
Activating and Supporting Family Caregivers in Dementia Care:

**An exploration of innovative approaches,
therapies and evidence based protocols**

thank you Caregiver Nation

www.caregivernation.org

Alzheimer's and Dementia Caregivers

Beth Kallmyer

Vice President, Care & Support
National Alzheimer's Association

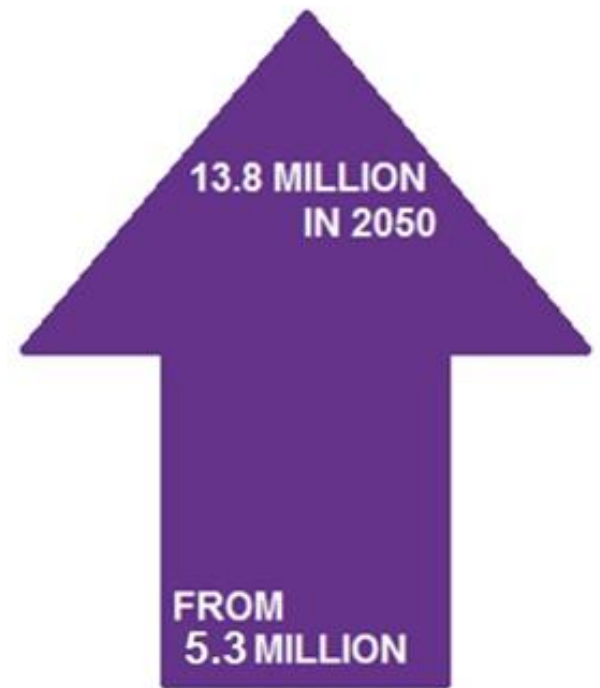
The Alzheimer's Dementia Epidemic Continues to Grow...

5.5

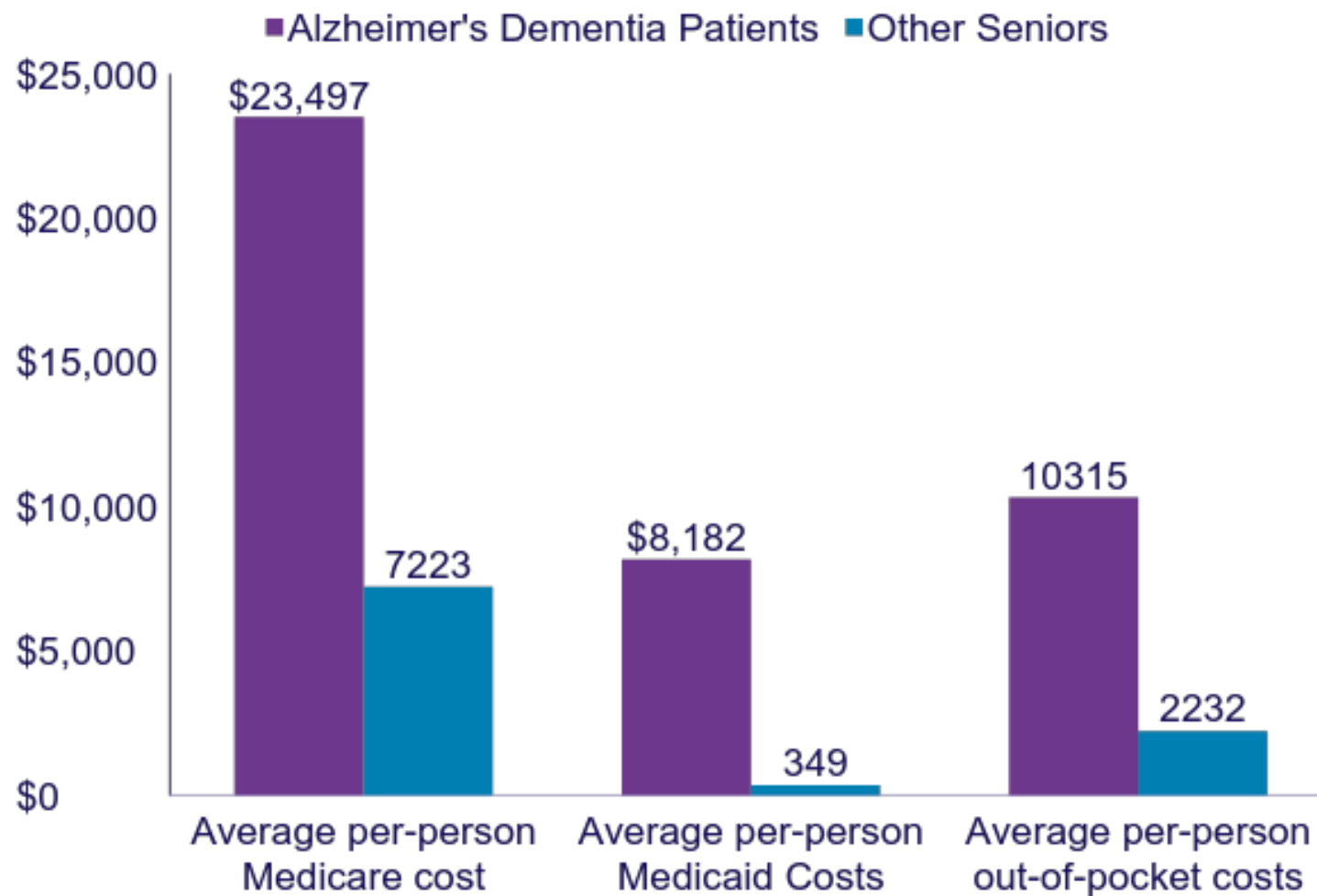
million Americans of **ALL** Ages
will have Alzheimer's dementia in 2017

The Numbers Continue to Rise...

By 2050, the number of people age 65 and older with Alzheimer's disease may nearly triple, from 5.3 million to a projected 13.8 million.



Costs of Dementia vs. Other Conditions



Why is Alzheimer's different than other diseases?

- Disease duration
- Loss of cognitive skills over time
- Caregivers provide help with all activities of daily living
 - Eating, dressing, bathing
- Dementia can cause agitation, paranoia, “sundowning”, aggression
- Health of caregivers suffers

Caregivers

Nearly 16 million caregivers for individuals living with Alzheimer's



Alzheimer's doesn't just happen to individuals — it happens to families.



The economic value of the unpaid care provided to those with Alzheimer's or other dementias totaled **\$230.1 billion** in 2016.

Alzheimer's doesn't just happen to individuals — it happens to families.

In 2016, Alzheimer's and dementia caregivers had **\$10.9 billion** in additional health care costs of their own due to the tremendous physical and emotional burden of caregiving.

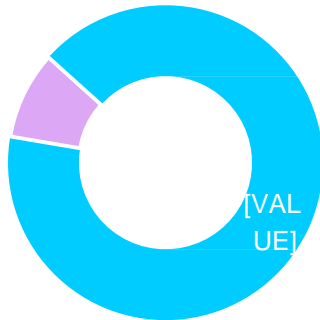


People think caregiving should be a group effort, but don't spread the responsibility accordingly.

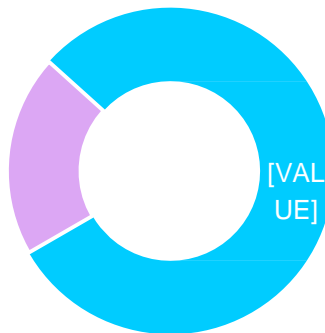
- *In fact, almost two out of every three caregivers say that feeling isolated or alone was a significant challenge in providing care for someone with Alzheimer's or another form of dementia.*
- *One in five caregivers wish they had created a network of caregivers that included other family members.*
- *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)

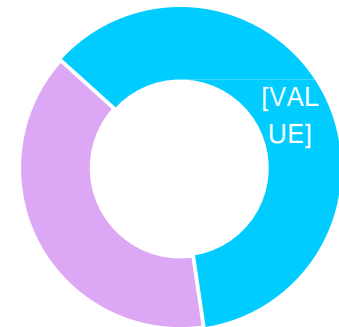
Different people should do different tasks so that no one person should do it all.



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)

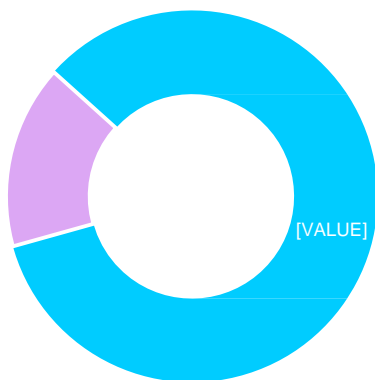
C4. To what extent do you agree or disagree with the following statements about giving care to someone with Alzheimer's or another form of dementia.

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%).

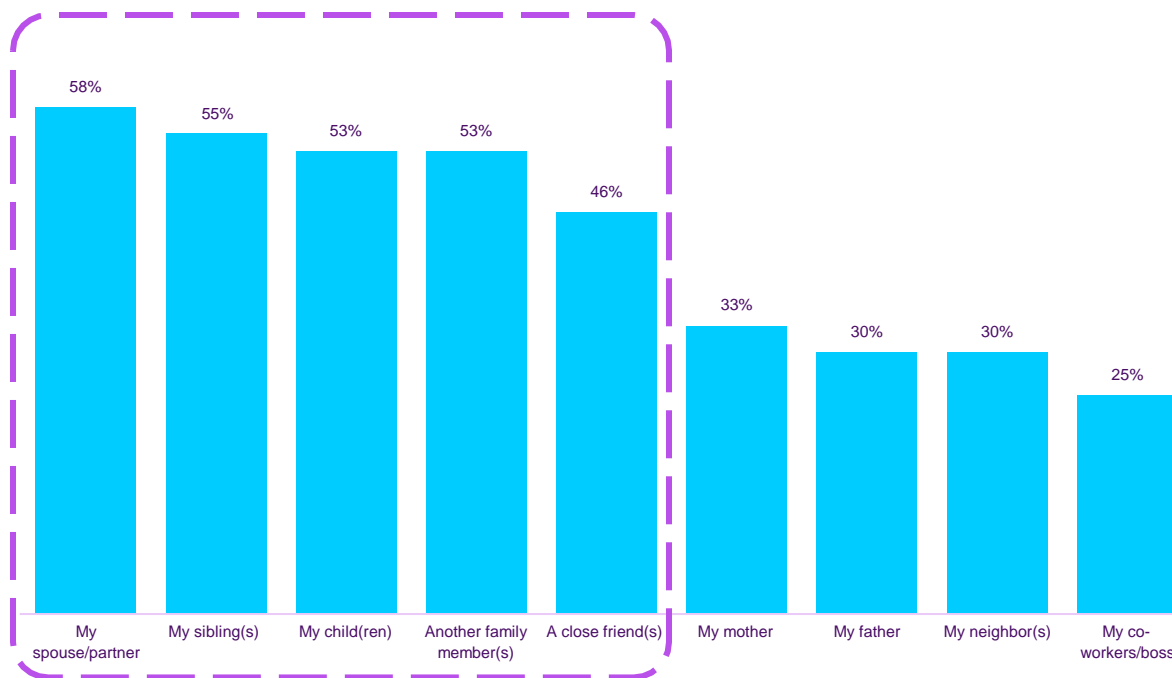
WANTED MORE SUPPORT

(% Selected at least one person)



WANTED MORE SUPPORT FROM...

(% T2B)



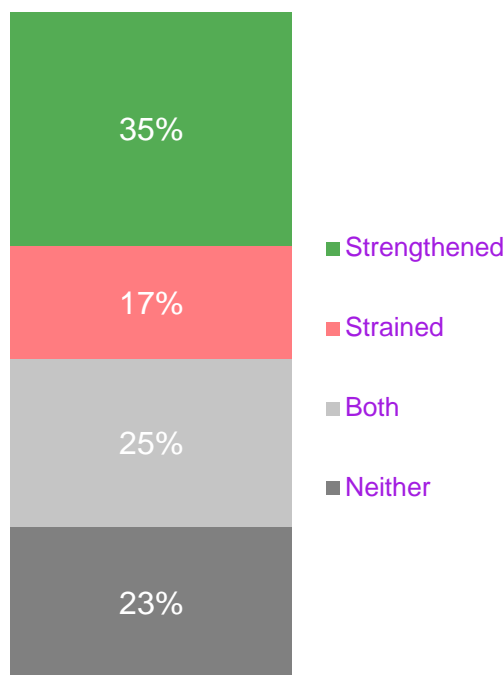
Base: Caregivers (n=502)

C17. Whom would you have liked to have been more involved during your time as a primary caregiver?

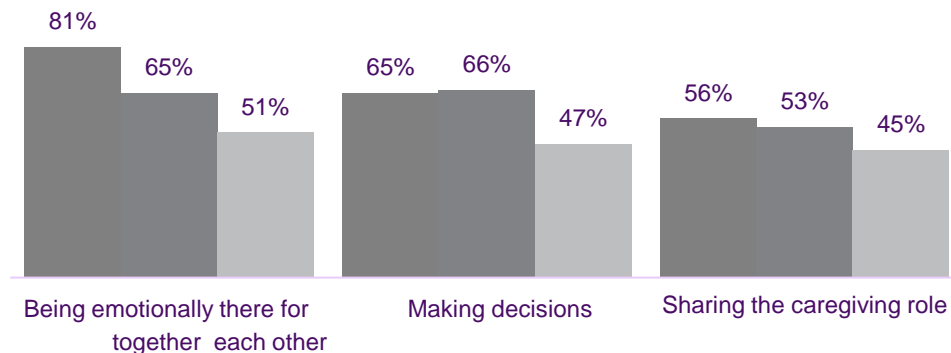
While families who supported each other found strength, the lack of support strained family relationships.

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

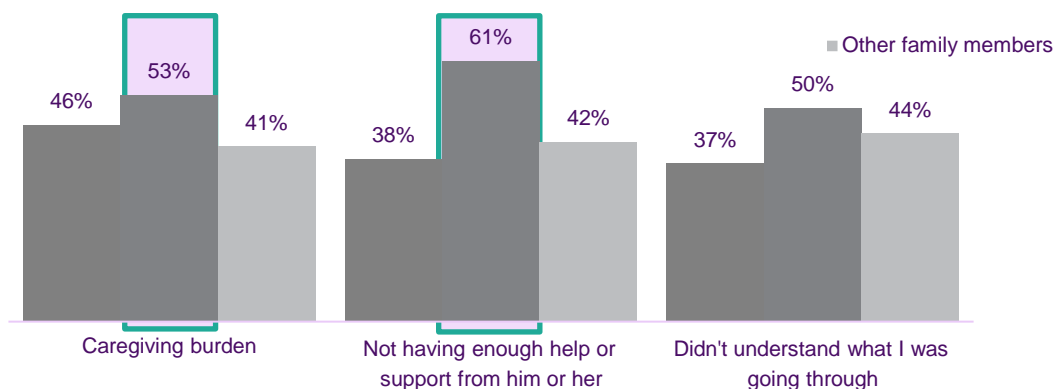
**CAREGIVING EFFECT ON
RELATIONSHIP WITH OTHERS**
(% Selected)



TOP 3 REASONS BEHIND STRENGTH
(% Selected)



TOP 3 REASONS BEHIND STRAIN
(% Selected)



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?

Emotional impact

Nearly

59 percent

of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high

and approximately

40 percent

report symptoms of depression

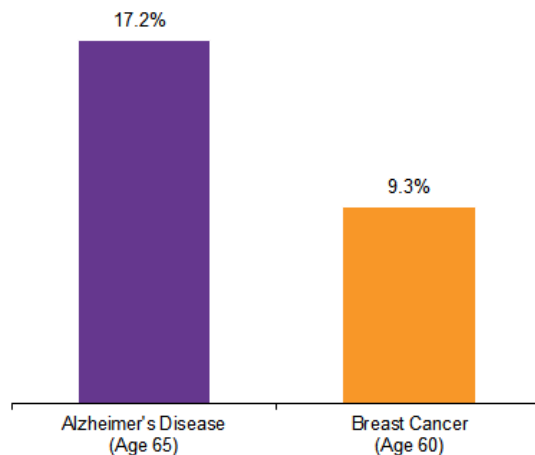
THE FACTS: ALZHEIMER'S IS AN EPIDEMIC IN AMERICA.

Women are at the epicenter of the Alzheimer's epidemic.

In her 60s, a woman's estimated lifetime risk for developing Alzheimer's disease is **1 in 6**. For breast cancer it is **1 in 11**.

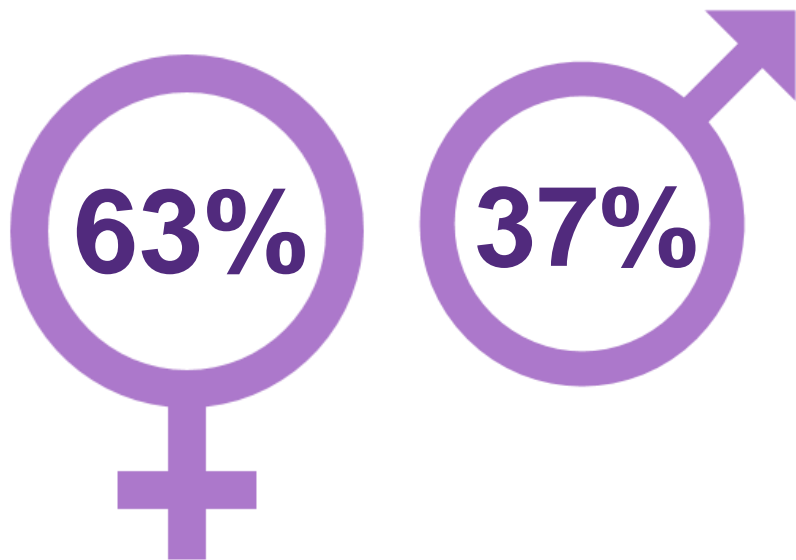
Almost **two-thirds** of Americans with Alzheimer's disease **are women**.

Remaining Lifetime Risk of Women Developing Alzheimer's Disease and Breast Cancer



There are **2.5 times more** women than men providing intensive **"on-duty" care** 24 hours a day for someone with Alzheimer's.

More than **60 percent** of Alzheimer's and dementia **caregivers are women**.

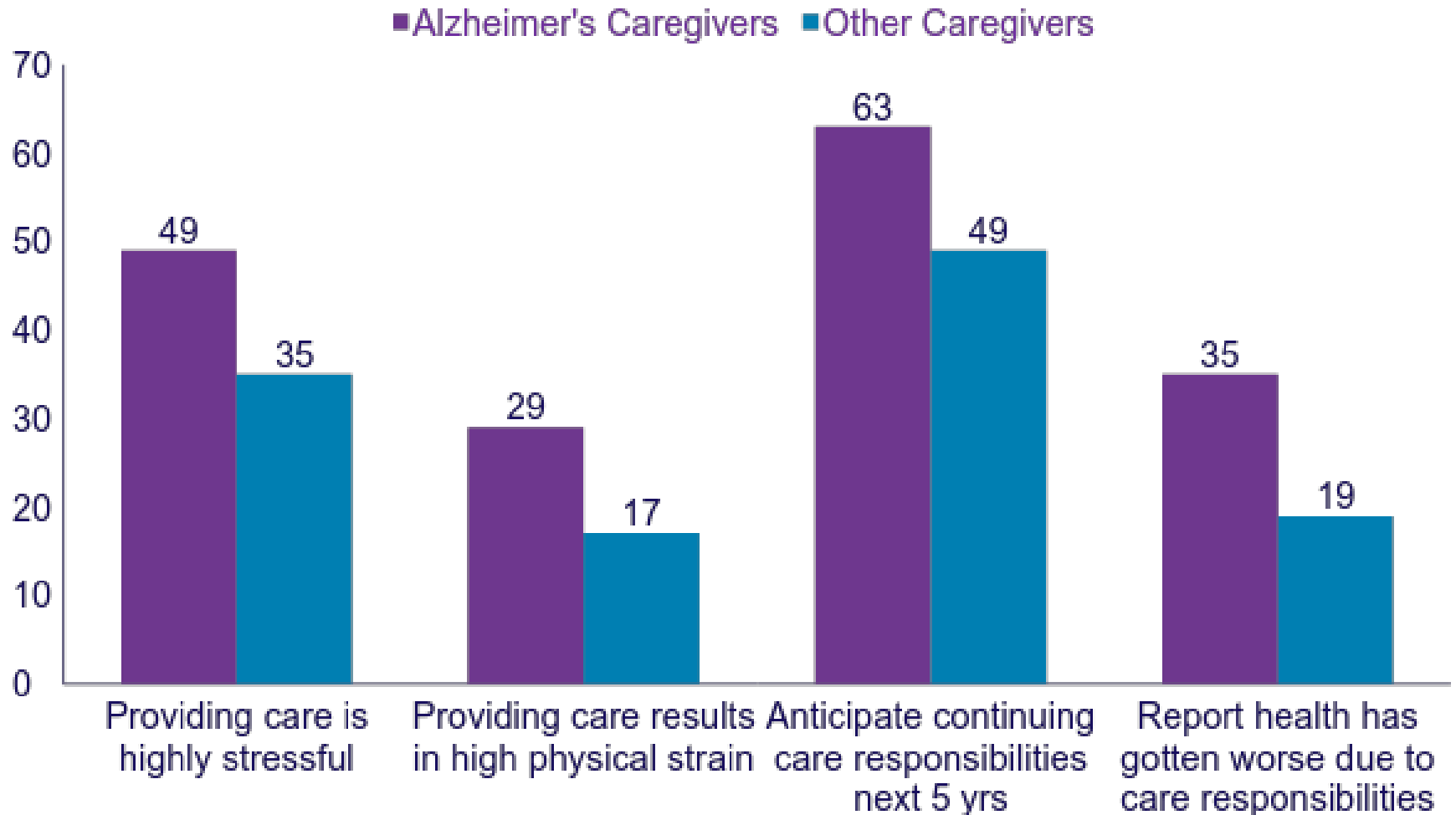


Have provided help
to someone with
dementia for more
than **5 years**

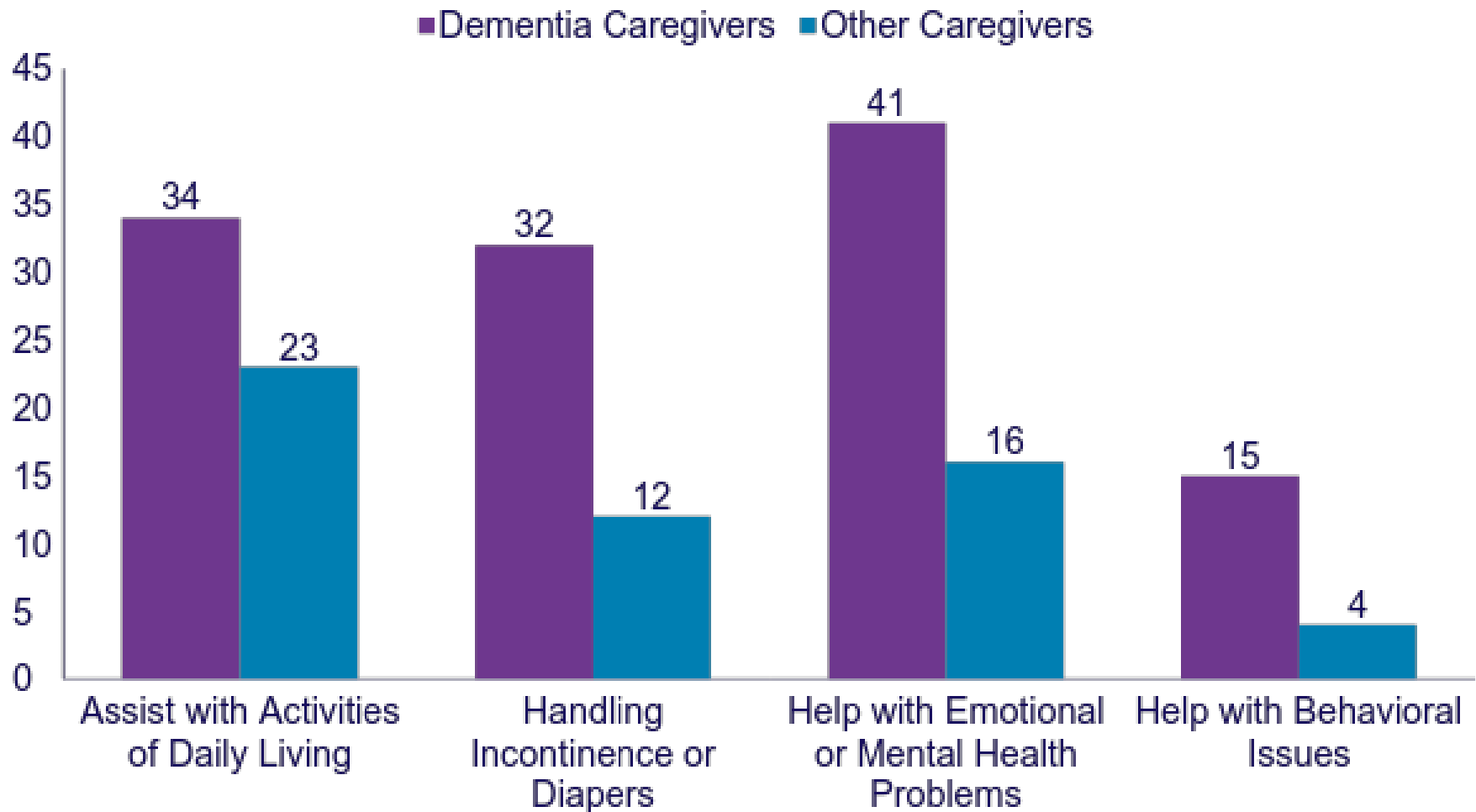
2x

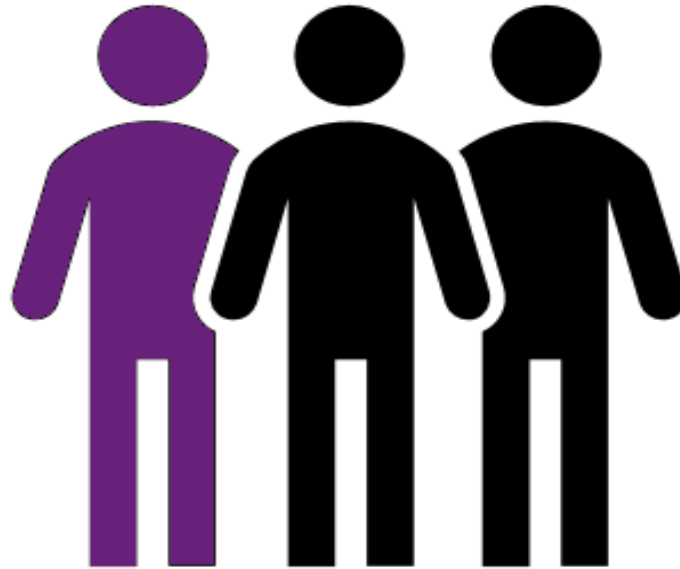
Twice as many
women caregivers
spend more than
40 hours per week
providing care

Burden on Alzheimer's Caregivers



Alzheimer's Caregivers Face Heavier Burdens





One-third of caregivers for people with Alzheimer's or another dementia report that their health has gotten worse due to care responsibilities compared to **19 percent** of caregivers without dementia

What can families do?

alzheimer's  association®

THE BRAINS BEHIND SAVING YOURS.®

**How to
Prepare for
Financial
Impact**

**Plan How to
Access
Care When
Time
Comes**

**Plan for
Retirement
and Future
Long-term
Care**

**Conduct
Inventory
of Financial
Resources**

**Call Local
Agency on
Aging To
Find
Resources**

**Investigate
Local Long-
term Care
Services**

Soon after a diagnosis is made

- Include the person living with Alzheimer's in planning discussions
- Put advance directives in place
 - Healthcare power of attorney
 - Financial power of attorney
- Discuss options for how care will be provided including the wishes of the person living with dementia

Become educated about what to expect

- Learn about Alzheimer's: disease progression, caregiving strategies and coping skills
- Build a care team
- Have regular family meetings to ensure everyone is informed and on board with the plan
- Investigate clinical trial opportunities

Engaging Caregivers Using A Coaching Framework

Laurie Herndon
Director, Clinical Program Innovation
Seniorlink



VOICE: DEMENTIA CARE

Moving Towards Person Centered Dementia Care:
How to have a “Memory Conversation” in the Home



What IS the memory conversation?

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inv
in
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a.

The Goals for the Memory Conversation



Memory Conversation “How To” In Four Parts



Person-Centered Coaching Guide

Person-centered coaching focuses on the person as a holistic being, taking into account their needs, feelings, cultural, physical and social contexts, and goals and aspirations. This helps us provide care that supports and honors the person by offering them choice and puts them at the center of their own care.

Characteristics of an Effective Coach

- ✓ Fosters trust
- ✓ Is self-aware
- ✓ Has highly attuned listening
- ✓ Asks effective questions
- ✓ Honors the goals, desires, dreams and wishes of the person they are coaching
- ✓ Communicates empathy and compassion
- ✓ Is flexible and can adjust to the needs of the situation and person in the moment
- ✓ Holds other to his/her own values, vision, goals

Trust

Trust is at the core of effective person-centered coaching. Here are some things to remember about trust:

- ✓ Trust is earned slowly and eroded rapidly.
- ✓ Trust is built up through small but consistent actions – it's earned.
- ✓ Once you have trust, you must always be aware of how your actions strengthen and foster or damage and undermine trust.
- ✓ Coaching has to be done from the place of sincerely being vested in helping the other person and focusing on what is important to them; this is the foundation of a person-centered approach.

"Trust is the glue of life. It's the most essential ingredient in effective communication. It's the foundational principle that holds all relationships." Stephen Covey

Coaching Process



Mind your Mindset: by having a person-centered mind-set

Build Awareness: by using effective questioning techniques

Acknowledge and Validate: to help the person feel heard and seen

Move the Action Forward: by facilitating the creation of positive, solution-focused, person-centered goals

Part 1: Mind Your Mindset



Minding Your Mindset

Advocacy
Telling



Inquiry
Asking

Good listeners have a huge advantage. For one, when they engage in conversation, they make people 'feel' heard. They 'feel' that someone really understands their wants, needs and desires. And for good reason; a good listener does care to understand.

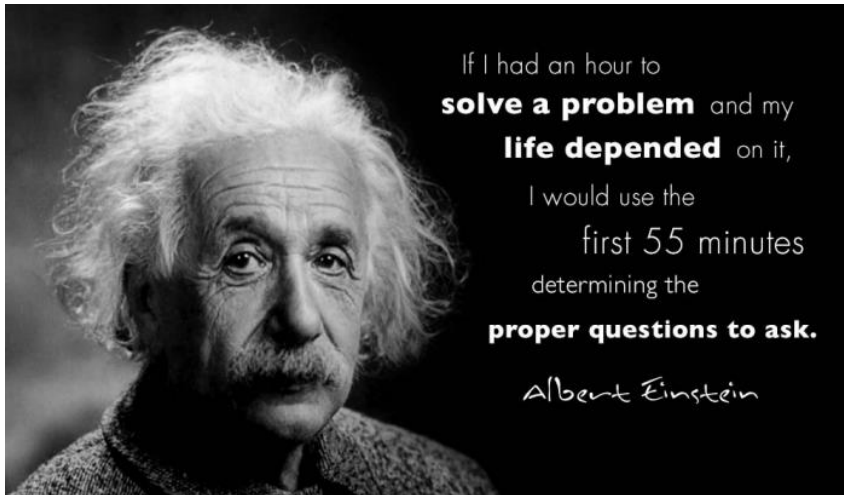
Simon Sinek



Part 2: Build Awareness



Building Awareness: Using Good Questions




Effective questions help you:

- Build trust and relationships
- Explore, clarify and understand the other person's world
- Learn about the person's feelings, thoughts, beliefs and behaviors
- Gather information
- Assist the person to make an informed decision
- Get to the root cause of issues and obstacles

Building Awareness: Types of Questions

- Open-ended versus close-ended questions
- Leading and judging questions versus neutral questions
- WHAT questions
- WHY and SO WHAT questions



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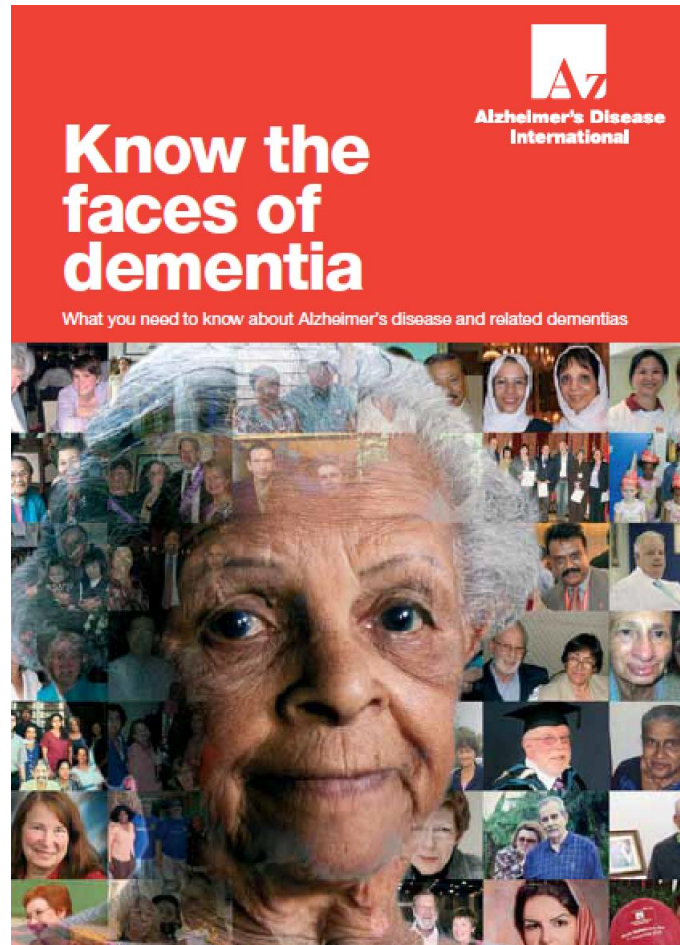
Coaching Process



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graph TD; A[Mind your Mindset] --> B[Build Awareness]; B --> C[Acknowledge & Validate]; C --> D[Move the Action Forward]; D --> A;
```

Mind your Mindset: by having a person-centered mind-set
Build Awareness: by using effective questioning techniques
Acknowledge and Validate: to help the person feel heard and seen
Move the Action Forward: by facilitating the creation of positive, solution-focused, person-centered goals

Building Awareness: Sharing Information



Part 3: Acknowledge and Validate



Statements that “Acknowledge”

- *It sounds like you're saying that...your dad is not the person he used to be*
- *Let me see if I understand...you feel like you are the only one in the family that is able to understand what your mom means when she is upset?*
- *It sounds like you felt really....tired*
- *That must have felt.....scary.*



Validate

Sample Validation Statements

- *I can understand why you would feel that way.*
- *That's natural, it can be very upsetting when something like that happens.*
- *You have a right to feel that way.*
- *Based on your how you interpreted the situation, it makes sense that you feel that way.*

Sample Recognition Statements:

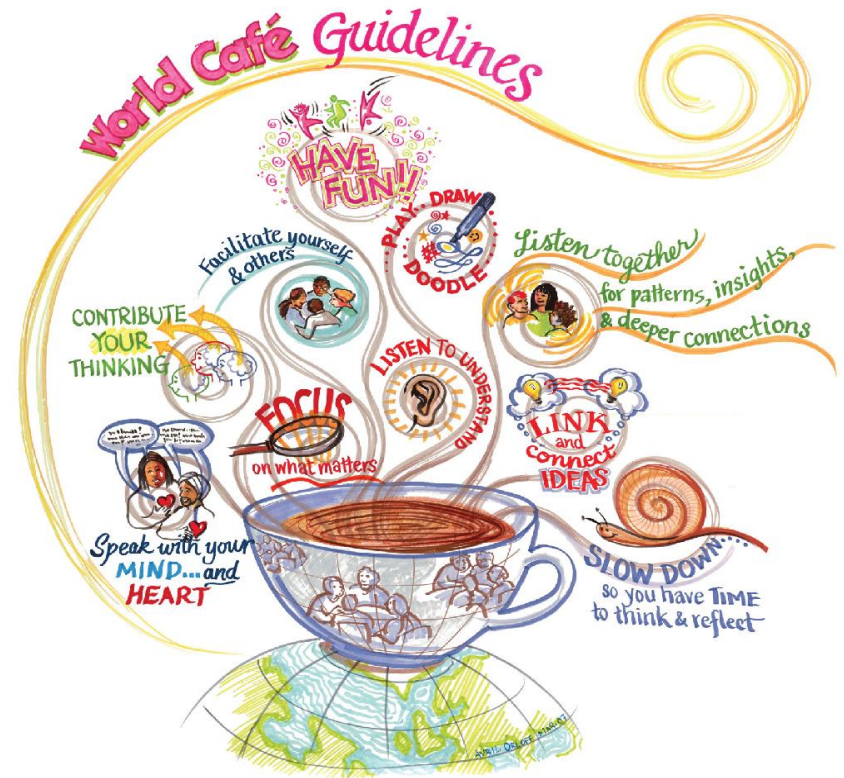
- *I was very impressed by the way you x. It may not have had the outcome you wanted, but you did an excellent job overcoming the obstacles.*
- *I can really see how committed you are to this. Your dedication and love really show how much you care.*

Part 4: Move The Action Forward



Activity: World Café

- An easy-to-use method for creating a living network of collaborative dialogue around questions that matter in service to real work.
- The World Café is built on the assumption that ... People already have within them the wisdom and creativity to confront even the most difficult challenges; that the answers we need are available to us; and that we are Wiser Together than we are alone



Activity: World Cafe

- Three ten minute rounds of discussion
- First Round: Select a table “host” who will take notes for the table
- Together, using guidelines here take ten minutes to answer questions posed
- At the end of ten minutes, all but the table host “travel” to another table where that table host welcomes them and gives a quick summary of previous discussion points
- Repeat

Questions:

- What barriers come to mind as you think about having a memory conversation with people with dementia or their caregivers?
- How might you use the steps in the coaching framework to overcome these barriers?

For more information:

www.alz.org

1-800-272-3900 - 24/7 Helpline

www.caregiverhomes.com

1-866-797-2333 - Care Advisory Unit
