#### Caring for the Caregiver: Adapting and Thriving in Your Role

Morgen Hartford, MSW Southern Arizona Regional Director

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## **Objectives**

- Identify who is a caregiver
- Understand issues that caregiving can present
- Identify symptoms and signs of stress, burnout and depression
- Outline practical strategies for self-care to enhance well-being

#### Who Are Caregivers?

## A caregiver is anyone who provides help to another person in need.



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## Do You Do Any of The Following For Another Person?

- Shopping
- Housecleaning
- Paying bills
- Assisting with medications
- Providing assistance with dressing, showering or bathing

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## Do You Do Any of The Following For Another Person?

- Visit a family member or friend in a nursing home
- Phone a family member / friend regularly to check on them or see how they are?

#### Whether formal or informal, YOU are caregiver.

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#### At Some Point Everyone Will...



#### **Be A Caregiver**

#### Or

#### **Need a Caregiver**

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## **Caregivers Today**

- More than 50 million Americans are caregivers today
- 80% of caregivers are informal caregivers
- 75% of caregivers are women
- 59% of caregivers are still working
- 51% are over the age of 65



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#### MORE THAN

**15 MILLION AMERICANS** provide unpaid care for people with Alzheimer's or other dementias

IN 2016 these caregivers provided an estimated **18.2 BILLION HOURS** of care valued at over **\$230 BILLION** 

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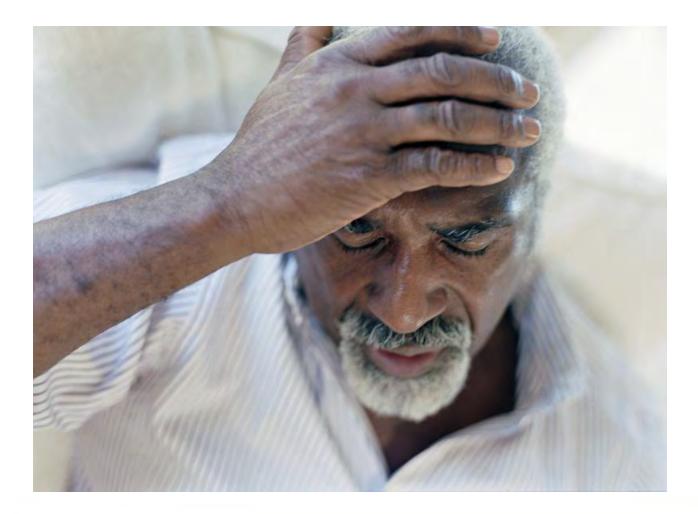
35% of caregivers for people with Alzheimer's or another dementia report that their health has gotten worse due to care responsibilities, compared to 19% of caregivers for older people without dementia

In 2017, Alzheimer's and other dementias will cost the nation \$259 billion By 2050, these costs could rise as high as \$1.1 TRILLION

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#### **The Impact of Caregiver Stress**



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## **Caregivers Deal With:**

- Emotional and physical strain
- Changing roles
- Changing relationships
- Competing demands / time deficits
- Increased isolation
- Financial burdens

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## Signs of Caregiver Stress: Physical

- Headaches
- Muscle tension
- Weight gain / loss
- Onset of chronic conditions (diabetes, heart problems, high blood pressure)
- Breathing problems / rapid pulse
- Exhaustion
- Upset stomach / bowel problems

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## Signs of Caregiver Stress: Emotional

- DENIAL
- Worry, fear, anxiety
- Anger, irritability, guilt
- Depressed mood, pessimism, lack of caring
- Memory loss, confusion
- Decreased problem-solving skills
- Feeling overwhelmed

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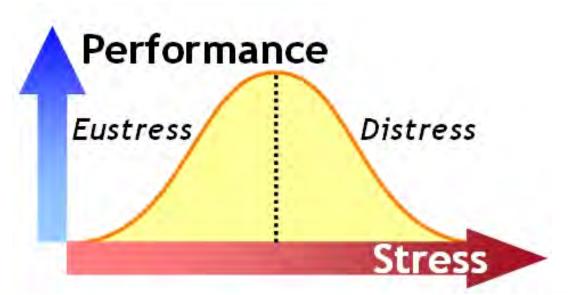
#### Signs of Caregiver Stress: Behavioral

- Nervous habits: teeth grinding, nail biting, pacing
- Sleep disorders
- Decreased concentration
- Smoking / drinking
- Crying
- Yelling, swearing, throwing things
- Giving up interests / withdrawal from social groups & family

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#### What is Stress?

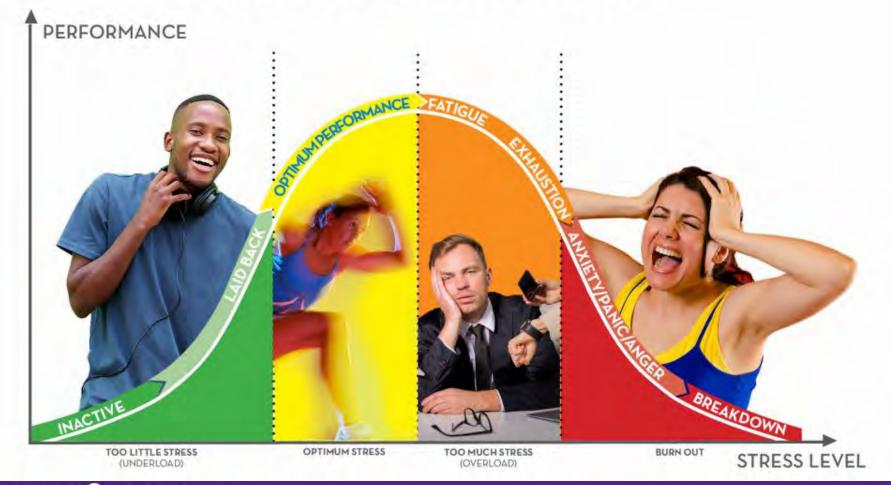
- Positive stress short term / happy events
- Negative stress too many at one time / unrelenting
- Stress has both an emotional and physical reaction



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#### **STRESS** & PERFORMANCE



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## **Caregiver Stress Check**

Do you....

- Feel like you have to do it all yourself, and that you should be doing more?
- Withdrawal from family, friends and activities that you used to enjoy?
- Worry that the person you care for is safe?
- Feel anxious about money or health care decisions?

## **Caregiver Stress Check**

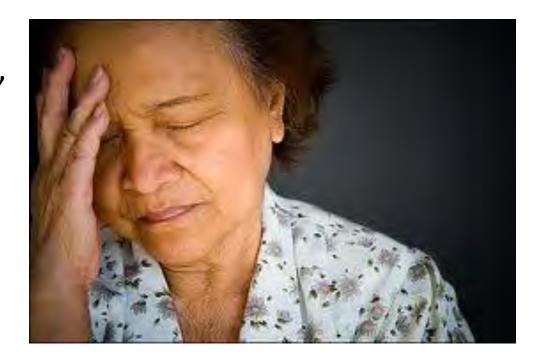
Do you.....

- Deny the impact of the disease and the effects on your family?
- Feel grief or sadness that your relationship with the person isn't what it used to be?
- Get frustrated and angry when the person with dementia continually repeats things and doesn't listen?
  - Have health problems that are taking a toll on you mentally and physically?



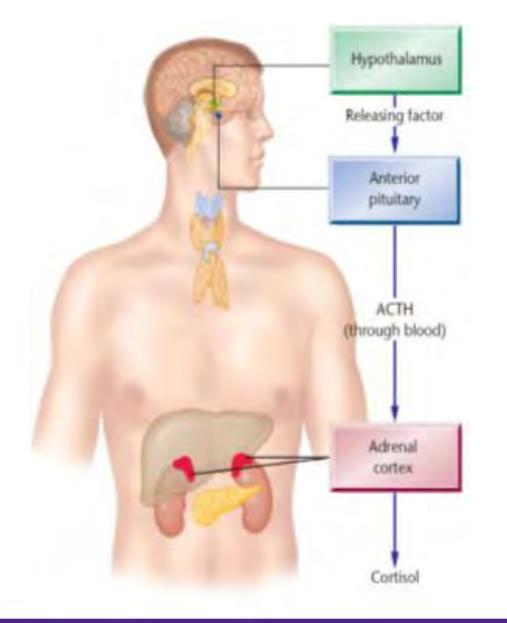
#### **Caregiver Stress Check: Results**

If you answered "yes" to any of these questions, you are likely experiencing stress.



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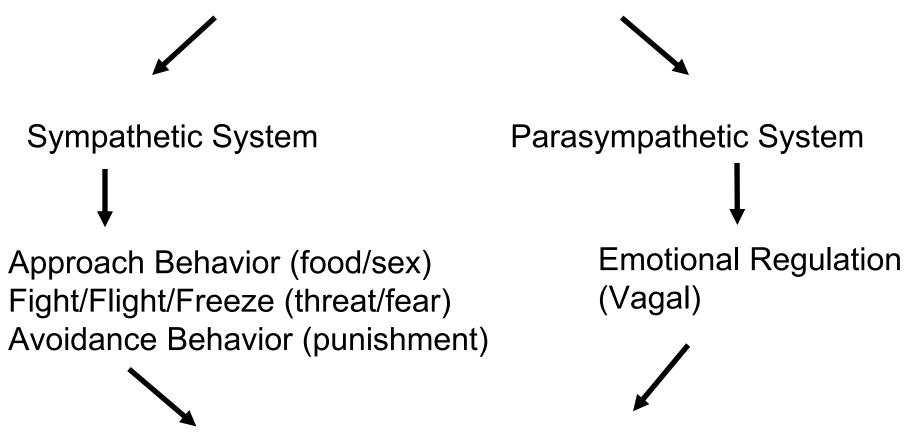


## Stress & the Body

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#### **Autonomic Nervous System**



**Behavior & Emotion** 

Adapted from RPBrown & PL Gerbert, 2012

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#### **Sympathetic Nervous System**



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## Parasympathetic Nervous System



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## Why is This Important?

- •Diminished immune responses, which means more frequent infection and increased risk of cancers
- Slower wound healing
- Higher incidence of hospitalization
- •Higher mortality rate
- •Poorer general health
- •Higher incidence of headaches, gastro-intestinal problems and insomnia
- •An increased risk of heart disease.

Family Caregiver Alliance, 2016

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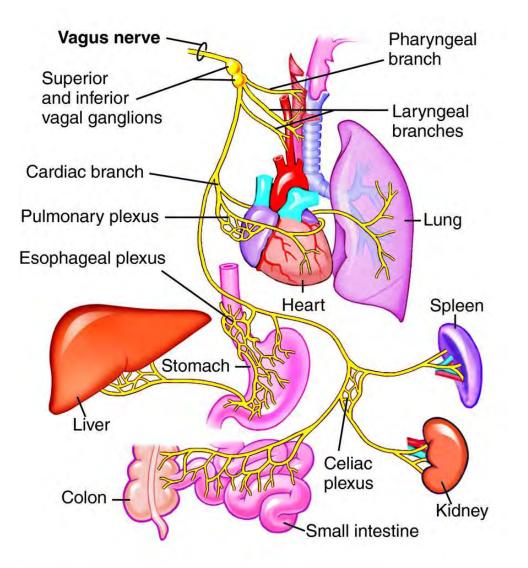
## What To Do? Tips to Help You Cope

- Recognize signs EARLY
- Identify sources of stress
- Understand what YOU can change and what cannot change – be realistic
- Give yourself credit, not guilt
- Take a break
- Take a BREATH!



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## What Happens in Vagus...

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#### Activation of the Parasympathetic Nervous System (PNS)

- •Vagus nerve, main pathway of PNS, is bidirectional
- •Breathing activates different pathways that stimulate the vagus nerve
- •Voluntary change in pattern of breath can alter activity of vagus nerve, emotional tone, attention and cognitive processes

Phillipot P & Blairy S., 2003

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#### **Let's Practice**



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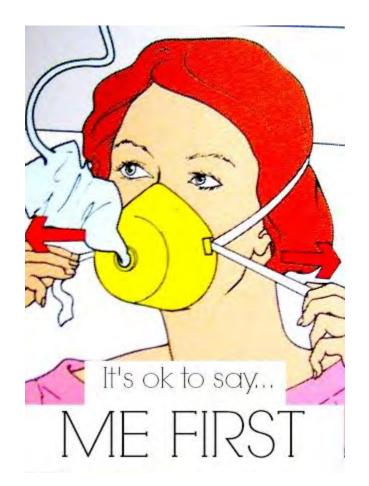
MUDRA

memegenerator.net

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#### **Seek Support for Yourself**



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Alzheimer's & Dementia 🔳 (2015) 1-9



#### Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective

Matthew Baumgart<sup>a</sup>, Heather M. Snyder<sup>b,\*</sup>, Maria C. Carrillo<sup>b</sup>, Sam Fazio<sup>c</sup>, Hye Kim<sup>a</sup>, Harry Johns<sup>d</sup>

> <sup>a</sup>Division of Public Policy, Alzheimer's Association, Washington, DC, USA <sup>b</sup>Division of Medical & Scientific Relations, Alzheimer's Association, Chicago, IL, USA <sup>c</sup>Division of Constituent Relations, Alzheimer's Association, Chicago, IL, USA <sup>d</sup>President & CEO, Alzheimer's Association, Chicago, IL, USA

Baumgart et al. 2016 *Alzheimer's & Dementia* 

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#### Factors that Increase/ Decrease Risk of Cognitive Decline

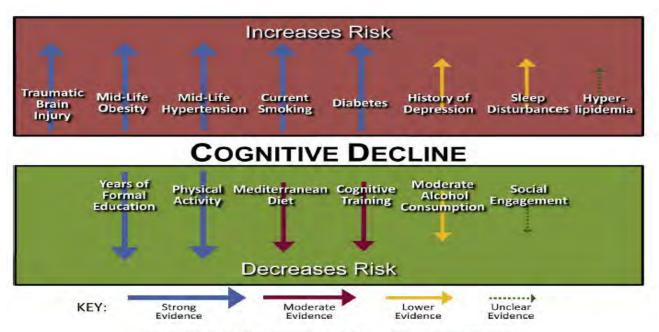


Fig. 1. Strength of evidence on risk factors for cognitive decline.

Baumgart et al. 2016 *Alzheimer's & Dementia* 

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#### Factors that Increase/ Decrease Risk of Dementia

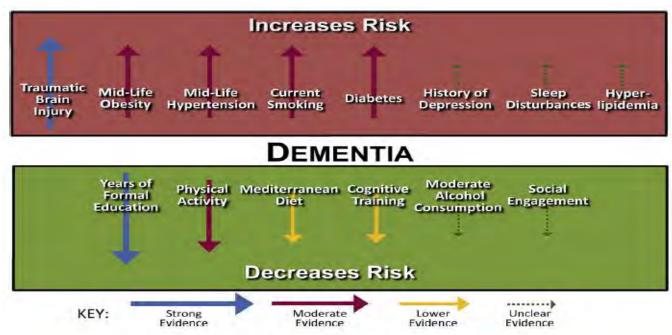


Fig. 2. Strength of evidence on risk factors for dementia.

Baumgart et al. 2016 *Alzheimer's & Dementia* 

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#### Break a Sweat

Stump

Yourself

Engage in regular cardiovascular exercise that elevates heart rate and increases blood flow. Studies have found that physical activity reduces risk of cognitive decline.

#### Hit the Books

Formal education will help reduce risk of cognitive decline and dementia. Take a class at a local college, community center or online.

#### **Butt Out**

Smoking increases risk of cognitive decline. Quitting smoking can reduce risk to levels comparable to those who have not smoked.

#### Follow Your Heart

Risk factors for cardiovascular disease and stroke – obesity, high blood pressure and diabetesnegatively impact your cognitive health.

Challenge your mind. Build a piece of furniture. Play games of strategy, like bridge.

#### **Buddy Up**

Staying socially engaged may support brain health. Find ways to be part of your local community or share activities with friends and family.

#### Take Care of Your Mental Health

Some studies link depression with cognitive decline, so seek treatment if you have depression, anxiety or stress.

#### **Heads Up!**

Brain injury can raise risk of cognitive decline and dementia. Wear a seat belt and use a helmet when playing contact sports or riding a bike.

#### **Fuel Up Right**

Eat a balanced diet that is lower in fat and higher in vegetables and fruit to help reduce the risk of cognitive decline.

Not getting enough sleep may result in problems with memory and thinking.

Catch

Some

Zzz's

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#### The Importance of Self-Care

- Decreases health problems
- Improves / maintains relationships
- Avoids "burnout"
- Reduces risk for depression
- Improves quality of care for care recipient



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## **Steps for Practicing Self-Care**

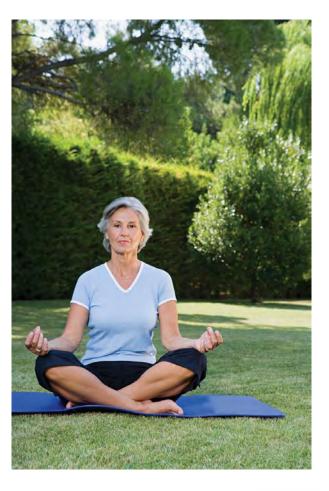
- 1. Practice relaxation
- 2. Nurture and nourish yourself
- 3. Know what condition you are dealing with
- 4. Make changes to the situation where possible
- 5. Know your resources!

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#### **Practice Relaxation**

- Stretching
- Music
- Mindful breathing
- Visualization
- Meditation



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#### **Nurture and Nourish Yourself**

- Exercise
- Nutrition
- Rest
- Limit caffeine & alcohol
- Socialization LAUGH!
- Get regular check ups



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## **Getting Support From Others Can:**

- Reduce stress and depression
- Increase knowledge and skill sets
- Increase coping & resiliency
- Improve quality of care and outcomes
- Help to avert crisis



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#### **Barriers to Getting Support**

- Beliefs
- Attitudes
- Lifelong patterns and habits
- Misconceptions
- Negative "Self-Talk"
- Not recognizing stress

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## **Know What You Are Dealing With**

- Understand the disease / condition
- Plan ahead
- Be honest about what you can / can't do
- Be aware of available programs / services

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### Make Changes to the Situation

- Assertive communication
- Arrange home health / respite
- Take scheduled breaks every day
- Accept help from others
- Join a support group
- Seek professional help

#### **Know Your Resources**

- Helplines
- Support Groups
- Education (CarePRO)
- Websites
- Support Circles
- Care Team
- Future Care Planning



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## Your Action Plan For Self-Care

- Make sure it is something YOU want to do
- Set goals that are reachable
- Ensure goals are specific to the stress indicator
- Answer each of these questions
  - What?
  - How much?
  - When?
  - How often?

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## **Caregiving: Joys & Rewards**

- New relationship with care participant
- Chance to give back and show love
- Sense of accomplishment
- Learn new skills, knowledge and inner strengths
- Increased compassion, personal growth
- New relationships through support groups
- Building memories

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## "Every day may not be good ... but there's something good in every day" - Alice Morse Earle

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## Thank you!

For More Information:

Alzheimer's Association 24 Hour Helpline 1-800-272-3900 mhartford@alz.org www.alz.org/dsw

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