A Guide for Those Supporting Loved Ones With Dementia or Cognitive Change

Based on the research of Jackie Pool¹ and Thomas Kitwood²

THE CARE THAT'S RIGHT, AT HOME®

Right at Home®
In Home Care & Assistance
Understanding Dementia and Cognitive Change

What Is Dementia?

Dementia is a chronic, worsening change in a person’s overall mental ability. Dementia is not a single disease, but a series of symptoms that affect memory, thinking, behavior and a person’s ability to complete everyday activities. Of the more than 100 different types or causes of dementia, Alzheimer’s is the most common. Symptoms of dementia, or cognitive change, can also be the result of other conditions such as stroke, infections, alcohol overuse, nutritional deficiencies and brain tumors.

Dementia and Aging

As adults age, they may take more time to process new information or may experience difficulty with memory. However, memory loss alone does not indicate that a person is living with dementia. According to the Alzheimer’s Association, at least two of the following core mental functions must be significantly impacted to be considered dementia:

1. Memory.
2. Communication and language.
3. Ability to focus and pay attention.
4. Reasoning and judgment.

5 Most Common Causes of Dementia

- Alzheimer’s disease — estimated in 60–70% of dementia cases
- Parkinson’s disease — a progressive neurological disorder that affects movement
- Vascular dementia — a blood circulation disorder estimated in 20% of dementia cases
- Traumatic brain injuries — brain malfunction caused by car accident, serious fall, concussions, etc.
- Huntington’s disease — an inherited disorder that breaks down brain nerve cells

*According to research by the World Health Organization (WHO)
Is Dementia Preventable?

Presently, only vascular dementia is preventable. By controlling blood pressure, cholesterol and weight, it is possible for an individual to reduce the risks for and even reverse vascular dementia. However, preventing other dementias is a constant research goal, with many studies focused on identifying risk factors associated with dementia.

Is Dementia or Alzheimer’s Treatable or Curable?

Until the root causes of a person’s symptoms of dementia are determined, it is not possible to implement a treatment plan. Remedies exist for dementia caused by metabolic and endocrine conditions such as hypothyroidism and nutritional conditions like vitamin B-12 deficiency. Studies suggest that it is possible to reverse symptoms of dementia caused by depression, adverse effects of drugs and substance abuse. While there are medications used to temporarily address a person’s symptoms of dementia, there is not a cure for Alzheimer’s and most other progressive dementias.

Researchers continue to feverishly study this widespread health crisis for possible answers and cures. Regardless of a person’s symptoms of dementia or a formal dementia diagnosis, families and care providers can proactively address their loved one’s symptoms of dementia and improve their quality of life by providing the right support.

Diagnosing Dementia

There is not a definitive test to diagnose dementia. However, family physicians who know your loved one’s medical history can help you understand the changes in your loved one. Family physicians can complete important lab tests and, because they know your loved one’s history, can help you determine if the changes you, or someone caring for them, are seeing in your loved one are caused by dementia. This means it is important to report all symptoms to your loved one’s physician; this will allow for a more accurate diagnosis and, more importantly, a symptom-management plan.

If your loved one does receive a dementia diagnosis, there are professional resources that can help your entire family. Unlike traditional support programs, Right at Home’s approach to dementia care and cognitive support is built on the belief that every person living with dementia or cognitive change has abilities to interact with their surroundings and to connect in new ways with their loved ones.

10 Persistent Dementia Signs and Symptoms

- Repetitive questioning and storytelling
- Odd or inappropriate behaviors
- Forgetfulness of recent events
- Repeated falls or loss of balance
- Personality changes
- Decline in planning and organization
- Changes in diet/eating habits
- Changes in hygiene
- Increased apathy
- Changes in language abilities, including comprehension

If you can visit them regularly, you may have already witnessed these changes in your loved one. If these changes persist for a long period of time, it is important to consult your loved one’s family physician or a geriatrician as soon as possible. If you live far away from your loved one, it may be challenging to recognize and report a change in condition or behavior. Professional caregivers, like those with Right at Home, are trained to recognize and report changes in the condition, behavior, communication and ability level of your loved one.

Supporting Cognitive Change
Once you determine you need outside help, whether temporary respite assistance or a plan for ongoing support, Right at Home can assess the needs of your family and your loved one to create a person-centered care plan to fit the unique circumstances of your family. We offer caregiving services for almost any family in practically any situation, and we are trained to recognize changes in your loved one’s behavior. We’re committed to providing the care that’s right for your loved one and giving you the peace of mind you deserve.

Caregiver Matching

Once you approve the Custom Care Plan, we match your loved one with the most appropriate caregiver possible by considering numerous factors: services needed, interests, and the personalities of both caregiver and client. Of course, if you ever have any concerns about a specific caregiver, we can promptly arrange a replacement.

Quality Care

Every Right at Home caregiver goes through an extensive interview process, including background and reference checks. Caregivers are trained and bonded/insured before ever caring for a client. Then, local supervisory staff visit your loved one’s home periodically to ensure things are going well and that caregivers are following the specifics of the Custom Care Plan.

Evaluating and Selecting a Caregiver

Caring for a loved one living with dementia is incredibly rewarding, but it can also be incredibly challenging. As you take on the additional role of family caregiver, it is important to maintain your own mental and physical well-being.

To be the best loved one and family caregiver you can be, you should periodically evaluate your well-being and be prepared to ask for help when you need it. It is important to ask for help, accept it when it is offered, and realize you don’t have to do it alone.

Help can be temporary, respite support when you need a break, or professional dementia care provided in the home by a specially trained professional caregiver.

As you care for your loved one, remember to take care of yourself by doing the following:

• Let go of guilt.
• Give yourself permission to say no.
• Make time for other friends and family members.
• Learn new ways to connect with your loved one.
• Exercise when you can.
• Let family and friends know that you need help.
• Identify ways to relieve stress and stay healthy.
• Make time to relax.
• Accept help when offered or seek it out if/when needed.
• Give yourself permission to say yes.
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• Exercise when you can.

Caring for your loved one with the most appropriate caregiver managed by a specially trained professional caregiver.

A trusted, professional, global home care agency, like Right at Home, positively addresses and manages each of these questions so you have peace of mind knowing your loved one is safe, secure and well cared for.

Ensure the Health and Well-Being of Family Caregivers

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Maintain Your Relationships

• Identify your internal support network, like friends and family members, that can help you through caring for your loved one.
• Identify your external support system, like a home care agency with bonded/insured caregiver, that can provide respite or professional in-home care when needed.
• Make time for other friends and family members.
• Learn new ways to connect with your loved one.

Self-Care and Emotional Well-Being

• Make time to relax.
• Identify ways to relieve stress and stay healthy.
• Let go of guilt.
• Exercise when you can.

Establish a Routine

• Give yourself permission to say yes.
• Give yourself permission to say no.
• Accept help when offered or seek it out if/when needed.
• Consider getting help to provide you with regular, much-needed respite time to re-energize and re-focus.

RightApproach®

A personalized Care Plan managed by professionals with caregiver matching based on a thorough assessment.

RightMission®

A resolute passion to improve the quality of life for those we serve means peace of mind for you.
Impact on Interactions

Dementia and cognitive change impact how your loved one views and interacts with the world around them. How would you feel if...

- You are feeling bored and restless at home, so you decide to go for a walk. But, you find all the doors have been locked and a stranger appears and tells you to sit down.
- You are late picking up your children from school and are in a hurry. But, the person you are with will not let you go.
- You open your door to a stranger who tells you it is time for you to take a bath.
- You are trying to get dressed, but it seems someone has sewn up the sleeves on your shirt, removed some buttons from your jacket and hidden your shoes.
- You are asleep in a chair in your home, when suddenly, you are awakened by a person you have never seen before who is trying to undress you.

Impact on Relationships

Dementia can change a person’s ability to communicate and interact with their surroundings:

- Communication: Finding the right words, Staying on topic, Remembering names, Coping with emotions
- Recognition: Recognizing faces, Reality versus fiction or hallucination, Recognizing objects, Different textures
- Perception: Seeing level changes like stairs, Seeing at night, Exploring textures
- Orientation: Estimating distance, Time and date awareness, Location awareness
- ANXIOUS, VULNERABLE, FRUSTRATED, SCARED

How Right at Home Defines Ability

As your loved one’s dementia or cognitive change progresses, their ability to complete daily activities will likely change. Jackie Pool is an Occupational Therapist with more than 30 years of experience in dementia care, who partnered with Right at Home to complete our RightCare approach to dementia and cognitive support. Jackie outlines four levels of ability for people living with cognitive change:

- Planned Ability Level: Able to plan activities and look for results, but may not be able to solve problems that arise.
- Exploratory Ability Level: Able to explore familiar activities and enjoy the experience of the activities, but may not look for a result from the activity.
- Sensory Ability Level: Able to respond to sensory stimulation and complete single-step activities, but may not have a conscious plan.
- Reflex Ability Level: Able to make reflex responses to direct sensory stimulation, but may not be aware of their environment.

These changes in ability CANNOT be controlled by your loved one. Also, these changes in ability might make your loved one feel ashamed, frustrated or angry. This can lead to their own isolation.

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2. Pay Attention to Nutrition

Malnutrition and undernutrition can lead to many health problems, but a lot of people do not realize that poor nutrition can worsen symptoms of dementia or even make people appear less able.

Unlike diabetes or heart disease, people with cognitive change do not require a special diet. However, preventing malnutrition and undernutrition by helping loved ones with a balanced diet is important. According to the United States Department of Agriculture, a balanced diet includes:

- Fruits
  - Berries, apples, oranges, grapefruit
- Vegetables
  - Spinach, kale, asparagus, broccoli
- Protein
  - Lean meats, oily fish, beans
- Grains
  - Whole-grain bread, oatmeal, brown rice
- Dairy
  - Low or fat-free milk, cheese

As you help your loved one with nutrition, remember that a “balanced” diet can mean different things for different people based on their preferences or health conditions such as diabetes, hypertension, gluten intolerance or vegetarianism.

3. Help With Well-Being

People living with dementia or cognitive change often have challenges coping with their emotions. This often leads to stress, anxiety, anger or depression, which can increase symptoms of dementia.

To Help Your Loved One Reduce Stress:
- Minimize overstimulation.
- Support familiar sleeping and bathing routines.
- Provide access to fresh air.
- Encourage mobility.
- Keep familiar photos and objects.

4. Support Their Perception and Safety

Cognitive change impacts your loved one’s ability to function in their surroundings in ways they normally might. This means that stairs, rugs, clutter and lighting can cause new challenges for your loved one.

To Help Your Loved One With Perception and Safety:
- Use contrasting, solid colors on walls, steps, beds, toilets and furniture.
- Remove rugs and clutter.
- Use night lights in bedrooms, hallways and bathrooms.
- Simplify the home, but maintain familiar organization and placement of items.
- Ensure adequate lighting.

5. Assist With Recognition and Orientation

Dementia and cognitive change impact your loved one’s ability to recognize things in their environment, to make choices from a large set of information and to recall processes.

To Help Your Loved One With Recognition and Orientation:
- Use images or pictures to help recognize items, and remember foods, people and objects.
- Prompt the next steps in a process.
- Label objects, household rooms and dangerous items.
- Present simple choices.

6. Keep Communication Flowing

Often cognitive change causes communication challenges and relationship breakdown in families. Because our identities are tied so closely to our relationships, cognitive change can lead to loss of self. Loss of self can result in isolation, depression and loneliness, which can worsen symptoms of dementia or cognitive change.

To Help Your Loved One Engage With the People Around Them and Communicate to the Best of Their Ability:
- Touch their hand, arm or shoulder to gain attention.
- Keep language simple.
- Socialize in small, familiar groups or one-to-one.
- Use their name.
- Make eye contact at eye level.
- Underestimating your loved one’s ability.
- Imposing our way of doing things.
- Guilt.
- Impatience.
- Multitasking.
Right at Home provides in-home care services to clients and equal employment opportunities to employees and applicants, without regard to race, color, religion, sex, national origin, age, disability or other protected class, in compliance with all applicable federal, state and local laws.

Each Right at Home office and business is independently owned and operated under a franchise agreement with Right at Home, Inc. For comments, questions or to learn more about Right at Home, please visit www.rightathome.net.

Call today for an in-home visit or more information.
P. 877.697.7537
rightathome.net

End Notes


2 Tom Kitwood, Dementia Reconsidered: The Person Comes First, (Berkshire, UK, Open University Press, 1997).


5 Ibid.

6 Ibid.

7 Ibid.

8 Ibid.

9 www.choosemyplate.gov.