# Recognizing Burnout In Those Caring For Patients with Dementia

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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.

# **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

# **Agenda**

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

# Why talk about this problem?



of uncompensated care in the U.S. each year



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

# **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



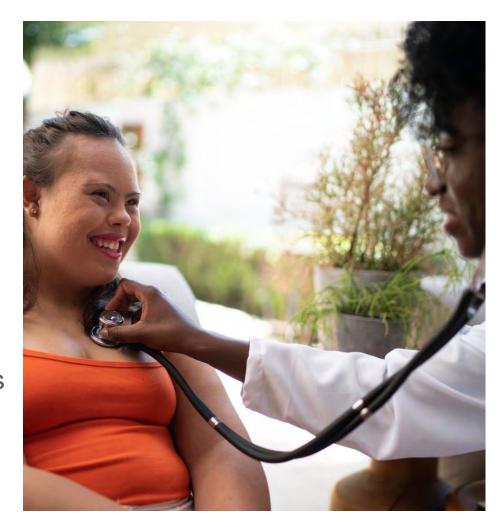
Caregiving is... the activity or profession of regularly looking after a child or a chronically ill elderly, or disabled person

### **Informal Caregivers**

- Any unpaid person providing care to another person
- A friend, child, spouse, inlaw, 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



# 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\*

# **Understanding Caregiver Dynamics**



### Caregiving Burden

- Objective concrete tasks (EX: ADL's/IADLs), including frequency and time spent completing the tasks that need to get done every day
- <u>Subjective</u> 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 <u>outcome of burden and stressor factors.</u>

# **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

# **Many Facets of Caregiving Burden**

### **PHYSICAL**

Therapies (PT, OT)
Errands, Chauffer, Valet
Home health duties
Garbage
Yard care

### **PERSONAL**

Care Plans, Transportation, Appts
Grooming & clean ups
Additional laundry work
Self care of own chronic conditions
Shopping & Finances

### **PSYCHOLOGICAL**

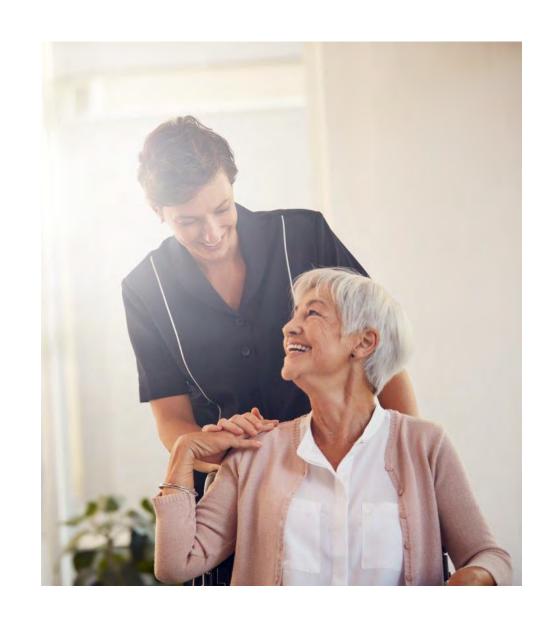
Watching the decline
Mental health counselor
Advance Care Planning (ACP)
No stimulating conversations
Constant re-directing behaviors
On-call 24/7/365
Refusing medications

Ostomy care
Catheter care
Medications given
First Aid / EMT
Falls and abrasions
Wound & laceration care

**MEDICAL / NURSING** 

# 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/supportingcaregivers.htm?ACSTrackingID=USCDC\_944-DM71712&ACSTrackingLabel=Year-in-Review%202021&deliveryName=USCDC\_944-DM71712



# 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

### HAWAII CAREGIVING



2019 Behavioral Risk Factor Surveillance System (BRFSS) Data



1 in 5 adults are caregivers

CARLGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or dissolating

### CARE CIVING CAN BE

### LENGTHY

Half have provided care for at least two years.



INTENSE

A third have provided pare for at least 20 hours per week



### WHO ARE CAREGIVERS?

59% tre woman

26% are 65 years old or older

35% are caring for a parent or parent-in-law-

25% of caregivers are providing care to someone with dementiar



### HOW DO CARRICIVERS HELP?



75% manuar household tasks.

### Nearly half assist with personal care.



### FUTURE CARECIMERS



ode.gov/aging

### **CAREGIVING AMONG WOMEN**

2015-2018 Behavioral Risk Factor Surveillance System (BRFSS) Data from Women in 44 States, Puerto Rico, and the District of Columbia.



1 in 4 Women are caregivers

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

### CAREGIVING CAN BE

### LENGTHY

Half have provided care for at least two years



### INTENSE

Nearly 1/3 have provided care for at least 20 hours per week



### WHO ARE CAREGIVERS?

20% are 65 years old or older

37% are caring for a parent or parent-in-law

10% are providing care to someone with dementia



### **HOW DO CAREGIVERS HELP?**



Over 80% manage household tasks

Nearly 60% assist with personal care





### **FUTURE CAREGIVERS**

1 in 6 **NON-CAREGIVERS** expect to BECOME **CAREGIVERS** within 2 years

cdc.gov/aging

April 2020



# **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: <u>Barriers to Equity in Alzheimer's and Dementia</u>
   <u>Care (cdc.gov)</u>

### CAREGIVING AMONG AFRICAN AMERICAN ADULTS

2015–2018 Behavioral Risk Factor Surveillance System (BRFSS) Data from African American adults in 44 States, Puerto Rico, and the District of Columbia



# Nearly 1 in 4 African American adults are caregivers

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

### CAREGIVING CAN BE

### LENGTHY Nearly half

have provided care for at least two years

INTENSE

One third have provided care for at least 20 hours per week





### WHO ARE CAREGIVERS?

60% are women

14% are 65 years old or older

33% are caring for a parent or parent-in-law

9% of caregivers are providing care to someone with dementia



### **HOW DO CAREGIVERS HELP?**



80% manage household tasks

Over 50% assist with personal care





### **FUTURE CAREGIVERS**

# 1 in 6 NON-CAREGIVERS expect to BECOME CAREGIVERS within 2 years

cdc.gov/aging

CS 294325-A

#### April 2020

# SUBJECTIVE COGNITIVE DECLINE AMONG AFRICAN AMERICAN ADULTS

2015–2018 Behavioral Risk Factor Surveillance System (BRFSS) Data from African American Adults in 50 States, Puerto Rico, and the District of Columbia: People Aged 45 Years and Older

1 in 8



African American
adults aged 45
years and older are
experiencing
Subjective
Cognitive
Decline

SCD is self-reported MEMORY PROBLEMS that have been GETTING WORSE over the past year.

**54%** of people with SCD had to give up day-to-day activities



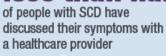


**85%** of people with SCD have at least one chronic condition

nearly one in two people with SCD say it interfered with social activities, work or volunteering



# less than half



47% of people with SCD need help with household tasks





### 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?



# **History of Burnout Research**

Workplace & health professionals (Freudenberger, 1975; C Maslach, 1976)

• Not widely studied

1500 publications Burnout becomes popularized in empirical research (Maslach & Schaufeil, 1993) Attempts to refine conceptualization and theory

Expands to different areas of life

Common use term, lacks centralized conceptualization Added to ICD-10, exclusive to occupational (World Health Organization, 2018)

 Few diagnostic criteria - "State of exhaustion"

1975–1976

1983-1990

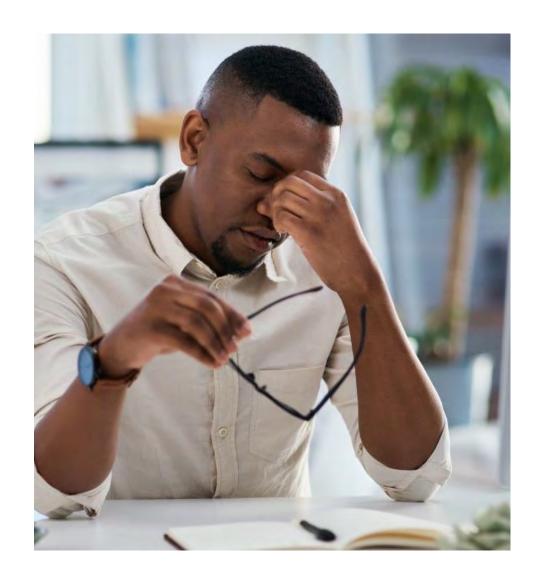
2000's

2010's

2018

### **Burnout**

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



### **Indicators of Exhaustion**

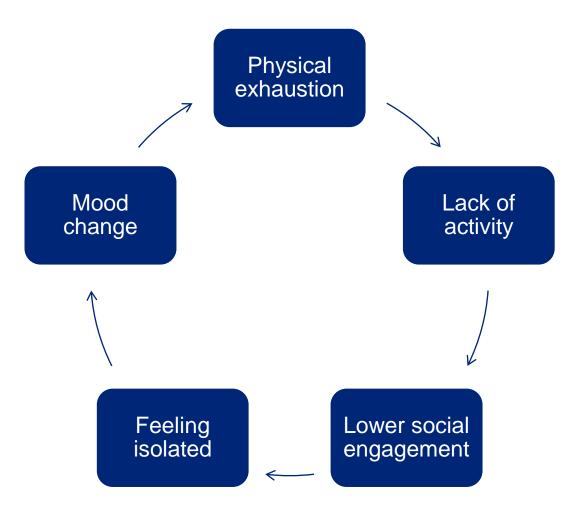
### Impacts manifest across domains

- 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**



# **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

# **JD-R Model Applied to Informal Caregiving**

Occupation	Informal Caregiving				
<ul> <li>Demands</li> <li>Physical costs (strenuous labor)</li> <li>Psychological costs (stress)</li> <li>Social costs (relationship impacts)</li> </ul>	<ul> <li>Burden</li> <li>Physical costs (ADL/IADL assistance)</li> <li>Psychological costs (stress/worry)</li> <li>Social costs (relationship with recipient or relationship impact)</li> </ul>				
<ul> <li>Resources</li> <li>Co-worker support</li> <li>Employee assistance programs</li> <li>Payment</li> <li>Desired advancement/training</li> </ul>	<ul> <li>Resources</li> <li>Social support</li> <li>Support services / professional care</li> <li>Reduction of financial burden</li> <li>Competency / reinforcement</li> </ul>				

### **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 & Jette, 1982; Buhr, Kuchibhatla, & Clipp, 2006)

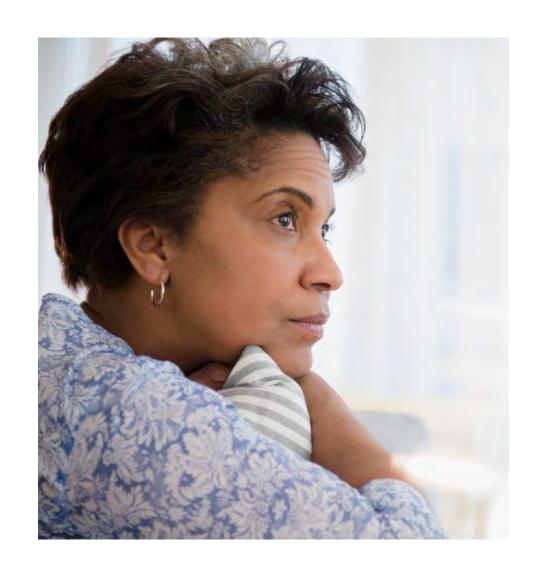
Prolonging transfer improves QoL and reduced financial burden



# **Caregiving Burdens and Stress**

### Health impacts of burden/burnout

- Nearly 1 in 5 caregivers reports fair or poor health
- Caregivers often <u>neglect their own health needs</u>, 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



# **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"

# 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 <u>created for informal caregivers</u>

• Informal Caregiver Burnout Inventory - 10 Item Form (James & Paulson, 2020)

# **Emerging Research on Caregiver Burnout**



### **Informal Caregiver Burnout Inventory (ICBI-10)**

(James & Paulson, 2020)

- 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.	Caregiving is physically exhausting.						

# 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

Ne Gerontologist Nr. 41, No. 5, 653-657 Copyright 2001 by The Gerontological Society of America

### The Zarit Burden Interview: A New Short Version and Screening Version

Michel Bédard, PhD, 12 D. William Molloy, MB, Larry Squire, MA, Sacha Dubois, BA, Judith A. Lever, MSc(A), and Martin O'Donnell, MRCP(I)

Purpose: The purpose of the study was to develop a short and a screening version of the Zarit Burden Interview ZBII that would be suitable across diagnostic groups of cognitively impaired older adults, and that could be used or cross-sectional, longitudinal, and intervention studies. Design and Methods: We used data from 413 careviers of cognitively impaired older adults referred to a nemory clinic. We collected information on caregiver surden with the 22-timen ZBI, and information about devandence in activities of daily living (ADLs) and the free yearcy of problem behaviors among care recipients. We used factor analysis and them-total correlations to reduce he number of thems while laxing into consideration diagnosis and change scores. Results: We produced a 12-time version (schort) and a 4-time version (screening) of

most consistently used in dementia caregiving research (Bedard, Pedlar, Martin, Malott, & Stones, 2000). It has been used in a variety of research designs, to discriminate between study participants (e.g., Molloy, Lever, Bédard, Guyart, & Butt, 1996), and to measure change over time, resulting from the progression of the care recipient's condition (e.g., Bédard, Molloy, Pedlar, Lever, & Stones, 1997), or from interventions aimed at reducing burden (e.g., Zarit, Antony, & Boutselis, 1987). A significant advantage of the popularity of the ZBI is that results

### The Zarit Burden Interview

- 0: NEVER
- 1: RARELY
- 2: SOMETIMES
- 3: QUITE FREQUENTLY
- 4: NEARLY ALWAYS

Please circle the response the best describes how you feel

Question		Score			
1 Do you feel that your relative asks for more help	han he/she needs? 0	1 2	3	4	
Do you feel that because of the time you spend we you don't have enough time for yourself?	ith your relative that 0	1 2	3	4	
3 Do you feel stressed between caring for your rela meet other responsibilities for your family or work		1 2	3	4	
4 Do you feel embarrassed over your relative's beh	aviour? 0	1 2	3	4	
5 Do you feel angry when you are around your rela	ive? 0	1 2	3	4	

### **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

# Responding to burden and burnout



### Burden

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



### **Burnout**

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

# **Supporting Caregivers: An Emerging Public Health Issue**

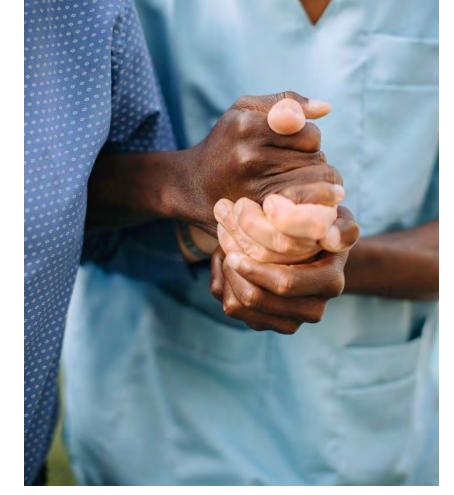
Millions of older adults and people with disabilities could not maintain independence without help of unpaid caregivers.

 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 <u>longevity</u> and <u>quality</u> of informal care.

# **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

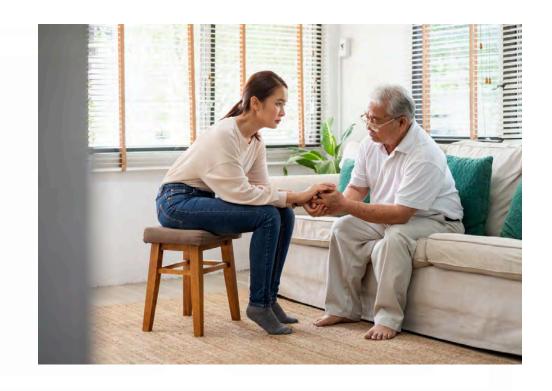
# Resources for Family Caregivers (Partial List)

- 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)

### **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.



### **Weekly Emails from the CDC**

CF

Centers for Disease Control and Prevention <no-reply@emailupdates.cdc.gov>
To O James, Gregory J

Retention Policy UHGInbox (90 days)

External Email

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# Alzheimer's Disease and Healthy Aging Alzheimer's Resources Resources Communication Resources Pata for Action Series Series







Expires 12/19/2022

### Reducing Alzheimer's Disease Risk



### Reducing Risk of Alzheimer's Disease



Making healthy lifestyle choices and managing chronic conditions can help lower your risk of Alzheimer's disease.

Learn more

Listen to the podcast

#### **Email from the Alzheimer's Association**

#### Dementia Caregiver Survey and upcoming events.



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Expires 12/24/2022

# LIVABLE FLORIDA LIVE WELL. AGE WELL.



#### We need your help with a very important survey!

The State of Florida, the Department of Elder Affairs, and the State Health Improvement Plan Priority Area 1 (DOEA/SHIP) aims to enhance support for those living with dementia and their caregivers through your responses to a dementia caregiver survey. Learn more below.

#### Background

Florida has the second-highest prevalence of Alzheimer's disease and related dementias (ADRD) with over 580,000 residents with a diagnosis. ADRD does not only affect the individual but also those who provide care for them and their family. In Florida, we have over 806,000 individuals providing unpaid care for their loved ones. This care is valued at over \$20.6 billion dollars. The number of people with ADRD is expected to increase in Florida by over 25 percent by 2025. Due to this reality, Florida is doing all it can to be dementia capable.

The dementia caregiver survey includes questions about:

- Support and services
- Caregiver health
- Respite and emergency respite programs
- Diagnosis and care planning

### 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.

### **Diversity In Healthcare Staff (continued)**

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

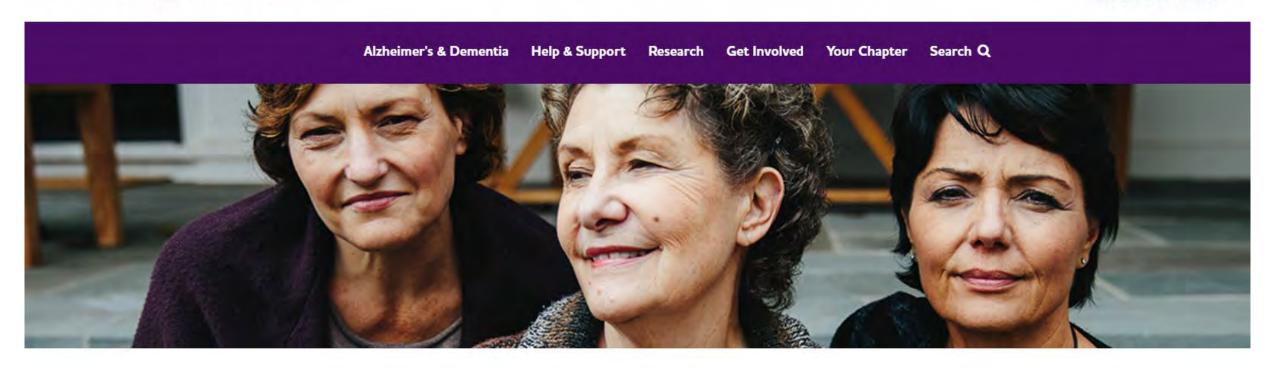
- Given their own experiences with discrimination, it is not surprising that non-White racial/ethnic populations feel it is important for Alzheimer's and dementia care providers to be more culturally competent.
- Responses from surveys indicate a strong desire for dementia health care providers who understand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

### **Alzheimer's Association Caregiving Webpages**

alzheimer's P association

bout News Events Professionals En Español E-ne

24/7 HELPLINE 800.272.3900



### Caregiving

Caregivers for Alzheimer's and dementia face special challenges.

### **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.

Alzheimer's Association Support Groups				Groups	*Groups mee	t in-person F	RSVP 800.272.3900 Updated 9/9/2021		
Type of group	County	Week	Week Day	Time	Location	Address	Facilitator	Notes	
Central a	nd North F	lorida C	hapter						
ES- Social	Brevard	Various	Monday	1:30 p.m.	One Senior Place	8085 Spyglass Hill Rd, Melbourne, FL 32940	Susan Blakeslee	Art Connects ALZ program, please call 800.272.3900 to register. Mondays, Aug. 16, 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 32168	Carolyn Land, Sheila Collins, Donna Bradley	Art Connects ALZ program, please call 800.272.3900 to register. Wednesdays, 9/29, 10/6, 10/13, 10/20, 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 Purdy and Anita Vargas	Please call 800.272.3900 to register. Couples Support Group for person with dementia (early stage) 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	850 S Palafox St., #103, Pensacola, FL 32502	Lelanya Taber		

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 8, 2022	9 a.m12 noon	In-Person	Walk to END ALZ - Pinellas County		<u>Learn More</u>	Pointer 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

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		<u>Learn More</u>	Raymond James Stadium	4201 N. Dale Mabry Hwy.	Tampa
Hillsborough	November 11, 2022	10 a.m2 p.m.	In-Person	Brain Bus Stop		Learn more	Employee Health Fair, Masonite		Tampa
Hillsborough	November 16, 2022	1 p.m2 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		<u>Learn More</u>	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	941.798.9622 ext. 402/404		Bradenton YMCA	3805 59th Street West	Bradenton
Manatee	November 2, 2022	10 a.m1 p.m.	In-Person	Brain Bus Stop		Learn more	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



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.

### **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.

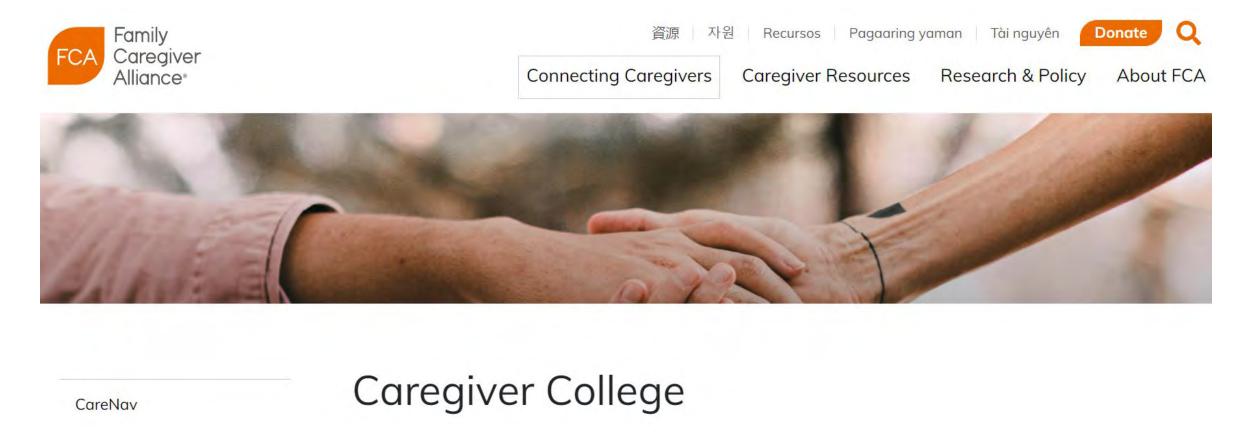
## These presentations allow caregivers to explore how communication changes when someone is living with Alzheimer's Disease

- 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

### Family Caregiver Alliance 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

### 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.

### **AARP Caregiving Site**



Link: AARP Resources for Caregivers and their Families

**BOLD Public Health Center of Excellence on Dementia Caregiving presents:** 

### The Public Health Opportunities and Challenges of Dementia Caregiving

June 14th-15th, 2022



### 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 socials 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

#### **Resources for Caregivers**

#### **ONECaregiver Resource Center**

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.

#### WeCareAdvisor

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.

#### Caring for People with Memory Loss Conference Virtual Library

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.

#### **Email from PHCOE**

#### Register for our upcoming event!



koffs004@umn.edu on behalf of phcoe-dc University of Minnesota <phcoe-dc@umn.edu>

Retention Policy UHGInbox (90 days)

Expires 1/4/2023

External Email

1 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



### **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

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/wpcontent/uploads/2020/08/AARP1316\_ExecSum\_CaregivingintheUS\_508.pdf

### Supporting Caregivers (CDC Site)

 https://www.cdc.gov/aging/publications/features/supportingcaregivers.htm?ACSTrackingID=USCDC\_944-DM71712&ACSTrackingLabel=Year-in-Review%202021&deliveryName=USCDC\_944-DM71712

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-advisorycouncil

Alzheimer's Association Caregiving Site:

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

Prevalence and Characteristics of Subjective Cognitive Decline Among Unpaid Caregivers:

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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/tJwtfumvrTgsHdXr4gyW3\_WbTSNwDzsDW\_38

Family Caregiving Advisory Council:

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

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/helpsupport/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

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

### **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

### **Questions?**

Thank you for your attendance today!

#### **Contact Information:**

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   Nicholas.James@va.gov

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