



Helping Families Cope

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

 Home
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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® 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 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 and behavioral changes 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 a dramatic and positive way. CARE: Changing Aging Through Research and EducationSM ("CARE") is a unique training approach for Home Instead CAREGiversSM. This booklet provides practical assistance from CARE to help family caregivers like you on your journey.

Featured is the Home Instead Senior Care network's approach to Alzheimer's or other dementias care. The approach focuses on personalizing the care experience, keeping your loved one engaged in life, and reducing behavior that is 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.

Capturing Life's Journey

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. Over time, the brain shrinks dramatically, affecting nearly all its functions. This means your loved one may experience changes in personality, relationships and abilities. These changes can be among the hardest for families to face.

The right approach to caring for your loved one with Alzheimer's disease or other dementias is key to maintaining your loved one's quality of life. That approach needs to ensure your senior's needs are at the forefront. Knowing key information, life experiences and personal preferences about your loved one helps caregivers provide dignified and respectful care. The Home Instead Senior Care network calls this approach Capturing Life's JourneySM.

People with dementia often use experiences from the past to make sense of the present. And accompanying that with the reality that a person with dementia can no longer store new information efficiently, gathering stories and information from your loved one's past helps to carry out this approach. By knowing and using the information, it will help you create meaningful activities, and provide personalized care.



Techniques to Capture Life's Journey

When you are on this journey, it might be helpful to gather information chronologically, or by topic. Some examples include family, youth, parents, and the childhood house, grammar school, teachers, pets and family traditions. A few other examples include marriage, milestone events, favorite movies and TV shows, people, food, etc.

You probably already know many of your loved one's important experiences, and these will be a great place for you to start finding out more. Many of their most vivid memories will be of times when they were growing up with their family. Accomplishments and careers are also important facts to find out more about.

There are a few ways that you can gather your loved one's life story:

- 1. Asking them directly**
- 2. Observing their surroundings**
- 3. Asking other family and friends**

When gathering information, be sure to use open-ended questions. Open-ended questions start with words like, "Tell me about"...or "Why" or "How." These types of questions prompt a more elaborate answer than a "yes" or "no." The questions will encourage your loved one to speak more or share a memory.

Another good way to gather information is by observing the home or room for objects that will yield clues. Even though you are likely to be familiar with your loved one's surroundings, once you start to ask more questions about an object you will learn much more to the story. You also may observe their non-verbal cues, facial expressions and gestures.

Keeping Your Loved One Engaged

When you know more about what your loved one may have enjoyed, engaging them in meaningful activities helps 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 may 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.

The approach of Capturing Life's Journey is essential to discovering meaningful activities for your loved one. Refer back to the techniques of asking open-ended questions, observing surroundings and talking with other family members and friends.

Managing Behaviors

Alzheimer's disease or 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. People with Alzheimer's disease or other dementias cannot control or understand how certain behaviors affect others.

Some common challenging behaviors include:

- Refusal
- Delusions (false beliefs)
- Aggression
- False accusations
- Wandering
- Agitation
- Repetition



Knowing how to respond when these problems occur can be difficult. But by Capturing Life's Journey, you can use the information to help reduce such problems for your loved one. This approach allows you to use the information from the past to offer comfort and minimize stress. For example, if your loved one does not want to get out of bed in the morning, you may know from the information you gathered that, as a child, they always had a big breakfast with bacon and eggs. You may offer this as a motivator to get your loved one up and ready for the day. Another example: if your loved one is trying to leave his or her surroundings, try to redirect them by saying, "Your favorite TV show is on in a few minutes." Knowing the life story helps you to engage and distract your loved one.

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 a 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. Our social support network are the people in our lives to whom we can turn to 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.

Finally, there are many relaxation techniques that can help counter the stressful situations in our lives. When we are tense, we often take shallow breaths. This only adds to our feeling of stress. Even just breathing deeply a few times a day can reduce feelings of anxiety. Meditation or yoga are excellent ways to reduce the feelings of stress related to caregiving. Try various relaxation techniques until you find one that fits your interests and lifestyle. They don't have to take a long time – simply breathing more slowly takes no time at all.

Practicing this combination of good self-care, staying connected to others, and relaxation techniques can help you go the distance as a caregiver with less stress and more enjoyment!

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 homeinstead.com to find your local office to ask about on-site training, or learn more at HelpForAlzheimersFamilies.com.

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

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

Home Instead's 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.

Books:

Stages of Senior Care: Your Step-By-Step Guide to Making the Best Decisions

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:

JANE POTTER, M.D.

Home Instead Center for Successful Aging at the University of Nebraska Medical Center

BRENDA KELLER, M.D.

Home Instead Center for Successful Aging at the University of Nebraska Medical Center

TOM MAGNUSON, M.D.

Home Instead Center for Successful Aging at the University of Nebraska Medical Center

ERIC RODRIGUEZ, M.D.

University of Pittsburgh Medical Center

GLENN SMITH, PhD.

Mayo Clinic

DR. AMY D'APRIX, MSW, PhD.

President and CEO, Dr. Amy Inc.

ROBERT STEIN

President and CEO, American Society on Aging

DAVID TROXEL

Co-author, A Dignified Life: The Best Friends Approach to Alzheimer's Care, A Guide for Family Caregivers

TANYA MARIE RICHMOND, MSW, CRCC, LCSW

CARES, UNC Chapel Hill School of Social Work

About Home Instead Senior Care

Founded in 1994 in Omaha by Lori and Paul Hogan, the Home Instead Senior Care network is the world's largest provider of non-medical in-home care services for seniors, with more than 950 independently owned and operated franchises providing in excess of 45 million hours of care throughout the United States, Canada, Japan, Portugal, Australia, New Zealand, Ireland, the United Kingdom, Taiwan, Switzerland, Germany, South Korea, Finland, Austria, Italy, Puerto Rico and the Netherlands. Local Home Instead Senior Care offices employ more than 65,000 CAREGivers worldwide who provide basic support services – assistance with activities of daily living (ADLs), personal care, medication reminders, meal preparation, light housekeeping, errands, incidental transportation and shopping – which enable seniors to live safely and comfortably in their own homes for as long as possible. At Home Instead Senior Care, it's relationship before task, while continuing to provide superior quality service that enhances the lives of seniors everywhere.





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