

# Living With Pandemic Stress: Tools for Dementia Caregivers

Presented by

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**TEXAS**<sup>™</sup>  
  
THE STATE OF MIND

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# Alzheimer's Texas

A privately funded voluntary health organization formed in 1982 to serve Central Texans with Alzheimer's disease and their caregivers.

## MISSION

To eliminate Alzheimer's disease and related disorders through the advancement of research and to enhance care and support for individuals, their families, and caregivers.

## VISION

To create and sustain a dementia capable Texas in which persons with Alzheimer's and related disorders, and their families, receive quality care, effective treatments, and meaningful support.



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# Learning Objectives

- To identify and address the signs of caregiver burnout exacerbated by chronic pandemic related stress.
- To better understand the impact of the current pandemic on people living with dementia and their caregivers.
- To learn practical tools for coping and living with chronic pandemic related stress.
- To think about and share ways we are supporting ourselves or others who are caring for people with dementia during the pandemic.



# Causes of Caregiver Burnout

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**Lack of Control**

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**Unrealistic Expectations**

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**Role Confusion**

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**Neglecting Emotional, Physical & Spiritual Health**

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**Unreasonable or Conflicting Demands**

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**Lack of Privacy**



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# Additional Pandemic Stressors for Caregivers



Suspended or  
reduced adult day  
care and other  
respite services

Reduced peer  
support, socialization,  
& recreation options

Reduced basic needs  
support, such as meal  
and medication  
delivery services

Increased financial  
stressors related to  
pandemic job loss

No visitor policies in  
hospitals

Delays in accessing  
healthcare due to  
exposure risk

Increased monitoring  
of loved one with  
dementia

Changes to case  
management, mental  
health, and support  
group services

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# Heightened Anticipatory and Disenfranchised Grief

***Anticipatory Grief*** – occurs before death (or another great loss). Rather than death alone, this type of grief includes many losses, such as the loss of a companion, changing roles in the family, fear of financial changes, and the loss of dreams of what could be.

***Disenfranchised Grief*** – also known as hidden grief or sorrow, refers to any grief that goes unacknowledged or unvalidated by social norms. This kind of grief is often minimized or not understood by others, which makes it particularly hard to process and work through.



# Impact on Caregivers

92% of Alzheimer's caregivers say their stress is higher now because of the coronavirus.

80% of these Alzheimer's caregivers reported having one or more symptoms that are typically found in individuals experiencing severe stress.

- ☐ sleep problems – 36%
- ☐ vigilance/being 'super alert' – 34%
- ☐ difficulty concentrating – 29%
- ☐ irritable/angry behavior – 25%
- ☐ trouble experiencing positive feelings – 23%

73% of those taking care of people with Alzheimer's disease at home are unsure what would happen to their loved one if they got sick with COVID-19.

42% of caregivers are unsure what to do if their loved one with Alzheimer's becomes sick.

*UsAgainstAlzheimer's A-LIST – April 2020*

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# What Can Caregivers Do?

- Assess for Caregiver Burnout
- Develop a Plan for Caregiver Burnout Prevention
- Create Contingency plans for Caregiver or Care Recipient with a COVID Diagnosis
- Access mental health services, support groups, & social support networks
- Utilize respite care, if safe.





## Signs of Caregiver Burnout

Withdrawal from friends, family and other loved ones	Getting sick more often
Loss of interest in activities previously enjoyed/withdrawal from social activities	Feelings of wanting to hurt yourself or the person for whom you are caring
Feeling sad, hopeless, and/or helpless	Emotional and physical exhaustion
Changes in appetite and/or weight	Irritability
Changes in sleep patterns	Inability to concentrate



# Assessing for Caregiver Burnout

- Routinely review the signs of caregiver burnout
- Journaling about thoughts, feelings, and experiences
- Talking with a loved one or friend about how they perceive your mental and emotional health
- Ask your primary care doctor or mental health professional to assess for symptoms of depression, anxiety, and/or trauma.
- Completing formal assessments for Caregiver Burnout or Functioning:
  - The Caregiver Self Assessment Questionnaire (American Medical Association)
  - Revised Scale for Caregiver Self Efficacy (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002)



# Developing a Caregiver Burnout Prevention Plan

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**What brings you joy in the time of COVID19??? What do you look forward to???**

- ☐ Meditation and deep breathing exercises
- ☐ Meal service or grocery delivery, when possible
- ☐ Simple, inexpensive, highly enjoyable meals
- ☐ Enjoyable exercise in the home or other safe area
- ☐ Phone calls or Zoom with friends and family
- ☐ Support groups, virtual or otherwise
- ☐ Recreational groups, virtual or otherwise, such as book clubs
- ☐ Safe, enjoyable activities with your loved one with dementia (walks, visiting a neighbor's dog, getting a drive through dessert, scrapbooking, watching a movie)
- ☐ Favorite music or podcast
- ☐ Favorite magazines, books, TV shows
- ☐ Scheduled meetings with members or leaders from your faith community
- ☐ Regular mental health support appointments
- ☐ Scheduled breaks with a COVID safe respite plan

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# Caregiver Burnout Prevention Plan-Sample

- ☐ Meditate for 10 minutes daily
- ☐ 4 hour block of respite each week provided by friend who is vaccinated
- ☐ While on respite, go to my favorite coffee shop, read, and/or shop at stores where I feel safe with my mask on.
- ☐ Listen to Spotify favorite playlist for at least an hour each day
- ☐ Order out for dinner twice a week (Wed. and Fri. when I am most fatigued)
- ☐ Virtual book club (Sat. with Kristy and Gayle)
- ☐ Therapy sessions twice a month
- ☐ Caregiver support group once a month through church
- ☐ Take Dad to Slaughter Creek Park for a brief walk twice a week
- ☐ Work on family scrapbooks with Dad handing me pictures and reminiscing
- ☐ Visit Brian and his dog at a safe distance outside three times a week
- ☐ Journal daily, with specific attention to my self care needs.



**Self Care –  
A Vital  
Part of  
Burnout  
Prevention**

## Self Care Action Plan

My Signs of Burnout

My Stress Relievers

People I Can Reach Out To for Support

Helpful Reminders

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# Caregiver Contingency Plans for COVID Diagnosis

Who will take care of your loved one if you become ill with COVID19?

Create a plan of care for an alternative caregiver with important information.

- Daily schedule
- Medications/Dosage/Schedule
- Healthcare Providers (PCP, Local Urgent Care, Psychiatrist, etc.)
- Emergency Contacts/Others supportive family/Friends (phone numbers, email)
- Important Caregiver Resources
- Location of important documents, such as MPOA, Living Will, and Out of Hospital DNR
- Make sure various providers have the alternative caregiver listed as an approved contact
- Use a template to help you organize this information.

What will the plan of care look like if both you and your loved one are diagnosed?

CDC – My Care Plan Template: <https://www.cdc.gov/aging/publications/features/caregivers-month.html>

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# Access Formal or Informal Emotional Support

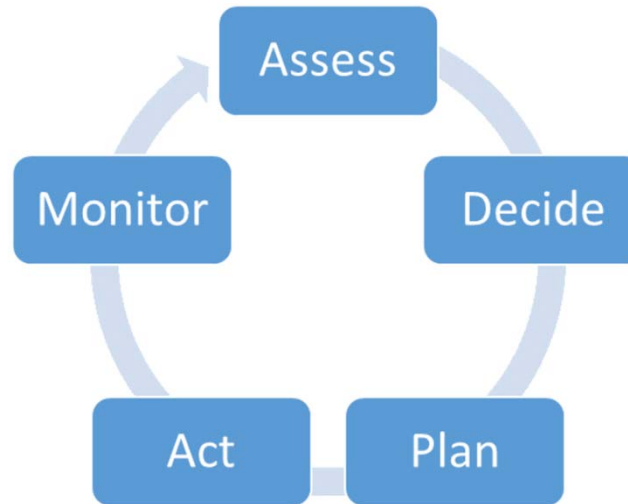
- Psychologists
- Clinical Social Workers
- Integrated Behavioral Health Clinics
- Support Groups (Dementia Caregivers, Anxiety, Depression)
- Faith Based Support Groups
- Faith Based Counseling
- Self Help/Self Management Groups (Examples: AA, NA)





# Accessing Respite Care

Caregivers should engage in ongoing assessment about whether respite care is safe for them and the person with dementia at any given time.



ARCH National Respite Network and Resource Center: <https://archrespite.org/national-respite-guidelines-for-covid-19>

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Questions?

What do you want us to know?

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