

# Transitioning Out of Community-Based Respite Care: When and How

Presented by

ALZHEIMER'S  
**TEXAS**<sup>™</sup>  
  
THE STATE OF MIND

Joan Asseff, LCSW-S

# Alzheimer's Texas

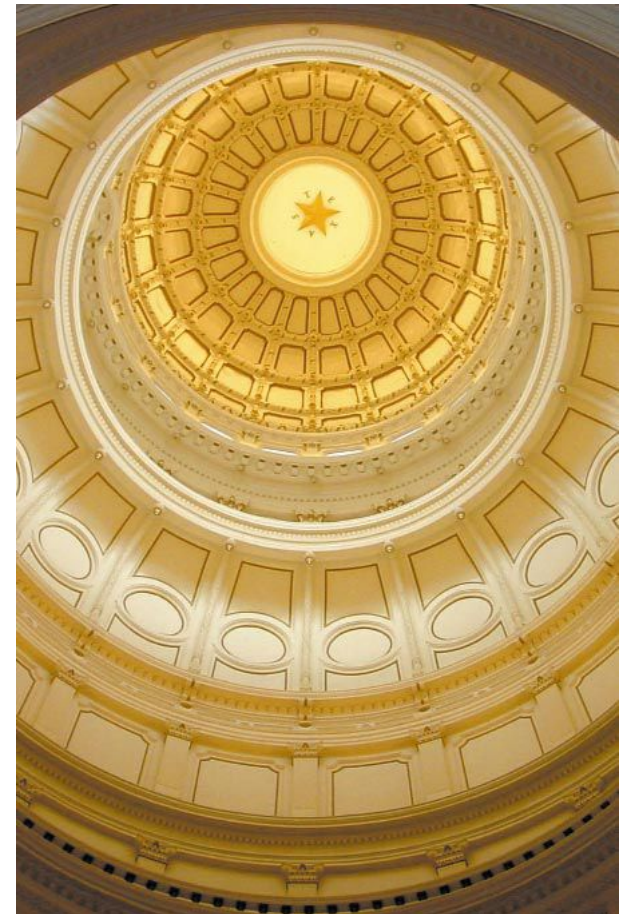
A privately funded voluntary health organization formed in 1982 to serve Central Texans with Alzheimer's disease and their caregivers.

## 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

- Identify signs and symptoms that might precipitate transition out of community-based respite care.
- Normalize the experience of transitioning out of a respite care group, including possible grief and loss for both caregivers and those living with dementia.
- Better understand practical, supportive methods for navigating this transition.
- Think about and share ways we are supporting ourselves or others who need to transition out of community-based respite care.

# Time for Transition: Signs and Symptoms

Frequent falls or injuries

Medical procedure with limited recovery

Stroke/Heart attack

Mood or behavioral changes that adversely impact the group

Lack of participation and/or enjoyment or ongoing distress

General decline in cognition and/or physical functioning

Unmanaged incontinence

Caregiver dissatisfaction



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# Normalizing Care Transitions

*“Inevitably, the time will come when a person with dementia needs to transition out of a community-based respite group.”*

In a sample of older adults diagnosed with dementia, 89.2% had at least one or more hospital stays and 54.9% had at least one stay in a skilled nursing facility in the past year (Callahan et al. 2015).

Among Medicare beneficiaries living with a diagnosis of Alzheimer’s Disease, 77% have three or more additional chronic conditions and 95% have at least one additional chronic condition (Centers for Medicare and Medicaid, 2016).

Persons living with dementia have greater odds of having potentially avoidable hospitalizations for their chronic conditions, such as diabetes and hypertension (Lin, Fillit, Cohen, & Neumann, 2013).



# Validate Experiences of Care Transitions

## Help

Help conceptualize transitions for persons with dementia not as events, but as another part of their dementia journey.

## Validate

Validate this transition by recognizing potential grief, loss, and chronic stress.

Disenfranchised Grief  
Anticipatory Grief  
Caregiver Burnout

## Provide

Provide time and space to hear the experiences of caregivers and persons living with dementia who are transitioning out of a respite care group.



# 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



# 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*



# Evidence-Based Strategies: Effective Care Transitions

Involve the individual and caregiver in establishing a respite plan of care, including goals of respite care.

Prepare and educate persons living with dementia and their caregivers about common transitions, such as eventually transitioning out of the respite care group.

Provide a Person-Centered approach to transitioning out of a respite group.

Create a strong interprofessional collaborative network to support persons living with dementia and their caregivers to make this transition effectively.



# **Involve the individual and caregiver in establishing a respite plan of care, including goals of respite care . . . .**

**Best outcomes for care transitions are associated with a person-centered, coordinated, responsive, and tailored approach.**

**Setting goals with individuals and caregivers can help everyone know when those goals are being met and when the respite group might no longer be the best fit.**

**If one does not already exist, consider adding the transition discussion to your respite group intake, monitoring, and discharge processes.**

**CDC – My Care Plan Template:**

**<https://www.cdc.gov/aging/publications/features/caregivers-month.html>**



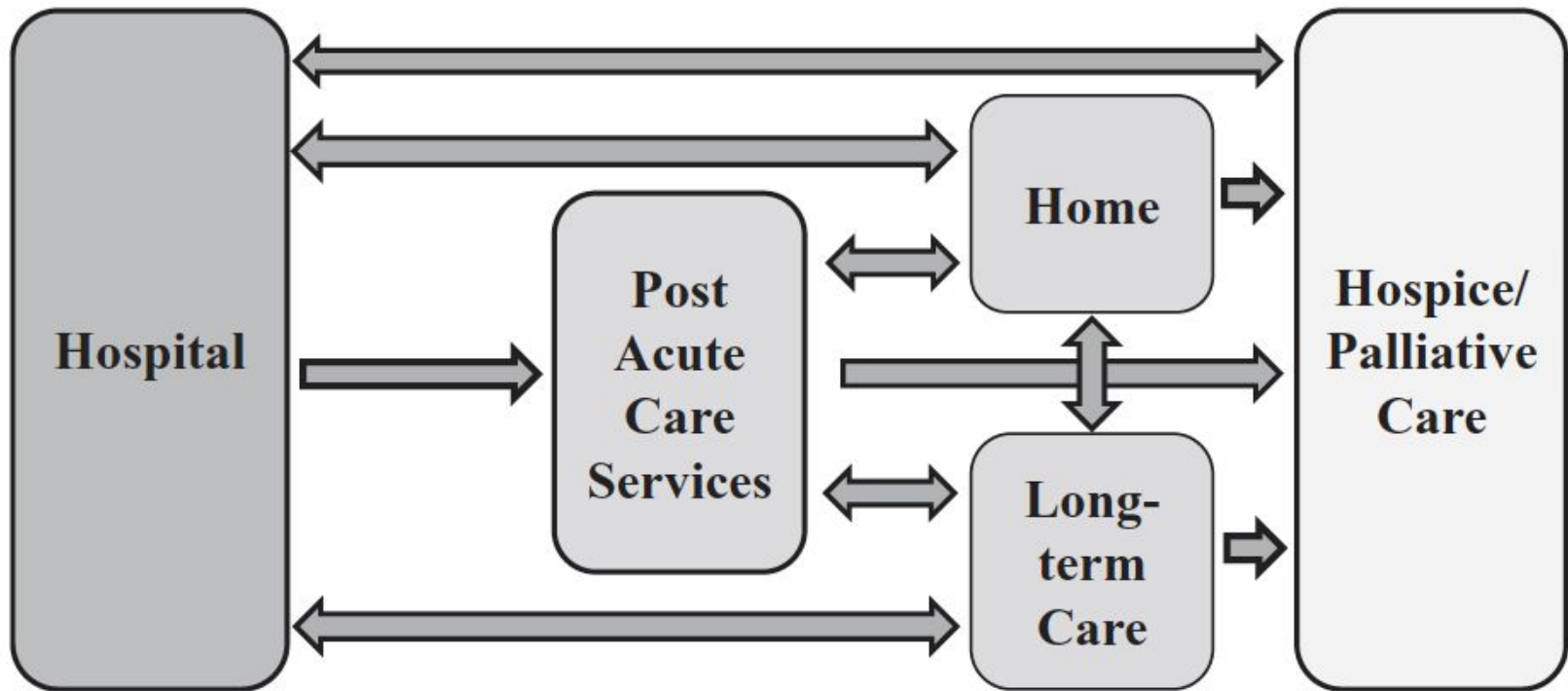
## **Prepare and educate persons living with dementia and their caregivers about common transitions, including the transition out of a respite care group . . .**

**This preparation should occur before, during, and after transitions, as part of an overall respite plan of care.**

**Provide literature and tools that normalize and educate individuals and caregivers on transitions throughout various levels of care.**

**Utilize routine follow up or “check-ins” to evaluate the respite plan of care, goals of respite care, and any potential need for an alternative form of respite care. “Is this group still meeting your and your loved one’s respite needs?”**





**Figure 1.** Common transitions in care across and between settings and providers.

(Hirschman and Hodgson, 2017)



# Provide a Person-Centered approach to transitioning out a respite group . . .

A Person-Centered approach is best practice.

A person-centered approach to care transitions considers the needs, preferences, values, cultural traditions, family system, and other factors identified by the person with dementia and their caregiver.

Many clinicians and healthcare providers are not trained in this approach.



# Create a strong interprofessional collaborative network to support persons living with dementia and their caregivers to make this transition effectively . . .

Be prepared to share resources with caregivers.

- Support Groups
- Attendant Care Organizations
- General and Mental Health Clinics
- Caregiver Support Agencies (Areas on Aging, Alzheimer's Texas, AGE, etc.)
- Geriatric or Medical Case Managers
- Texas Health and Human Services **855-YES-ADRC** (855-937-2372);  
<https://www.hhs.texas.gov/services/aging/long-term-care/aging-disability-resource-center/are-you-a-family-caregiver>
- Private Duty Caregivers

Have a process for follow up with the caregiver transitioning out of your respite group.



Evidence-Based  
Interventions  
for  
Transitional  
Care

Karen B Hirschman, PhD, MSW, Nancy A Hodgson, PhD, RN, FAAN, Evidence-Based Interventions for Transitions in Care for Individuals Living With Dementia, *The Gerontologist*, Volume 58, Issue suppl\_1, February 2018, Pages S129–S140, <https://doi.org/10.1093/geront/gnx152>

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Questions?

What do you want us to know?



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