

# Dementia Guide *for Families*



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Caring for a loved one experiencing memory loss can feel overwhelming. From understanding the diagnosis to creating a safe environment for your loved one to exploring Memory Care options, there is much to consider. The Memory Care team at BHI Senior Living created this guide to provide guidance and support. While life has certainly changed, your loved one can still find joy, it may just look a little different.



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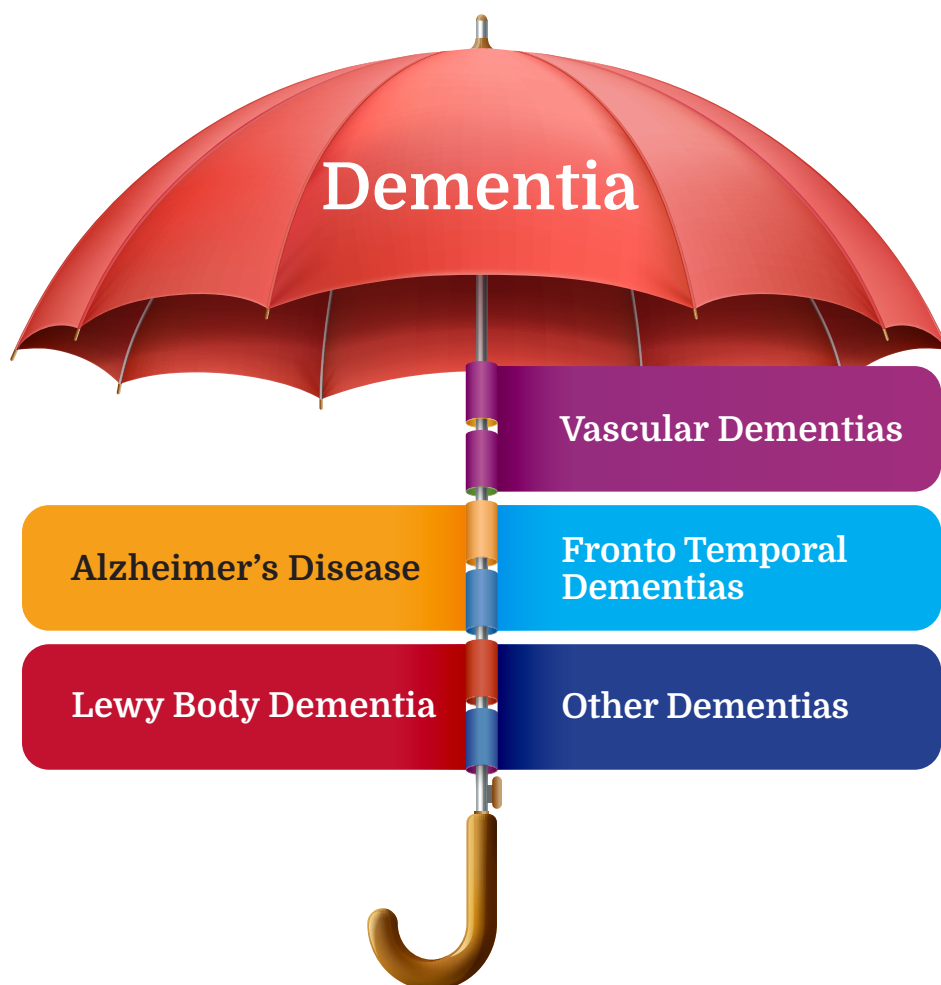
## SECTION 1

# Understanding Dementia

## Understanding Dementia

Dementia is an overarching term for an individual's changes in memory, thinking or reasoning. There are many possible causes of dementia. It's important to understand that it is different from normal changes that come with age.

We often use dementia as an umbrella term to describe a disease. This is similar to saying someone has cancer—though the person has a specific type of cancer. Many different diseases and conditions cause symptoms of dementia. Alzheimer's is the most common disease and the one we hear about most. Others include Lewy body dementia, vascular dementias, frontotemporal dementias, and Parkinson's disease.



## Warning Signs of Dementia

While there is a set of symptoms that many reference when seeking a dementia diagnosis, there are some symptoms that are more common.

- Memory loss
- Difficulty performing familiar tasks
- Problems with language
- Disorientation to time and place
- Poor or decreased judgment
- Problems keeping track of things
- Misplacing things
- Changes in mood and behavior
- Trouble with images and spatial relationships
- Withdrawal from work or social activities



## The Importance of Seeing a Doctor

While you may suspect a dementia diagnosis, it is critical to seek out advice of a doctor. Just as there are many types of dementia, there are some types that are irreversible and some that are



classified as reversible dementias. A doctor will do a thorough examination of the patient's medical history and run a comprehensive list of tests to help decipher persisting symptoms. While there are various symptoms and tests, a definitive diagnosis from a medical specialist is highly recommended. Once confirmed, it will be important for you as a caregiver to explore Memory Care options.

## What to Expect After a Dementia Diagnosis?

We understand that a dementia diagnosis is life changing for both your loved one and the entire family. Once diagnosed, there is a likelihood that you will experience a wave of emotions as you adjust to the news.

Those diagnosed, and their families, may experience any number of these common emotions once a diagnosis is confirmed:

- Anger
- Denial
- Depression
- Resentment
- Fear
- Isolation
- Relief



While it is normal to ride an emotional roller coaster post-diagnosis, it is important that your family promptly seek out a community to assist in adjusting to the news. The emotional health of the family is just as important as a confirmed medical diagnosis from a doctor. The journey in determining medical care, Memory Care options, and emotional support for your loved one, you as a caregiver, and the family will likely be ongoing.

People with dementia experience many communication challenges, including

difficulty in finding or identifying words. They will experience difficulty remembering things, speak less often, and communicate more via gestures. The impact of dementia on your loved one will be intense, however as caregivers and family members, it's important to be mindful that any shifts in their behavior is unintentional.

It's a marathon and not a sprint to determine what solutions best fit your families needs.



## SECTION 2

# Caring for a Loved One Experiencing Dementia



# Caring for a Loved One Experiencing Dementia

Adapting to life as a caregiver for someone with dementia will take some time, and it's natural for the adjustment to affect various aspects of your life. While so much will change—such as your schedule, how you connect with your loved one, and even how your home is set up—one of the most important things to remember is that your loved one is still there. They may not be able to communicate as they once did or remember every detail of the past, but they can still experience both life and joy.

## 6 Things to Know About Someone with Dementia

- **I can still smell the flowers.**  
I don't garden anymore, but I can still smell the flowers. Bring me some roses. This will remind me of my past.
- **I can still communicate.**  
I can't talk the way I used to, but I can still communicate. Be patient as I try. This will help me feel connected.
- **I can still wash my face.**  
I can't take a bath by myself anymore, but I can still wash my face. Assist me with direction. This will help me feel purpose.
- **I can still sing.**  
I can't dance unassisted anymore, but I can still sing. Help me enjoy music. This will enrich my life.
- **I can still move my body.**  
I can't walk unassisted anymore, but I can still move my body. Walk with me and support me if I stumble. This will help me feel engaged.
- **You are key to the quality of my life.**





# Tips for Communicating with a Person Living with Dementia

Communicating with a loved one experiencing dementia can be challenging. Remember, the symptoms are taking over the person and the adjustment will take some getting used to over time.

Here are a few tips to help you communicate:

## Realize Your Challenge

There will be good days and bad days.

## Be Patient

Tolerate compassionately any delays or provocation.

## Offer Reassurance

Listen attentively & empathize.

## Minimize Noise

Noise can disturb and confuse.

## Avoid Arguing

Do not contradict.

## Use Non-Verbal Cues

Gestures, touch & facial expressions.

## Be Precise

Avoid pronouns such as “they,” “he,” or “she.”

## Keep It Simple

Make sure questions can be answered with yes or no.



People experiencing memory loss can still feel. Holding a hand, placing a gentle hand on the shoulder, or giving them a hug are all things you can regularly do to both connect and communicate with them. Also remember that this syndrome affects each person differently.

As you’re adapting to the diagnosis, you are also adjusting to how you interact with your loved one. Try not to make any assumptions and assertions about how he or she will communicate moving forward.

“Touch is a language seen by the blind, heard by the deaf and felt by everyone.”

MARY JUDD

## What is Sundowning?

Behavioral changes will be common as the journey progresses. As a caregiver, you will notice that your loved one will periodically express some unwelcome fluctuations in behavior. A common behavioral change expressed by individuals with dementia is due to something referred to as sundowning.

**Sundowning occurs as daylight changes into evening. At this time, many people living with dementia express restlessness, agitation, irritability, and/or confusion.** This may continue into the night and the person may have difficulty staying in bed. These behaviors may also be triggered by the individual's environment and his/her inability to express those needs. For example, the person may be experiencing thirst, hunger, pain, or the need to use the restroom.



## Here are a few approaches to help reduce sundowning:

- Make sure they aren't overstimulated.
- Create a routine such as calming music in evenings or saying a prayer.
- They may be tired, so reserve part of the day for relaxation or a nap.
- Reduce noise and clutter.
- Distract with a favorite object, activity or snack.
- Close curtains at dusk and turn on lights so shadows aren't as confusing.
- Assess the person for pain.



## SECTION 3

# Adapting Your Home for Quality of Life for the Person Living with Dementia

# Adapting Your Home for Quality of Life for the Person Living with Dementia

If you are caring for your loved one in your own home post-diagnosis, then it will be important to create spaces that are conducive to your loved one's needs as they evolve. A dementia-friendly home will help them feel more connected and thrive more in a new normal. Even if behaviors and mannerisms change, it'll be important to help them feel a sense of independence, feel safe, and be settled in an environment that is conducive to who they are becoming.

## Dementia-friendly Design

Key elements to a dementia-friendly design include **good lighting**, **good color choices**, and **good contrast**. You'll also want to incorporate familiar objects in the space that are both personal and meaningful.

**Following are four key ways to achieve good lighting in your home for your loved one:**

1. Compensate your loved ones eyesight that will be affected by both the syndrome and symptoms. Adjusting the level of lighting in your home is very important.
2. Try to use daylight as a source as much as possible. Keep curtains open throughout the day to allow the sun to flow in.
3. Use ambient lighting, such as table lamps or wall mounted lights versus a large overhead light that might make one feel like he is in an institution.
4. In-home lighting should match the cycle of natural day to night. This helps circadian rhythm and will help maintain a quality sleep pattern for your loved one.



Key spaces in your home that should be properly adapted for your loved one include the kitchen, the bathroom, your immediate outdoor living area (or, the garden), the bedroom, and the living/family room area. Your loved one will also need some private space to be alone from time to time as well. Below are some ideas for how to make a couple of these key spaces adaptive to your loved one's evolving needs:

## Bedroom

- Block out blinds so they don't see shadows.
- Consider removing mirrors.
- Have a direct sight line to the bathroom.
- Contrast lighting between the wall and light switch.

## Kitchen

- Include a safety on and off switch for both the stove and oven.
- Be sure the gas is cut off on the stove at all times.
- Include see-through cabinets in the space.



# Montessori for Dementia

A great way to increase a sense of being, create a sense of space, and engage the senses is to incorporate the Montessori model within the living environment. The Montessori model helps to build self-worth in dementia patients—and help them connect with the outside world despite the diagnosis.

## The Montessori philosophy includes four key attributes:

- Enables individuals to be as independent as possible.
- Have a meaningful place both at home and within the community.
- Encourages them to accept themselves as they are and possess high self-esteem.
- Encourages your loved one to make meaningful contributions at home or in the community.

You can incorporate this philosophy in your approach in various ways. For example, you can encourage your loved one to learn how to set the table independently, fold towels or socks, brush the dog, or even arrange flowers.



## SECTION 4

# Self Care for Caregivers



# Self Care for Caregivers

The demands of caring for a loved one experiencing dementia can be physically, mentally, and emotionally demanding. When caring for others takes center stage, caregivers often forget to take care of themselves. Just like being on an airplane, we have to put our own oxygen masks on before assisting those next to us. That same principle is applicable here as well. Self-care is one of the most important parts of providing care for someone else, and it's also most often forgotten.

To be the best caregiver you can be, and to protect your own long-term health and well being, it's important to make self care a priority.

## Recognizing Signs of Built Up Stress

It's normal to feel stress while taking care of a loved one experiencing dementia. These feelings can be magnified if you're overwhelmed with other life matters.

It's important to recognize the signs that pent-up stress may be causing in your life. These signs may include:

- Headaches and/or body aches
- Disruption in sleep patterns
- Digestive issues
- Weight gain or loss
- Having a short fuse; being quick to anger or irritation



- Losing interest in activities or hobbies that once brought you joy
- Reliance on alcohol, drugs, or prescription medications

If not addressed, the implications of this stress load can be serious. The Family Caregiver Alliance reports caregivers experience higher levels of stress, anxiety, and depression. Studies also show that caregivers are less likely to seek regular medical care for themselves and experience twice the rate of chronic conditions, including heart disease, cancer, diabetes, and arthritis.

# Tips for Taking Care of Yourself while Caring for a Loved One

As a caregiver, you cannot stop the impact of dementia on your loved one, but you can take responsibility for your own personal health and well being so that you don't neglect yourself while providing needed care. There are resources and tools available that can help ensure you take proper care of yourself.

**Here are some tips we recommend you consider as you continue along this journey:**

## Ask for help

It can be difficult to ask for help, especially if you feel as though all of the responsibility is on your shoulders since you're providing care and support for a loved one. Identify several tasks that would ease the load of caregiving and seek out support from another family member or a trusted friend that can provide assistance. You might find that those you approach for support are eager to be there for you. And of course you will directly benefit from having additional breathing room and space.

## Stay connected

Try not to close yourself off and isolate from friends and family. Make it a point to reach out to those in your circle and maintain connections that are important to you. You might even consider seeking out a support group in the community or access local resources that can be an outlet to help you decompress and pro-

cess all that's changing and happening around you. Be assured that you are not alone in what you are experiencing. Others in your shoes may have new ideas and strategies for caregiving and self care. The more you reach out and connect with those in your circle, the more you'll grow and learn how they've coped as well if they've been in a similar situation.



## Prioritize health basics

Be sure to make regular eating and sleeping a habit. At times, stress can detract from those basic habits that we need to both function and survive, especially during a stress occurrence such as this. There are also instances where we can rely on sleep and food too much. Consider being intentional about maintaining a nourishing and balanced diet. If for no other reason, do it for the energy you need to provide that needed care and support. Ultimately, it'll reduce stress for you both.

## Reinstate old routines

When a major life occurrence alters our behavioral patterns, it's easy to lose a bit of who we are and neglect prior enjoyments:

- What did you do before you were a caretaker?
- Did you go to the gym at 5 a.m.?
- Maybe you enjoyed lunch with friends once a week

While we understand that it may be challenging, try not to sacrifice the tasks or events that made you happy or feel more complete as you provide care for your loved one. While you're trying to provide care for your loved one, we recommend that you hold onto things that cause you to feel joy as well. Not only does maintaining a sense of self provide a break, but it can also give you further motivation and encouragement in your day.

## Talk with your Doctor

When caring for a loved one that's been diagnosed with dementia, it's important to also keep track of your own health needs. This means keeping up with your doctors' appointments. Get regular checkups, stay current on your vaccinations, and let your doctor know that you are a caregiver. Talk openly with him or her about how it's going and any concerns you may have.

As we've said before, your overall health and well being is very important to your ability to be a caregiver.



## Engage in Respite Care

As a caregiver, taking a break can have a positive impact on your physical and mental health. Think of it this way: businesses offer vacation time to employees for a reason. And often, they insist on it so that employees are taking care of their own well-being and are not burned out. Vacation time is both offered and encouraged so that employees return feeling refreshed, renewed, and reenergized.

At BHI Senior Living, we offer something called Respite Care. Your loved one will stay in one of our furnished suites for a short period of time and receive excellent care from our experienced, caring staff. He or she will also enjoy BHI's activities and amenities. And as a caregiver, you'll be able to reap benefits from our environment as well. With Respite Care, you can take the time you need to recharge best worry-free.



## SECTION 5

# How to Know When it's Time for Memory Care?

## How to Know When it's Time for Memory Care

This is a common question and one that many struggle with while caring for a loved one experiencing dementia. It is best to ask yourself a few questions. Is my loved one in need of more care than I can provide? Is my own personal physical and mental health declining? Would my loved one benefit from being around others like themselves where they can feel successful and form friendships?

### What is Memory Care?

A Memory Care community specializes in the well-being of the person “living with dementia”. The goal is to provide the best “quality of life” possible for the person along their journey. This includes a Life Enrichment program where staff are trained in dementia and life enrichment activities. A Memory Care community can provide support for family with dementia education and caregiver support groups.

### Common Signs Memory Care Could Benefit Your Loved One

There are several common signs to keep in mind as you consider Memory Care as a viable option to support your loved one.

#### Dementia Diagnosis

While it's common to become forgetful with age, routinely forgetting important dates, names and tasks might be a sign of dementia or a dementia-related condition.



If your loved one has been diagnosed with Alzheimer's, dementia or a dementia-related condition, now is the time to start researching Memory Care options. Living at home for as long as possible is often encouraged in the beginning stages as long as there are no serious safety concerns.

Studies show that it's helpful to transition individuals into Memory Care before later stages of dementia occur so they can form relationships and connections with the staff and have a say in their care.

#### Safety Concerns

Memory loss can bring about new daily challenges. It's possible your loved one might go for a walk but forget where they were going or how to get home. Memory loss can also lead to more falls as people sometimes lose their habitual knowledge of where the curb ends or where they left an item around the house that



might be a tripping hazard. If you are starting to grow concerned about your loved one's everyday safety, it's time to start discussing Memory Care.

### Increased Health Issues

Memory loss can take a toll on your loved one's overall health. They might experience sleep issues due to losing track of days and times. They might struggle remembering to take medication or the proper dose. Preparing proper meals can also become challenging and lead to rapid weight loss and weakened immune systems. If you see an increase in health issues as a result of memory loss, it might be time for Memory Care.



### Living in Deteriorating Conditions

Memory loss can sometimes lead to the deterioration of a loved one's home and living conditions. This might mean bills are going unpaid. There might be a stack of dishes in the sink at all times. Things might be messier than usual. Your loved one might also forget to go food shopping or take out the trash.

Sometimes memory loss can pose challenges for your loved one's personal hygiene. They might forget to shower, brush their teeth or neglect other basic grooming.

If you notice your loved ones living conditions are starting to deteriorate this might be a sign that they could benefit from Memory Care and additional support from trained professionals.







## Additional Resources:

Family Caregiver Alliance

<https://www.caregiver.org/caregiver-statistics-demographics>

Making Your Home Dementia Friendly

<https://www.brightfocus.org/alzheimers/article/making-your-home-dementia-friendly>

Rethinking Dementia

<https://rethinkingdementiami.org/>

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