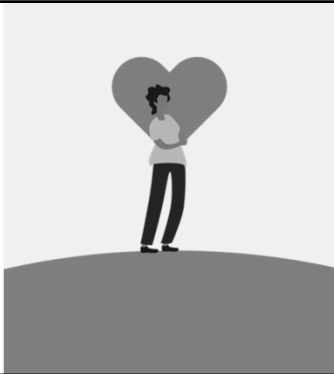


## Recognizing Burnout In Those Caring For Patients with Dementia

**Gregory James, DO, MPH, CMD**  
UnitedHealth Group / Optum, Home & Community  
Senior Medical Director, North Region US and FL Market

**Nicholas James, PhD**  
Staff Psychologist  
Orlando Veterans Affairs (VA) Health Care System



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### Speaker Disclosures

Dr. Gregory James is a full-time employee of UnitedHealth Group; Optum, Home & Community Division

Dr. Nicholas James has no conflicts to disclose for this presentation.

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### Learning Objectives

- Describe the primary causes of burnout for the caregivers of patients that are under our care
- Describe the application of burnout theory
- Be able to recognize and explain the signs and symptoms of burnout in informal caregivers
- Identify the resources and methods to get these caregivers the help and treatment they need for their burnout

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### Agenda

- **Introduce the topic of Caregiving**
- **Burnout**
  - Common Themes
  - Research
  - Detection
- **Caregiver Burnout Assistance**
  - Support Groups and Resources
  - Educational Programs
- **References**

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### Why talk about this problem?



**34 BILLION HOURS**

of uncompensated care in the U.S. each year



**\$500,000,000,000**

of annual economic impact each year

Burnout is an incredibly common experience, yet identification of those at high risk of burnout impacting their health and functioning remains a difficult task

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### Increasing Demand for Caregivers (CDC)

- Need for caregivers is growing with the aging US population
- The number of caregivers increased from 43.5 million in 2015 to about **53 million** in 2020, or more than **1 in 5 Americans**
- By 2030, est. **73 million people** in the United States will be **65 years or older**
- Many will require assistance from at least one caregiver to maintain quality of life and independence
- More than **two-thirds of the US population** will likely need help with tasks in their lifetime



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Caregiving is . . . *the activity or profession of regularly looking after a child or a chronically ill elderly, or disabled person*

#### Informal Caregivers

- Any unpaid person providing care to another person
- A friend, child, spouse, in-law, siblings, other family members
- Highly heterogeneous
  - Almost anyone can be a caregiver, therefore, can't easily profile who is the 'average' caregiver

#### Professional Caregivers

- Wide-range of occupations
  - Physicians
  - Advanced Practice Clinicians (APCs)
  - Nurses
  - CNAs
  - Mental-health aides
  - Many more
- Most/All of us attending this presentation today



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### Differences: Professional vs Informal\* Caregiving

#### Structural differences

- Organizational support (Human Resources, Training Programs)
- Vacation / PTO
- Co-workers & support staff

#### Role differences

- Caring for family\* vs stranger
- Chosen job vs unexpected role\*
- Shift work vs up to 24/7/365\*

#### Task differences

- Training/experience level differences\*
- Greater range of ADLs and IADLs\*
- Typically, no known end in sight\*

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### Understanding Caregiver Dynamics



#### Caregiving Burden

- Objective** – concrete tasks (EX: ADL's/IADL's), including frequency and time spent completing the tasks that need to get done every day
- Subjective** – stress and emotional impact related to concrete caregiving tasks



#### Common Stressors

- Any secondary stressor associated with taking on caregiving role
- Highly variable



#### Caregiver Burnout

- Experience of exhaustion (physical, mental, interpersonal) resulting from an imbalance of task-strain and from protective factors
- Identifiable outcome of burden and stressor factors.

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## Caregiving Stressors

### Common stressors of caregiving:

- Taking on the role unexpectedly
- Major shifts in life plans
- Reduced self-care time
- Decreased social activity/support
- Difficult-to-access resources (education, financial, burden)

### Exacerbated by pre-existing issues in relationship (strains the relationship)

- Previous Relationship Dynamics (spouse/partner/childhood):
  - Abuse (verbal, physical, sexual, financial)
  - Neglect (physical, emotional)

A new caregiver often has less than 48 hours to learn and assume all the roles

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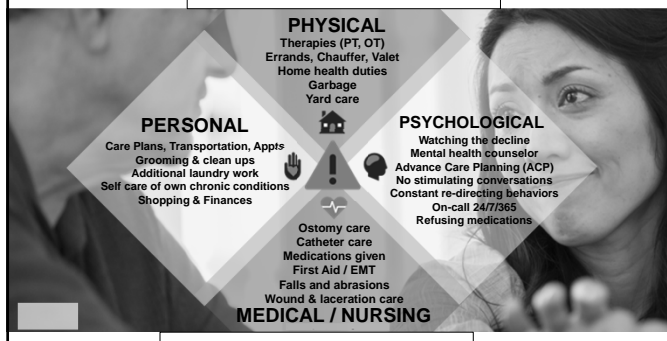
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## Many Facets of Caregiving Burden



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## Caregivers: A Snapshot (CDC)

- 58% of caregivers are women
- ≈1/3 of caregivers provide a minimum of **at least 20 hours of care a week**
- Typically lack formal training
- 79% care for adults aged >50, and 76% of care recipients are > 65
- One-in-six people expect to become a caregiver within the next two years

• SOURCE: [https://www.cdc.gov/aging/publications/features/supporting-caregivers.htm?ACSTrack=USCDC\\_844-DM71712&ACSTrackLabel=Year-10-Review%202021&DeliveryName=USCDC\\_844-DM71712](https://www.cdc.gov/aging/publications/features/supporting-caregivers.htm?ACSTrack=USCDC_844-DM71712&ACSTrackLabel=Year-10-Review%202021&DeliveryName=USCDC_844-DM71712)



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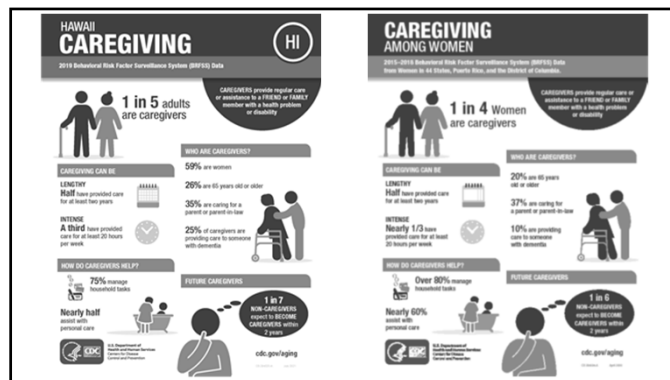
## Financial Strains of Caregiving (CDC)



### Caregiving can have a negative financial effect on caregivers

- Leaving work early or taking time away from work, resulting in lost wages
- Nearly 20% employed caregivers stopped working, 40% reduced working hours
- Almost 80% of caregivers report paying out-of-pocket for routine/medical expenses for care recipients
  - The average annual out-of-pocket cost for caregivers is **\$7,200**, and nearly **\$9,000** for caregivers of someone with dementia

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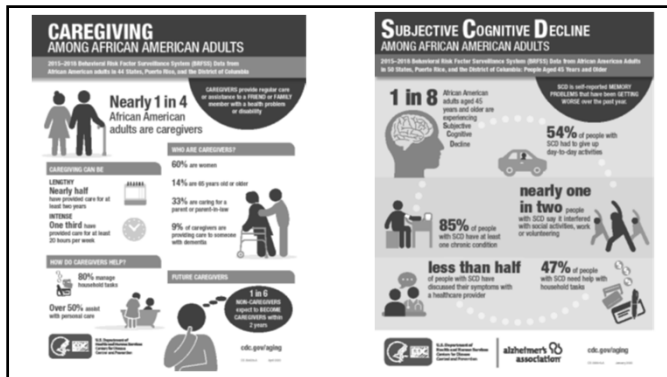


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## Equity in Dementia Care

- People of color face discrimination when seeking health care for Alzheimer's disease and related dementias.
- Findings from two national surveys conducted by the Alzheimer's Association show that Black Americans reported the highest level of discrimination in dementia health care
- This was followed by Native Americans, Asian Americans, and Hispanic Americans.
- Link: [Barriers to Equity in Alzheimer's and Dementia Care \(cdc.gov\)](https://www.alz.org/newsroom/2020/04/2020-04-20-barriers-to-equity-in-alzheimers-and-dementia-care)

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## Introduction To Burnout

The word "burnout" has become ubiquitous  
Seems to sum up the stress, exhaustion, and  
disaffection that many of us are feeling

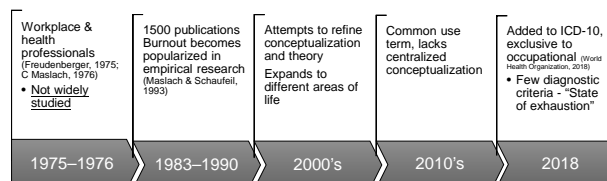
The past 1-2 years more than most

- What does the term "burnout" actually mean?
- How does burnout differ from depression or stress?
- What can individuals, employers, and society do to combat burnout?



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## History of Burnout Research



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## Burnout

- *Physical or emotional exhaustion involving a sense of reduced accomplishment and loss of personal identity* (Mayo Clinic)
- Common theme is **exhaustion**
- 50-65% of the healthcare workforce reports high levels of burnout (Derning et al., 2021; Jalli et al., 2021)
- Primarily used in occupational settings
  - But can occur in non-occupational settings that may be similar to work



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## Indicators of Exhaustion

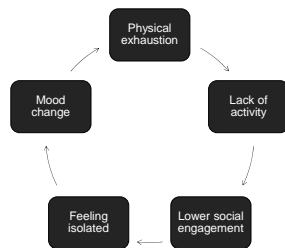
Impacts manifest across domains

- **Physical** (sleeplessness, somatic symptoms, fatigue)
- **Mental** (irritability, loss of motivation)
- **Interpersonal** (lower social engagement or interest in socialization)

Burnout is **globally impactful**

- (Christina Maslach, Jackson, Leiter, Schaufeli, & Schwab, 1986)

### Cyclical relationship



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## Application of Burnout Theory



**Job Demands-Resources (JD-R) model**  
(Demerouti, Bakker, Nachreiner, & Schaufeli, 2001)

### • Occupational demands

Physical, psychological, or social costs  
Increases as frequency, intensity, and duration of high-cost tasks

### • Job resources

Reduction of cost, stimulation of growth, and reward

### • Burnout is an indicator of this imbalance

Imbalance leads to poor work quality, health impairment, and attrition

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### JD-R Model Applied to Informal Caregiving

Occupation	Informal Caregiving
<b>Demands</b> <ul style="list-style-type: none"> <li>Physical costs (strenuous labor)</li> <li>Psychological costs (stress)</li> <li>Social costs (relationship impacts)</li> </ul>	<b>Burden</b> <ul style="list-style-type: none"> <li>Physical costs (ADL/IADL assistance)</li> <li>Psychological costs (stress/worry)</li> <li>Social costs (relationship with recipient or relationship impact)</li> </ul>
<b>Resources</b> <ul style="list-style-type: none"> <li>Co-worker support</li> <li>Employee assistance programs</li> <li>Payment</li> <li>Desired advancement/training</li> </ul>	<b>Resources</b> <ul style="list-style-type: none"> <li>Social support</li> <li>Support services / professional care</li> <li>Reduction of financial burden</li> <li>Competency / reinforcement</li> </ul>

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### Burnout Outcomes

Impact in caregiver health or caregiving role

- Depression**

Associated with burden

Many known negative outcomes

- Premature transfer to LTC**

Closest parallel to "workplace attrition"

- Difficult to measure

Often due to difficult tasks such as incontinence or problematic behaviors

(Branch & Jeter, 1982; Bura, Kucharska, & Clipp, 2006)

Prolonging transfer improves QoL and reduced financial burden



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### Caregiving Burdens and Stress

Health impacts of burden/burnout

- Nearly 1 in 5 caregivers reports fair or poor health

- Caregivers often neglect their own health needs, increasing their risk of having multiple chronic conditions

- Nearly 40% have at least two chronic diseases:

- 1 in 7 has heart disease or stroke (1 in 5 in those 65+)

- National Alliance for Caregiving and AARP study found **nearly 25% of US caregivers** say caregiving has made their health worse



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### Symptoms of Problematic Burnout



- Social withdrawal
- Decreased self-care (physical/mental)
- Changes in appetite, weight or both
- Changes in sleep habits and/or patterns
- Feeling ill or tired more often
- Feeling overwhelmed or constantly worried
- Frequent headaches, bodily pain or other physical problems.
- Quote: "I cannot recall the last time I did anything for myself"

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### Support

#### Social support

- Can provide "breaks" or "days off"
- Perceived support inversely related to burden (Chiou, Chang, Chen, & Wang, 2009; Haley et al., 1987)

#### Financial

- Social programs
- Professional services

#### Emotional

- Caregiver support groups, family involvement
- Psychotherapy to address acute symptoms / coping skills

#### Time for self-care or completing necessary tasks

#### Professional support (transportation, professional nursing, legal / financial planning)

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### How do we detect caregiver burnout?



Measures of Burnout are primarily occupational

- **Maslach Burnout Inventory**  
(Maslach, Jackson, Leiter 1997)
- **Copenhagen Burnout Inventory**  
(Kristensen et al., 2005)

Both lack of validations studies for informal caregivers

Measure created for informal caregivers

- **Informal Caregiver Burnout Inventory** - 10 Item Form  
(James & Pauson, 2020)

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## Emerging Research on Caregiver Burnout



### Informal Caregiver Burnout Inventory (ICBI-10) (James & Paulson, 2000)

- 10 Questions, 5-Point-Likert Scale (score of 0 to 40)
- Higher scores indicate higher levels of burnout
- Good discriminate validity of burnout vs depression
- Validated specifically for informal caregivers of older adults
- Subscale for deficient support

Burnout Questionnaire	Agree completely	Agree a little	Neither agree / disagree	Disagree a little	Disagree completely
1. I feel burned out from caregiving.					
2. I do not have the time or energy to take care of myself.					
3. I feel physically drained.					
4. Caring for my physically exhausting.					

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## How do we detect caregiver burden?

Measurement of Burden is well-established

### • Zarit Burden Interview (Zarit, Reever, Bach-Peterson, 1980)

#### Subjective burden

Gold Standard measure

22-, 12-, or 6- item versions

### • Activities of Daily Living Checklist (PBS & AARP, 2008)

#### Objective burden

– ADL: bathing, toileting, eating

– IADL: Shopping, cooking, driving



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## Detection to Action

### Detect

Brief Questionnaires  
(ADL/IADLs, Zarit  
Burden Interview, ICBI-  
10)

Co-occurring needs  
(caregiver  
medical/psychological  
disorders going  
unaddressed)

### Assess Needs

Ask questions directly  
Use responses from  
questionnaires

### Provide Resources

Educational, Support,  
Self-care, Therapy,  
Legal, Financial  
Local / National

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## Responding to burden and burnout



### Burden

- Resources to alleviate objective burdens
  - Financial
  - Educational
  - Professional / community support
  - Physical strain



### Burnout

- Self-care
- Support groups
- Psychotherapy
- Caregiver interventions (REACH, Savvy Caregiver)

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## Why do caregiving and burnout coexist?

Promises made between spouses or partners to keep them at home, rather than placement in an appropriate nursing or assisted living facility, when they had little idea of:

- What kind of care would be needed
- What kind of life they were committing themselves to
- Financial strains after paying for acute care
- Lack of Long-Term Care insurance
- Drastic change in relationship dynamics



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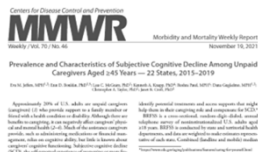
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## Morbidity & Mortality Weekly Report (MMWR); Nov 2021

Prevalence and Characteristics of Subjective Cognitive Decline Among Unpaid Caregivers Aged ≥45 Years – 22 States, 2015–2019

- 1 in 8 unpaid caregivers (age 45+) reported subjective cognitive decline (SCD)
  - SCD = Self-reported experience of worsening confusion or memory loss over the past year.
- SCD was higher among caregivers (12.6%) than non-caregivers (10.2%).
- Caregivers with SCD were more likely than those without SCD to report chronic health conditions, a history of depression, and frequent activity limitations.



(MMWR Weekly / November 19, 2021 / 70(46):1591–1596)

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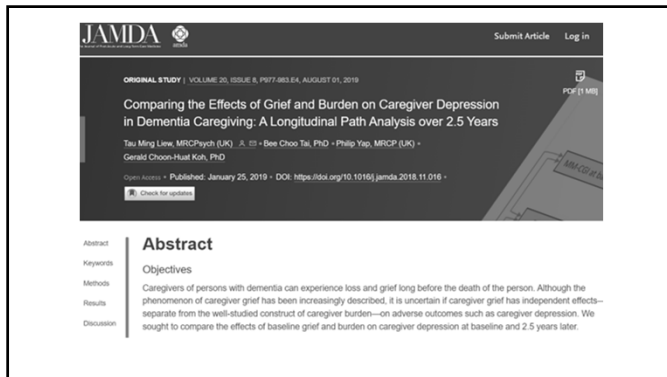
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### JAMDA Article Conclusions

Grief can amplify the effect of burden at baseline and can have an independent effect on depression over time. Caregiver grief has a "latent phase"

- Effects may have a delayed onset.

The findings highlight the need to:

- Identify and address caregiver grief in dementia services
- Present a window of opportunity to improve caregiving outcomes, especially during the "latent phase" when caregivers have only begun to encounter loss and grief but have yet to fully experience the debilitating effects of depression.

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### Supporting Caregivers: An Emerging Public Health Issue

Millions of older adults and people with disabilities could not maintain independence without help of unpaid caregivers.

- Assistance with routine tasks help care recipients remain in the community.

2017 Census data indicates 1.7 million licensed beds in nursing facilities, 1 million licensed beds in residential care communities (CDC Vital and Health Statistics, 2019)

- 41.8 million estimated US caregivers
- 76% care for one individual (24% for two +)

**Conservatively, 30+ million individuals age 50+ received unpaid caregiving in past 12 months.** (AARP & NAC, 2020)

**Preventing burnout increased longevity and quality of informal care.**

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### How to Support Caregivers?



Negotiate times to check in on them



Make sure they are managing their own health care needs



Help them with errands, chores, and other tasks



Provide emotional and social support



Encourage them to seek mental health services if necessary



Help them create and manage a care plan for the person they care for

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### Resources for Family Caregivers (Partial List)

- Centers for Disease Control and Prevention (CDC)
- The Public Health Center of Excellence on Dementia Caregiving (PHCOE)
- Family Caregiver Alliance (FCA)
- Caregiving Resource Center
- Alzheimer's Association
- American Association of Retired Persons (AARP)

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### CDC Email to Providers

#### Supporting Caregivers: An Emerging Public Health Issues

Caregivers help maintain the health and well-being of older adults and people with disabilities or chronic health conditions. Learn about caregiving, caregivers, and their challenges and risks.



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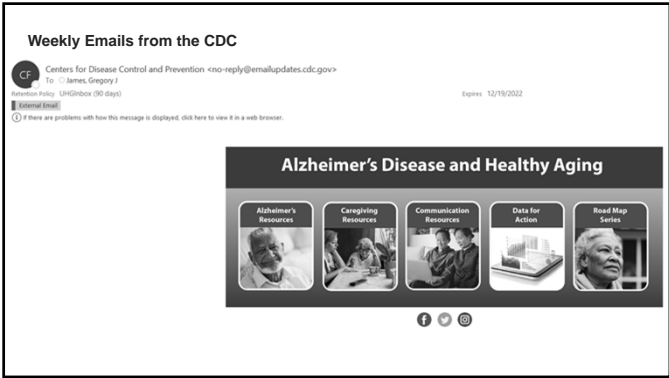
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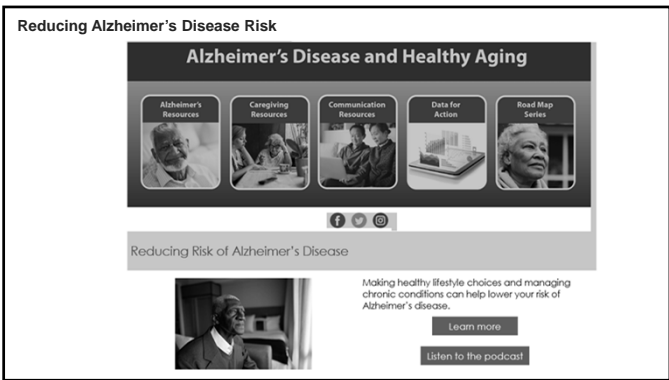
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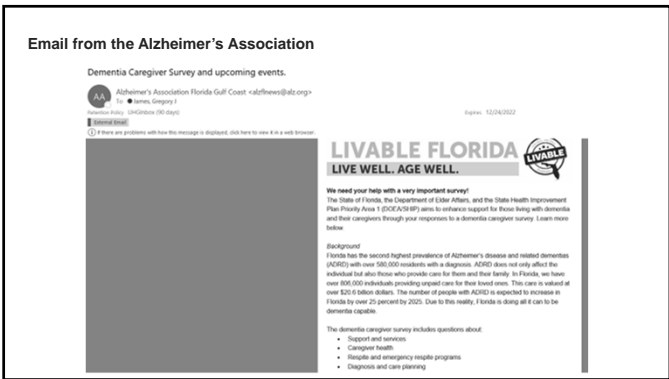
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### Lack of Diversity In Health Care Staff Creates Barriers

- Understanding how different racial and ethnic group's view, access, and experience health care is critical to improving the health care system and helping health providers care for an increasingly diverse population.
- It is projected that people of color will account for over half (52%) of the population in 2050.
- Characteristics of health care systems that contribute to disparities should be acknowledged.
- These include implicit bias on the part of health care providers.
- Cultural and language barriers can also hinder patient-provider relationships.

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### Diversity In Healthcare Staff (continued)

#### Minority Populations Desire Health Care Providers Who Understand Their Ethnic or Racial Background:

- Given their own experiences with discrimination, it is not surprising that non-White racial/ethnic populations feel it is important for Alzheimer's and dementia care providers to be more culturally competent.
- Responses from surveys indicate a strong desire for dementia health care providers who understand different racial and ethnic backgrounds, but many survey respondents say access to these providers is lacking.

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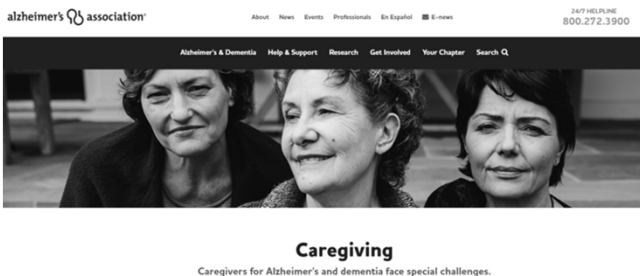
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### Alzheimer's Association Caregiving Webpages



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## Caregiver Resources (continued)

From the Alzheimer's Association

### Other program opportunities

Use Community Resource Finder to search for other programs including locations where the Brain Bus will be visiting, Alzheimer's education programs like Caregiver College and social programs for people in the early stages of dementia. Click below to learn more.

[Community Resource Finder](#)

### Support Groups

View all in-person, virtual and telephonic support groups including groups for caregivers and people with early stage dementia. Click on the button below or call 800.272.3900 to learn more.

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Alzheimer's Association Support Groups										*Groups meet in-person	RSVP 800.272.3900	Updated 9/6/2021	
Type of group	County	Week	Week Day	Time	Location	Address	Facilitator	Notes					
Central and North Florida Chapter													
ES- Social	Brevard	Various	Monday	1:30 p.m.	One Senior Place	4005 Spinglens Hill Rd, Melbourne, FL 32940	Susan Blakeslee	Art Connects ALZ program, please call 800.272.3900 to register Mondays Aug. 15, 23, and 30, Sept. 13 and 20.					
ES- Social	Seminole	Various	Wednesday	1 p.m.	One Senior Place	715 Douglas Ave. Altamonte Springs, FL 32714	Pamela Levin	Art Connects ALZ program, please call 800.272.3900 to register Weds. Sept. 8, 15, 22 and 29, Oct. 6, 13, 20, 27, and Nov. 3, 10, and 17.					
ES- Social	Volusia	Various	Wednesday	10:30 a.m.	The Hub	132 Canal St., New Smyrna Beach, FL 32159	Carolyn Lund, Sheila Caffee, Donna Bradley	Art Connects ALZ program, please call 800.272.3900 to register Wednesdays, 9/29, 10/5, 10/12, 10/19, 10/27, 11/3, 11/10.					
ES- Couples	Seminole	1st	Wednesday	10:30 a.m.	One Senior Place	715 Douglas Avenue Altamonte Springs, FL 32714	Martha Pundy and Anita Vargas	Please call 800.272.3900 to register. Couples Support Group for persons with dementia (early stages) and care partner.					
ES- Social	Seminole	Various	Wednesday	1 p.m.	One Senior Place	715 Douglas Ave. Altamonte Springs, FL 32714	Pamela Levin	Memories in the Making program, please call 800.272.3900 to register. Dates include September 8, 15, 22, and 29, October 6, 13, 20, 27, and November 3, 10, and 17.					
Caregiver	Escambia	2nd	Tuesday	6 p.m. CT	Anchor Neuroscience	800 S Palafox St. #103, Pensacola, FL 32502	Letanya Taber						

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Alzheimer's Association, Florida Gulf Coast Chapter, Program Schedule									
COUNTY	DATE	TIME	TYPE	TITLE	RSVP	LOCATION	ADDRESS	CITY	
Pinellas	September 14, 2022	11 a.m.	In-Person	ALZ STARS		Barbara S. Ponce Public Library	7770 52nd St. N.	Pinellas Park	
Pinellas	September 21, 2022	11 a.m.	In-Person	Understanding Alzheimer's and Dementia		Barbara S. Ponce Public Library	7770 52nd St. N.	Pinellas Park	
Pinellas	October 6, 2022	9 a.m. -12 noon	In-Person	Walk to END ALZ - Pinellas County	Learn More	Poirer Park	1000 3rd St. S.	Saint Petersburg	
Pinellas	October 19, 2022	11 a.m.	In-Person	ALZ STARS		Barbara S. Ponce Public Library	7770 52nd St. N.	Pinellas Park	
Pinellas	November 9, 2022	11 a.m.	In-Person	ALZ STARS		Barbara S. Ponce Public Library	7770 52nd St. N.	Pinellas Park	
Pinellas	December 7, 2022	11 a.m.	In-Person	ALZ STARS		Barbara S. Ponce Public Library	7770 52nd St. N.	Pinellas Park	
Pinellas	December 7, 2022	12 p.m.	In-Person	10 Warning Signs of Alzheimer's	800.272.3900	The Oaks of Clearwater	420 Bay Ave.	Clearwater	

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Alzheimer's Association, Florida Gulf Coast Chapter, Program Schedule									
COUNTY	DATE	TIME	TYPE	TITLE	RSVP		LOCATION	ADDRESS	CITY
Hillsborough	October 22, 2022	9 a.m.	In-Person	Walk to END ALZ - Tampa		<a href="#">Learn More</a>	Raymond James Stadium	4201 N. Dale Mabry Hwy.	Tampa
Hillsborough	November 11, 2022	10 a.m.-2 p.m.	In-Person	Brain Bus Stop		<a href="#">Learn More</a>	Employee Health Fair, Masonite		Tampa
Hillsborough	November 16, 2022	1 p.m.-2 p.m.	In-Person	10 Warning Signs of Alzheimer's	800.272.3900		David Barksdale Senior Center	1801 N. Lincoln Ave.	Tampa
Lee	October 1, 2022	TBD	In-Person	Walk to END ALZ - Fort Myers		<a href="#">Learn More</a>	Florida SouthWestern College	8099 College Pkwy	Fort Myers
Manatee	September 20, 2022	10 a.m. - Noon	In-Person	Understanding Alzheimer's and Dementia	941.792.3141		Palma Sola Presbyterian Church	6510 3rd Ave. West	Bradenton
Manatee	September 27, 2022	11:30 a.m.	In-Person	LUNCH & LEARN- Healthy Living for Your Brain and Body	941.708.9622 ext. 402-404		Bradenton YMCA	3805 59th Street West	Bradenton
Manatee	November 2, 2022	10 a.m.-1 p.m.	In-Person	Brain Bus Stop		<a href="#">Learn More</a>	Senior Fair at the Lakewood Ranch YMCA	5100 Lakewood Ranch Blvd	Lakewood Ranch

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## Alzheimer's Association Virtual Caregiver College

Brain Bus

Disaster Preparedness

Early Stage Services

Education Programs

Discoveries

Virtual Caregiver College

Think About It

For Professionals

**VIRTUAL CAREGIVER COLLEGE**

Online education series presented by the Alzheimer's Association

When it comes to dementia caregiving, knowledge is power. Join us for a series of interactive, online educational classes to help you build your caregiver tool kit.

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## Alz Assoc Caregiver College (continued)

Communication is more than just talking and listening

- It is also about sending and receiving messages
- Through attitude, tone of voice, and body language.
- As the disease progresses individuals living with Alzheimer's or other dementias lose the ability to use words, but families can find new ways to connect.

These presentations allow caregivers to explore how communication changes when someone is living with Alzheimer's Disease

- Learn how to interpret the verbal and behavioral communication
- Identify strategies to help you connect and communicate at each stage of the disease.

Learn about important legal and financial issues to consider

- How to put plans in place
- How to access legal and financial resources near the caregiver

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**Family Caregiver Alliance Caregiver College**

Family Caregiver Alliance

Resources | 资源 | 课程 | Recourses | Pagaaring yamam | Tsi ngyayin | Donate

Connecting Caregivers Caregiver Resources Research & Policy About FCA



CareNav

Caregiver College

- <https://www.caregiver.org/connecting-caregivers/events-classes/caregiver-college/>
- Based in San Francisco, CA – has links to resources in other states as well

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**FCA Caregiver College (continued)**

College for learning and sharing is offered in two ways:

- As a day-long program
- In a series of 4 classes on consecutive weeks.

Class is open to anyone, is FREE, and includes valuable information and hands-on practice on

- Transferring skills
- Incontinence care and toileting
- Bathing, hygiene and grooming
- Dressing
- Dental care, feeding and nutrition
- Dealing with behavioral issues
- Caregiver self-care

Time is allowed for interaction with other caregivers and sharing of information in a confidential setting is encouraged.

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**AARP Caregiving Site**

AARP

Family Caregiving

Basics Care at Home Nursing Homes Medical Financial & Legal Life Balance Community Local Resources & Solutions Stories



FREE Feb. 9 Event: Debut with Matt Paxton  
Get expert tips on downsizing. Register now

Caregiving Guide for Veterans and Their Families  
Helpful tips and resources for your caregiving journey

Financial Workbook for Military Caregivers  
A tool for health, housing and money management

Call Our Resource Line at 1-877-533-5885  
Free help for individuals taking care of a loved one

Caregiving Resources Available in Spanish  
Tips and advice en Español

- Link: AARP Resources for Caregivers and their Families

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**PUBLIC HEALTH CENTER OF EXCELLENCE ON DEMENTIA CAREGIVING**

About - Programs & Resources - Technical Assistance 2022 Conference -

BOLD Public Health Center of Excellence on Dementia Caregiving presents:

## The Public Health Opportunities and Challenges of Dementia Caregiving

June 14th-15th, 2022

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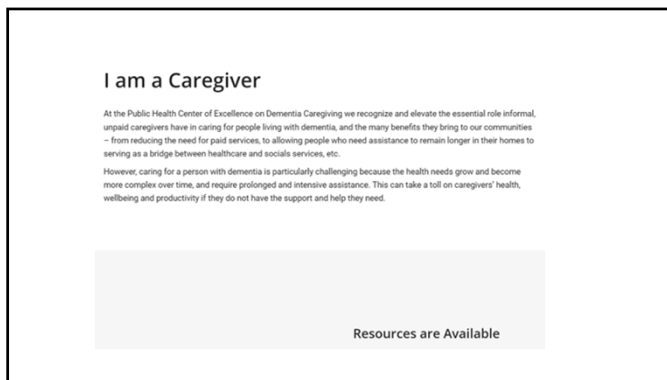
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### I am a Caregiver

At the Public Health Center of Excellence on Dementia Caregiving we recognize and elevate the essential role informal, unpaid caregivers have in caring for people living with dementia, and the many benefits they bring to our communities – from reducing the need for paid services, to allowing people who need assistance to remain longer in their homes to serving as a bridge between healthcare and social services, etc.

However, caring for a person with dementia is particularly challenging because the health needs grow and become more complex over time, and require prolonged and intensive assistance. This can take a toll on caregivers' health, wellbeing and productivity if they do not have the support and help they need.

**Resources are Available**

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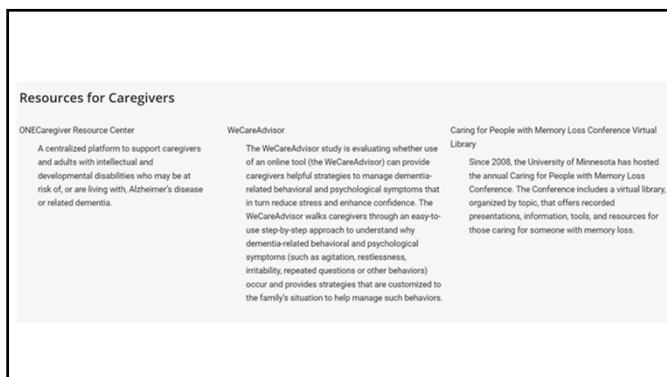
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### Resources for Caregivers

<b>ONEcaregiver Resource Center</b> A centralized platform to support caregivers and adults with intellectual and developmental disabilities who may be at risk of, or are living with, Alzheimer's disease or related dementia.	<b>WeCareAdvisor</b> The WeCareAdvisor study is evaluating whether use of an online tool (the WeCareAdvisor) can provide caregivers helpful strategies to manage dementia-related behavioral and psychological symptoms that in turn reduce stress and enhance confidence. The WeCareAdvisor walks caregivers through an easy-to-use step-by-step approach to understand why dementia-related behavioral and psychological symptoms (such as agitation, restlessness, irritability, repeated questions or other behaviors) occur and provides strategies that are customized to the family's situation to help manage such behaviors.	<b>Caring for People with Memory Loss Conference Virtual Library</b> Since 2008, the University of Minnesota has hosted the annual Caring for People with Memory Loss Conference. The Conference includes a virtual library, organized by topic, that offers recorded presentations, information, tools, and resources for those caring for someone with memory loss.
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**Email from PHCOE**

Register for our upcoming event!



koff004@umn.edu on behalf of phcoe-dc University of Minnesota &lt;phcoe-dc@umn.edu&gt;

To:

Information today: 1/4/2023 (30 days)

Expires: 1/4/2023

External email

ⓘ If there are problems with how this message is displayed, click here to view it in a web browser.

Greetings Public Health colleagues,

We are excited to announce our upcoming event "Natural Disasters and Dementia Caregivers: A Roundtable Discussion on Public Health Action!"

We will explore the role and opportunities for public health agencies to support people living with dementia and their family caregivers through preparedness, response and recovery from natural disasters.

See below for more details and registration.

We hope to see you there!

Your PHCOE-DC team



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**Summary**

- Reviewed the effects of a vast amount of uncompensated care in the U.S. each year (~\$500 billion)
- Identified the primary causes of burnout for caregivers of patients
- Described differences between Formal and Informal Caregiving
- Described the application of Burnout Theory
- Reviewed the signs and symptoms of burnout in caregivers
- Identified multiple resources and methods to get these caregivers the help and treatment they need for their burnout

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**References – 1**

Podcast: created July 2021; by Christina Maslach, PhD

- <https://www.apa.org/research/action/speaking-of-psychology/burnout#>

Caregiving:

- <https://www.caregiving.org/caregiving-in-the-us-2020/>

Caregiving Executive Summary:

- [https://www.caregiving.org/wp-content/uploads/2020/08/AARP1316\\_ExecSum\\_CaregivingintheUS\\_508.pdf](https://www.caregiving.org/wp-content/uploads/2020/08/AARP1316_ExecSum_CaregivingintheUS_508.pdf)

Supporting Caregivers (CDC Site)

- [https://www.cdc.gov/aging/publications/features/supporting-caregivers.htm?ACSTrackingID=USCDC\\_944-DM71712&ACSTrackingLabel=Year-in-Review%202021&deliveryName=USCDC\\_944-DM71712](https://www.cdc.gov/aging/publications/features/supporting-caregivers.htm?ACSTrackingID=USCDC_944-DM71712&ACSTrackingLabel=Year-in-Review%202021&deliveryName=USCDC_944-DM71712)

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**References – 2**

Prevalence and Characteristics of Subjective Cognitive Decline Among Unpaid Caregivers:

- <https://www.cdc.gov/mmwr/volumes/70/wr/mm7046a1.htm>

Behavioral Risk Factor Surveillance System (BRFSS):

- <https://www.cdc.gov/aging/data/index.htm>

Family Caregiving Advisory Council:

- <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>

Alzheimer's Association Caregiving Site:

- <https://www.alz.org/help-support/caregiving>

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**References – 3**

Prevalence and Characteristics of Subjective Cognitive Decline Among Unpaid Caregivers:

- <https://www.cdc.gov/mmwr/volumes/70/wr/mm7046a1.htm>

Behavioral Risk Factor Surveillance System (BRFSS):

- <https://www.cdc.gov/aging/data/index.htm>

Alzheimer's Association Caregivers College:

- [https://alz-org.zoom.us/meeting/register/tJwtfumvrTgsHdXr4qyW3\\_WbTSNwDzsDW\\_38](https://alz-org.zoom.us/meeting/register/tJwtfumvrTgsHdXr4qyW3_WbTSNwDzsDW_38)

Family Caregiving Advisory Council:

- <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>

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**References – 4**

Podcast: *Why we're burned out and what to do about it* by Christina Maslach, PhD

- <https://www.apa.org/research/action/speaking-of-psychology/burnout#>

Alzheimer's Association: Specific for Caregivers of Dementia Patients

- [https://www.alz.org/help-support/caregiving?&wt.mc\\_id=enews2021\\_10\\_06&utm\\_source=enews-aff-38&utm\\_medium=email&utm\\_campaign=enews-2021-10-06](https://www.alz.org/help-support/caregiving?&wt.mc_id=enews2021_10_06&utm_source=enews-aff-38&utm_medium=email&utm_campaign=enews-2021-10-06)

CDC - Caregiving:

- [https://www.cdc.gov/aging/publications/journal.htm?ACSTrackingID=USCDC\\_944-DM71712&ACSTrackingLabel=Year-in-Review%202021&deliveryName=USCDC\\_944-DM71712](https://www.cdc.gov/aging/publications/journal.htm?ACSTrackingID=USCDC_944-DM71712&ACSTrackingLabel=Year-in-Review%202021&deliveryName=USCDC_944-DM71712)

JAMDA Article: Comparing the Effects of Grief and Burden on Caregiver Depression in Dementia Caregiving (Published - January, 25, 2019)

- [https://www.jamda.com/article/S1525-8610\(18\)30665-0/fulltext](https://www.jamda.com/article/S1525-8610(18)30665-0/fulltext)

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### Potential Future Studies of this Topic

- Studies linking Caregiver Burnout to Emergency Room Visits, Unnecessary Hospital Admissions and Readmissions
- Support models for Caregivers that will reduce the healthcare expenditures attributed to those they care for

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### Questions?

Thank you for your attendance today!

Contact Information:

- **Gregory James, DO, MPH, CMD**  
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- **Nicholas James, Ph.D.**  
[Nicholas.James@va.gov](mailto:Nicholas.James@va.gov)

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