### Alzheimer's & Brain Awareness Month 2017

### Alzheimer's Association Survey



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### **METHODOLOGY**

The Alzheimer's Association commissioned a 15-minute, online survey among a sample of n=1,502 U.S. adults ages 18+. Respondents were split into three groups with 250 currently giving care to someone with Alzheimer's, 252 previously having given care to someone with Alzheimer's, and 1,000 individuals who have never given care. The margin of error for this sample is  $\pm$ -3.1% at the 95% confidence level. The survey was fielded between April 19 and April 25, 2017.



### **KEY FINDINGS**

- It often takes a village to care for someone with Alzheimer's, but far too many people are doing it alone.
- People fear becoming a burden to their families, but they are not planning accordingly.
- Strain between siblings and lack of appreciation top Alzheimer's caregiving stressors.



### While more people fear being diagnosed with Alzheimer's than dying, they fear burdening their loved ones the most.

• People are 52% more likely to worry about being a burden to their loved ones than they are to be worried about death itself.

Being a burden to my spouse/partner 71% 70% Being a burden to my child(ren) Being unable to support myself 70% financially 70% Not being able to care for myself Losing the ability to remember day-to-64% day tasks Losing the ability to recognize or 59% remember loved ones Being diagnosed with 59% Alzheimer's/dementia Having to move into a nursing home 56% Having nobody to take care of me 55% 55% Having a heart attack 46% Dying

FEARS OF AGING (% Selected - Non-caregivers)

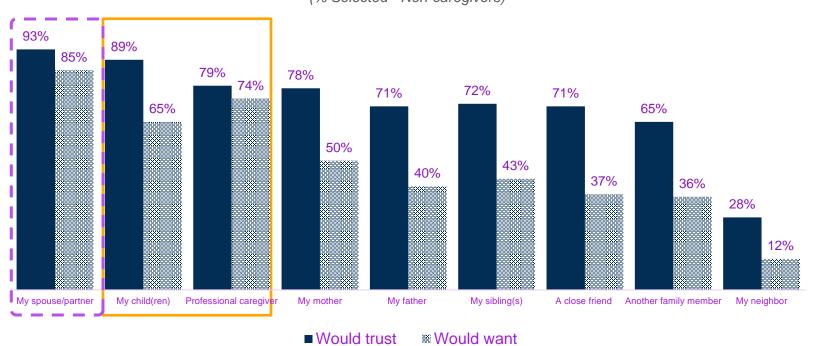
Base: Non-caregivers (n=1,000)

A1. To what extent do you worry about each of the following when it comes to aging?

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## Most people want their spouse to be their caregiver; while they trust their children, they would prefer a professional caregiver.

- 27% fewer people would want their children to take on the role than they would trust them.
- Professional caregivers are trusted as much as the respondent's own mother and 14% more desirable a caregiver than their children.



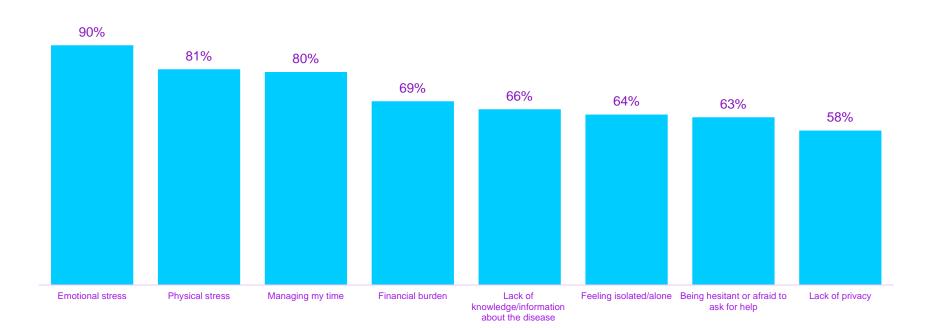
WOULD TRUST VS. WOULD WANT TO BE YOUR PRIMARY CAREGIVER (% Selected - Non-caregivers)

Base: Non-caregivers (n=1,000)

A5. If you were diagnosed with Alzheimer's or another form of dementia tomorrow, how much would you trust the following people with being your primary caregiver? A6. If you were diagnosed with Alzheimer's or another form of dementia tomorrow, how much would you want the following person(s) to be your primary caregiver?



### Stress, especially emotional, is the largest challenge of caregiving for Alzheimer's.



CHALLENGES OF CAREGIVING (% T2B)

Base: Caregivers (n=502) C5. How challenging are each of the following as a primary caregiver?



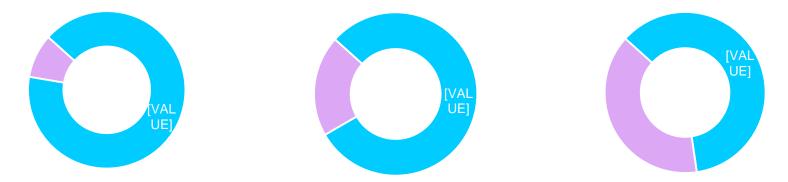
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## People think caregiving should be a group effort, but don't spread the responsibility accordingly.

- In fact, almost two out of every three caregivers say that feeling isolated or alone was a significant challenge in providing care for someone with Alzheimer's or another form of dementia.
- One in five caregivers wish they had created a network of caregivers that included other family members.
- Half of all caregivers felt like they couldn't talk to anyone in social settings or work about what they were going through.

#### PERCEPTIONS OF THEIR OWN CAREGIVING EXPERIENCE (% T2B)

Different people should do different tasks so that no one person should do it all. It takes a village to care for someone with Alzheimer's/dementia. I have spread the responsibility of caregiving among my family or close friends.



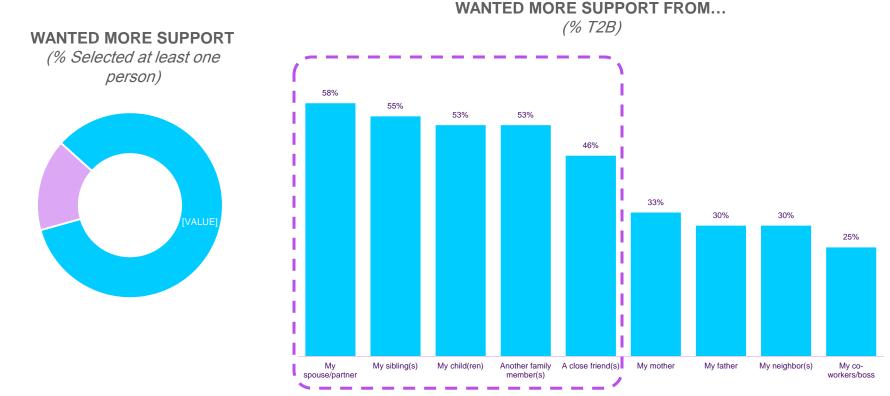
Base: Caregivers (n=502) C4. To what extent do you agree or disagree with the following statements about giving care to someone with Alzheimer's or another form of dementia.



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# More than 4 in 5 caregivers would have liked more support especially from their family.

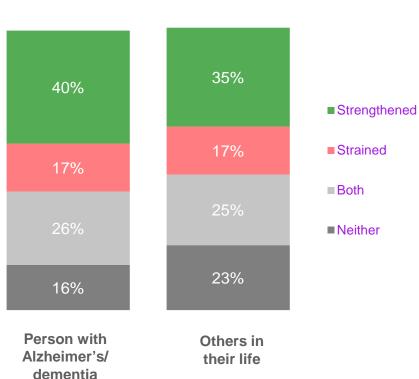
- Almost three-fifths of caregivers specifically wanted more help from their spouse or partner.
- The number one reason people didn't give care for someone who had Alzheimer's or another form of dementia was that they felt like another family member had already taken on the responsibility (74%) – followed by not living in the same area (62%).



Base: Caregivers (n=502) C17. Whom would you have liked to have been more involved during your time as a primary caregiver?

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### Dementia can simultaneously strengthen and strain relationships.



#### CAREGIVING EFFECT ON RELATIONSHIPS (% Selected)

Base: Caregivers (n=502)

C8. Has being a primary caregiver strengthened or strained your relationship with the person who had or has Alzheimer's or another form of dementia?

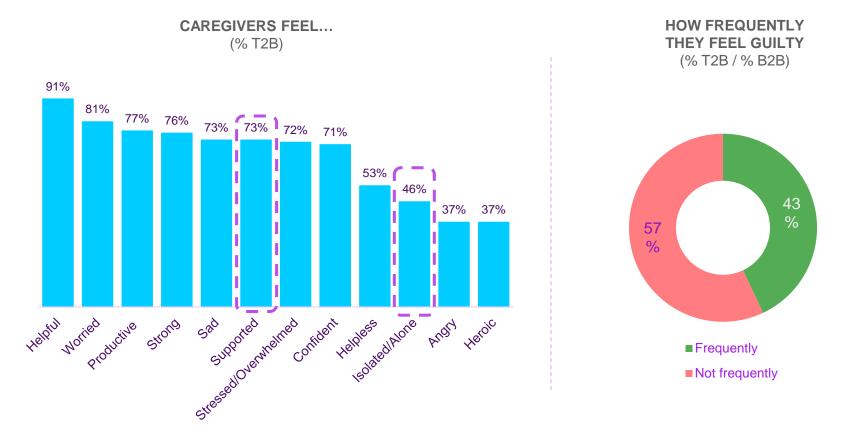
C11. Has being a primary caregiver primarily strengthened or strained your relationships with others in your life, not including the person with Alzheimer's or another form of dementia?

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## When explaining the feelings around caregiving in words, the complex nature becomes apparent.

• Although around three-fourths of all caregivers feel supported, almost half feel isolated or alone.



Base: Caregivers (n=502)

C23. How frequently did/do you feel guilty during your time as a primary caregiver to someone with Alzheimer's or another form of dementia? C3. How much do the following describe how you feel/felt as a primary caregiver?



## Two-thirds of caregivers who found strength in the experience felt like they had a new perspective on life.



#### Base: Caregivers (n=502)

C8. Has being a primary caregiver strengthened or strained your relationship with the person who had or has Alzheimer's or another form of dementia? C9. In what ways has being the primary caregiver strengthened your relationship with the person who had or has Alzheimer's or another form of dementia?

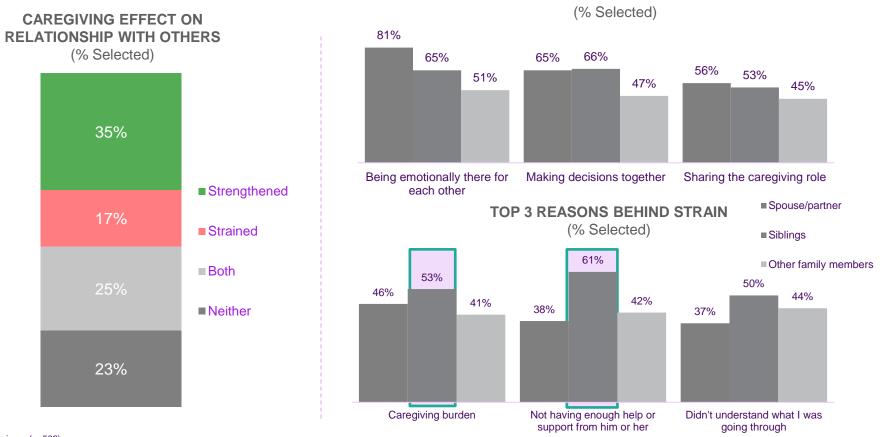
C10. In what ways has being the primary caregiver strained your relationship with the person who had or has Alzheimer's or another form of dementia?



# While families who supported each other found strength, the lack of support strained family relationships.

• Relationships with their <u>siblings</u> were strained more than any other family members - this includes not having enough of their help/support.

**TOP 3 REASONS BEHIND STRENGTH** 



Base: Caregivers (n=502)

C11. Has being a primary caregiver primarily strengthened or strained your relationships with others in your life, not including the person with Alzheimer's or another form of dementia?

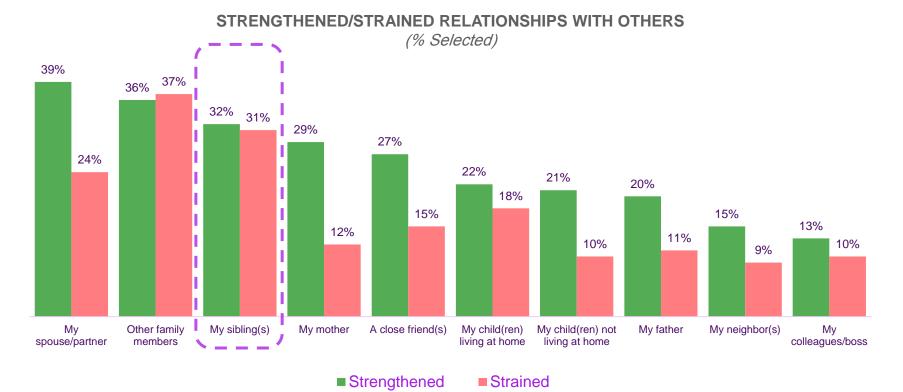
C14. What specifically caused the strength in your relationship with others, not including the person with Alzheimer's or another form of dementia?

C15. What specifically caused the strain in your relationship with others, not including the person with Alzheimer's or another form of dementia?



## Almost all relationships were more strengthened than strained, especially with their spouse/partner and mother.

• The relationship between siblings was equally as likely to be strained as it was to be strengthened.



Base: Caregivers (n=502)

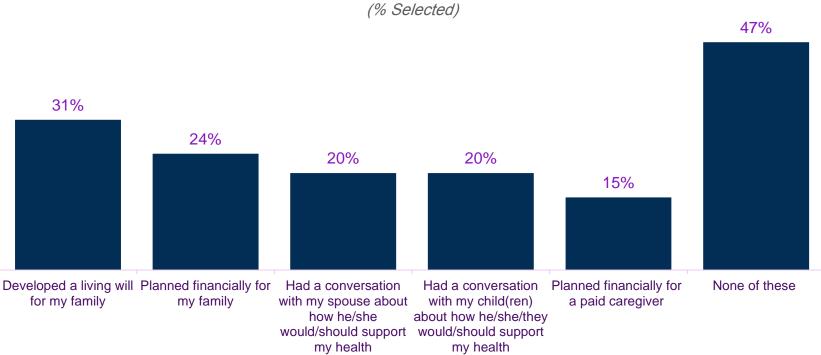
C12. With whom was your relationship strengthened due to your role as a primary caregiver?

C13. With whom was your relationship strained due to your role as a primary caregiver?



# Only 53% of people have made preparations for their future caregiving needs.

• Only 20% have discussed care wishes with their spouses.

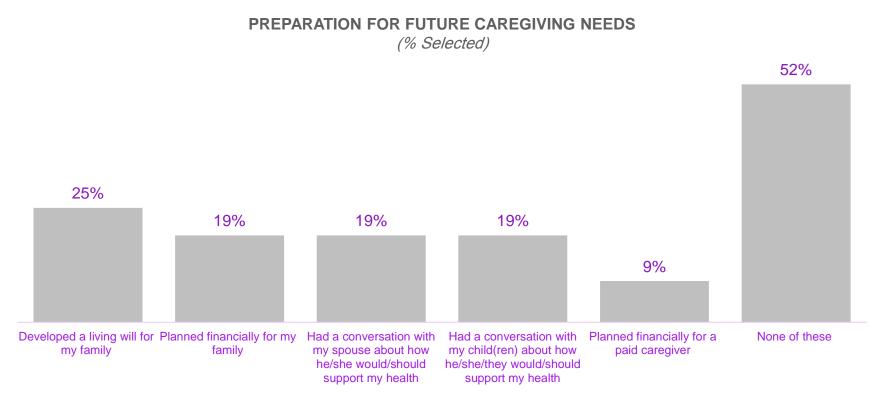


PREPARATION FOR FUTURE CAREGIVING NEEDS

Base: Non-caregivers (n=1,000) A2. Which of the following have you done in preparation for any caregiving needs you may need in the future?

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### Despite a desire for professional care, concerningly fewer than a tenth of boomers have planned financially for help.



Boomer

Base: Non-caregivers (n=1,000) A2. Which of the following have you done in preparation for any caregiving needs you may need in the future?

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