Assistance with insurance or public benefits (32%).
- Help with scheduling appointments (31%).
- Training on how to care for someone with thinking or memory problems (31%).
- Help managing behavioral symptoms (31%).
- Help understanding the health care system (30%).
- Help finding services to take a temporary break from caregiving (30%).

Figure 25

Anticipated Outcomes for Caregivers of a Navigator Program



The findings highlight services more relevant to dementia care navigation than care navigation for other health conditions, such as respite services, managing behavioral symptoms and support for unanticipated needs outside of regular clinic hours in the form of the helpline. Typically, community-based organizations provide these services. Although 1 in 3 caregivers (30%) have received nonmedical supports and services, such as meal delivery, home care aides, or companions to give time away from caregiving, only 17% found these resources with the help of a person providing care navigation services.

**Community-Based Resources May Address Some Stressors**

Community-based resources and services can play an important role in supporting caregivers. While many of these services are delivered outside traditional health care settings, finding ways to connect caregivers to these resources should be viewed as an essential deliverable in dementia care navigation.

The three most helpful community-based resources cited by caregivers in the survey were local caregiver support groups (41%), respite programs (38%) and availability of financial resources in the community (37%). These resources could alleviate some of the top stressors, like worries about costs and expenses and getting help taking a break (Figure 27).

Caregivers of all races and ethnicities surveyed pointed to connections to local adult daycare programs as a valuable navigation service (Asian, 45%; Black, 36%; Hispanic, 35%; White, 28%).

**Non-Physician Health Care Workforce Survey Results**

**“Care Navigator” is a Known Term in Health Care**

Three in 4 health care workers who provide navigator-type services (77%) are familiar with the term “care navigator.” Nonmedical professionals (CHW, HHA or MSW) were the most familiar, with 4 in 5 (83%) indicating they had heard this term before.

**Many Professionals Already Provide Navigation Services, but This is not Their Focus**

Health care workers participating in the survey spend roughly half (53%) their time providing navigator-type services, even if they do not refer to themselves as care navigators (Figure 28, page 106). Nearly 1 in 3 of the patients they provide navigation services for have cognitive issues, including MCI, Alzheimer’s disease or other dementia (Figure 28, page 106). The vast majority of respondents (93%) say that caregivers or family are almost always involved in discussions of navigation-type services — with or without the person they are caring for.

Figure 26

Care Navigator Services That Would Be Valuable to Dementia Caregivers

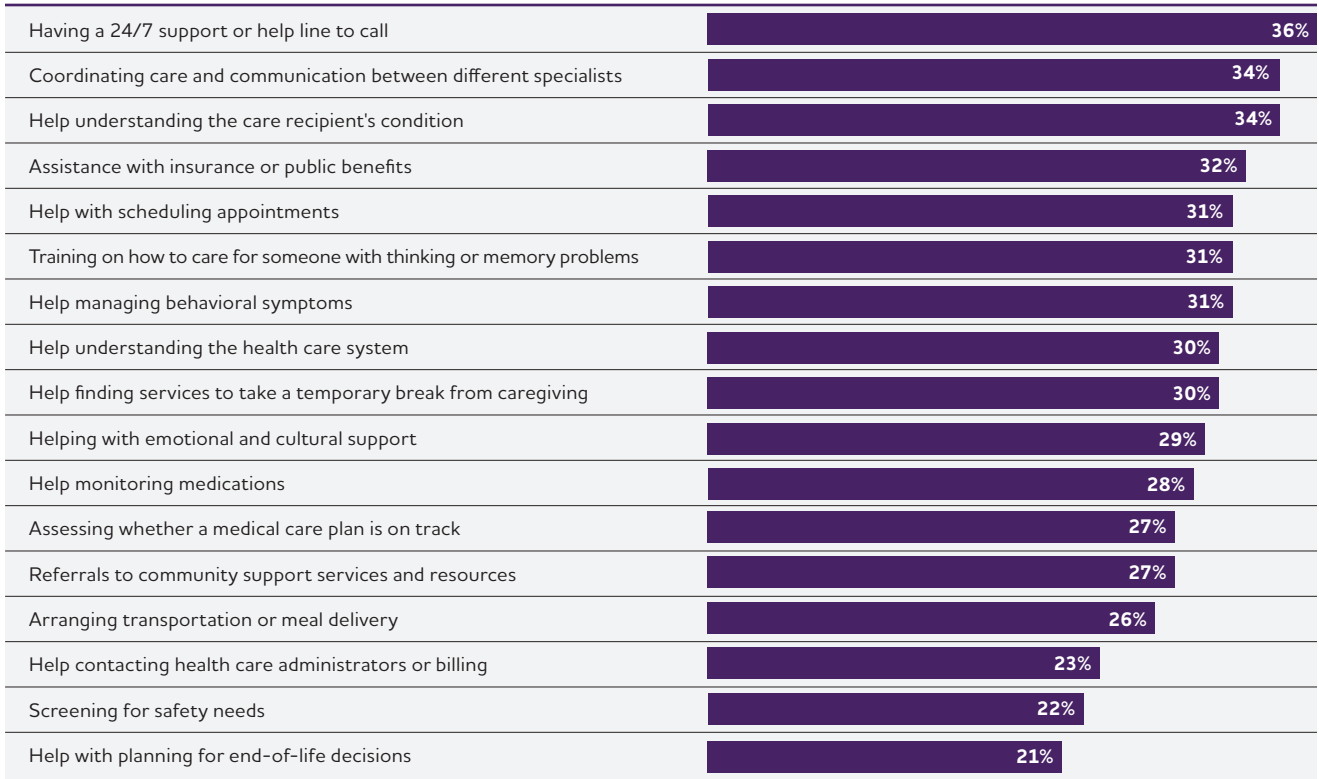


Figure 27

Community-Based Services That Would Be Valuable to Dementia Caregivers

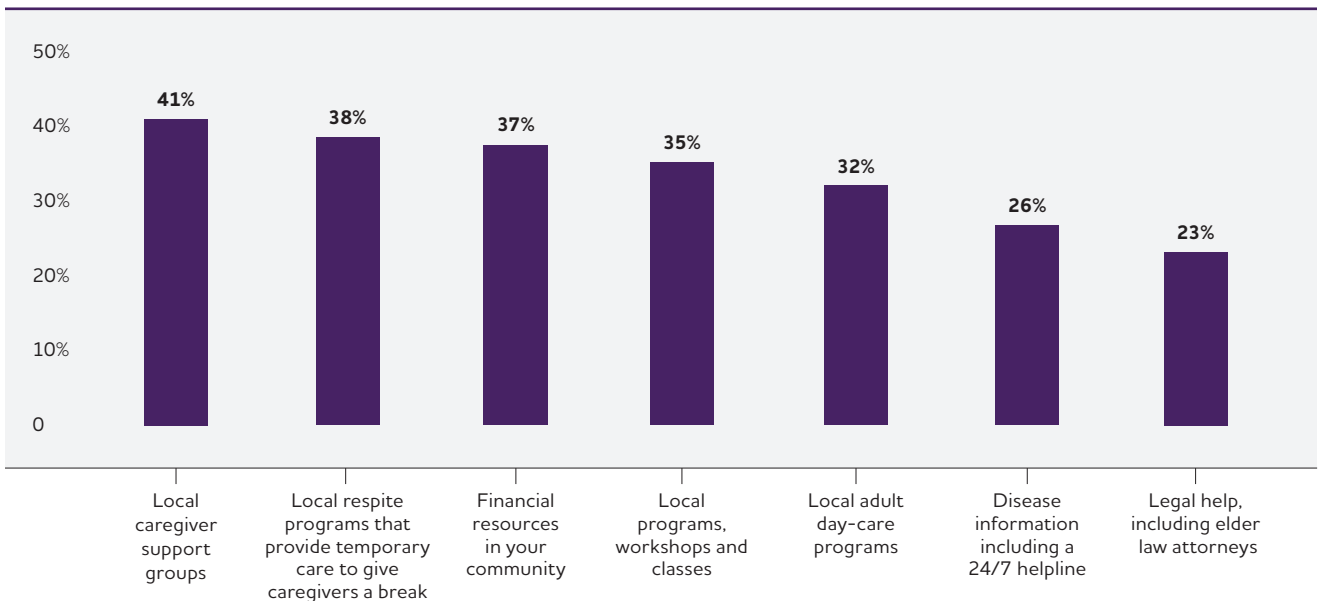
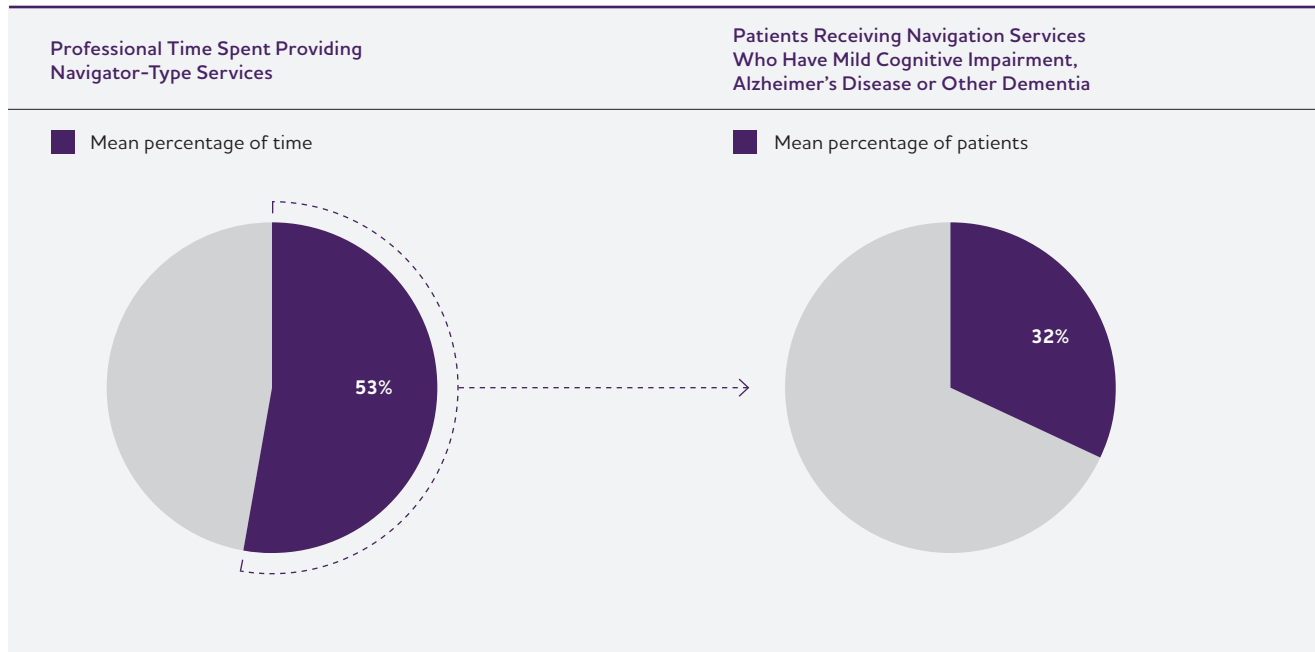


Figure 28

Time Spent on Navigator-Type Services and Percentage of Patients with Cognitive Issues Receiving Navigation Services



Nearly all health care workers in the survey provide support for medical and nonmedical needs, with only 5% focusing exclusively on one type of need (Figure 29). The most frequently provided navigator services are referrals to community support services and resources (75%), helping with emotional and cultural support (68%) and screening for safety needs (66%) (Figure 30). Of those top navigation services, referrals to community support are more often provided by nonmedical professionals, whereas screening for safety needs is most often performed by medical professionals.

Unsurprisingly, medical professionals tend to offer more medically-related navigation services, such as screening for safety, assessing if the medical plan is on track, monitoring medications and staffing helplines (Figure 30). They also viewed these services as more valuable to patients and families than nonmedical professionals did. Nonmedical professionals, on the other hand, report that they are more often involved in making referrals to community resources, disease education, assisting caregivers looking for respite care, arranging transportation or meal delivery and insurance-related support such as working with billing or insurers (Figure 30).

Further illustrating the complicated nature of dementia care and the need for navigation as outlined earlier in the Special Report, health care workers also report that they are heavily involved in guiding patients and families through the health care system. Nearly 2 in 3 health care workers (62%; predominantly nonmedical professionals) help patients and caregivers understand the health care system, and more than 1 in 2 health care workers say they coordinate care and communication with specialists (Figure 30).

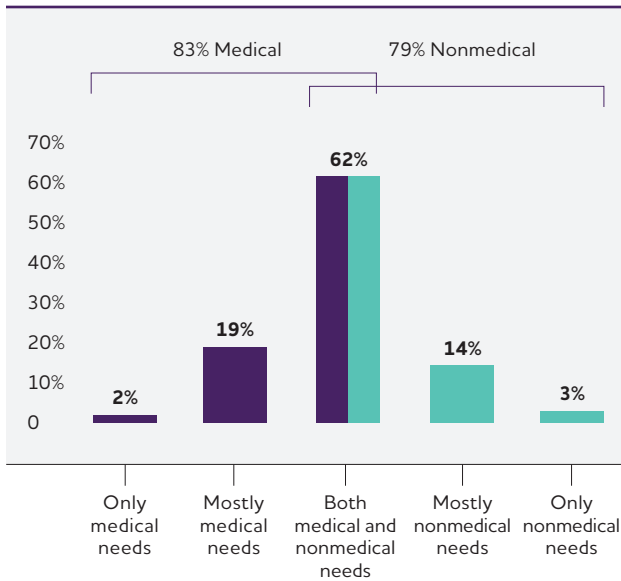
**Greatest Value From Navigators is in Connections to Community Support and Services**

More than 2 in 3 health care workers (68%) said the top service provided, referrals to community support services and resources, was the most valuable navigation offering (Figure 31). The top five most valuable navigation services according to survey respondents were:

- Referrals to community support services and resources (68%).
- Training on how to care for someone with dementia (63%).
- Help managing behavioral symptoms (62%).
- Helping with emotional and cultural support (59%).
- Coordinating care and communication between different specialists (59%).

Figure 29

Focus of Dementia Care Support Provided



More than half of respondents also said that finding respite services to take a temporary break from caregiving, understanding the health care system, and screening for safety needs were valuable.

Interestingly, there were two notable disconnects between what health care workers perceive as valuable and what they deliver in the form of navigation services. The first is training for family members on how to care for someone with dementia. Whereas 63% of survey respondents rated this as valuable, only 2 in 5 (40%) provide such training. The second disconnect was in the utility of a 24/7 helpline. This feature of navigation was valued by 1 in 3 health care workers (33%), yet only 15% are currently providing this service.

Figure 30

Services Provided That Support Dementia Care for Patients and Their Families

	⊕ Provided especially by medical professionals	👤 Provided especially by nonmedical professionals
Referrals to community support services and resources		75%
Helping with emotional and cultural support		68%
Screening for safety needs	66%	
Help understanding the health care system		62%
Help managing behavioral symptoms		60%
Coordinating care and communication between different specialists		57%
Help understanding mild cognitive impairment or dementia		53%
Help monitoring medications	52%	
Help with planning for end-of-life decisions		50%
Assessing whether a medical care plan is on track	44%	
Help finding services to take a temporary break from caregiving		43%
Arranging transportation or meal delivery		41%
Assistance with insurance or public benefits		41%
Training on how to care for someone with dementia		40%
Help contacting health care administrators or billing		25%
Providing support via a 24/7 help line	15%	



Figure 31

Most Valuable Services in Supporting Dementia Care for Patients and Their Families

⊕ Seen as especially important by medical professionals	
Referrals to community support services and resources	68%
Training on how to care for someone with dementia	63%
Help managing behavioral symptoms	62%
Helping with emotional and cultural support	59%
Coordinating care and communication between different specialists	59%
Help finding services to take a temporary break from caregiving	57%
Help understanding the health care system	57%
Screening for safety needs	⊕ 54%
Help understanding mild cognitive impairment or dementia	50%
Help monitoring medications	⊕ 50%
Help with planning for end-of-life decisions	49%
Assistance with insurance or public benefits	47%
Assessing whether a medical care plan is on track	37%
Arranging transportation or meal delivery	36%
Providing support via a 24/7 help line	⊕ 33%
Help contacting health care administrators or billing	24%

**Nonmedical Professionals Communicate More Frequently With Patients and Families**

Two in 5 nonmedical professionals (39%) report they connect with individuals living with dementia and their families every two weeks, and 1 in 3 (32%) make contact every month. Medical professionals typically communicate with patients every two weeks (28%) and every month (24%). However, medical professionals report that they are more likely to communicate every 3 months and 6 months than nonmedical professionals (15% vs. 7% and 5% vs. 1%). This distinction between medical and nonmedical professionals may be a result of the cadence of follow-up visits with a physician, and medical professionals may be more likely to incorporate navigation services into a routine visit. Across groups, 1 in 4 health care workers (23%) discuss dementia care services only as needed.

On average, nonmedical professionals interact most often with patients and families:

- All health care workers: 12 times per year.
- All medical professionals (NP, PA or RN): 11 times per year.
- All nonmedical professionals (CHW, HHA or MSW): 14 times per year.

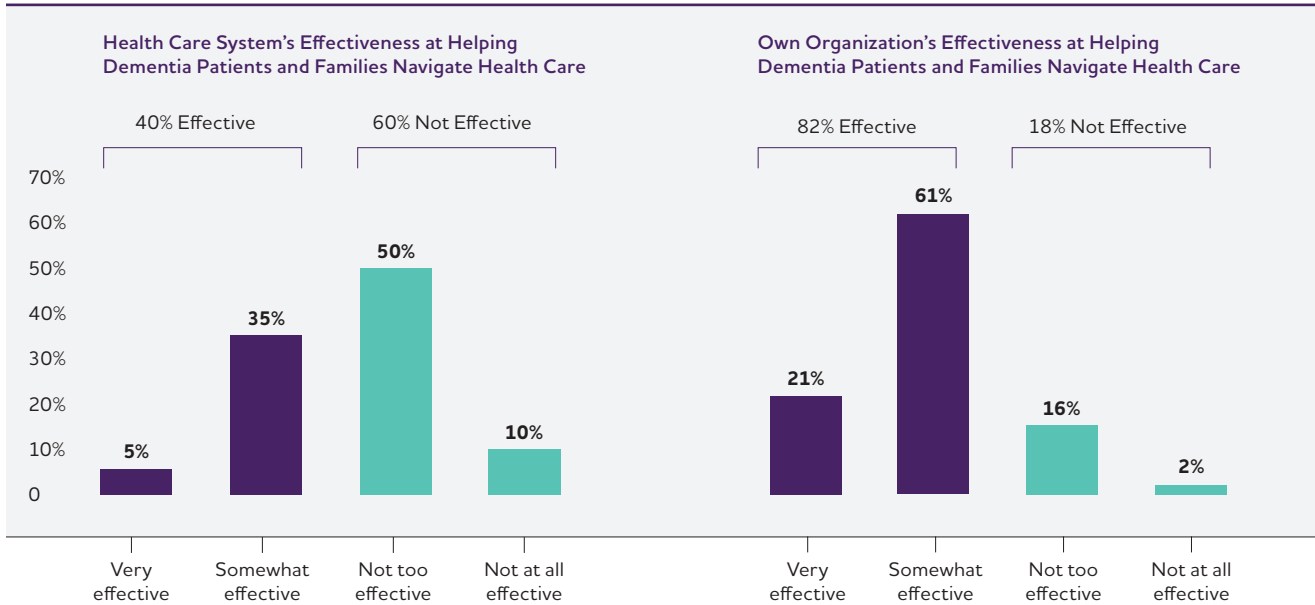
**Health Care Workers Providing Navigation-Type Services Use Traditional Communication Channels Instead of Newer Technologies**

In-person visits and phone calls are by far the most common channels for dementia care navigation and dramatically outpace usage of newer technologies like video conferencing, email, patient portals and text messaging. Care navigation services are 3 to 4 times more likely to be provided in-person or by phone than other channels, and most communication still occurs at in-person visits.

There are some distinctions in how medical and nonmedical professionals deliver navigation services. Medical professionals communicate more often via a patient portal than nonmedical professionals (19% vs. 14%). The most striking difference is how nonmedical professionals appear to have gravitated toward digital communication, possibly because they engage with patients and families more regularly. Nonmedical professionals use video conferencing and email to reach patients and families twice as often as medical professionals (29% vs. 11% and 26% vs. 12%, respectively). Nonmedical professionals also report using a phone call to communicate more often than medical professionals (76% vs. 62%).

Figure 32

Health Care Workers' Views on the Effectiveness of Dementia Care Navigation



**Training in Dementia Care Navigation is Lacking and Not Standardized**

Three in 4 health care workers providing navigation services indicated that they received no formal training in dementia care navigation. The 1 in 4 health care workers who did receive some kind of training were predominantly nonmedical professionals and received a median of 30 hours of formal training. On the other hand, medical professionals received a median of 20 hours of formal training.

If they received formal training, more than 1 in 2 surveyed received it from their employer (59%), not from colleges, universities or other outside programs, such as a certificate or public health program. Except for nonmedical professionals being more likely than medical professionals to have exposure to navigation training during college or university coursework (47% vs. 23%), there were no differences between the groups surveyed.

**Dementia Care is Rarely the Sole Focus of Navigation Activities, but Health Care Workers Still Feel Knowledgeable**

Four in 5 health care workers (80%) have navigation experience in non-dementia medical specialties, and fewer than 1 in 10 (7%) focus primarily on providing navigator support and services to people living with dementia. Most providing navigation services (93%) feel at least somewhat knowledgeable about MCI, Alzheimer's disease and other dementia but only about 1 in 3 (36%) report they are very knowledgeable.

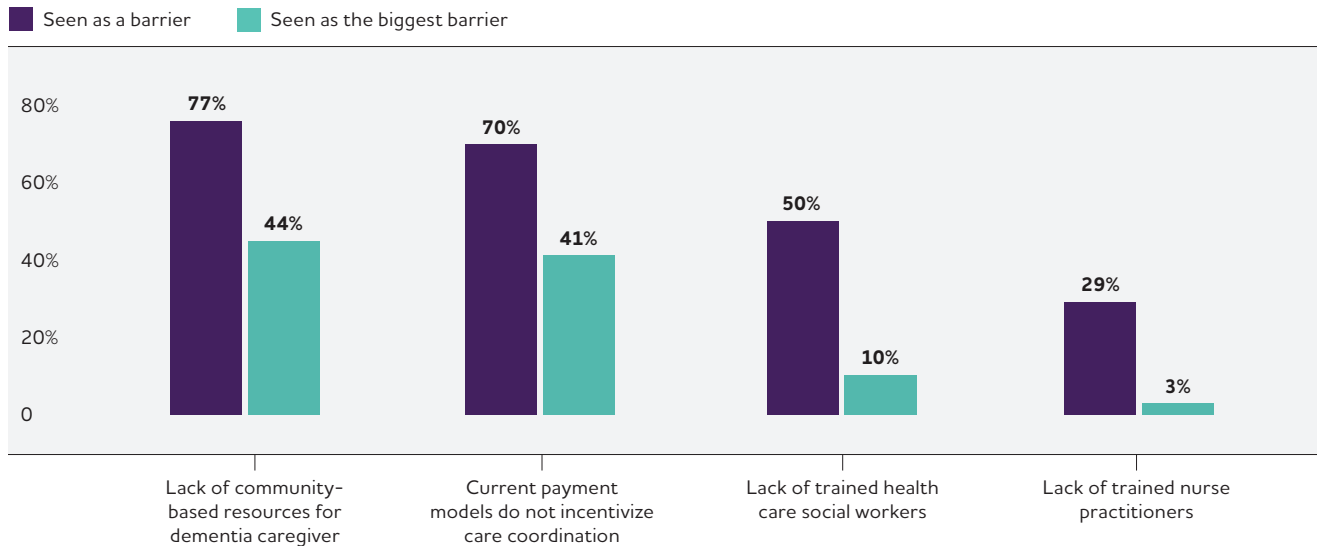
Central to effective, valuable navigation that benefits patients and families is a strong knowledge of dementia care support and resources in health care settings and the community. Nearly 9 in 10 health care workers (86%) feel knowledgeable about directing dementia patients and caregivers to appropriate health care resources, but fewer than 1 in 3 (30%) report feeling very knowledgeable. Four in 5 (82%) feel knowledgeable about directing dementia patients and caregivers to community resources, but only 31% say they are very knowledgeable.

When the group is separated into medical or nonmedical professionals, nonmedical professionals report feeling better equipped and more knowledgeable than medical professionals about health care resources (93% vs. 81%) and community-based resources (92% vs. 75%). Understandably, nonmedical professionals feel more capable, given that they are more likely to communicate regularly with patients and caregivers and could have received formal training on delivering navigation services. Additionally, some health care workers categorized as nonmedical professionals in this survey, such as community health workers or home health aides, may have direct exposure or interaction with resources in the community.

A crucial component of dementia care today is familiarity with new and emerging treatment options and awareness of clinical trials. Nearly all health care workers surveyed believe it is important to be familiar with new treatments (98%) and with clinical trial options (93%).

Figure 33

Barriers to Dementia Care Navigation



**The Health Care System Could Do More to Help People Navigate Dementia Care**

Health care workers shed light on current deficits in dementia care. Sixty percent believe that the U.S. health care system is not effectively helping patients and their families navigate dementia care (Figure 32). They perceive their own organization’s efforts more positively, however, with 4 in 5 saying that their organization is effective (somewhat effective [61%] or very effective [21%]) at providing dementia care; (Figure 32). Nearly half surveyed (46%) say their organizations do not have a clearly defined process for care coordination and clinical pathways for patients with MCI, Alzheimer’s disease or other dementia.

Health care workers pointed to a lack of community-based resources for dementia caregivers and current payment models that do not incentivize care coordination as the greatest barriers to dementia care navigation (Figure 33). More than 3 in 4 of the health care workers surveyed (77%) identified a lack of community-based resources as a barrier, and 44% viewed it as the greatest barrier. Seven in 10 (70%) called out restrictions in current reimbursement as a barrier, with 41% saying this was the greatest barrier. Interestingly, health care workers did not identify workforce shortages as a top limitation for dementia care navigation (Figure 33). There were no differences in perceived barriers to dementia care navigation between medical and nonmedical professionals.

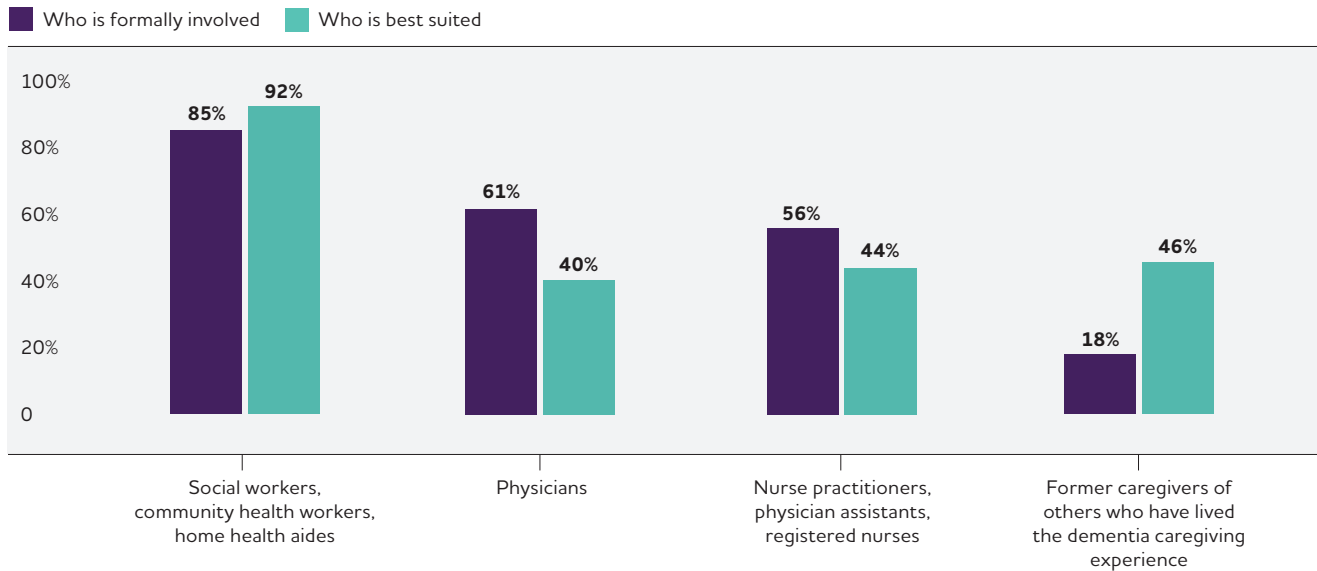
Almost 9 in 10 health care workers (87%) feel that developing alternative payment models is important in providing future care coordination for people diagnosed with dementia.

**Nonmedical Professionals Are Best Suited to be Dementia Care Navigators**

Survey respondents overwhelmingly agreed that nonmedical professionals are best suited to provide navigation services (Figure 34). Within their organizations, those surveyed reported that social workers, community health workers, and home health aides are more often formally involved in care navigation, and 9 in 10 reported that these individuals are best suited to offer navigation services. The next group of individuals health care workers believed are suited for navigation roles are former caregivers or others who have lived the caregiving experience, but few reported that these individuals are formally involved in dementia care navigation at their organizations. Surprisingly, nearly 2 in 3 health care workers indicated that physicians at their organization are involved in helping patients and caregivers navigate health care but fewer than half of the health care workers surveyed think that physicians are best suited for this work.

Figure 34

Professionals Who Help Dementia Patients and Caregivers Navigate Health Care



**A Path Forward: Revolutionizing Dementia Care With Person-Centered Navigation**

As the complexity of health care for Alzheimer’s and other dementias continues to challenge individuals living with dementia and caregivers alike, the Alzheimer’s Association dementia caregiver and non-physician health care workforce surveys call attention to the urgent need for person-centered dementia care navigation and care delivery solutions for health systems, health care professionals, caregivers and people living with dementia.

Dementia care management is emerging as an ideal model to unravel dementia care complexity, improve outcomes and lower costs (Figure 35).<sup>978</sup> Care navigation is a crucial component that touches all other aspects of care management, such as caregiver education and training, care coordination, medication management, management of chronic conditions, safety assessments, and advance care planning.<sup>978</sup> Dementia care navigation, as part of comprehensive dementia care management, has the potential to revolutionize care if it is:

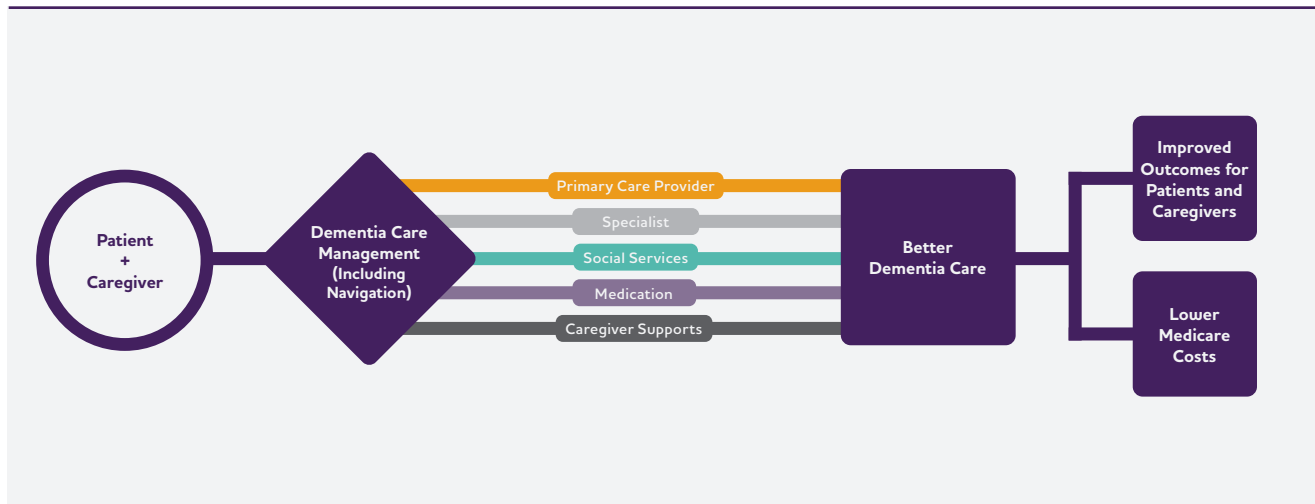
- Person-centered to meet the evolving, unique needs of all individuals living with Alzheimer’s or other dementia.
- Durable yet adaptable to accommodate new treatments, new diagnostics and other improvements to care.
- Comprehensive to cover medical and nonmedical needs.
- Coordinated to connect disparate care teams and community resources.
- Feasible regardless of health system structure.
- Cognizant of geographic and socioeconomic barriers.

Ultimately, the goal of care navigation is to improve the quality of life for people living with dementia, reduce caregiver stress and enable people living with dementia to live in their homes and communities as long as possible.

The GUIDE Model is a reason for optimism that emphasizes streamlined care coordination and robust support for caregivers — including forging a vital connection with a dedicated care navigator — and creating an alternative payment model to reimburse physicians (see What is GUIDE? on page 94).<sup>986</sup> However, while the GUIDE Model offers one potential approach toward enhancing dementia care navigation, it is a limited pilot program that will not be delivered by all health care providers nor available to all patients with dementia. Therefore, it is important for health systems, private insurers and other stakeholders to develop their own strategies to help people living with dementia and their caregivers navigate care.

The Special Report survey results brought to light three themes to advance dementia care navigation efforts:

1. Formalizing the dementia care navigator role and increasing navigator proficiency in dementia care.
2. Scaling and expanding access to dementia care navigation programs.
3. Creating direct lines to dementia care navigators.

The Ideal Future State of Dementia Care<sup>978</sup>

### Formalize the Dementia Care Navigator Role

Survey responses revealed a noteworthy trend: many health care workers are undertaking navigator duties in addition to their usual responsibilities. Ideally, practices and health systems should transition from ad hoc navigation support to formalizing dedicated dementia care navigator roles that are recognized for their vital and essential contributions to interdisciplinary, person-centered dementia care.

As mentioned in the Workforce section (see page 64), several decades of research support the value of collaborative models that bring different health professionals together, such as social workers, registered nurses and non-clinical care managers, physicians and advanced practice providers, and direct care workers, including nurse aides, nursing assistants, home health aides and personal care aides.<sup>754, 755</sup> If these individuals are the spokes in the dementia care wheel, the care navigator is the hub — supporting patients and caregivers as they find their way through the dementia care ecosystem. Given that this is a relatively new role in the dementia workforce, it's crucial for organizations to create a practice framework to seamlessly integrate dementia care navigators into existing teams and workflows to effectively coordinate longitudinal care that spans the disease course.

### Increase Dementia Proficiency to Cultivate Specialist Navigators

In identifying ideal candidates for navigator roles, medical and nonmedical professionals agreed that community health workers, social workers and home health aides are best suited to be dementia care navigators. Despite receiving some formal education in navigation, often

as part of college coursework or employer-provided training, these professionals are typically trained as generalists. Supplemental training and resources are necessary to build a solid foundation in both the practical and emotional aspects of dementia care. Their skills and compassion for the challenges caregivers and individuals living with dementia face could be enhanced with supplemental dementia-specific training and resources, such as:

- Materials for health care workers from the Health Resources & Services Administration.<sup>996</sup>
- Professional development programs in dementia care recognized by the Alzheimer's Association.<sup>997</sup>
- The Care Ecosystem Toolkit from the University of California, San Francisco (UCSF) Memory and Aging Center.<sup>998</sup>
- Home health clinician manuals from the Wisconsin Alzheimer's Institute.<sup>999</sup>
- Caregiver training videos from UCLA Health.<sup>1000</sup>
- Resources, webinars, presentations and toolkits from the National Alzheimer's and Dementia Resource Center.<sup>1001</sup>
- Community health worker training for participants in programs funded by the Administration for Community Living-Alzheimer's Disease Program Initiative (ACL-ADPI).<sup>982</sup>
- Resources and webinars on brain health and dementia from the National Association of Community Health Centers.<sup>1002</sup>

To bolster the training and resources outlined here, the Alzheimer's Association is developing a person-centered navigator training curriculum and certification that is slated for release in late 2024. This curriculum, which

incorporates the Alzheimer's Association's evidence-based Dementia Care Practice Recommendations, has the potential to increase the proficiency of care navigators, ensuring that they are well-equipped to meet the distinct needs of individuals living with dementia and their caregivers. Investment in navigator training and development could yield a marked improvement in the overall quality and effectiveness of dementia care.

### **Incentivize Scalability of Dementia Care Navigation to Expand Reach**

Fee-for-service payment has dominated the health care market. Under these structures, health care providers are paid for individual services they perform, such as office visits or tests.<sup>1003</sup> Experts have long argued that fee-for-service is inefficient because it encourages the delivery of more potentially unnecessary care while discouraging care coordination.<sup>1004</sup> The U.S. health care system is increasingly transitioning from fee-for-service structures to alternative payment models, including value-based payment.<sup>1004</sup> Often called "volume to value," the goal of value-based payments is to restructure the approach "from one that incentivizes volume to one that rewards value."<sup>1005</sup>

Dementia care is not immune from financial incentives.<sup>984, 1006, 1007</sup> Health care workers in this year's survey believed that current reimbursement systems fail to incentivize dementia care and are one of the greatest barriers to dementia care navigation. They strongly believe that alternative payment models are important in providing future care coordination for people diagnosed with dementia.

### **Work to Make Existing and Future Dementia Care Navigation Programs Visible and Accessible**

According to this year's caregiver survey, awareness of dementia care navigators remains low despite the recognized value of navigation. This may, in part, be due to variations in terminology used by different health care providers, inconsistent definitions or that these individuals simply do not yet exist within organizations. Depending on the setting, what is defined as dementia care navigation in this Special Report may also be called memory care navigation, care navigation, a navigator program, dementia navigation or not have terminology at all, but simply be services provided to patients.<sup>990, 992</sup>

Future programs must focus on elevating the visibility of navigation services through targeted outreach efforts. This involves leveraging community resources, social media and health care settings to inform and educate dementia caregivers about the support available to them. A compendium that defines terms and lists programs by region could be a useful tool to empower individuals living

with Alzheimer's or other dementia and their caregivers. Furthermore, integrating care navigation into primary care and specialty clinics can ensure that more patients and families benefit from these services from the onset of their dementia care journey.

Another key factor limiting access to existing dementia care navigation programs is their location. Existing dementia care navigation programs are typically housed within large health systems or academic medical centers, putting them out of reach for many individuals from rural and underrepresented communities who receive care from hospitals or clinics within their community.<sup>992</sup> In anticipation of the growing need for dementia care navigation programming, the Alzheimer's Association created the Dementia Care Navigation Roundtable, which will help organizations establish best practices, support implementation and increase access to navigation programs.

### **Leverage 24/7 Helplines and Technology to Create Direct Lines to Care Navigators**

Dementia caregivers reported that the most valuable service that care navigation could offer would be a 24/7 helpline. The Alzheimer's Association currently offers a 24/7 helpline that performs some navigation activities, such as assisting individuals with Alzheimer's or other dementia and their caregivers with recommendations for finding qualified care providers, general information about legal, financial and care decisions, and referrals to local programs and services.<sup>1008</sup> Ideally, access to 24/7 assistance would be connected directly with an individual's interdisciplinary care team. This allows the care team to manage longitudinal care, proactively assess any changes needed in care and potentially mitigate unnecessary emergencies.

While dementia caregivers and health care workers acting as navigators still prefer traditional communication methods such as phone calls and in-person visits for everyday communication, there is an opportunity to integrate technology solutions to streamline care coordination and support; these solutions should be viewed as complementary to existing person-centered approaches rather than replacements. Several companies are exploring on-demand virtual and app-based dementia care navigation, and the GUIDE Model supports contracting with suppliers to meet care delivery requirements that participants in the model wouldn't otherwise be able to meet on their own.<sup>986</sup> Digital platforms can offer caregivers and patients easier access to resources, appointment scheduling and direct communication with care navigators. However, any technological solution must be user-friendly and accessible to all caregivers, regardless of their familiarity

with digital tools, and compatible with any platforms used by health care providers. Navigators should be trained on how to communicate effectively through different channels.

## **Conclusion**

The path forward for person-centered dementia care navigation is illuminated by the insights and experiences of dementia caregivers and health care professionals. The first step on this path is to establish proficient, dedicated dementia care navigators as a new role in the interdisciplinary dementia care workforce. Then, by addressing these key areas — training, person-centered care, accessibility, collaboration, novel payment models, and technology — future dementia care navigation programs can build on the learnings of their predecessors. Such efforts strive to improve the quality of life for individuals living with dementia and their caregivers and pave the way for a more sustainable, efficient and compassionate health care system.

## Appendices

### End Notes

- A1. Racial and ethnic identifiers: Facts and Figures keeps the racial and ethnic terms used in source documents when describing study findings. When not referring to data from specific studies, adjectives such as “Black,” “Hispanic” and “White” may be used (for example, Black populations and Hispanic communities).
- A2. Estimated prevalence (number and proportion) of Americans age 65 and older with Alzheimer’s dementia for 2024: The estimated 6.9 million individuals ages 65 years and older with Alzheimer’s dementia and the estimated numbers of individuals with Alzheimer’s in each age group were reported from a study that used data from the Chicago Health and Aging Project (CHAP) in combination with population projections from the U.S. Census.<sup>241</sup> The number, 6.9 million, is higher than estimated from previous study that also combined CHAP and U.S. Census data. This is because the more recent study used updated Census projections and incorporated information from Hispanic/Latino American individuals. The proportion of the population with Alzheimer’s dementia (among people age 65 and older and by age group) is calculated using as the numerators the numbers of people with Alzheimer’s dementia, as reported by the recent study in CHAP.<sup>241</sup> The denominators were the U.S. Census population projections for the specific age groups of interest.
- A3. Differences between CHAP and HRS-HCAP estimates for Alzheimer’s dementia prevalence: The number of people estimated to have any form of dementia in the U.S. in 2016 from the Health and Retirement Study’s (HRS) Harmonized Cognitive Assessment Protocol (HCAP; 4.92 million) is lower than the CHAP estimate of how many people were living with Alzheimer’s dementia only (6.07 million).<sup>160</sup> This is because of differences in dementia ascertainment between the two studies: both studies used scores on batteries of cognitive tests, but the HRS-HCAP study additionally required an informant report of functional impairment (i.e. disability). Because the more stringent threshold for dementia in HRS-HCAP may miss people with mild Alzheimer’s dementia, the Association believes that the larger CHAP estimates may be a more relevant estimate of the burden of Alzheimer’s dementia in the United States.
- A4. Criteria for identifying people with Alzheimer’s or other dementias in the Framingham Heart Study: From 1975 to 2009, 7,901 people from the Framingham Study who had survived free of dementia to at least age 45, and 5,937 who had survived free of dementia until at least age 65 were followed for incidence of dementia.<sup>286</sup> Diagnosis of dementia was made according to the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) criteria and required that the participant survive for at least 6 months after onset of symptoms. Standard diagnostic criteria (the NINCDS-ADRDA criteria from 1984) were used to diagnose Alzheimer’s dementia. The definition of Alzheimer’s and other dementias used in the Framingham Study was very strict; if a definition that included milder disease and disease of less than six months’ duration were used, lifetime risks of Alzheimer’s and other dementias would be higher than those estimated by this study.
- A5. Projected number of people with Alzheimer’s dementia, 2020-2060: This figure comes from the CHAP study.<sup>241</sup> Other projections are somewhat lower (see, for example, Brookmeyer et al.<sup>1009</sup>) because they relied on more conservative methods for counting people who currently have Alzheimer’s dementia.<sup>43</sup> Nonetheless, these estimates are statistically consistent with each other, and all projections suggest substantial growth in the number of people with Alzheimer’s dementia over the coming decades.
- A6. Annual mortality rate due to Alzheimer’s disease by state: Unadjusted death rates are presented rather than age-adjusted death rates in order to provide a clearer depiction of the burden of mortality for each state. States such as Florida with larger populations of older people will have a larger burden of mortality due to Alzheimer’s — a burden that appears smaller relative to other states when the rates are adjusted for age.
- A7. Number of family and other unpaid caregivers of people with Alzheimer’s or other dementias: To calculate this number, the Alzheimer’s Association started with data from the Behavioral Risk Factor Surveillance System (BRFSS) survey. Since 2016, all states and the District of Columbia utilized the BRFSS caregiver module. This module identified respondents age 18 and over who had provided any regular care or assistance during the past month to a family member or friend who had a health problem, long-term illness or disability. The module asks a series of follow-up questions, including asking the caregiver to identify what the main health problem, long-term illness, or disability that the person they care for has. One of the reported condition categories is “Alzheimer’s disease, dementia, or other cognitive impairment.” In the BRFSS surveys conducted in 2019 and after, an additional follow-up question was included, asking if the caregiving recipient also had dementia in addition to their main condition. Prior to 2019, the survey did not include caregivers of recipients for whom dementia was not their main condition, so these numbers were imputed using data collected in 2019 by the National Alliance for Caregiving (NAC)/AARP survey. The NAC/AARP survey asked respondents age 18 and over whether they were providing unpaid care for a relative or friend age 18 or older or had provided such care during the past 12 months. Respondents who answered affirmatively were then asked about the health problems of the person for whom they provided care: 11% of respondents reported dementia as the main condition of their care recipient, while 26% of all respondents reported the presence of dementia. Using this ratio in combination with BRFSS data, the Alzheimer’s Association was able to determine the percentage of adults in all states and the District of Columbia who are caregivers for individuals living with Alzheimer’s or another dementia. These percentages were applied to the estimated number of people age 18 and older in each state in July 2023, using U.S. Census Bureau data available at: <https://www.census.gov/programs-surveys/popest/data/tables.html>. This resulted in a total of 11.457 million Alzheimer’s and dementia caregivers across all 50 states and the District of Columbia.
- A8. Number of hours of unpaid care: The BRFSS survey asks caregivers to identify, within five time frames, the number of hours they provide care in an average week. Using the method developed by Rabarison and colleagues,<sup>441</sup> the Alzheimer’s Association assumed the midpoint of each time frame was the average number of hours for each caregiver within that time frame and then calculated the overall average number of hours of weekly care provided by dementia caregivers in each state. This number was then converted to a yearly average and multiplied by the number of caregivers in each state<sup>47</sup> to determine the total number of hours of care provided. When added together, across all 50 states and the District of Columbia, the total number of hours provided by Alzheimer’s and dementia caregivers is 18.376 billion hours.
- A9. Value of unpaid caregiving: For each state, the hourly value of care was determined as the average of the state minimum hourly wage<sup>1010</sup> and the most recently available state median hourly wage of a home health aide. (For Nevada, the minimum wage used was the average of the minimum wage for those who are not provided health insurance and the minimum wage for those who are provided health insurance.)<sup>908</sup> The average for each state was then multiplied by the total number of hours of unpaid care in that state<sup>48</sup> to derive the total value of unpaid care. Adding the totals from all states and the District of Columbia resulted in an economic value of \$346.585 billion for dementia caregiving in the United States in 2023.



- A10. The 2014 Alzheimer's Association Women and Alzheimer's Poll: This poll questioned a nationally representative sample of 3,102 American adults about their attitudes, knowledge and experiences related to Alzheimer's and dementia from Jan. 9, 2014, to Jan. 29, 2014. An additional 512 respondents who provided unpaid help to a relative or friend with Alzheimer's or a related dementia were asked questions about their care provision. Random selections of telephone numbers from landline and cell phone exchanges throughout the United States were conducted. One individual per household was selected from the landline sample, and cell phone respondents were selected if they were 18 years old or older. Interviews were administered in English and Spanish. The poll "oversampled" Hispanics/Latinos, selected from U.S. Census tracts with higher than an 8% concentration of this group. A list sample of Asian Americans was also utilized to oversample this group. A general population weight was used to adjust for number of adults in the household and telephone usage; the second stage of this weight balanced the sample to estimated U.S. population characteristics. A weight for the caregiver sample accounted for the increased likelihood of female and White respondents in the caregiver sample. Sampling weights were also created to account for the use of two supplemental list samples. The resulting interviews comprise a probability-based, nationally representative sample of U.S. adults. A caregiver was defined as an adult over age 18 who, in the past 12 months, provided unpaid care to a relative or friend age 50 or older with Alzheimer's or another dementia. Questionnaire design and interviewing were conducted by Abt SRBI of New York.
- A11. Lewin Model on Alzheimer's and dementia costs: These numbers come from a model created for the Alzheimer's Association by the Lewin Group. The model estimates total payments for health care, long-term care and hospice — as well as state-by-state Medicaid spending — for people with Alzheimer's and other dementias. The model was updated by the Lewin Group in January 2015 (updating previous model) and June 2015 (addition of state-by-state Medicaid estimates). Detailed information on the model, its long-term projections and its methodology are available at: [alz.org/trajectory](http://alz.org/trajectory). For the purposes of the data presented in this report, the following parameters of the model were changed relative to the methodology outlined at [alz.org/trajectory](http://alz.org/trajectory): (1) cost data from the 2018 Medicare Current Beneficiary Survey (MCBS) were used rather than data from the 2008 MCBS; (2) prevalence among older adults was assumed to equal the prevalence levels from Rajan and colleagues<sup>241</sup> and included in this report (6.9 million in 2024), rather than the prevalence estimates derived by the model itself; (3) estimates of inflation and excess cost growth reflect the most recent relevant estimates from the cited sources (Centers for Medicare & Medicaid Services [CMS] actuaries and the Congressional Budget Office); and (4) 2014 state-by-state data from CMS on the number of nursing home residents and percentage with moderate and severe cognitive impairment were used in lieu of 2012 data. The Lewin Model's state-specific Medicaid costs for 2020 and 2025 are based on an earlier estimate of state prevalence than reported here (Weuve J, Hebert LE, Scherr PA, Evans DA. Prevalence of Alzheimer disease in U.S. states. *Epidemiology* 2015;26(1):E4-6).
- A12. All cost estimates were inflated to year 2023 dollars using the Consumer Price Index (CPI): All cost estimates were inflated using the seasonally adjusted average prices for medical care services from all urban consumers. The relevant item within medical care services was used for each cost element. For example, the medical care item within the CPI was used to inflate total health care payments; the hospital services item within the CPI was used to inflate hospital payments; and the nursing home and adult day services item within the CPI was used to inflate nursing home payments.
- A13. Average annual per-person payments for health care and long-term care services for Medicare beneficiaries age 65 and older with and without Alzheimer's or other dementias: Payments are unadjusted, and therefore, do not account for differences in patient characteristics, such as age or sex. Additionally, payments are based on health care utilization and payments in 2018, prior to the COVID-19 pandemic, and do not reflect any pandemic-related changes in utilization.
- A14. Enrollment in fee-for-service Medicare versus Medicare Part C: Individuals eligible for Medicare can enroll in traditional Medicare, also referred to as fee-for-service Medicare and original Medicare, or Medicare Advantage, also referred to as Medicare Part C.<sup>1011</sup> With traditional Medicare, beneficiaries can receive care from any doctor or hospital that accepts Medicare in the United States. Generally, beneficiaries can seek care from a specialist without a referral. Traditional Medicare has fixed cost sharing, which includes coinsurance of 20% of the Medicare-approved amount for services covered by Part B after the deductible is met. Individuals enrolled in traditional Medicare can also enroll in Medicare Supplemental Insurance (also referred to as Medigap) to help cover the out-of-pocket costs. Traditional Medicare does not have an annual limit on the amount beneficiaries pay out-of-pocket. Benefits are the same for all individuals enrolled in traditional Medicare. Individuals enrolled in traditional Medicare can also enroll in a Medicare Part D plan to cover some of the costs of prescription drugs. Medicare Part D enrollment has a separate premium. With Medicare Advantage, individuals must enroll in a specific private plan. Premiums, benefits and out-of-pocket costs may vary across plans. Medicare Advantage plans have an annual limit on the amount individuals pay out-of-pocket. Individuals enrolled in a Medicare Advantage plan are not allowed to enroll in Medigap. Medicare Advantage plans are also allowed to offer additional benefits not included in traditional Medicare, such as vision, hearing and dental services as well as some non-health care benefits, such as transportation costs and gym memberships. Many Medicare Advantage plans include prescription drug coverage (Medicare Part D). Individuals enrolled in a Medicare Advantage plan have a specific network of doctors and hospitals that enrollees need to use for services to be paid by the Medicare Advantage plan. Additionally, individuals enrolled in a Medicare Advantage plan may need a referral to see a specialist. Enrollment in Medicare Advantage has increased dramatically over the past decade, with 51% of all Medicare beneficiaries enrolled in a Medicare Advantage plan in 2023 compared to 29% in 2013.<sup>918</sup>
- A15. Medicare Current Beneficiary Survey Report: These data come from an analysis of findings from the 2018 Medicare Current Beneficiary Survey (MCBS). The analysis was conducted for the Alzheimer's Association by Health Care Cost Institute.<sup>863</sup> The MCBS, a continuous survey of a nationally representative sample of about 15,000 Medicare beneficiaries, is linked to Medicare claims. The survey is supported by the U.S. Centers for Medicare & Medicaid Services (CMS). For community-dwelling survey participants, MCBS interviews are conducted in person three times a year with the Medicare beneficiary or a proxy respondent if the beneficiary is not able to respond. For survey participants who are living in a nursing home or another residential care setting, such as an assisted living residence, retirement home or a long-term care unit in a hospital or mental health facility, MCBS interviews are conducted with a staff member designated by the facility administrator as the most appropriate to answer the questions. Data from the MCBS analysis that are included in *2024 Alzheimer's Disease Facts and Figures* pertain only to Medicare beneficiaries age 65 and older.

For this MCBS analysis, people with dementia are defined as:

- Community-dwelling survey participants who answered yes to the MCBS question, “Has a doctor ever told you that you had Alzheimer’s disease or dementia?” Proxy responses to this question were accepted.
- Survey participants who were living in a nursing home or other residential care setting and had a diagnosis of Alzheimer’s disease or dementia in their medical record
- Survey participants who had at least one Medicare claim with a diagnostic code for Alzheimer’s or other dementias in 2008. The claim could be for any Medicare service, including hospital, skilled nursing facility, outpatient medical care, home health care, hospice or physician, or other health care provider visit. The diagnostic codes used to identify survey participants with Alzheimer’s or other dementias are 331.0, 331.1, 331.11, 331.19, 331.2, 331.7, 331.82, 290.0, 290.1, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 291.2, 294.0, 294.1, 294.10 and 294.11.

Costs from the MCBS analysis are based on responses from 2018 and reported in 2023 dollars.

A16. Differences in estimated costs reported by Hurd and colleagues:

Hurd and colleagues<sup>862</sup> estimated per-person costs using data from participants in ADAMS, a cohort in which all individuals underwent diagnostic assessments for dementia. One reason that the per-person costs estimated by Hurd and colleagues are lower than those reported in *Facts and Figures* is that ADAMS, with its diagnostic evaluations of everyone in the study, is more likely than MCBS to have identified individuals with less severe or undiagnosed Alzheimer’s. By contrast, the individuals with Alzheimer’s registered by MCBS are likely to be those with more severe, and therefore more costly, illness. A second reason is that the Hurd et al. estimated costs reflect an effort to isolate the incremental costs associated with Alzheimer’s and other dementias (those costs attributed only to dementia), while the per-person costs in *2024 Alzheimer’s Disease Facts and Figures* incorporate all costs of caring for people with the disease (regardless of whether the expenditure was related to dementia or a coexisting condition).

A17. For the health care workforce survey, medical and nonmedical respondents were required to meet the following screening criteria:

- Spend at least 20% of professional time interacting directly with patients or caregivers.
- Report at least 10% of their patients being age 60 or older.
- Spend at least 10% of professional time performing navigation-type services.
- Report at least 10% of patients for whom they perform these services having Alzheimer’s disease, other dementia or mild cognitive impairment (MCI).

Dementia care navigation was defined as the following for this group:

Whether or not you consider yourself a care navigator, do you provide any of these types of care, support or services in your current role?

- Patient education around diagnosis, treatment options and resources.
- Patient referrals to clinical specialists.
- Patient referrals to clinical trials.
- Patient referrals to social workers.
- Patient referrals to community-based services.
- Patient scheduling (labs, care team appointments, etc.)
- Patient assistance with insurance.

## Appendices

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The Alzheimer's Association acknowledges the contributions of Joseph Gaugler, Ph.D., Bryan James, Ph.D., Tricia Johnson, Ph.D., Jessica Reimer, Ph.D., Kezia Scales, Ph.D., Sarah Tom, Ph.D., M.P.H., Jennifer Weuve, M.P.H., Sc.D., and Jarmin Yeh, Ph.D., M.P.H., M.S.S.W., in the preparation of *2024 Alzheimer's Disease Facts and Figures*.

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