



# CAREGIVER TRAINING CAMP

# Caregiver Playbook

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# Caregiver Playbook

## Overview

1. The six stages that caregivers go through during their caregiving journey (based on the framework by Denise M. Brown, from [www.CareGiving.com](http://www.CareGiving.com))
2. The different domains of caregiving tasks
3. Tasks for each stage of caregiving
4. A brief list of resources to get you started in each stage of caregiving

Please note that resources listed here are just to get you started and are not intended to be a complete list. There are many great agencies in central Texas to help you on your caregiving journey.

Please note that the person receiving care will be referred to as “your person” or “the person” throughout this guide.

## Key to symbols

### Resource

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AGE of Central Texas  
[www.ageofcentraltx.org](http://www.ageofcentraltx.org)



Caregiving in Central Texas:  
A Community Resource Guide  
[www.agingervicescouncil.org](http://www.agingervicescouncil.org)



Website



Publication, booklet, or book

### Domain of Caregiving

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Maintaining the Household



Advocacy & Care Coordination



Physical Support



Decision-making & Surrogacy



Emotional & Social Support

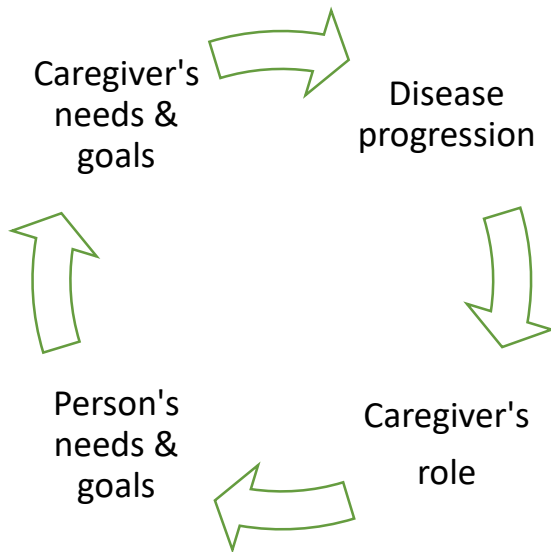


Caregiver Self-care



Health & Medical Care

## Caregiving changes over time



As the disease progresses over time, the caregiver's role also changes. Additionally, the person's needs and goals change and the caregiver's needs & goals change. This guide is intended to help you navigate these changes and provide you with a starting point in your current stage of caregiving.

This is not a clear cut process; however, transition from one stage of caregiving to another is often prompted by a tipping point. Often, a tipping point is found in the physical domain (see below), and relates to what care is needed and where it is provided. For example, is there care that cannot be provided in the person's home? Has a large change in medical status occurred, such as a hospitalization? A tipping point does not necessarily mean that a large change must take place; however, it is important to reassess the caregiving situation when one occurs.

## What stage of caregiving am I in?

**Stage 1:  
The Expectant  
Caregiver™**

**In the near future, I may help a family member or friend.**  
Feeling concerned about person needing assistance, based on person's age, medical condition(s), and/or living situation.

**Stage 2:  
The Freshman  
Caregiver™**

**I'm beginning to help a family member or friend.**  
Starting to assist person and learning about what caregiving tasks need to be done

**Stage 3:  
The Entrenched  
Caregiver™**

**I am helping a family member or friend.**  
Experiencing daily or constant involvement with caregiving

<b>Stage 4: The Pragmatic Caregiver™</b>	<b>I am <i>still</i> helping a family member or friend.</b> Approaching caregiving with a practical and realistic approach, caregiver has accepted the caregiving role and uses community services for help and support
<b>Stage 5: The Transitioning Caregiver™</b>	<b>My role is changing.</b> Caregiving as I know it is ending, because my person lives in a care facility.
<b>Life After Caregiving</b>	<b>My caregiving has ended.</b> Finding new meaning and purpose in life after caregiving

## What are the domains of caregiving?



### Maintaining the Household

Household tasks are also known as supportive care, or Instrumental Activities of Daily Living (IADLs) and include:

- Shopping
- Laundry
- Meal preparation
- Transportation
- Medication management
- Bills & money management
- Using the phone or other forms of communication



### Physical Support

Physical care is also known as Activities of Daily Living (ADLs) and include:

- Mobility
  - Walking
  - Transferring (getting in & out of bed; moving between bed & wheelchair)
- Bathing or showering
- Grooming
- Dressing
- Feeding
- Toileting
  - Getting to & from the toilet
  - Maintaining continence
  - Handling incontinence



## Emotional & Social Support

Quality of life and overall wellbeing are built on emotional health and connectedness to others. Caregiving tasks in this domain include:

- Providing companionship
- Discussing ongoing life challenges with the person
- Facilitating & participating in leisure activities
- Helping the person manage emotional responses
- Managing family conflict
- Troubleshooting problems



## Health & Medical Care

Most likely these are the tasks that come to mind when people generally think of caregiving and include:

- Monitoring the person's condition
- Medication management
- Symptom management
- Interpreting behaviors
- Nutrition
- Managing acute conditions (such as fever or infection)



## Advocacy & Care Coordination

Caregivers speak up for your person's wishes and making sure that they have the best health care and quality of life. Tasks include:

- Navigating systems of care (medical and community services)
- Making decisions about participation in programs & services
- Serving as a primary communication link among all parties



## Decision-making & Surrogacy

Assessing the need for legal and financial documents, such as:

- Advanced Directives
  - Directive to Physicians ("Living Will")
  - Texas Out-of-Hospital Do Not Resuscitate Order
- Powers of Attorney
  - Financial
  - Medical
- Living Trusts
- Wills



## Caregiver self-care

What can you do on a regular basis to keep yourself healthy?

### Caregiver's

- Physical health
- Mental health
- Financial health
- Goals for his/her life
- Goals for successful caregiving
- Coping with emotions related to caregiving
- Coping with changes in relationship with your person
- Emotions related to historical relationship with person and other family members

## Stage 1: The Expectant Caregiver™

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*In the near future, I may help a family member or friend.*

*Learn and understand your person's needs: health, financial, legal and emotional.*

*Prepare, research options, gather information.*

## Caregiving Tasks



Talk with the person and:

- Ask about feelings and values related to their health and quality of life.
- Learn about daily routine & preferences. What is most meaningful to them in their daily life?
- Inquire about important social connections, activities, and events.
- Support them in documenting significant events and stories from their life, if they wish to do so.



Understand and document medical & health status (providers, diagnoses, insurance, medications, etc.)



Talk with other family members and friends who may be involved in caregiving. Have an open discussion about your concerns and the person's values and preferences.



Get legal & financial affairs in order.

- Ask to join your person as they meet with important professionals.



What are your goals for your life as you embark on caregiving?

- What brings you joy? How can you make some time for that in your daily life?
- What steps can you take for **your** overall health and well-being?

## Where to start



**AGE Caregiver Information and Resources Center** has information, education, resources, ideas, and 1-1 caring consultations to help you and your person navigate the challenges of aging. Email us at [resourcecenter@ageofcentraltx.org](mailto:resourcecenter@ageofcentraltx.org).

More information about our services for caregivers can be found at: [www.ageofcentraltx.org/index.php/caregivers](http://www.ageofcentraltx.org/index.php/caregivers)



**Caregiving in Central Texas: A Community Resource Guide** is a free, published book that provides an overview of resources by service type in Central Texas. [www.agingservicescouncil.org](http://www.agingservicescouncil.org)



**Family Caregiver Alliance** has an array of resources, including a caregiving 101 guide for those starting out on the caregiving journey. [www.caregiver.org](http://www.caregiver.org)



**AARP Prepare to Care** is a practical tool with information, resources and checklists to help you get organized and find support. [www.aarp.org/caregiving/prepare-to-care-planning-guide](http://www.aarp.org/caregiving/prepare-to-care-planning-guide)

## Stage 2: The Freshman Caregiver™

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*I'm beginning to help a family member or friend. Starting to assist person and learn about what caregiving tasks need to be done.*

*Experiment to find solutions that work and to move on from what doesn't.*

## Caregiving Tasks



### Organize finances

- Develop a budget, keep track of expenses, set up a filing system for bills and receipts.
- What financial resources are needed? What community services provide financial support?



Learn about techniques to provide physical care. For example, proper transfer and bathing techniques. This learning will help to provide the best care for your person and to have confidence in your caregiving skills.



### Reflect on current emotions:

- How are you and your person getting along?
- What is causing stress for both of you?
- Continue to ask the person about their needs & wishes. What are their fears about the future? What are yours?



Learn as much as you can about the disease or condition and the expected disease progression.

### Create a system to stay organized:

- Detail information about person's medical history, medications, needs, questions and notes from doctor's visits, changes and concerns about person, etc.



Schedule regular family check-ins or meetings to keep everyone informed of person's situation, needs, expectations for care, etc.



### Check-in with yourself about your emotional support and quality of life.

- Find ways to spend time alone and to enjoy your hobbies and interests.
- Think about what caregiving duties you are comfortable and not comfortable with. What steps can you take to prepare?
- Join a caregiver support group to talk with others experiencing similar challenges.

### Schedule regular caregiving breaks.

- Use community services, family members, friends, etc.



- Even if you feel you don't need regular breaks now, you will have them in place for when you do feel you need them.

Ask: What if.... and create a back-up plan to address these possibilities.

## Where to start



**Caregiver Conferences and seminars** provide opportunities to learn about different aspects of caregiving and connect with other caregivers.

[www.ageofcentraltx.org/index.php/caregivers](http://www.ageofcentraltx.org/index.php/caregivers)

**AGE Caregiver Resources and Information Center** can connect you with community services that may help you wherever you are in your caregiver journey, including information about financial assistance.

Email us at [resourcecenter@ageofcentraltx.org](mailto:resourcecenter@ageofcentraltx.org).



**Section: Case Management** can help you identify and access needed services and resources and can support your person in living independently. [www.agingservicescouncil.org](http://www.agingservicescouncil.org)



**Daily Caring** sends daily information directly to caregivers over email, including articles, practical tips, and caregiver support.

[www.dailycaring.com](http://www.dailycaring.com)



**CareSharing: A reciprocal approach to caregiving and carereciveing and the complexities of aging, illness or disability** by Marty Richards

The book describes a unique approach to caregiving, "caresharing," where the "cared for" and the "carer" share a deep sense of connection. Each has strengths and resources. Each can teach the other. Each can share in grief, hope, wisdom and forgiveness.

**The ABA/AARP Checklist for Family Caregivers: A Guide to Making It Manageable** By Sally Balch Hurme

This book of checklists and to-do lists helps you navigate, track, record, and update the many details of caregiving. If you aren't sure where to start, the book includes step by step, what you need and why.

[www.aarp.org/entertainment/books/bookstore/home-family-caregiving/info-2016/ebook-checklist-caregivers.html](http://www.aarp.org/entertainment/books/bookstore/home-family-caregiving/info-2016/ebook-checklist-caregivers.html)

## Stage 3: The Entrenched Caregiver™

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*I am helping a family member or friend; daily or constant involvement with caregiving.*

*Find the strength to continue. Accept help and support.*

### Caregiving Tasks



Create a daily routine for your person and for yourself.  
Think about current household budget in terms of future financial needs for care. How do finances impact care decisions?



What are your person's current physical needs? How can they be met, respecting both of your limits and values?

Understanding your person's limits will help schedule your day and organize your help.

- Limits will change regularly, so be aware of change in tolerance and fatigue.
- If you aren't sure how much help to schedule, add more than you think you might need – you can't have too much help.



There will be bad moments or bad days; forgive yourself and your person. Continue regular emotional support for your person and for yourself.



Continue to learn about disease progression to prepare for the future.



Increase help from community services as your person's needs increase and as their disease progresses.



Recognize your limits, in your caregiving role and in your day.

- Identify times, tasks, responsibilities that bring dread, frustration or anger. How can you arrange help and support?
- Your limits aren't failures but opportunities to put in place solutions to stay successful.

Set boundaries which protect your time, values, and well-being.

- For example, tell your person and others when you are not available because you are taking your daily break.

Take regular weekly, monthly, annual breaks or vacations and arrange for family or facility care.

## Where to start



**CaregiverU** offers free, evidence-based caregiver classes in many locations in Central Texas. **Powerful Tools for Caregivers** is a series of classes designed to empower family caregivers of older adults to take better care of themselves. The “tools” learned in the six week series benefit caregivers by helping them reduce stress, improve caregiving confidence, establish balance in their lives, communicate their needs, make tough decisions and locate helpful resources. For more information and to find a class near you, please visit [www.caregiverucentx.org](http://www.caregiverucentx.org).

The **AGE Thrive Social & Wellness Centers** provide exceptional daytime care for older adults with physical needs or memory loss. Your person can enjoy an active, social day while receiving the care and support he or she needs in a vibrant community setting. [www.ageofcentraltx.org/index.php/caregivers/adult-day-health-care-centers](http://www.ageofcentraltx.org/index.php/caregivers/adult-day-health-care-centers)

The **Health Equipment Lending Program** provides free durable medical equipment, such as wheelchairs and shower chairs, as well as incontinence supplies. Email us at [equipment@ageofcentraltx.org](mailto:equipment@ageofcentraltx.org) or call 512-600-9288.



**Family Caregiver Alliance YouTube Channel** offers a variety of instructional videos such as, transfer skills, bathing, dressing, and many more skills. [www.youtube.com/user/CAREGIVERdotORG](http://www.youtube.com/user/CAREGIVERdotORG)



**Caring for Your Parents: The Complete Family Guide (AARP®)** offers both sensitive counsel and a practical road map. The book guides readers through a new, creative approach to caregiving that turns familial duty into a journey of emotional development and resolution. [www.aarp.org/entertainment/books/bookstore/home-family-caregiving/info-2016/how-to-care-parents.html](http://www.aarp.org/entertainment/books/bookstore/home-family-caregiving/info-2016/how-to-care-parents.html)

## Stage 4: The Pragmatic Caregiver™

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*I am still helping a family member or friend. I'm wondering when it's time to make a big change, like moving to a care facility or hiring round-the-clock care.*

- *Approaching caregiving with a practical and realistic approach, caregiver has accepted the caregiving role*
- *First person experience caring for person in a variety of situations & settings*
- *Using community services to help person*

*Reflect to gain a greater acceptance and understanding of your person and your caregiving journey. Welcome opportunities for connection and forgiveness.*

### Caregiving Tasks



Make sure finances are arranged for the additional care that is now needed.



In what areas is the person requiring more assistance than you feel you can give?



Do you feel that the challenges are outweighing the benefits in the current caregiving situation – for both of you?  
Are you experiencing a lot of conflict with your person, on a daily basis?  
Are you both frequently frustrated?  
Where you can, use creativity to make daily tasks fun – play music, tell jokes etc.



Are there medical or health needs that you find extremely challenging?  
Do you feel a minor change in the person's health condition could cause a health crisis?



Does the current caregiving situation meet the person's values, as they have been discussed in the past?



Let go of the past, your expectations, and focus on the present and what serves you.

What does it mean to be successful in your caregiving? Are your expectations realistic?

Start to think about your future – your dreams and what brings you joy.

## Where to start



**AGE Caregiver Resources and Information Center** connects you with local to Central Texas housing navigator resources, for how to find facility care. Email us at [resourcecenter@ageofcentraltx.org](mailto:resourcecenter@ageofcentraltx.org).

The **AGE Thrive Social & Wellness Centers** provide exceptional daytime care for older adults with physical needs or memory loss. Your person can enjoy an active, social day while receiving the care and support he or she needs in a vibrant community setting.

[www.ageofcentraltx.org/index.php/caregivers/adult-day-health-care-centers](http://www.ageofcentraltx.org/index.php/caregivers/adult-day-health-care-centers)



**Section: Housing Alternatives** includes information about different levels of care, what to look for in a facility, and questions to ask.

[www.agingservicescouncil.org](http://www.agingservicescouncil.org)



**Long-Term Care Information-** National Institute on Aging

[www.nia.nih.gov/health/caregiving/long-term-care](http://www.nia.nih.gov/health/caregiving/long-term-care)

**When It's Time for a Nursing Home** by Barry J. Jacobs

[www.aarp.org/caregiving/basics/info-2017/parents-nursing-home-choices-bjj.html](http://www.aarp.org/caregiving/basics/info-2017/parents-nursing-home-choices-bjj.html)



**When Someone You Love Needs Nursing Home, Assisted Living, or In-Home Care** by Robert F. Bornstein PhD and Mary A. Languirand PhD

This guide provides answers, dispels myths, anticipates needs, and provides strategies for dealing with every aspect of in-home and facility care.

## Stage 5: The Transitioning Caregiver™

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*My role is changing. Caregiving as I know it is ending, because my person lives in a care facility. My focus is now on my relationship with the person, supervising facility care, and coping with this change.*

## Caregiving Tasks



Monitor physical care at facility to ensure that it aligns with person's values.



Return to your relationship with the person prior to caregiving. Be present with and focus on enjoying time with your person, in whatever way feels right to you.

Get support with difficult emotions, for either you or your person.

Find joy in shared activities and times of connection with your person, family, and friends. Think about your relationship with your person – as a family member or friend, not just as a caregiver.



Consider hospice care, with a focus on quality of life, support and comfort.



Advocate for your person with the staff and management of the care facility.



Make sure care facility makes decisions in line with person's documented preferences and values.



Acknowledge that you have done everything you could for your person. Look back on your caregiving with pride.

Take breaks as you feel it is best – for both you and your person.

Allow time to grieve and process your emotions – about the person, about caregiving, about this change. Be patient with yourself and with this transition.

Start thinking about what you will do when caregiving ends. Be curious about what's next for you.

## Where to start



**AGE Caregiver Resources and Information Center** can help you find information, resources, and support for your unique situation and stage of caregiving. Email us at [resourcecenter@ageofcentraltx.org](mailto:resourcecenter@ageofcentraltx.org).



**Section: End of Life and Hospice Care**  
[www.agingservicescouncil.org](http://www.agingservicescouncil.org)



**Transition to Care** has tips on transition to a facility  
[www.careconversations.org/transition-care](http://www.careconversations.org/transition-care)

### **Transitioning From Primary Caregiving: How to Adapt Your Role in Long-Term Care**

[www.familynursingcare.com/transitioning-from-primary-caregiving-how-to-adapt-your-role-in-long-term-care](http://www.familynursingcare.com/transitioning-from-primary-caregiving-how-to-adapt-your-role-in-long-term-care)



### **Meditations for Caregivers: Practical, Emotional, and Spiritual Support for You and Your Family** By Barry J. Jacobs Psy.D., Julia L. Mayer Psy.D.

This book is a blend emotional of spiritual motivation to maximize the gains of caregiving while minimizing the strains. Sections include accepting your feelings, embracing rewards, seeking support and managing stress, with anecdotes from the authors' personal and clinical experiences. [www.aarp.org/entertainment/books/bookstore/home-family-caregiving/info-2016/meditations-for-caregivers.html](http://www.aarp.org/entertainment/books/bookstore/home-family-caregiving/info-2016/meditations-for-caregivers.html)

## Life After Caregiving

*Finding new meaning and purpose in life after caregiving. Integrate your former role as a caregiver into your life going forward.*

### Caregiving Tasks



Treasure memories of your person and celebrate them in the way that feels right to you.



Consider sharing the information you have learned with other caregivers, especially wisdom earned about navigating healthcare and community services.



Appreciate the challenges you overcame, the new skills you developed, and the lessons learned.

Honor the person you provided care for by finding a meaningful life after caregiving.

## Where to start



**AGE Caregiver Resources and Information Center** can answer your questions and help point you in the right direction for the next chapter of your life. Email us at [resourcecenter@ageofcentraltx.org](mailto:resourcecenter@ageofcentraltx.org).



**Section: Support Groups**  
[www.agingservicescouncil.org](http://www.agingservicescouncil.org)



**The Christi Center** provides grief support groups, information and resources. More information can be found at [www.christicenter.org](http://www.christicenter.org)

### **When Caregiving Ends – The Family Caregiver Alliance**

[www.caregiver.org/when-caregiving-ends](http://www.caregiver.org/when-caregiving-ends)

### **Taking Care Of Yourself & Managing Time After Being A Caregiver**

[www.thememorycenter.com/taking-care-of-yourself-managing-time-after-being-a-caregiver/](http://www.thememorycenter.com/taking-care-of-yourself-managing-time-after-being-a-caregiver/)



**After Caregiving Ends, A Guide to Beginning Again: Support, Suggestions and Stories to Help You Heal and Step Into Next** by Denise M Brown

This book has guidance to help you cope with two losses—the loss of your caregiving role and the loss of your family member or friend – and find a way to move forward into the next chapter.

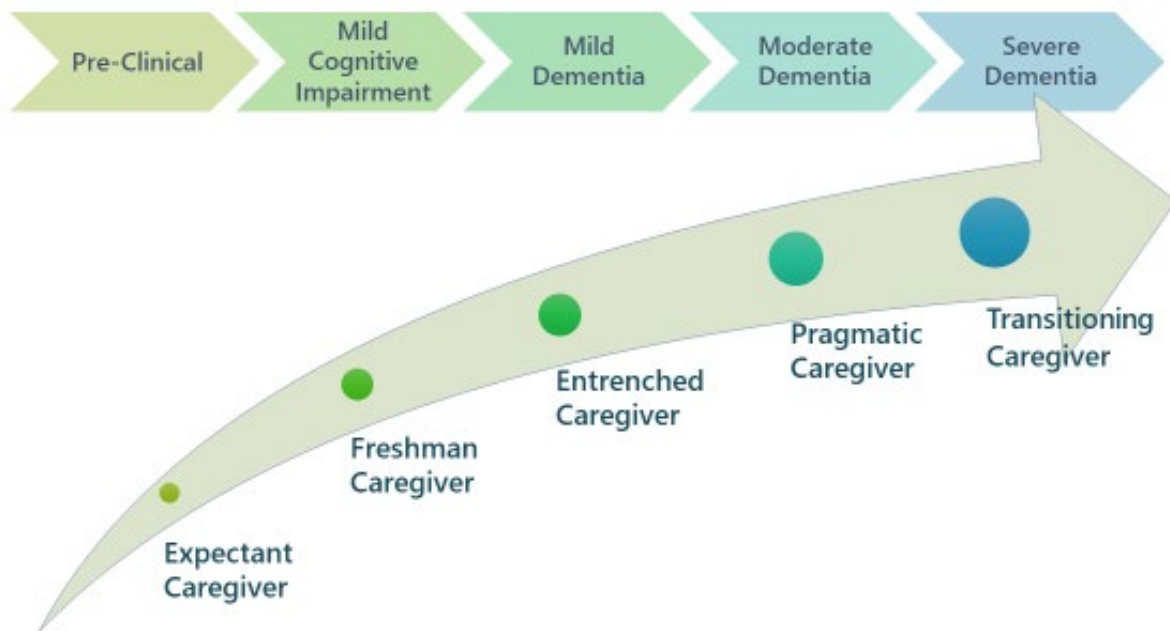
**The Aftereffects of Caregiving** by Gary Joseph Leblanc

This book helps you find ways to reinvent yourself after caregiving.



# Special Topic: Dementia

*This section covers information specific to caring for someone with dementia, in addition to the information listed above. Due to the unique nature of dementia, as the disease progresses, a caregiver's focus shifts from supporting independence to providing safety. The stages of caregiving may follow the stages of dementia, but the path is different for each person and symptoms can fluctuate day to day.*



The Nature of Caregiving Changes as Dementia Progresses

## Stages of dementia

*Please note:*

- Each person ages in their own unique fashion, and symptoms of dementia may vary from person to person
- Stages do not necessarily progress in order; in many people the stages overlap and symptoms fluctuate throughout the day
- If you have concerns about changes in memory or thinking, whether your own or someone you know, it is very important to talk to a doctor.

## Pre-clinical

Some changes in thinking are common as people get older, for example:

- Increased difficulty finding words and recalling names
- More problems with multi-tasking
- Mild decreases in the ability to pay attention



*For more information:*

How the Aging Brain Affects Thinking, National Institute on Aging  
[www.nia.nih.gov/health/how-aging-brain-affects-thinking](http://www.nia.nih.gov/health/how-aging-brain-affects-thinking)

## Mild Cognitive Impairment

People living with mild cognitive impairment are still able to carry out almost all normal daily activities. This diagnosis indicates changes in memory or thinking beyond what is expected from an aging brain but symptoms are not as severe as dementia. Symptoms include:

- Losing things often
- Forgetting to go to events or appointments
- Having more trouble coming up with words



*For more information:*

What Is Mild Cognitive Impairment? National Institute on Aging  
[www.nia.nih.gov/health/what-mild-cognitive-impairment](http://www.nia.nih.gov/health/what-mild-cognitive-impairment)

*Alzheimer's disease is the most common form of dementia, where the first symptoms are typically memory problems. Each stage is described briefly below.*

## Mild (Early stage) Alzheimer's disease

Independent functioning in most areas of life. Symptoms include:

- Problems coming up with the right word or name
- Challenges performing tasks in social or work settings
- Forgetting material that was just read
- Losing or misplacing a valuable object
- Impaired reasoning or judgement
- Increasing trouble with planning or organizing

## Moderate (Middle stage) Alzheimer's disease

Greater difficulty performing routine tasks. Symptoms include:

- Remembering significant details about their life, but forgetting many events
- Increased challenges expressing themselves
- Feeling moody or withdrawn
- Confusion about where they are or what day it is
- Needing help choosing proper clothing for the season or the occasion
- Changes in sleep patterns, such as sleeping during the day and becoming restless at night
- Increased risk of wandering and becoming lost
- Personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand-wringing or tissue shredding

## Severe (Late stage) Alzheimer's disease

Need extensive help with daily activities and personal care round-the-clock.

Symptoms include:

- Inability to carry on a conversation; may still say words or phrases, but communicating physical needs becomes difficult
- Significant personality changes may take place
- Losing awareness of recent experiences as well as of their surroundings; not responding to their environment
- Changes in physical abilities



*For more information:*

What Is Alzheimer's Disease? National Institute on Aging

[www.nia.nih.gov/health/what-alzheimers-disease](http://www.nia.nih.gov/health/what-alzheimers-disease)

*Other types of dementia have different symptoms, especially in the early stages; those are described below.*

## Lewy Body Dementia

Lewy body dementia is a disease associated with abnormal deposits of a protein in the brain, called Lewy bodies. Changes in chemicals in the brain caused by the

Lewy bodies can lead to problems with thinking, movement, behavior, and mood. Symptoms include:

- Changes in movement, such as slowness, gait changes, balance challenges
- Fluctuating confusion - unpredictable changes in concentration, attention, alertness, and wakefulness from day to day and sometimes during the day
- Visual hallucinations (seeing things that aren't really there)
- Sleep disturbances
- Challenges with attention
- Visual and spatial changes, such as difficulty judging distances or misidentifying objects
- Difficulty with planning, multitasking, problem solving, and reasoning
- Changes in mood and behavior, such as poor judgement or loss of initiative
- Memory loss symptoms may appear as the disease progresses



*For more information:*

What Is Lewy Body Dementia? National Institute on Aging  
[www.nia.nih.gov/health/what-lewy-body-dementia](http://www.nia.nih.gov/health/what-lewy-body-dementia)

## Vascular dementia

Vascular dementia is caused by strokes and other vascular brain injuries that cause significant changes to memory, thinking, and behavior. Cognition and brain function can be significantly affected by the size, location, and number of brain injuries. Symptoms include:

- Changes in language
- Impaired judgment or ability to make decisions
- Difficulty planning or organizing
- Slowed thinking and difficulty problem solving
- Changes in movement, such as slow gait or poor balance



*For more information:*

Vascular Contributions to Cognitive Impairment and Dementia  
National Institute on Aging  
[www.nia.nih.gov/health/vascular-contributions-cognitive-impairment-and-dementia](http://www.nia.nih.gov/health/vascular-contributions-cognitive-impairment-and-dementia)

## Frontotemporal Dementia

Symptoms of frontotemporal disorders vary from person to person and from one stage of the disease to the next as different parts of the brain - the frontal and temporal lobes - are affected. In general, changes in the frontal lobe are associated with behavioral symptoms, while changes in the temporal lobe lead to language and emotional disorders. Symptoms include:

- Personality changes, such as acting impulsively
- Behavior changes, such repeating the same activity over and over
- Changes in language, including speech and understanding
- Changes in movement, such as difficulty walking, tremors, or clumsiness
- Problems with executive functioning (planning, thinking through steps of a task, self-monitoring, and correcting behavior)
- Emotional changes, such as apathy (lack of interest in things) or exaggerated emotions
- Difficulty “reading” social signals

*For more information:*



What are the Symptoms of Frontotemporal Disorders?  
National Institute on Aging

[www.nia.nih.gov/health/what-are-symptoms-frontotemporal-disorders](http://www.nia.nih.gov/health/what-are-symptoms-frontotemporal-disorders)

## Mixed Dementia

A combination of two or more types of dementia, mixed dementia is common among people living with dementia. A number of combinations are possible. For example, some people have both Alzheimer's disease and vascular dementia. It may not be clear exactly what symptoms are coming from which type of dementia, as a person may experience a mix of symptoms.

*For more information:*



What Is Mixed Dementia? Causes and Diagnosis  
National Institute on Aging

[www.nia.nih.gov/health/what-mixed-dementia-causes-and-diagnosis](http://www.nia.nih.gov/health/what-mixed-dementia-causes-and-diagnosis)

## Caregiving Stages, Tasks, and Resources When Caring for Someone with Dementia

### Stage 1: The Expectant Caregiver™

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*I have concerns about the memory or thinking of a family member or friend, but don't yet have a formal diagnosis.*



What assistance can be put in place now to help the person live how they want to for as long as possible? Consider IADLs and frame support as supporting the person's values, goals, and preferences.



Talk with your family member or friend to understand what fears or concerns they have about their overall health, living situation, memory or cognition. How can you best support them?



Gather information: What are the signs that I should seek medical help for my person? What symptoms of memory or thinking should I be concerned about?



Ask the person if you can attend doctor's appointments with them to better understand their overall medical condition as a partner in care.



Get legal and financial documents in order, so that the person's values can be followed in the years to come.  
Ask the person about their values. What is most important to them?



What are your fears and concerns? Talk with others who are in similar situations.

### Where to start



**Caregiver support groups offered by the Memory Connections program** are designed for care partners of people living with early stage dementia. Led once a month by licensed professionals, the groups can provide you with support, tips, and advice from others facing similar challenges. For more information about times and locations, please email us at [memoryinfo@ageofcentraltx.org](mailto:memoryinfo@ageofcentraltx.org)



## Memory, Forgetfulness, and Aging: What's Normal and What's Not? – National Institute on Aging

[www.nia.nih.gov/health/memory-forgetfulness-and-aging-whats-normal-and-whats-not](http://www.nia.nih.gov/health/memory-forgetfulness-and-aging-whats-normal-and-whats-not)

**Know the 10 signs Checklist: Early Detection Matters – Alzheimer’s Association** is a checklist of early symptoms of memory concern, differences from normal aging, and a place to make notes to talk with your doctor. [www.alz.org/media/Documents/10-signs-checklist.pdf](http://www.alz.org/media/Documents/10-signs-checklist.pdf)



***Please note – there is currently no scientific, evidence-based guaranteed way to prevent or cure dementia of any type, including Alzheimer’s disease.***

### **The End of Alzheimer's: The First Program to Prevent and Reverse Cognitive Decline** by Dale Bredesen

This book outlines 36 metabolic factors (micronutrients, hormone levels, sleep) that can trigger "downsizing" in the brain. The protocol shows us how to rebalance these factors using lifestyle modifications like taking B12, eliminating gluten, or improving oral hygiene.

## Stage 2: The Freshman Caregiver™

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*Family member or friend has a diagnosis of **Mild Cognitive Impairment** or **mild (early stage) dementia**.*



- Oversight may be all that is required; look for the balance between oversight and independence.
- Consider using verbal and visual cues.
- There may be concerns about driving safety. Seek support from the doctor.



What safety concerns does the person have? Does the caregiver have? What future safety concerns are anticipated? How can we prepare?



- Talk with person: what does it mean to you to live well with dementia?
- How is the person coping with their diagnosis? What emotional & social support would help them cope? They may be feeling loss, embarrassment, and uncertainty.
- If they do not wish to acknowledge their diagnosis, how can you and others support them in living their best life?



- Gather information: What does my person's diagnosis mean?
- Begin participating in medical appointments as a care partner. Discuss with the person how you will talk with your medical team together.
- Keep an eye out for when the person is no longer safe to administer their own medications.



- Communicate with the person being cared for (include them in decisions as much as possible; and as much as they want).
- Find balance between person's needs and caregiver needs when determining course of action.
- Start to become familiar with programs and services for people with dementia & discuss them with your person.
- Consider telling others about the diagnosis. Who would the person like to tell, and how?



In the early stages of dementia, getting legal documents and affairs in order is crucial. Be sure to check any documents that rely on the person with dementia, as well.



You may find that your person isn't giving as much to your relationship as before. You may grieve the future that you hoped to have before the diagnosis. There may be a rollercoaster of emotions. Take time to care for yourself, and seek out caregiver support groups.

## Where to start



**Memory Connections early memory loss support program** offers weekly brain exercise and emotional support activities for people living with



early stage dementia or mild cognitive impairment. Offered at 5 different locations around central Texas. For more information, please visit: [www.ageofcentraltx.org/index.php/seniors/early-memory-loss-supprt](http://www.ageofcentraltx.org/index.php/seniors/early-memory-loss-supprt)



### **Section: Alzheimer's and Dementia**

[www.agingservicescouncil.org](http://www.agingservicescouncil.org)



### **At the Crossroads - Family Conversations About Alzheimer's Disease, Dementia & Driving** - The Hartford Financial Services Group, Inc. and the MIT AgeLab

This guidebook helps families determine when it's time for a person with dementia to stop driving and helps them cope with driving cessation.

[www.thehartford.com/resources/mature-market-excellence/publications-on-aging](http://www.thehartford.com/resources/mature-market-excellence/publications-on-aging)



**The By Us For Us© Guides** are a series of guides created by a group of talented and passionate persons with dementia and/or partners in care. The guides are designed to equip persons with dementia with the necessary tools to enhance their well-being and manage daily challenges. Guides are available online and in hard copy.

[www.the-ria.ca/resources/by-us-for-us-guides](http://www.the-ria.ca/resources/by-us-for-us-guides)

## **Stage 3: The Entrenched Caregiver™**

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*Family member or friend is living with mild (early stage) to moderate (middle stage) dementia.*



As the disease progresses, the person will need more cues and reminders, and tasks will need to be simplified. Find ways to continue to involve the person in the tasks of the household – we all want to help and feel needed.



Find the balance between cueing and providing physical assistance. Support the person in staying independent with as many tasks as possible, for as long as possible.



The relationship between you and the person is changing, as the person is less able to contribute to the relationship as they did in the past. You may find yourself looking outside the relationship for social and emotional support. The balance of power in the relationship may also be shifting, as the caregiver takes on more tasks and responsibility.



Keep the person at the center of conversations during medical appointments.



Keeping family and friends informed on the progression of the disease is important. Think of ways for them to be involved and offer those opportunities to them.



Caregiver makes complex decisions more independently. Involve the person in more straight-forward decisions to the extent possible. They are still able to articulate preferences, values, and choices.



Schedule frequent breaks before you need them. A person with dementia may take more time to adjust to changes. The sooner you integrate help into your daily routine, the more likely it is the person will adjust and accept it.

## Where to start



**CaregiverU** offers free, evidence-based caregiver classes in many locations in Central Texas. **Savvy Caregiver Class** provides in-depth practical training for family caregivers of persons with dementia. The 6, 2 hour classes cover topics such as the progressive impact of the illness on the person and the skills needed to manage day-to-day caregiver responsibilities. For more information and to find a class near you, please visit [www.caregiverucentx.org](http://www.caregiverucentx.org).

The **AGE Thrive Social & Wellness Centers** provide exceptional daytime care for older adults with physical needs or memory loss. Your person can enjoy an active, social day while receiving the care and support he or she needs in a vibrant community setting.

[www.ageofcentraltx.org/index.php/caregivers/adult-day-health-care-centers](http://www.ageofcentraltx.org/index.php/caregivers/adult-day-health-care-centers)

**AGE Caregiver Resources and Information Center** offers one-on-one consultation to support you in the challenges you are facing as a caregiver. Information about and assistance in finding a program that is a good fit for your person’s symptoms and goals. Email us at [resourcecenter@ageofcentraltx.org](mailto:resourcecenter@ageofcentraltx.org).  
[www.ageofcentraltx.org/index.php/caregivers](http://www.ageofcentraltx.org/index.php/caregivers)



**Section: Respite Care**

[www.agingservicescouncil.org](http://www.agingservicescouncil.org)



**Alzheimer’s Texas** has list of respite programs for your person, caregiver support groups for you, among other services.

[www.txalz.org/how-we-can-help-programs-services](http://www.txalz.org/how-we-can-help-programs-services)



**Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide**

– National Institute on Aging

This comprehensive, easy to read guide has caregiving information and advice specific to Alzheimer’s Disease and dementia. Learn caregiving tips, safety information, common medical problems, and how to care for yourself. [www.order.nia.nih.gov/publication/caring-for-a-person-with-alzheimers-disease-your-easy-to-use-guide](http://www.order.nia.nih.gov/publication/caring-for-a-person-with-alzheimers-disease-your-easy-to-use-guide)

## Stage 4: The Pragmatic Caregiver™

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*Family member or friend is living with moderate dementia.*



The person may not be aware of tasks that need to be completed, but may enjoy participating in simple activities alongside the caregiver.



Physical assistance is a daily task. Determine how much the person is able to participate in the task and support them in doing all that they can.



As “windows” of clarity become rarer, the caregiver learns to enjoy, but not expect, them.



Medical care focuses on the person's values and preferences and how to support those in their daily life.



Make decisions based on knowledge of the person's values. Your needs are more and more important in decision-making



When needing assistance with decisions, you turn to others, as person is less able to understand and discuss complex, abstract topics. Determine how much information the person should receive.



You may find yourself no longer relating to your person as spouse, child, friend, etc. and only as a caregiver. Try to find ways to connect based on your shared history, and encourage others to do the same. Ask for and accept help whenever and wherever it comes from.

## Where to start



The **AGE Thrive Social & Wellness Centers** provide exceptional daytime care for older adults with physical needs or memory loss. Your person can enjoy an active, social day while receiving the care and support he or she needs in a vibrant community setting.

[www.ageofcentraltx.org/index.php/caregivers/adult-day-health-care-centers](http://www.ageofcentraltx.org/index.php/caregivers/adult-day-health-care-centers)



### **Residential Care - Alzheimer's Association**

Information about types of residential care, a care facility checklist, costs, and how to choose a care setting

[www.alz.org/help-support/caregiving/care-options/residential-care](http://www.alz.org/help-support/caregiving/care-options/residential-care)

### **Finding Long-Term Care for a Person with Alzheimer's – National Institute on Aging**

Residential care options, questions to ask when visiting, and how to make moving day easier

[www.nia.nih.gov/health/finding-long-term-care-person-alzheimers](http://www.nia.nih.gov/health/finding-long-term-care-person-alzheimers)



**Untangling Alzheimer's: The Guide for Families and Professionals-A Conversation in Caregiving by Dr. Tam Cummings**

Written by a gerontologist, this book provides a compassionate overview of the stages of Alzheimer's disease and its progression. Other topics include the physiology of Alzheimer's, communication techniques, activities, and end-of-life care. Case studies personalize and illustrate the information provided.

## Stage 5: The Transitioning Caregiver™

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*Family member or friend is living with severe (late stage) dementia.*



All necessary tasks are completed on behalf of the person.



Body language (the person's and yours) becomes the primary tool to communicate emotions.

Spend time being with the person, in whatever way feels right to you. We all want to feel connected, even if we can't express it. Physical touch and sitting with a group and passively participating can foster connection.



Consider hospice care to promote quality of life.



Rely on knowledge regarding the person's values and preferences to make decisions.



Emotional support, doing things you enjoy, and deciding how much time you will spend with the person are all ways to take care of yourself.

### Where to start



**AGE Caregiver Resources and Information Center** provides information and support wherever you are in your caregiving journey, including information about where to find caregiver support groups.

Email us at [resourcecenter@ageofcentraltx.org](mailto:resourcecenter@ageofcentraltx.org).

[www.ageofcentraltx.org/index.php/caregivers](http://www.ageofcentraltx.org/index.php/caregivers)



## **6 Ways of Helping Your Loved One Adjust to a Nursing Home** **By Esther Heerema, MSW**

[www.verywellhealth.com/help-a-loved-one-with-dementia-adjust-to-a-nursing-home-97697](http://www.verywellhealth.com/help-a-loved-one-with-dementia-adjust-to-a-nursing-home-97697)

### **Late-Stage Caregiving – Alzheimer’s Association**

Information about what to expect and your role as a caregiver

[www.alz.org/help-support/caregiving/stages-behaviors/late-stage](http://www.alz.org/help-support/caregiving/stages-behaviors/late-stage)

### **End-of-Life Care for People with Dementia – National Institute on Aging**

[www.nia.nih.gov/health/end-life-care-people-dementia](http://www.nia.nih.gov/health/end-life-care-people-dementia)

## Life After Caregiving

*Finding new meaning and purpose in life after caregiving. Integrate your former role as a caregiver into your life going forward.*

*Finding new meaning and purpose in life after caregiving. Integrate your former role as a caregiver into your life going forward.*

### **Caregiving Tasks**



Treasure memories of your person and celebrate them in the way that feels right to you.



Consider sharing the information you have learned with other caregivers, especially wisdom earned about navigating healthcare and community services.



Appreciate the challenges you overcame, the new skills you developed, and the lessons learned.

Honor the person you provided care for by finding a meaningful life after caregiving.

## Where to start



**AGE Caregiver Resources and Information Center** can answer your questions and help point you in the right direction for the next chapter of your life. Email us at [resourcecenter@ageofcentraltx.org](mailto:resourcecenter@ageofcentraltx.org).



**Caregiving and Ambiguous Loss** - Family Caregiver Alliance and written by Pauline Boss

Dementia is unique in the disease's fluctuation of symptoms – the rollercoaster of absence and presence is a very stressful kind of loss— what author Pauline Boss calls ambiguous loss.

[www.caregiver.org/caregiving-and-ambiguous-loss](http://www.caregiver.org/caregiving-and-ambiguous-loss)



**Ambiguous Loss and Grief in Dementia - A resource for individuals and families** – Alzheimer Society of Canada

[www.alzheimer.ca/sites/default/files/files/national/core-lit-brochures/ambiguous\\_loss\\_family\\_e.pdf](http://www.alzheimer.ca/sites/default/files/files/national/core-lit-brochures/ambiguous_loss_family_e.pdf)

## Appendices

- A. What are Activities of Daily Living (ADLs) & Instrumental Activities of Daily Living (IADLs)?
- B. Comparison of Residential Housing Options
- C. Senior Housing & Care Quick Reference
- D. What (Central Texas) Programs Are Available for Older Adults with Dementia?
- E. Safety for People with Dementia - When is my family member with dementia no longer safe alone?
- F. When Living at Home is No Longer an Option; How to Recognize that it's Time for Assisted Living (dementia)

## Sources

1. The Caregiving Years: An Introduction and The Caregiving Years Tip Sheet  
Denise M. Brown, Founder of CareGiving.com  
<https://www.caregiving.com/the-caregiving-years/>
2. Stages of Alzheimer's, Alzheimer's Association  
<https://www.alz.org/alzheimers-dementia/stages>
3. Patient Safety and Quality: An Evidence-Based Handbook for Nurses, Chapter 14 Supporting Family Caregivers in Providing Care  
<https://www.ncbi.nlm.nih.gov/books/NBK2665/>
4. Families Caring for an Aging America, Chapter 3 Family Caregiving Roles and Impacts  
[https://www.ncbi.nlm.nih.gov/books/NBK396398/#sec\\_000057](https://www.ncbi.nlm.nih.gov/books/NBK396398/#sec_000057)
5. Caregiver Burden in Different Stages of Alzheimer's Disease  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5439478/>