

FACTSHEET

JUNE 2019

alzimpact.org

Alzheimer's Respite Care Infrastructure

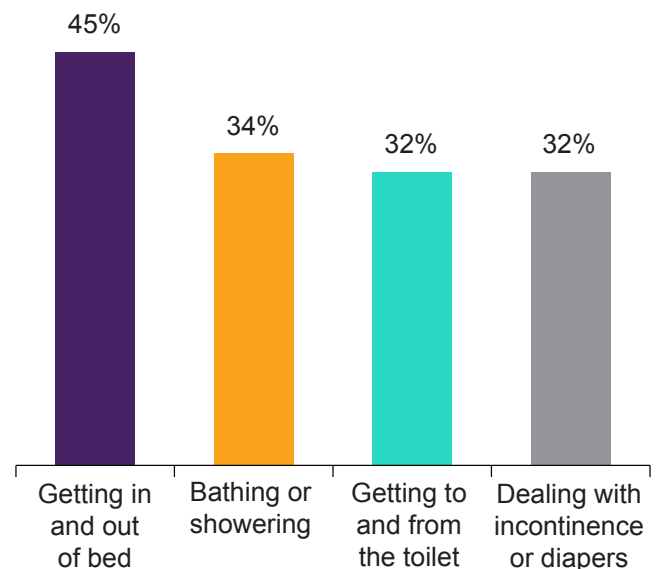
Families and friends undertake the majority of caregiving for individuals with Alzheimer's.

- Eighty-three percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers—and over half of families caring for an older adult are caring for someone with dementia.
- In 2018, more than 16 million family and friends provided 18.5 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economic value of nearly \$234 billion.

Caring for people with Alzheimer's and other dementias is very intimate, very intrusive, and especially burdensome.

- Nearly 80 percent of older adults with dementia receive help with a daily personal care activity such as bathing, dressing, grooming, or eating.
- About one-third of Alzheimer's caregivers deal with incontinence or diapers. For caregivers of older adults without dementia, just 12 percent help with this personal care task.
- Of the unpaid Alzheimer's and dementia caregivers, 86 percent have provided care for at least the past year, and half have been providing care for four or more years.
- Nearly two-thirds of Alzheimer's caregivers expect to continue having care responsibilities for at least five years.

Proportion of Dementia Caregivers Who Provide Help With Specific Daily Activities



The heavy burden of caring for someone with Alzheimer's affects the health and well-being of the caregivers themselves.

- Caregivers of people with dementia are twice as likely to report substantial emotional, financial, and physical difficulties as caregivers of people without dementia.
- Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high. As many as 40 percent of family caregivers of people with Alzheimer's and other dementias suffer from depression.

Respite services, including in-home personal care and adult day care, can provide family caregivers with much needed relief and support.

- Respite services provide temporary, substitute care that gives the caregiver a break from his or her caregiving duties. The services can be provided in a variety of settings, including the individual's home, assisted living facilities, and nursing homes.
- This temporary relief enables caregivers to ensure their loved ones continue to receive quality care while giving themselves an opportunity to manage and improve their own health.
- Some respite services also provide individuals with dementia a safe environment to participate in activities that are designed to match their needs and abilities.

Respite services are often too expensive and inaccessible for dementia caregivers.

- The median cost for an in-home, personal care aide is \$22 per hour. This cost has increased an average of 2.5 percent each year over the last five years.
- The median cost of services at an adult day center is \$72 per day.
- While state Medicaid programs cover some respite and other home and community-based services (HCBS), age and financial eligibility rules often exclude many families living with Alzheimer's.
- Those families who do not qualify for assistance must shoulder these costs themselves—or go without—which only compounds the stress and burden of caregiving.

What Can States Do?

- Fund Alzheimer's-specific respite programs at appropriate levels, regardless of an individual's age or financial status.
- Review existing state respite programs to ensure they meet the needs of individuals and families living with Alzheimer's.
- Support increased access to home and community-based services (HCBS) and respite care programs.

Without respite support, many families of those with dementia spend down their income and assets in order to qualify for Medicaid coverage of nursing home care.

- While the cost of respite care and other HCBS can be expensive for an individual family, it is a much less expensive alternative for state Medicaid programs than the cost of institutional care.
- However, state HCBS coverage is not guaranteed and often underfunded—even though such programs often align with individual desires to age in place while maintaining a high quality of care.

States must expand their funding for respite care.

- To equip caregivers with the support they need, state respite services should be funded at levels that allow participants to access these services without regard to age or financial status.
- State programs supporting family caregivers can reduce caregiver burnout and ultimately save the state significant future long-term care costs.