

# Helping Families Cope

A guide for those caring for a loved one with Alzheimer's Disease or Other Dementias



It's the diagnosis that can strike dread in the hearts of family caregivers: Alzheimer's disease. That's because this illness and other dementias often steal from older adults what they treasure most: their identity. That's a traumatic prospect both for older adults and the family members who love and care for them.

The Home Instead Senior Care<sup>®</sup> network knows the havoc these conditions can wreak in the lives of seniors and their families. In fact, many of the seniors served throughout the network have dementia. So we've witnessed the fear and loss that older adults face. We've come to understand how Alzheimer's disease or other dementias steal from family caregivers as well. These conditions can take their energy, peace of mind and happiness.

If you're living it now, you know all too well. If your loved one just received the diagnosis, you're likely anxious about the future – for your loved one and yourself.

You want your senior to be safe and engaged in life. But given the memory or cognitive and behavioral symptoms that sometimes accompany dementia, how can you ensure this happens? And how do you also take good care of yourself while providing excellent care to your family member?

Wherever you are in the journey, the Home Instead Senior Care network can help in an impactful and positive way. Alzheimer's Disease or Other Dementias CARE: Changing Aging Through Research and Education® ("CARE") is a unique training approach for Home Instead CAREGivers<sup>SM</sup>. This booklet provides practical assistance from the CARE program to also help family caregivers like you on your journey.

Featured in this booklet is the Home Instead Senior Care network 's approach to Alzheimer's or other dementias care. The approach focuses on individualizing the care experience, keeping your loved one engaged in life, and understanding and helping to minimize behavioral and cognitive symptoms that could be a sign of unhappiness in your loved one. There is also a section about you, the caregiver, which provides realistic ideas about how you can take good care of yourself. Finally, additional information and resources will offer other avenues of support.

# Relationship Centered Care

With a dementia diagnosis comes a mountain of uncertainty. What does the future hold? What is your role? How will this condition impact your loved one?

Alzheimer's disease or other dementias lead to nerve cell death and tissue loss in the brain; in short, the brain is failing. This means your loved one may experience changes in personality, relationships and abilities. This could also include the inability to communicate wants and needs, which can cause an increase in cognitive or behavioral symptoms. These changes can be among the hardest for families to face.

With the brain failing and causing all of these changes, it's essential to understand the right approach when caring for your loved one with Alzheimer's disease or other dementias. The approach needs to ensure the person's needs are at the forefront in order to maintain quality of life. The approach also needs to continue to foster the relationship between the caregiver and care recipient. The Home Instead Senior Care network calls this approach Relationship Centered Care.

By knowing and using the information learned through the relationship, it will help you to engage your loved one in meaningful activities, where they can contribute and feel relevant in this likely confusing time. Knowing their preferences and routines will help you anticipate needs and provide individualized care.

Families often find it useful to gather information and record chronologically or by topic into a journal or notebook. This can help all those involved in the care understand key information, successful techniques or trigger points for the person. Information that will help the care situation includes favorite meals, routines, important family members, significant events in their life story and even preferences in time and place. The more you know, the better equipped you will be to help enhance the quality of the person's life.



# Understanding Cognitive Symptoms

According to the U.S. Alzheimer's Association, the most common cognitive symptoms of Alzheimer's disease include:

- · Memory loss that disrupts daily life
- Difficulty completing familiar tasks
- Challenges with planning and problem solving
- Confusion with time and place
- Trouble understanding visual images and spatial relationships
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood or personality
- Problems with speaking and writing

Any of these symptoms may not be obvious at first and may be dismissed as someone just becoming forgetful or "getting old." The person may believe the symptoms are not that serious or do not happen very often, while a family member may recognize a severe change in the person. Something that was easy to do last month may be more challenging now, which can cause stress on the entire family.

During this time, it's important to remember that the person with dementia is likely living with fear and uncertainty, and trying to find a way to maintain their life and independence. A few tips to keep in mind if these symptoms occur:

Treat the person with dignity and respect. Live in their world and in the moment, trying not to judge or correct, but to maintain their dignity.

Try asking for the person's opinion or compliment the person.

Keeping the person in as much control as possible will help to ease the fear. Avoid arguments and situations that may embarrass the person.

Match their behavior and be patient. Making the person feel comfortable and relaxed will help relieve the stress they may be feeling. Show empathy by putting their needs first and trying to understand how hard this must be.

# **Understanding Behavioral Symptoms**

Alzheimer's disease and other dementias affect the way seniors think and feel and, subsequently, how they act. Your loved one may do things that are uncharacteristic or even odd. In general, behavioral symptoms can be seen as a form of communication, an expression of preference or indicating an unmet need. Because language is often affected by dementia, people with this disease may "tell" you about their needs or issues by "showing" you. By acting in a certain way, they may be trying to communicate what they want or need. By "listening to what they do," it's possible to understand and manage that unmet need.



It is helpful to group these needs by:

- Physical needs
- Emotional needs
- Social needs
- Environmental needs

Knowing how to respond when these symptoms is the key to care being provided. But by understanding the triggers to the symptoms and knowing the person's routines and preferences, you may be able to help reduce the stress that individual is feeling. Other tips include:

- Redirect or "change directions." Changing the topic or mood from bad to good and creating a more positive and safe result are the objectives.
- Give simple choices. Offering simple choices helps the person feel in control. Someone with dementia may feel he or she has no control over life.
- Be Proactive. Plan ahead and anticipate needs. Because the person is in a constant state of change, be prepared to adapt daily to changes.
   Some examples of behavioral symptoms include:
  - Aggression/anger
  - Anxiety/agitation
  - Delusions/hallucinations
  - False accusations

- Refusal
- Repetition/fixation
- Sexual inappropriateness
- Wandering

# Keeping Your Loved One Engaged

When you know more about what your loved one may have enjoyed, engaging them in meaningful activities can help them feel safe, secure and valued. Such an approach also can help them stay connected to daily life.

Research conducted for the Home Instead Senior Care network tells us activities are very important for those with Alzheimer's disease or other dementias because they create positive, emotional experiences helping to diminish the distress that can lead to challenging behaviors. Socializing also is important, for the same reason.

We may think of activities as something "special" that we do, but this does not have to be the case. Even simple tasks like folding the laundry or making a meal can be considered activities. The goal is to engage your loved one in activities that are meaningful to their life and enjoyable for you both.

There are several benefits to engaging your loved one in activities:

- Bring fun and happiness Laughter is great for all of us and doing a fun activity can create happiness.
- Reduce boredom Boredom can prompt seniors to become frustrated, agitated or depressed, causing them to wander off or insist on going somewhere. Activities can help maintain familiar routines which may help reduce confusion.
- Help make activities of daily living (ADLs) easier When you turn
  a bath into an opportunity to smell different soaps, or when getting
  dressed becomes a chance to discuss fashion or special colors,
  personal care tasks often are easier because your loved one is happier
  and less stressed.

Staying engaged and stimulated helps to lift a person's spirits and sense of accomplishment. It fosters a positive and enjoyable relationship between people.

# Taking Care of Yourself

The demands of caring for a person with dementia can force you to focus all your energy on their care. Neglecting your own needs could be a costly mistake. In fact, many of us feel that if we take care of ourselves we are being selfish. The truth is, it's imperative that we take care of ourselves, or we won't have the health or energy to care for anyone else. Just like the battery in our cell phones, we need recharging too.

Research shows that many people start neglecting their own care when they are caring for others. You want to make sure that you don't fall into that trap. It is even more important when you are a caregiver to focus on your self-care so that you have the energy and good health needed to continue caring for your loved one. Make sure you get enough sleep, exercise regularly, eat well-balanced meals, and drink plenty of fluids. And make sure you continue to get your regular medical checkups and preventive tests.



There are three key areas to consider when caring for yourself:

- Self-care
- Nourishing connections with others
- Relaxation techniques

Research supports the idea that to stay healthy, physically and emotionally, we need a strong social support network. A social support network includes the people in your life to whom you can turn for emotional and practical support. As a caregiver, you may be struggling to get everything done; however, it is important that you build in time for the relationships that nurture you — even if it is just having a phone conversation or a cup of coffee with someone who will really listen to you. If you are so inclined, you might also include maintaining spiritual or religious practices that nurture you and keep you connected to others.

# Additional Resources:

### Workshops for Family Caregivers

The Home Instead Senior Care network offers training for families caring for loved ones with Alzheimer's disease or other dementias. These sessions provide valuable information and an opportunity to seek support from others in similar situations. Visit <a href="https://doi.org/10.21/10.21/10.21/20.2

### HelpForAlzheimersFamilies.com

This site contains valuable information and support for those caring for loved ones with Alzheimer's disease or other dementias.

# Alzheimer's and Other Dementias Daily Companion App

A free iOS or Android mobile app for Alzheimer's or other dementias caregivers is available in the app store for download. Caregivers can search on situations they are struggling with, and the app will return immediate and relevant suggestions. These tips are compiled by experts as well as family caregivers dealing with Alzheimer's or another dementia illness. The app includes more than 500 searchable tips and practical suggestions.

# CaregiverStress.com®

This site contains a wide selection of helpful tips, educational videos and other resources for family members and professionals.

### Home Instead's CAREGivers

CAREGivers are trained through a person-centered approach to caring for your loved one. Just a few hours a week of professional care can help you care for yourself, as well as your loved one.

### Confidence to Care

For caregivers looking for a more in-depth resource, the book *Confidence to Care . . . A Resource for Family Caregivers Providing Alzheimer's Disease or Other Dementias Care at Home* is filled with helpful tips and strategies, care approaches and conversation starters for families dealing with the most common actions and behavioral symptoms of dementia, along with a section on help for the family caregiver and other resources.

<u>Stages of Senior Care: Your Step-By-Step Guide to Making the Best Decisions</u> by Paul and Lori Hogan

A Dignified Life: The Best Friends Approach to Alzheimer's Care, A Guide for Family Caregivers by David Troxel and Virginia Bell

# The Experts

A panel of experts with a variety of knowledge within the aging field has worked with the Home Instead Senior Care network to develop content and enhance the Alzheimer's Disease or Other Dementias CARE Training Program, including:

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# About Home Instead Senior Care

Founded in 1994 in Omaha, Nebraska, by Lori and Paul Hogan, the Home Instead Senior Care® network provides personalized care, support and education to help enhance the lives of aging adults and their families. Today, this network is the world's leading provider of in-home care services for seniors, with more than 1,000 independently owned and operated franchises that are estimated to annually provide more than 50 million hours of care throughout the United States and 16 other Countries. Local Home Instead Senior Care offices employ approximately 65,000 CAREGivers<sup>SM</sup> worldwide who provide basic support services that enable seniors to live safely and comfortably in their own homes for as long as possible. The Home Instead Senior Care network strives to partner with each client and his or her family members to help meet that individual's needs. Services span the care continuum -- from providing companionship and personal care to specialized Alzheimer's care and hospice support. Also available are family caregiver education and support resources. At Home Instead Senior Care, it's relationship before task, while striving to provide superior quality service.





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