

# FACTSHEET

MAY 2017

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## The RAISE Family Caregivers Act

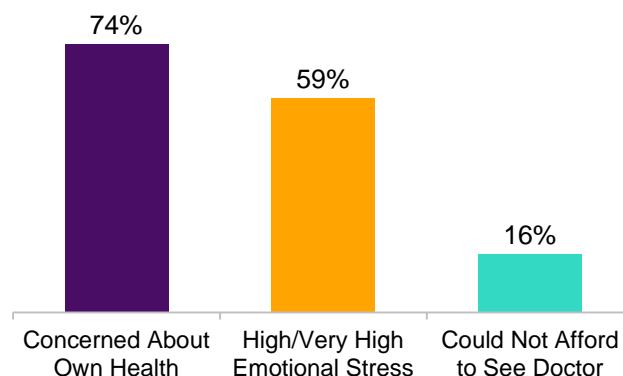
**Caring for people with Alzheimer's and other dementias is often very intimate, intrusive and burdensome.**

- Nearly 80 percent of older adults with dementia receive help with a daily personal care activity such as bathing, dressing, grooming or eating.
- Two-thirds of unpaid Alzheimer's and dementia caregivers engage in medical and nursing tasks such as administering injections and tube feedings, catheter and colostomy care, monitoring blood pressure, and giving medications. And they are twice as likely as other caregivers to say they have great difficulty performing these tasks.
- On average, an Alzheimer's and dementia caregiver provides nearly 28 hours of care per week, with 1 in 4 caregivers providing more than 40 hours each week.
- Among Alzheimer's and dementia caregivers, 69 percent have provided care for at least the past year, and 39 percent have been providing care for four or more years.

### Alzheimer's Caregivers, 2016

- More than **15 million** Americans provided unpaid care to individuals with Alzheimer's and other dementias.
- In total, these family members and friends provided care for **18.2 billion** hours.
- The economic value of this care is estimated at more than **\$230 billion**.

### Health Effects of Caregiving, by Percent of Alzheimer's Caregivers



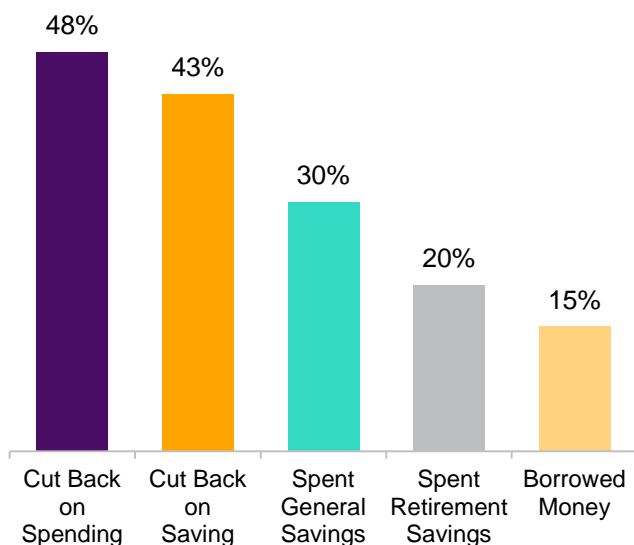
**The care provided by Alzheimer's and dementia caregivers creates health problems for the caregivers.**

- Nearly 75 percent of dementia caregivers are somewhat or very concerned about maintaining their own health since becoming a caregiver.
- 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 report symptoms of depression.
- The physical and emotional impact of caregiving on Alzheimer's and dementia caregivers resulted in an estimated \$10.9 billion in increased caregiver health costs in 2016.
- Despite these higher costs, 16 percent of dementia caregivers say they needed to see a doctor in the past year but could not afford it.

### The toll of caregiving extends beyond effects on health and also includes negative effects on employment, income and financial security.

- More than 1 in 6 Alzheimer's and dementia caregivers had to quit work entirely either to become a caregiver in the first place or because their caregiving duties became too burdensome.
- Among Alzheimer's and dementia caregivers who are employed full or part time, 57 percent said they had to go in late, leave early, or take time off because of their caregiving responsibilities.
- On average, Alzheimer's care contributors – those who are caregivers and/or contribute financially to a person's care – lose over \$15,000 in annual income as a result of reducing or quitting work to meet the demands of caregiving.
- Alzheimer's care contributors are 28 percent more likely than other adults to eat less or go hungry because they cannot afford to pay for food.

### Financial Steps Taken to Help Pay for the Needs of Someone with Alzheimer's, by Percent of Care Contributors



### The burden of caregiving is exacerbated because Alzheimer's and dementia caregivers often cannot get the help they need.

- Of the Alzheimer's caregivers who provide care that includes medical and nursing tasks, 80 percent say they were unprepared to engage in such activities.
- More than half (56 percent) say that no one – not a doctor, nurse, or social worker – ever asked them what they needed to care for their loved one. And more than 75 percent say that no one ever asked what they needed to care for themselves.
- More than a quarter of dementia caregivers have difficulty finding affordable services, such as home aides, respite care, and transportation.
- This hits especially hard on women dementia caregivers. They are disproportionately more likely than their male counterparts to say they need – but do not get – individual counseling, support groups, and respite care.

### Consistent with the *National Plan to Address Alzheimer's Disease* and to address the needs of all caregivers, the *Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (S. 1028)* would:

- Require the U.S. Department of Health and Human Services to develop a national strategy to address the needs of caregivers, including education and training, long-term services and supports, and financial security.
- Require the plan to be updated annually.
- Create a Family Caregiving Advisory Council to provide advice on how the federal government can recognize and support family caregivers.