



FAMILY CAREGIVING FOR PEOPLE WITH DEMENTIA

Dementia is one of the most expensive and time-consuming health conditions to care for in the United States. Four out of five older adults with dementia live outside of nursing homes. Unpaid family members provide the overwhelming majority of help and supervision these individuals need to live in their own homes or apartments.

Dementia, including Alzheimer's disease, is a chronic disorder affecting memory, thinking, and social abilities severely enough to impair daily life. Over time, it limits people's ability to live independently.



WHO IS AFFECTED?

DEMENTIA IS MORE FREQUENT AT OLDER AGES. IT AFFECTS

1 IN 4 PEOPLE
OVER AGE 80.

1 IN 3 UNPAID CAREGIVERS

NATIONWIDE IS HELPING SOMEONE WITH DEMENTIA.

PEOPLE WITH DEMENTIA ACCOUNT FOR **HALF OF THE MOST SEVERELY DISABLED OLDER PEOPLE** NOT IN NURSING HOMES.

This means they receive help with three or more basic personal care activities, such as:



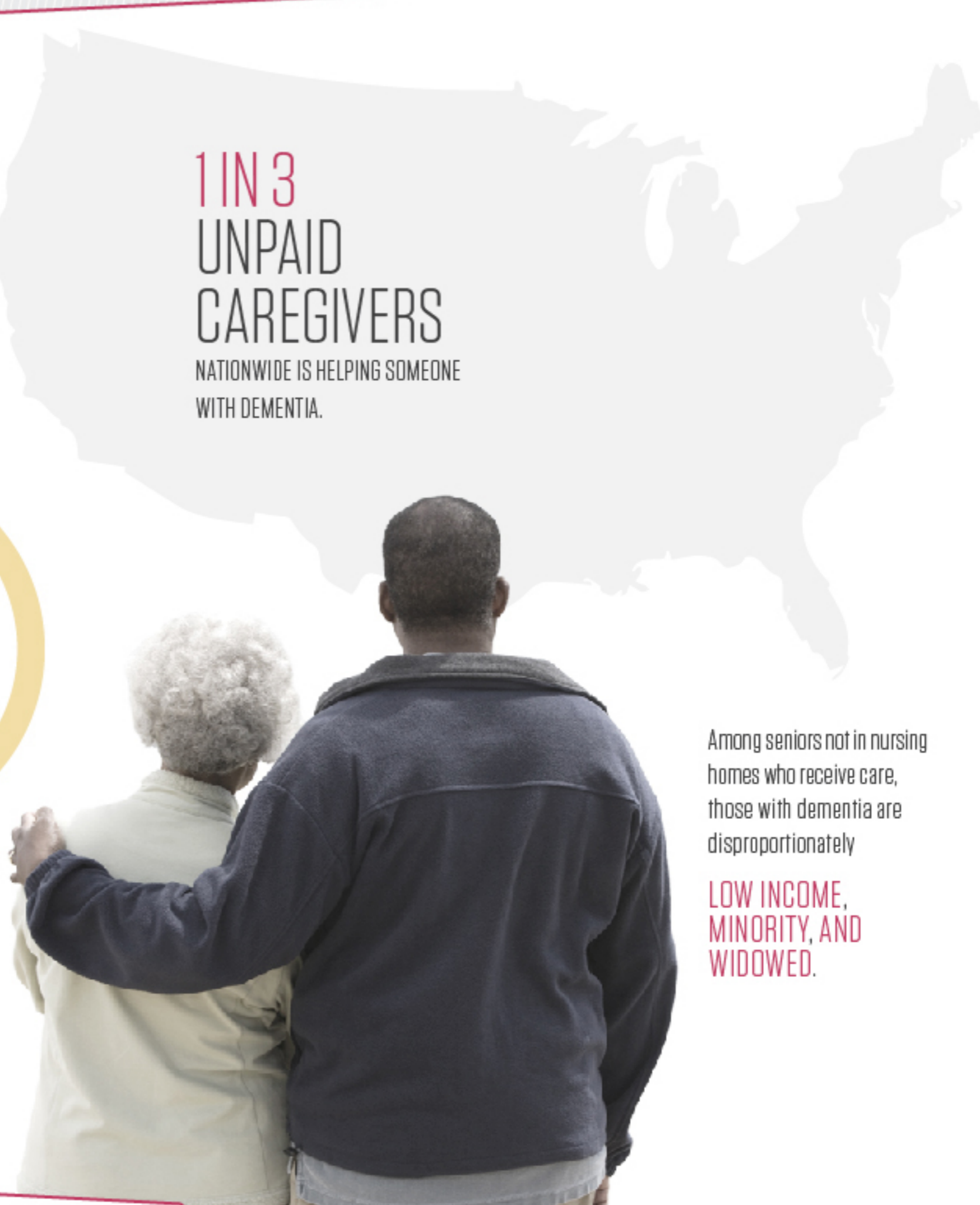
Dressing



Eating



Using the bathroom



Among seniors not in nursing homes who receive care, those with dementia are disproportionately

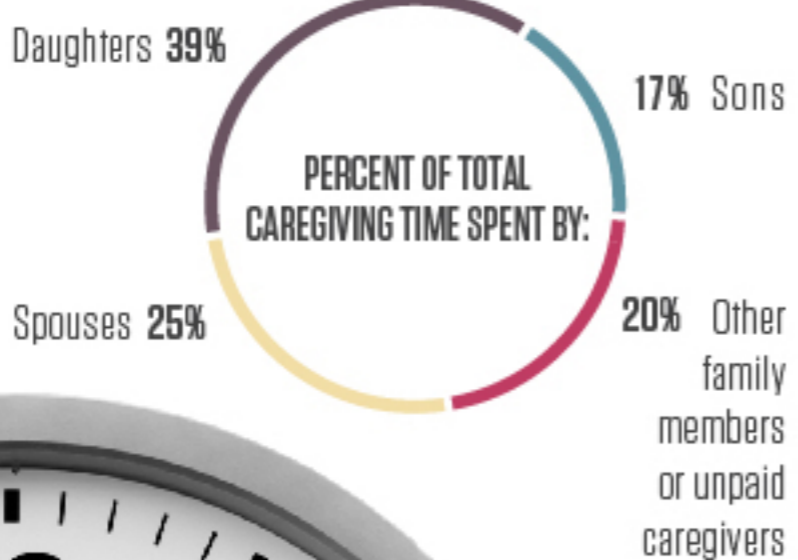
LOW INCOME, MINORITY, AND WIDOWED.

MORE HOURS OF CARE

Although people who have dementia represent **10%** of people 65+, they receive **40%** of all hours of unpaid care provided.

6 BILLION HOURS OF UNPAID CARE are provided every year to people with dementia not living in nursing homes.

DAUGHTERS AND SPOUSES PROVIDE THE MOST HOURS OF CARE.



AVERAGE HOURS OF CARE for adults age 65+ who received informal unpaid care:

WITH DEMENTIA
55 hours per week

vs.

WITHOUT DEMENTIA
26 hours per week

That's twice as many hours of care per week for someone with dementia, more than one full-time job.



HIGHER COSTS

Dementia is the most costly U.S. health condition.

If you add the value of unpaid caregiving by family and others, the total costs of dementia add up to

\$215 billion per year.*

These costs could more than double by 2040 as the large baby boom generation ages.

AVERAGE OUT-OF-POCKET COSTS ARE HIGHER

\$62,000 vs. \$34,000

in the last five years of life for patients with dementia compared to others because Medicare does not cover the supervision and personal care dementia patients need.

TOP THREE MOST EXPENSIVE HEALTH CARE CONDITIONS**

#1 Dementia
\$109 billion



#2 Heart disease
\$102 billion



#3 Cancer
\$77 billion



LARGER CAREGIVING BURDEN

Most family caregivers for those with and without dementia recognize the positive aspects of caregiving

— feeling emotionally connected to the care recipient and assured that they were receiving good care.

BUT

dementia caregivers are **3x** more likely to report substantial

NEGATIVE CONSEQUENCES

compared with caregivers to those without dementia (18 percent vs. 6 percent).

Caring for a spouse with dementia at the end of life is more likely to take a lasting toll on the caregiver's

PHYSICAL HEALTH
MENTAL HEALTH
COGNITIVE FUNCTIONING



than caring for someone with another condition.

LOOKING FOR MORE HELP

Family caregivers of people who have dementia are

TWICE as likely to look for support services,

like respite care, training, and financial assistance, than caregivers for those with other conditions (12 percent vs. 6 percent).

They are also more likely to use these services.



WHAT CAN BE DONE?

More support could be provided for the kind of care that people with dementia and their caregivers need most —

- Long-term, home-based assistance with daily activities
- Help navigating the medical care system
- Respite care
- Caregiver training
- Financial assistance



SOURCES

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* The total direct health care costs of dementia when including unpaid caregiving is estimated to be between \$159 billion or \$215 billion, depending on how the care and lost wages are valued.

** For annual direct health care costs (includes medicine and nursing home care) in 2010 dollars.

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