

Supporting Family Caregivers: At Home and in Residential Care

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Today's Presentation

- Importance of family caregivers
- Impact of family caregiving
- Effective caregiver interventions
- Community resources
- Working with caregivers (Case examples)
- Your questions

Poll Question #1

How many of you are currently providing care to a loved one with dementia or have provided care in the past?

Importance of Family Caregivers



IN 2020, DEMENTIA CAREGIVERS PROVIDED
AN ESTIMATED **15.3 BILLION HOURS**
OF UNPAID CARE VALUED
AT NEARLY **\$257 BILLION.**

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Type of Care Provided

Dementia Caregiving Tasks

Instrumental activities of daily living

Medication management

Follow up on treatment recommendations

Personal activities of daily living

Behavior symptom management

Care management

Emotional support

Decision-making

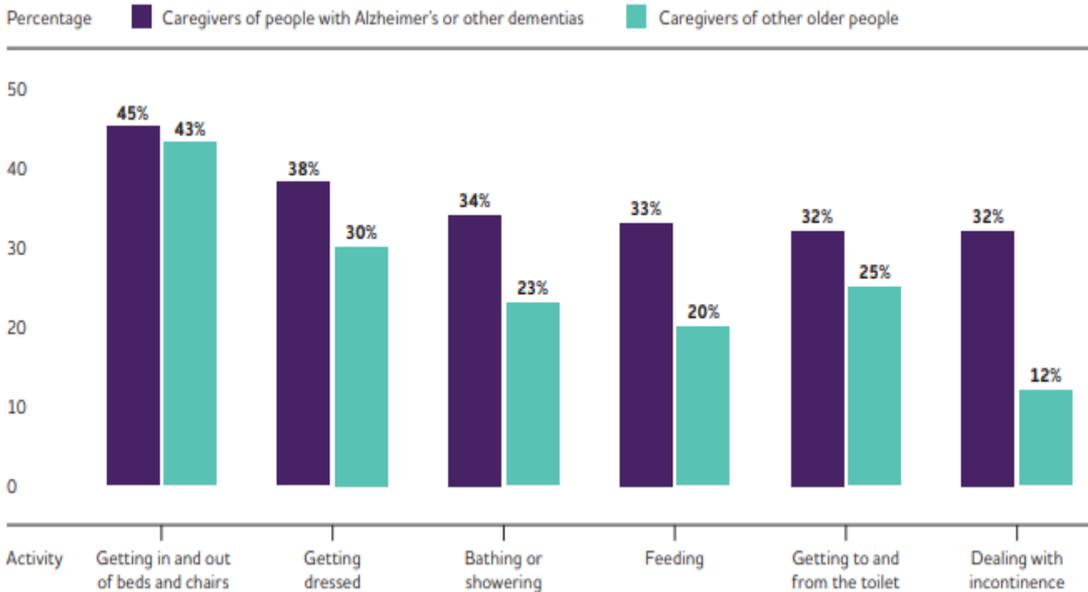
Poll Question #2

True or False?

Caregivers for older adults with dementia provide more hours of care than caregivers for older adults without dementia.

Focus on Dementia Caregivers

Proportion of Caregivers of People with Alzheimer's or Other Dementias Versus Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015



Dementia caregivers provide 27 more hours of care per month on average than caregivers for people without dementia.

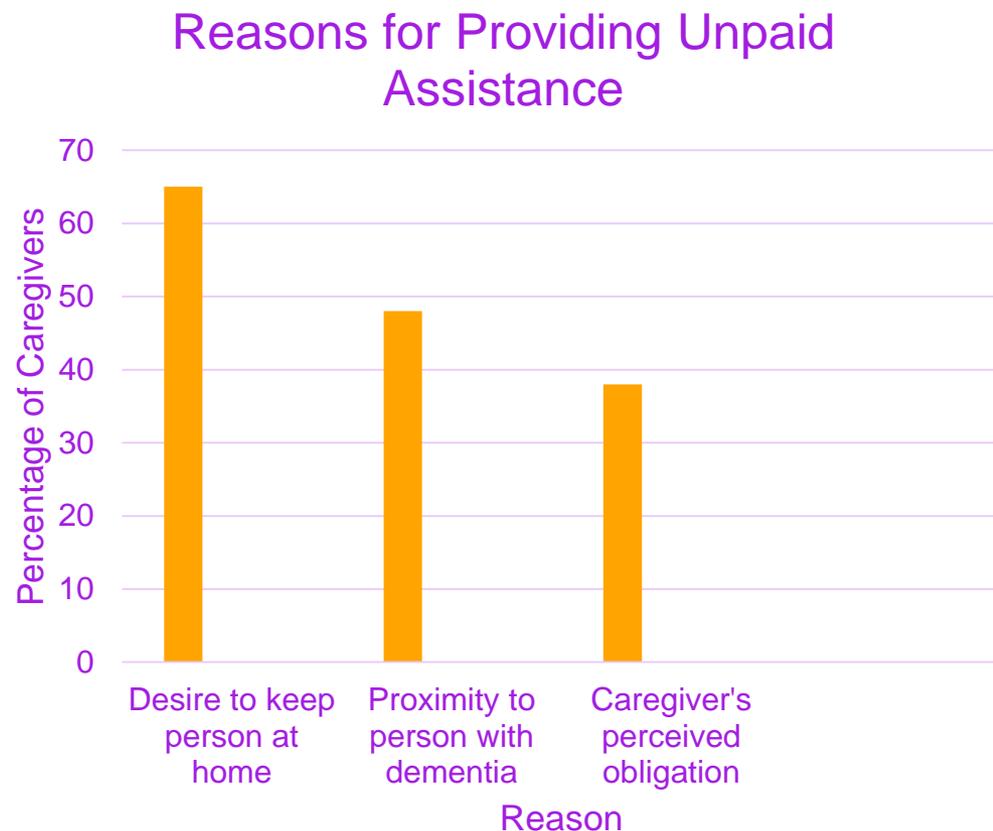
From 2020 Alzheimer's Association Facts & Figures Report

Who are the caregivers?

- Nearly 2/3s of caregivers are women.
- 30% are 65 and older.
- 41% have a household income of \$50,000 or less.
- 66% live with the person in the community.
- 1/4 are “sandwich generation caregivers.”



Motivation for Caregiving



Caregivers also indicate love and a sense of duty when explaining why they provide care to loved one with dementia.

Poll Question #3

Compared to caregivers for older adults without dementia, caregivers for older adults with dementia report higher levels of:

- a. Physical stress
- b. Emotional stress
- c. Financial stress
- d. All of the above

Impact of Family Caregiving



- Physical
- Emotional
- Financial
- At home versus residential care

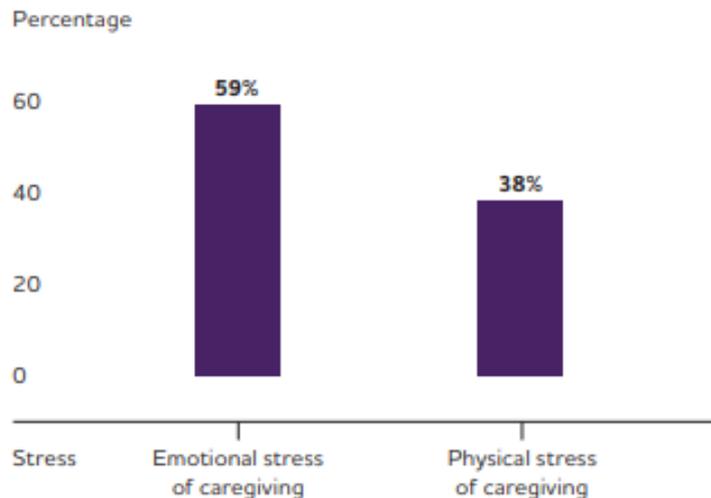
Why is dementia caregiving different?

- Loss of judgment, orientation and ability to communicate
- Diminished understanding of disease
- Changes in personality and behavior
- Stigma associated with dementia
- Need for increasing assistance
- Sleep deprivation

Physical and Emotional Stress

FIGURE 10

Percentage of Caregivers Who Report High to Very High Stress Due to Caregiving



- Loss of sleep
- Anxiety
- Depression
- Caregiver health concerns

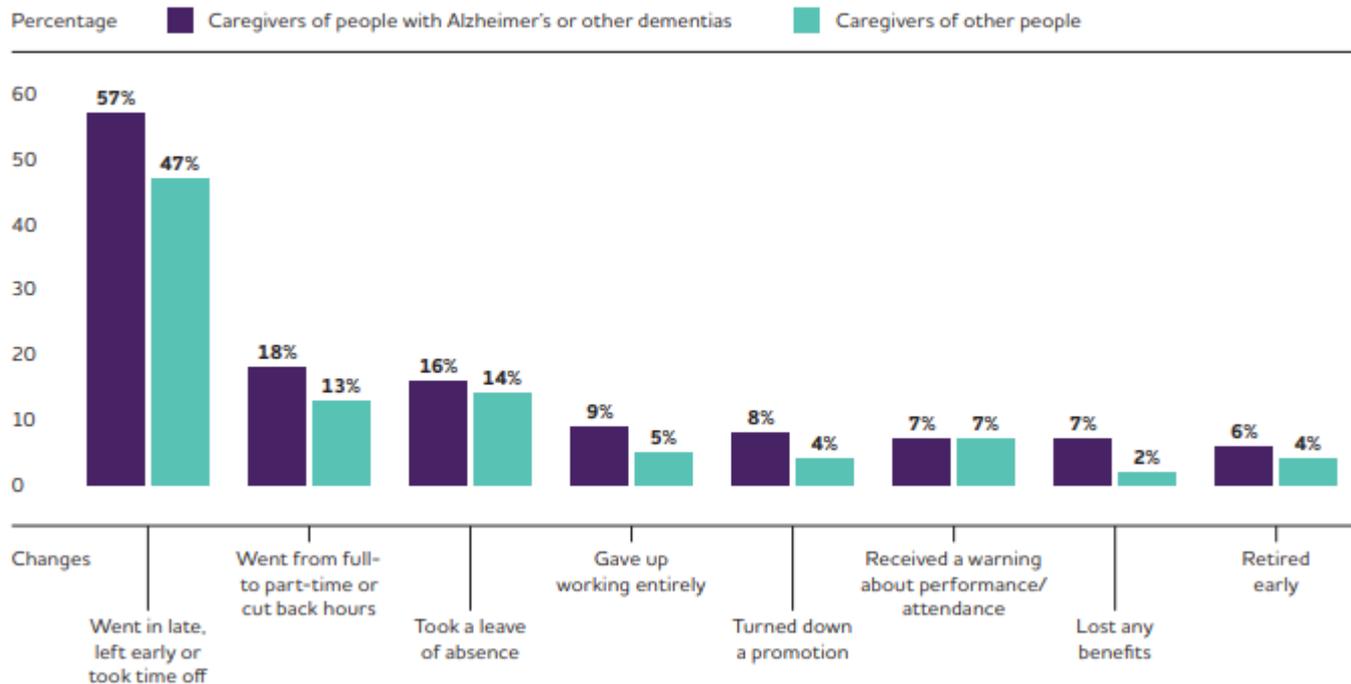
From: 2020 Alzheimer's Association Facts & Figures

Signs of Caregiver Stress

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness
- Irritability
- Lack of concentration
- Health problems

Financial Impact

Work-Related Changes Among Caregivers of People with Alzheimer's or Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving



From: 2020 Alzheimer's Association Facts & Figures

Racial and Ethnic Disparities in Caregiving



Older Black Americans are **2X AS LIKELY** to have Alzheimer's or other dementia than Whites, yet **ONE-THIRD** believe discrimination would be a barrier to receiving Alzheimer's care.

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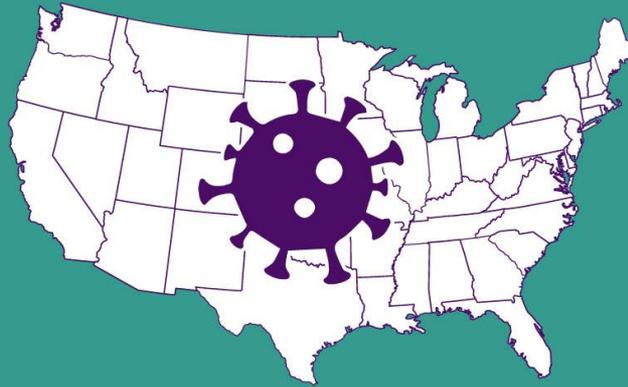
- Greater care demands
- Lower use of formal services
- Greater depression
- More hours of care provided

Impact of Residential Placement

- Stress
- Guilt
- Grief
- Depression



COVID-19 and Caregiving



IN THE UNITED STATES,
ALZHEIMER'S AND DEMENTIA DEATHS
HAVE INCREASED 16%
DURING THE COVID-19 PANDEMIC.

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Caregiver Interventions

Case management

Psychoeducational approaches

Counseling

Respite

Support groups

Multicomponent approaches

Characteristics of Effective Interventions

- Active involvement of caregivers
- Tailored and flexible to meet changing needs
- Benefits for caregiver and person living with dementia



Spotlight on Effective Interventions

- Psychoeducational programs
 - The Savvy Caregiver Program
 - Alzheimer's Association education programs
- Support groups
- Respite
- Multicomponent approaches
 - 24/7 Helpline
 - Dementia Care Coordination
 - Family Caregiver Support Program

Psychoeducational Programs

- Structured programs that provide disease education, information about resources, and skill-building
- Use multiple teaching methods
- Led by professionals and volunteers with specialized training

The Savvy Caregiver Program

- 12 hour program (2 hour sessions over 6 weeks)
- Evidence-based
- Adapted for telephone and virtual delivery
- Translated into Spanish
- Geared for middle stages of dementia

Topics include:

Career of the caregiving

Types of dementia

Behavioral symptoms

Adapting tasks and activities

Decision-making

Alzheimer's Association Caregiver Education Programs

Individual Programs

- Effective Communication
- Understanding and Responding to Dementia-Related Behavior
- Dementia Conversations

Series

- Living with Alzheimer's for Caregivers
 - Early
 - Middle
 - Late
- Living for Alzheimer's for People with Alzheimer's

Support Groups

- Less structured than psychoeducational or psychotherapeutic approaches
- Opportunity to share feelings, concerns and experiences to overcome isolation and learn coping strategies



Support Group Formats

- Extended turns
- Discussion
- Open sharing
- Educational speaker/presentations
- Closing tradition

Group Dynamics

Impact of group size, experiences, and personalities

Role of the facilitator

Changing nature of groups

Respite

In-home care services

- Companion
- Personal care or home health aide
- Homemaker
- Skilled care services

Adult day centers

- Socialization and activities
- Supervision
- Meals
- Often assistance with personal care and transportation

Residential care

- Temporary stays in a skilled nursing or assisted living facility
- Overnight care for caregivers to take extended break or vacation

Informal support

- Assistance from family and friends
- Care calendar websites

Overcoming Caregiver Concerns

- Cost
- Reliability
- Guilt
- Asking for help
- Acceptance by the person with dementia



Multicomponent Approaches

- Incorporate multiple strategies to assist caregivers including education, support, skill-building and respite
- Can be short-term or long-term

24/7 Helpline

Dementia Care Coordination

Family Caregiver Support Program

24/7 Helpline

- Learn about symptoms of dementia
- Get referrals to local programs and resources
- Get information about legal, financial and care decisions and treatment options

- 800.272.3900
- www.alz.org
- Live chat 7:00AM-7:00PM CST

Available in over 200 languages



One Call Makes a Difference

Assessment

- Identify presenting issue and underlying concerns
- Focus on needs, expectations, weaknesses and strengths

Interventions

- Disease education
- Person-centered care strategies
- Supportive listening and validation
- Care planning

Action steps

- Connection to support and resources
- Realistic actions that caregiver agrees to take
- Consideration of barriers and resources

Summary

- Resources to be provided
- Follow up that can be expected

Dementia Care Coordination



- Grant-funded program in New England offered by MA/NH Chapter
- 33 partners
- Over 1,800 referrals last year
- Includes 3 follow ups in year after initial care consultation

Family Caregiver Support Program

- Counseling and training
- Referrals to services and resources
- Respite care

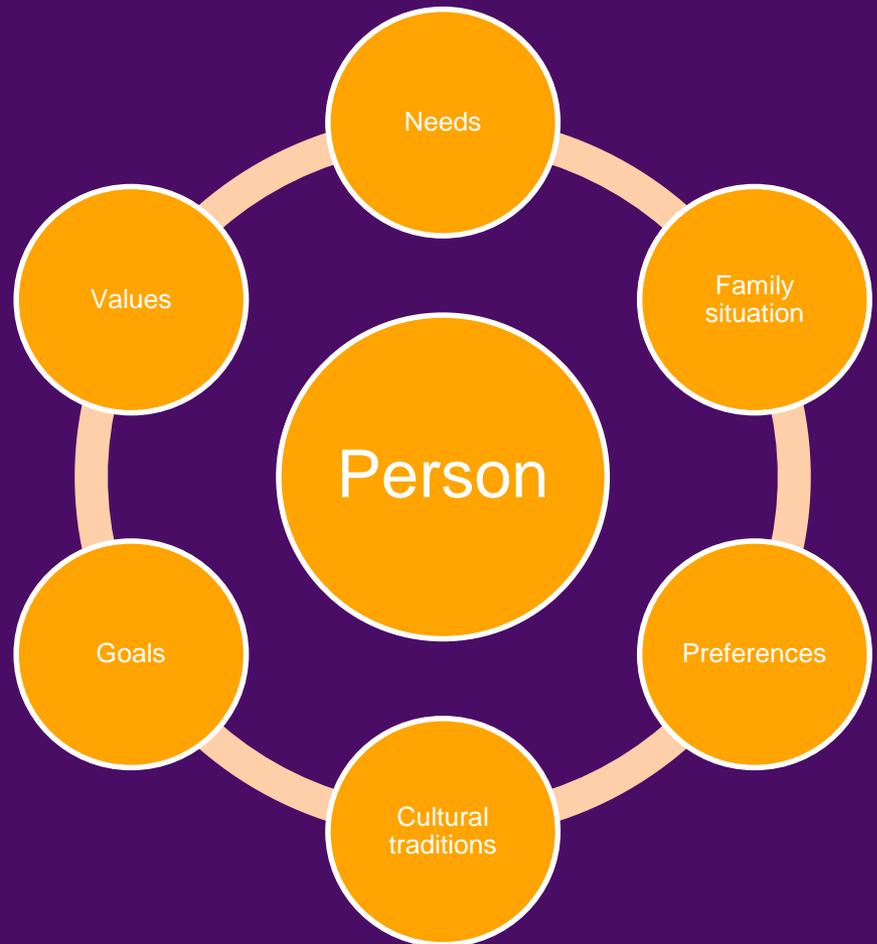
Administered by the Massachusetts Executive Office of Elder Affairs and provided by local Aging Services Access Points (ASAPs)

Community Resources

- Alzheimer's Association 800.272.3900 (alz.org)
 - 24/7 Helpline
 - Support Groups
 - Education Programs
- Healthy Aging Center of Excellence 978.946.1211 (healthyliving4me.org)
 - Savvy Caregiver
- Family Caregiver Support Program 800.422.6277 (mass.gov/family-caregiver-support-program)
- National Area Agency on Aging (n4a.org)

Working with Caregivers

- There is no one size fits all approach to supporting caregivers.
- Person-centered approach
 - Caregiver
 - Person living with dementia



Case Example #1: At Home

Mary is the primary caregiver for her husband, Joe, who was diagnosed with Alzheimer's disease 6 years ago. Joe is dependent on Mary for all ADLs. Mary and Joe are both 80 years old and in good physical health. Mary and Joe's children are concerned that Mary seems exhausted and short-tempered. Mary prides herself on her ability to handle things on her own and her frugality. Mary used to be very social, but Joe has always been very private and does not like guests in the home.

- What kind of interventions do you think would be helpful for Mary and Joe?
- What barriers would interfere with implementing interventions?
- What did you learn about Mary and Joe that would be helpful in introducing some interventions?

Conclusions

- Family caregivers play a critical role in the care and support of people living with dementia—at home or in residential care.
- Family caregiving can be rewarding but also have serious impact on the health, emotional and financial well-being of caregivers.
- Taking a person-centered approach to supporting caregivers and introducing interventions can help to alleviate some of the negative outcomes of caregiving.

Questions