



A Guide to Supporting Loved Ones With

Dementia or Cognitive Change



Let's start talking about living.[®]

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Based on the research of
Jackie Pool¹ and Thomas Kitwood²

Understanding Dementia or Cognitive Change

What Is Dementia?

Dementia is a chronic change in a person's overall mental ability. Dementia is not a specific disease, instead it is 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 Disease is the most well known.

Symptoms of dementia, or cognitive change, can also be the result of other conditions such as stroke, acute or chronic infections, alcohol abuse, nutritional deficiencies and brain tumors, just to name a few.

Dementia and Aging

As adults age, they may take more time to process new information or may experience difficulty with memory, this is a cognitive decline but may not be dementia. Memory loss alone does not indicate that a person is living with dementia. According to the Alzheimer's Association³, at least two of the following core mental functions must be significantly impacted to be considered dementia:

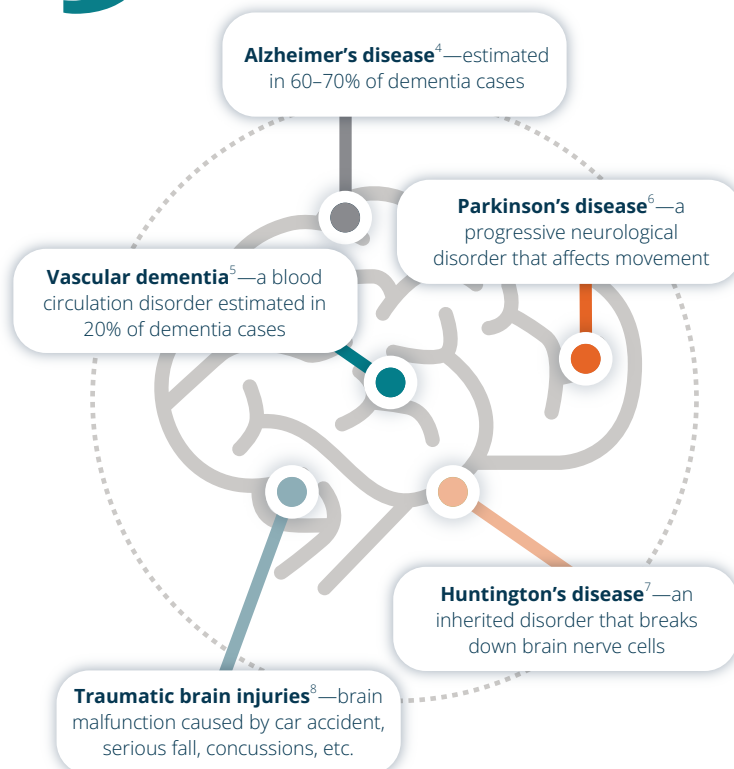
- 1 Memory.
- 2 Communication and language.
- 3 Ability to focus and pay attention.
- 4 Reasoning and judgment.
- 5 Visual perception.

Alzheimer's

is the **6th** leading cause of death in America.*

*According to research by the World Health Organization (WHO)

5 Most Common Causes of Dementia*



10 Persistent Dementia Signs and Symptoms

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

Diagnosing Dementia

There is not a definitive test to diagnose dementia. However, family healthcare providers who know your loved one's medical history can help you understand the changes in your loved one. These healthcare providers 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 are caused by dementia. This means it is important to report all symptoms to your loved one's healthcare provider; 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 other cognitive changes has abilities to interact with their surroundings and to connect in new ways with their loved ones.



10 Keys to Right at Home's Approach



Ability

We create a care environment that empowers the client and their current abilities.



Personhood

We incorporate the client's life history, routines and preferences into the Individualized Care Plan.



Lifestyle

We collaborate with the client and family to set goals and create support activities in the areas of nutrition, socialization, wellness and awareness to minimize overall cognitive change.

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 ongoing studies focused on identifying risk factors associated with dementia and determining how to treat some of the challenging behaviors and symptoms.

Know Your Risk Factors for Dementia

- | | | |
|-----------------------|------------------------------|--|
| ▶ High blood pressure | ▶ Heart disease | ▶ Reduced social interaction
(e.g., home alone, less contact with others) |
| ▶ Diabetes | ▶ Family history of dementia | ▶ Stress and depression |
| ▶ Poor nutrition | | |

Is Dementia 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, Parkinson'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 or a formal dementia diagnosis, families and care providers can proactively address their loved one's symptoms and improve their quality of life by providing the right support.

How Dementia Can Impact Families

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...

Anxious - 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.

Angry - 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.

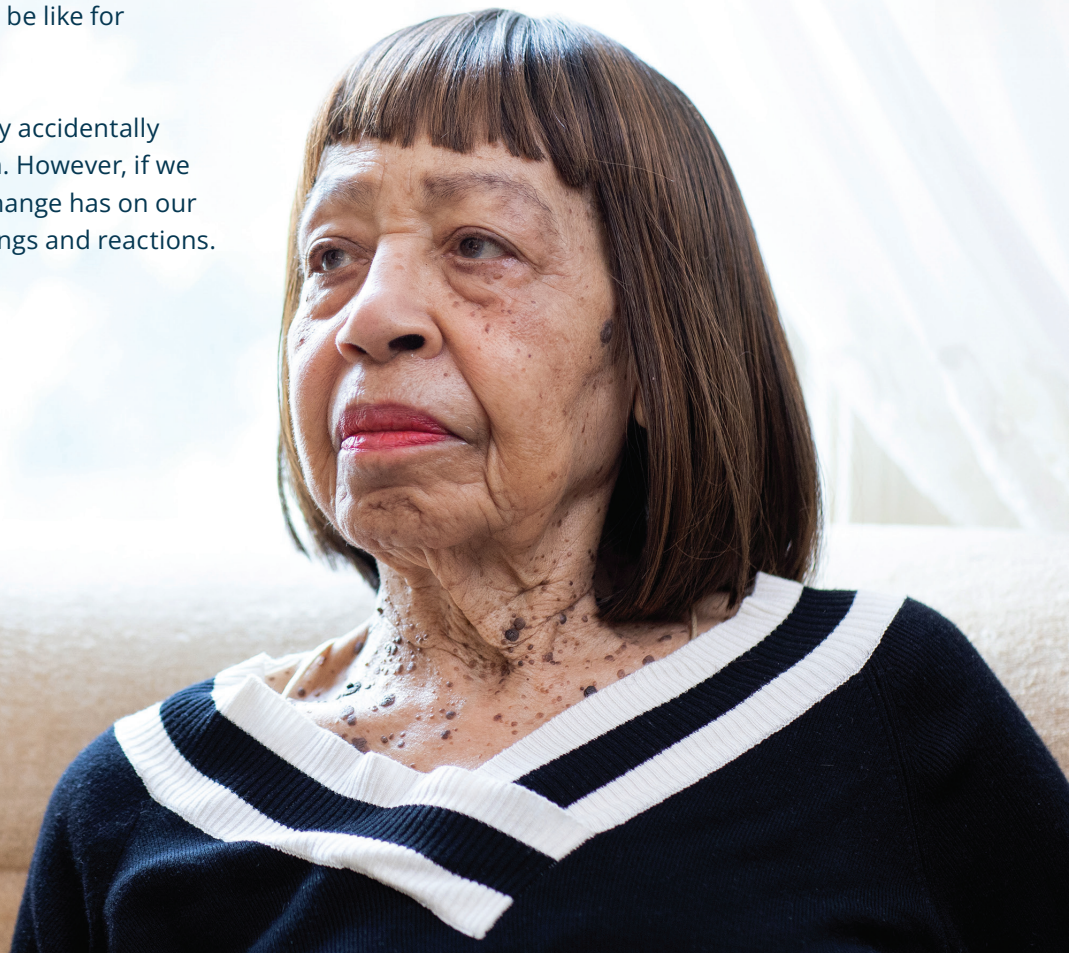
Vulnerable - You open your door to a stranger who tells you it is time for you to take a bath.

Frustrated - 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.

Scared - 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.

This is a small taste of what life can be like for someone with dementia.

In trying to help loved ones, we may accidentally cause fear, confusion or frustration. However, if we understand the effects cognitive change has on our loved ones, we can limit these feelings and reactions.



Impact on Relationships

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

Communication

- ▶ Finding the right words
- ▶ Remembering names
- ▶ Staying on topic
- ▶ Coping with emotions

Perception

- ▶ Seeing level changes like stairs'
- ▶ Recognizing different textures
- ▶ Seeing at night

Recognition

- ▶ Recognizing faces
- ▶ Reality versus fiction or hallucination
- ▶ Recognizing objects

Orientation

- ▶ Estimating distance
- ▶ Location awareness
- ▶ Time and date awareness

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.

55 million

people have dementia worldwide. This number is expected to rise to 78 million in 2030 and 139 million in 2050.*

Caring for a Loved One With Dementia

While each form of dementia or cognitive change is unique, there are techniques that can be used to enhance a person's quality of life. These techniques can also help families find new ways to connect with their loved one, despite cognitive change.

1 Focus on Ability, Not Disability

As sons, daughters and spouses, it is incredibly challenging to watch the abilities of our loved ones decline because of dementia or cognitive change. However, regardless of how advanced a person's dementia or cognitive change is, they still can interact with the people and environment around them, though that interaction may be different than families are used to.

Focusing on your loved one's abilities to complete daily activities and care activities, rather than compensating for their disabilities, improves your loved one's confidence, engagement, emotional well-being, and physical well-being while potentially reducing your loved one's frustration, anger, apathy, and depression. This empowers your loved one's ability to complete activities also allows family members to connect with their loved one as a family member, rather than as a care provider.

Confidence

Engagement

Emotional
Well-BeingPhysical
Well-Being

Frustration

Anger

Apathy

Depression

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 approach to dementia and cognitive support. Our program 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.

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 capable.

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 Agriculture⁹, a balanced diet includes:



Dairy

Low or fat-free milk, cheese



Protein

Lean meats, oily fish, beans



Fruits

Berries, apples, oranges, grapefruit



Grains

Whole-grain bread, oatmeal, brown rice



Vegetables

Spinach, kale, asparagus, broccoli

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.

To Help Your Loved With Nutrition and Dining:

- ▶ Limit distractions
- ▶ Keep a familiar place setting
- ▶ Prepare colorful foods
- ▶ dine with your loved one
- ▶ use different solid-color plates, napkins and placemats



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
- ▶ Provide access to fresh air
- ▶ Encourage mobility
- ▶ Keep familiar photos and objects
- ▶ Support familiar sleeping and bathing routines



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 items not necessary to the activity.
- ▶ Ensure adequate lighting
- ▶ Use night lights in bedrooms, hallways and bathrooms
- ▶ Simplify the home, but maintain familiar organization and placement of items

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:

- ▶ Label objects, household rooms and dangerous items
- ▶ Present simple choices
- ▶ Remove items not necessary to the activity
- ▶ Prompt the next steps in a process
- ▶ Use images or pictures to help recognize items, and remember foods, people and objects

6 Keep Communication Flowing

Often cognitive change causes communication challenges and relationship breakdowns 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
- ▶ Make eye contact at eye level
- ▶ Use their name
- ▶ Socialize in small, familiar groups or one-to-one

You Can Also Help Your Loved One by Recognizing That Families Accidentally Create Barriers to Communication

- ▶ Impatience
- ▶ Imposing our way of doing things
- ▶ Multitasking
- ▶ Guilt
- ▶ Underestimating your loved one's ability

Ensure the Health and Well-Being of Family Caregivers

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:

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 caregivers, that can provide respite or professional in-home care when needed.

Self-Care And Emotional Well-Being

- Make time for other friends and family members.
- Learn new ways to connect with your loved one.
- 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.



How Right at Home Can Help

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 an individualized plan of care 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 individual behavior. We're committed to providing the care that's right for your loved one and giving you the peace of mind you deserve.



Custom Plan Of Care

When you call us, we'll ask questions to form a basic needs assessment, then set up an in-home visit. After our initial meeting, we develop a Custom Plan of Care tailored to your loved one's specific needs, and make detailed recommendations on services. Before implementing we review the Plan of care with you in detail, modifying it as you and your loved one see fit.



Caregiver Matching

Once you approve the Plan of Care, 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 their Plan of Care.



Dementia Care

Right at Home's Approach to Dementia & Cognitive Support is recognized by the Alzheimer's Association® for incorporating the evidenced-based Dementia Care Practice Recommendations in the following topic areas: Alzheimer's and dementia, person-centered care, assessment and care planning, activities of daily living, and behaviors and communication.



Questions to Ask When Hiring a Caregiver

If you decide on home care, there are several questions you should ask the home care agency to ensure your loved one remains safe, healthy and happy:

Finding the Right Person



Registry/Direct Hire

Are caregivers employees of the company you pay for care?	Yes	Maybe
Does the company verify that caregivers can legally work in the United States?	Yes	Maybe
Have all caregivers undergone rigorous criminal, abuse registry and reference background checks?	Yes	Maybe
Are caregivers trained before they are assigned to homes, and do they receive ongoing training?	Yes	No

Liability



Registry/Direct Hire

Are Social Security, federal and state taxes, and unemployment insurance paid so the family is not legally responsible?	Yes	No
If the caregiver is injured at the residence, is workers' compensation insurance (or the equivalent) paid so the family is not legally responsible?	Yes	No
Is professional liability insurance for the caregiver paid so the family is protected?	Yes	No
Are the caregivers bonded/insured?	Yes	No

Quality of Care



Registry/Direct Hire

Does the company conduct supervisory home visits to verify quality care is being provided?	Yes	No
Does the company provide qualified replacement care if the scheduled caregiver cannot make it?	Yes	No
Does the company develop a personalized, written care plan?	Yes	No
Does the company document what services were completed during each shift?	Yes	Maybe

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.



Call today for a FREE in-home care assessment or for more information.

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