



The
John A. Hartford
Foundation



Age-Friendly Insights:

Older Adults Want More Government Support for Dementia Caregiving

Survey shows high support for training, respite care and paid leave

The John A. Hartford Foundation (JAHF) commissioned a survey of more than 1,000 U.S. adults 50 and older to understand their views on dementia care and support. Findings include:

Adults 50+ overwhelmingly want policies that support older adults with dementia and their caregivers.

- ▶ The vast majority of adults want the government to support caregiving and workforce benefits, such as **training to help provide better care** (92%), **payment for in-home assistance or respite care** (91%), **payment for time spent caregiving** (84%), **support groups with other caregivers** (84%) and **paid leave** (81%) to provide caregiving.
- ▶ **Women and Black respondents voice the strongest support.**
 - Black respondents (92%) and women (85%) are more likely than white respondents (76%) and men (77%) to say it is important for the government to ensure workforce benefits exist that enable them to take paid leave if they are caring for someone with dementia.
- ▶ **Adults who are a typical working age (50-64) are especially in favor of workforce support for caregiving.**
 - 88% of adults ages 50-64 say it would be important for the government to ensure workforce benefits that enable them to take paid and unpaid leave to care for someone with dementia, compared to 74% of adults age 65+.

“Older adults and their family caregivers need comprehensive support when facing a dementia diagnosis. Polling shows that older adults overwhelmingly favor government actions to increase training, respite care and paid leave for caregivers. The John A. Hartford Foundation and its partners will continue to develop resources and advance strong policies that promote high-quality, age-friendly dementia care that improves the lives of patients and caregivers alike.”

—*Terry Fulmer,*
PhD, RN, FAAN
President, JAHF



If they were to receive a dementia diagnosis, older adults want support from health care and social service providers to meet their needs.

► **Primary care physicians are seen as a top source of information and care.**

- More than half of adults (56%) would consult their primary care provider first if they had concerns about their memory or the memory of a family member.
 - Older adults age 65+ are even more likely to turn to their primary care provider first (62%).
 - Women (61%) are more likely than men (50%) to first consult their primary care provider.

► **Most older adults (90%) say being able to remain in their home would be important to them if they were diagnosed with dementia.**

- Black respondents (79%) are more likely than white respondents (60%) to say that being able to remain in their home would be very important to them.
- 69% of respondents with household incomes below \$60k say that being able to remain in their home would be very important to them; 57% of those with household incomes above \$100k say being able to stay in their home would be very important.

► **Programs to ease the burden on caregivers are a top priority for older adults.**

- If diagnosed with dementia, 96% of respondents say that not being a burden on family and friends would be important to them.

► **Programs that ease the financial burden on older adults with dementia and their caregivers are important.**

- 94% of respondents say that being able to pay for their care would be important to them if they were diagnosed with dementia.
- 83% of respondents say they would be concerned about personally experiencing financial stress if they were a caregiver to someone diagnosed with dementia.



Nearly six in 10 older adults report concern over dementia.

► **57% of adults are concerned about the potential impact of dementia.**

- Closely behind their concern over other common causes of death: cancer (65%), heart disease (61%) and stroke (59%).

Women are more concerned about dementia and caregiving responsibilities than men.

► **Women are considerably more concerned about the potential impact of dementia on their own health than men (64% compared to 49%).**

► **Women are considerably more concerned than men about how a dementia diagnosis would affect their life or their family.** If diagnosed with dementia, women are more likely than men to say that the following things would be very important to them:

- Not being a burden on family and friends (85% compared to 69%)
- Being able to pay for their care (83% compared to 69%)
- Having a family member or friend to help care for them (61% compared to 47%)

► **Women are more likely to be concerned about their role as a caregiver for someone diagnosed with dementia.** They are more concerned than men about:

- Emotional stress (95% compared to 81%)
- Finding care options or support (95% compared to 80%)
- Physical stress (93% compared to 74%)
- Financial stress (84% compared to 81%)
- Experiencing loneliness or isolation (78% compared to 64%)



Find help in locating or providing high-quality, age-friendly dementia care:

For Caregivers:

- [Best Programs for Caregiving: For Caregivers](#) – database to find dementia caregiving programs
- [My Health Checklist](#) – helps patients prepare for a health care appointment
- [Patient Priorities Care](#) – guides priority-setting for complex conditions, [including dementia](#)

For Clinicians/Health Systems:

- [Best Programs for Caregiving: For Professionals](#) – database to implement dementia caregiving programs
- [UCLA Alzheimer's and Dementia Care Program](#) – dementia co-management model for health systems
 - Includes [training webinars](#) and [educational curricula](#) for primary care
- [National Dementia Care Collaborative](#) – guidance for health systems to adopt evidence-based approaches to dementia care
- [Age-Friendly Health Systems](#) – free Action Communities to implement the 4Ms of age-friendly care, including Mentation

For Policymakers/Advocates:

- [GUIDE Model](#) – a dementia care payment model from the CMS Innovation Center
- [National Strategy to Support Family Caregivers](#) – a whole-of-society plan to support caregivers
 - [Act on RAISE](#) – an advocacy campaign to help partners implement the National Strategy
 - [SupportCaregiving.org](#) – resources to help states, employers, funders and others implement the National Strategy

For additional resources on dementia care, [click here](#).

This poll is part of [Age-Friendly Insights](#), a JAHF series measuring opinions on issues related to improving the care of older adults and support for family caregivers.

“My wish is that everyone who has dementia or is a caregiver for someone living with dementia has care from a Dementia Care Specialist or a team that is there for support, available for questions that come up, and walks through the process of what to expect and what could help to manage the dementia care.”

—Caregiver in UCLA Alzheimer's and Dementia Care Program