

# Staying Connected

A Guidebook for Families  
Living with Dementia





At MBK Senior Living, we believe that when a person has Alzheimer's or another dementia-causing condition, it does not just affect the person, but the entire family. It is extremely important that families and friends stay connected to their loved ones, that each resident feels connected to the world and our team members create connections daily.

People with dementia are often challenged to communicate effectively and have a hard time understanding what caregivers are asking of them. This can lead to fear or frustration throughout daily activities. And over time, even though the person with dementia can't remember specific frustrating moments, they can

develop a general distrust of formerly trusted loved ones. But there is a remedy. When caregivers engage in fun, loving, focused activities together — sharing laughter, joy, reminiscing, focus tasks, music and creativity — the patterns of meaningful connection will evolve into a trust bond between the person with dementia and the caregiver.

MBK Senior Living's care philosophy involves gathering residents' histories and stories to develop a personalized approach to engagement and caring. We become partners with our residents and you, their loved ones. Memory care not only enhances the quality of life for residents but also impacts all those who care for residents with dementia. The way in which we develop each day for our memory care residents is based on the best evidence-based methods to promote cognitive function, physical and spiritual well-being. For example, we encourage morning sunlight exposure, mid-morning exercise, afternoon rest and night time routines to promote the best quality sleep. Sleep quality is linked to cognitive function and afternoon mood.

We are here to make your memory care decision as clear and stress-free as possible. We will guide and support you and your family in any way that we can. When choosing a dementia care community, it is important to know the basics of Alzheimer's and dementia to better understand the "what" and "why" of the things that we do daily. This guidebook will help you better understand dementia, how it affects daily life in a memory care community and prepare for what life will be like moving to a memory care community.



# Introduction to Alzheimer's Disease and Dementia

## ***About Alzheimer's disease***

Alzheimer's disease is not a normal part of aging — it is a progressive brain disease that causes problems with memory, thinking and behavior. Alzheimer's is the leading cause of dementia, a general term for loss of memory and other cognitive abilities serious enough to interfere with daily life.

## ***Risk factors***

Experts believe that Alzheimer's develops as a complex result of multiple factors rather than one overriding cause. The only exception to this is inheriting one of three rare genes that directly



cause the disease. These genes account for about 1 percent of all cases. The other 99 percent of Alzheimer's cases are believed to be caused by a wide range of risk factors. These include, but are not limited to, advanced age, family history of Alzheimer's and lifestyle factors such as diet, exercise and smoking.

## ***Symptoms***

The symptoms of Alzheimer's disease are more than simple lapses in memory or age-related changes. People with Alzheimer's disease experience memory loss as well as difficulties communicating, learning, thinking, and reasoning. As the disease progresses, individuals may also experience changes in personality and behavior, such as anxiety, suspicion, or agitation, as well as delusions or hallucinations.

To help identify problems early, the Alzheimer's Association has created a list of 10 Warning Signs of Alzheimer's disease ([alz.org/10signs](http://alz.org/10signs)).



## *Diagnosis*

A physician should be consulted about concerns with memory, thinking skills and changes in behavior so the cause can be determined. This is especially important because some dementia-like symptoms can be reversed if they are caused by treatable conditions, such as depression, drug interactions, thyroid problems, excess use of alcohol or certain vitamin deficiencies.

An early diagnosis allows individuals with dementia to take advantage of available treatments as soon as possible.

There is no single diagnostic test that can determine if a person has Alzheimer's disease. However, diagnostic tools and criteria make it possible for physicians to make a diagnosis of Alzheimer's with an accuracy of about 90 percent. The diagnostic process may involve a thorough medical history, mental status and mood testing, a physical and neurological exam, and tests (such as blood tests and brain imaging) to rule out other causes of dementia-like symptoms. This process may take more than one day or visit.



# Dementia Expressions

Dementia can cause a person to act in different or unpredictable ways. Some people become anxious or aggressive, are more uninhibited, or use language that they wouldn't have in the past. These changes can lead to frustration or tension between you and your loved one. You may also experience other people's loved ones' behaviors when visiting a memory care neighborhood. MBK Senior Living teams receive training on how to respond to these dementia expressions, and it is important that you recognize and understand them as well. Changes in behavior can be caused by physical discomfort, over-stimulation, unfamiliar surroundings, complicated tasks, or frustrating interactions. Below is a short list of the types of expressions that we encounter regularly in memory care.

***Agitation/Restlessness and Wandering*** — Individuals in an agitated state are mentally and physically excited. The result is often a mix of restless actions that have no apparent purpose. They may also exhibit emotional outbursts or overreactions to a situation that has become overwhelming or threatening. There could be a few different causes to consider: anxiety from an unfamiliar environment, lack of sleep, over stimulation, pain or needing to use the restroom. Promoting sleep, reminiscing, encouraging proper nutrition and hydration, regular bathroom reminders and pain check-ins are all potential ways to address wandering.

**Sundowning** — During the late afternoon and evening individuals may experience increased agitation and restlessness, and be more sensitive to environmental stimuli and stress. Sundowning behavior is not an inevitable symptom of Alzheimer's but is more likely a result of the lifestyle Alzheimer's and other dementia causing illnesses can impose. Good sleep, hydration, nutrition, exercise, pain management, morning sun exposure, and social interaction will dramatically reduce the frequency of sundown behaviors.

**Paranoia and Suspiciousness** — Likely due to not being able to remember recent events, it is normal for people with dementia to blame others for their confusion. We take a “don't argue” approach and use Validation techniques to help the person feel heard and understood. See below for more on Validation.

**Hallucinations** — Seeing, hearing, feeling, or smelling something that is not there is a typical dementia symptom. As with paranoia, we very rarely argue or try to tell the person that the hallucinations are not real. Too often, the hallucinations are very real to the person experiencing them and if we argue, it makes them feel even more frightened because they feel like we are refusing to help them solve a very scary problem. Instead, we try to come up with creative ways to chase off whatever seems to be there. For example, we may have a spray bottle with water that we can use to spray on spiders or snakes. Sometimes the person thinking that we have a snake repellent will make the snake hallucination go away.

**Delusions** — The person believes something not real is true. For instance, they may believe that they are at work and complain about “all the work you make them do around here.” Validation is the best approach to handle this. With this example, we might declare this “the weekend” and plan some relaxing weekend activities for the resident who feels like this workplace is becoming a burden.

**Hyperorality** — It can be typical for someone in later stage dementia to want to put everything within their reach into their mouth. This means being careful about what is placed on a table in front of a person. We do not have silk flower arrangements and may remove condiments from the tables of people who tend to do this.

**Sexual Expression** — It is not uncommon for a person with dementia to develop an attachment to or interest in another resident regardless of his or her marital status or past relationships. This desire might seem out of character or unusual but it is important to remember that individuals with dementia can still have the same drives and underlying emotions as when they were younger. All residents retain their personal rights, including rights to sexual expression and engagement, even when they are married or in another relationship. It is important that team members and family react to the resident with patience and understanding. If intimacy occurs, team members will try to determine the individuals’ level of awareness and consent. Safety is our priority and dignity is our goal. We will notify both responsible parties of the relationship and address your concerns. Many families in this situation find the support of others who have gone through it very helpful, and we can guide you to a support group.



# Communication

As people living with dementia lose the ability to process and use language, communication becomes increasingly challenging. Here are some tips for communicating effectively:

1. Gain attention prior to communicating
2. Go slowly and give ample time for responses
3. Stay below and in front of the person you are talking with
4. Use gestures
5. Do not end a sentence with a question (for example, “okay?”)
6. Establish and maintain eye contact
7. Communicate one point at a time
8. Use simple language
9. State ideas in positive rather than negative terms (for example, instead of saying, “don’t drop it,” say “hold it tight.”)
10. Avoid questions and use clear statements
11. Smile and remain calm
12. Do not apply reason and logic — these are often not relevant to the person with dementia’s experience

## Reality Orientation vs. Validation

It can be tempting to try to help your loved one re-learn the reality of a situation. Some may think that this is a way to help a person with dementia regain old memories and some are trying to defend their own actions when accused by their loved one of wrongdoing.

In either case, typically people with dementia are not going to regain memories in this way. Some memory can be stimulated, and brain health can be promoted, but not by directly trying to re-learn facts. If you engage in continued confrontations about reality, the person with dementia will slowly lose trust for those who argue with them. This can be damaging to the care giving relationship.

Instead of trying to orient your loved one to reality, use a validating approach. Try to understand the feelings they are having and respond first to the underlying emotion. For example, if your mom asks, “Where is dad?” Instead of saying, “Dad died ten years ago, Mom,” — which could evoke strong negative emotions — try responding in a way that acknowledges why she might be looking for Dad and gives a reasonable explanation for his absence. “Dad is usually around, isn’t he? Well, you know Dad, he’s probably tinkering with something. But I’m here, Mom, and I know where they keep the ice cream.”

The best way for you to help promote memory and brain function is to engage your loved one in memory function activities that are appropriate for their level of dementia, stimulating, and positive. Reminiscing and music are very therapeutic. Exercise and sunlight also promote brain health. Here are some visit tips on how to use brain healthy activities to promote better, more enjoyable visits while helping your loved one stay healthy.

# Visit Tips

Visiting a person living with dementia is not always easy. It is normal to be at a loss for words or ideas about what to do when you visit your loved one. Here are some suggestions for making the most of your time together.

- Try to be patient and supportive — their experience is very different from yours
- Limit distractions — turn off the TV or go to a quieter area
- Sunlight, exercise, hydration, reminiscing, and music are brain healthy activities



## *Things to Avoid:*

- Arguing or correcting facts — instead, agree with the underlying emotion, be supportive and then change the subject
- Reasoning or trying to explain the situation when the person will not remember
- Talking a lot about the move, why it happened, selling the house, or other stressful topics if your loved one does not seem to comprehend and gets very upset by it

## What to do:

- Talk to the Director about bringing pets and kids
- Visit when not rushed and don't stay so long that it becomes exhausting
- Create visit rituals and set a reliable visit schedule whenever possible
- Do something together like fold clothes, make flower arrangements, watch a sporting event, or stuff envelopes
- Listen to hymns or say prayers together
- Look at a photo album or watch home movies
- Bring and share favorite music
- If you play an instrument, bring it, and play for the group
- Use objects — props — for reminiscing (photos, memorabilia)
- Remember, you do not need to be present to send your love. Email something to a team member who can share it with your loved one, such as a letter, card, photo or a video clip



# Safety & Security

Connections for Living by MBK™ neighborhoods are secured with magnetic locks; a security code must be entered to open the neighborhood's doors. In an emergency, the locks are disabled allowing for evacuation. The rest of the time, only MBK Senior Living team members have the door codes. While this means ringing a doorbell and waiting for a team member for entry, it is the only way to truly ensure the safety and security of our residents.

MBK Senior Living has strict chemical safety policies. When a resident has dementia and cannot keep their items secured, team members will secure all personal care products that pose a risk to memory care residents. All personal care supplies, food and snack items should be given to a team member to secure and not placed directly in the resident's apartment.

While it can be challenging to keep some residents with dementia from wandering throughout the Connections for Living by MBK™ neighborhood, and at times people wander into each other's apartments, we do not lock apartment doors except under two conditions: 1) the resident can have and maintain their own apartment key and does not have a roommate who cannot, or 2) the resident is inside the apartment.





# Moving into a Connections for Living by MBK™ Neighborhood

When preparing for a move, first realize that if your loved one has resided in the same location for a long time, the move can be traumatic. People with short term memory challenges are typically unable to cognitively map new environments and may never remember their apartment number or location, or where and why they moved. This means initial anxiety and frustration is common. They will, however, usually settle in after about 30 days if we prepare for the transition together.



First, the most important thing for you to do is assist the Director in filling out the Lifestyle Survey form. We need to understand current preferences and routines, and we also need detailed information about old stories, hobbies, and habits to help us build familiarity with your loved one.

While we do evaluate case-by-case scenarios, it is typically better for your loved one to arrive to an apartment that is fully furnished. It is very rarely helpful to the person with dementia to participate too much in deciding what to take — this depends on their ability to remember what is happening. The furnishings should be as familiar as possible. Replace furnishings only if absolutely needed for safety reasons — otherwise, Mom’s old familiar bed or Dad’s old familiar chair are an opportunity to build security and comfort from the first day. Please hang familiar photos and artwork and set up the apartment in a way that closely mimics home.

We often build “legacy boards” for our residents. Please provide the needed photos, trinkets, or other items as requested by the Director. The displays are used for: 1) your loved one who may have more trouble remembering numbers but can use the legacy board to identify his or her new apartment, 2) our other families and residents to know more about your loved one to promote connections and 3) for our team to have an opportunity to reminisce and connect prior to engaging in care activities (which helps them to be more successful).



Please go through all drawers before moving a piece of furniture in; you might be surprised by what we find in the dresser drawers of some of our new residents. Your Director will provide you with a list of prohibited items. Label your loved one's items. Use a laundry-proof marker to mark clothing items. Please be aware, however, that we value dignity over some other concerns, so you may see your loved one's roommate wearing something that belongs to your loved one. If that person dressed him or herself and seemed pleased about it, our staff might not correct them and instead wait until bedtime to retrieve the item. If it is upsetting your loved one, we will try to correct the situation in the most dignified way for both. Your patience is very much appreciated.



Unfortunately, we cannot accommodate special laundry instructions because we do laundry for many people in one laundry room. If you want your loved one to have fine washables, you will need to collect those for cleaning and return them. You will also need to be ready for us to make a mistake and toss it in the wash with hot water items! Most people opt for a wash and wear wardrobe. More about valuables in memory care will be reviewed with you by the Executive Director.

## Questions and Resources

Please contact: \_\_\_\_\_ with questions

Our quarterly online support group:

Eric Portnoff, Regional Director of Wellness Programming,  
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## References and Resources

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Feil, N. (1993). *The Validation breakthrough: Simple techniques for communicating with people with "Alzheimer's-type dementia."* Baltimore, MD, US: Health Professions Press.

Gwyther, L. P. (2001). *Caring for people with Alzheimer's Disease: A manual for facility staff* 2nd ed. American Healthcare Association and Alzheimer's Association

Power, A. G. (2010) *Dementia Beyond Drugs, Second Edition: Changing the Culture of Care*, Baltimore: Health Professionals Press

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Alzheimer's Association: [www.alz.org](http://www.alz.org)

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### Books Recommended for Family Caregivers

1. The 36-Hour Day: A Family Guide to Caring for People with Alzheimer's Disease, Other Dementias, and Memory Loss in Later Life by Nancy L. Mace and Peter V. Rabins. 4th ed. Baltimore: Johns Hopkins University Press, 2006
2. Mayo Clinic Guide to Alzheimer's Disease: The Essential Resource for Treatment, Coping and Caregiving by Ronald Petersen, ed. Rochester, MN: Mayo Clinic Health Solutions, 2006
3. Alzheimer's Early Stages: First Steps for Family, Friends and Caregivers by Daniel Kuhn, MSW, and David A. Bennett, MD. 2nd ed. Alameda, CA: Hunter House Publishers, 2003
4. Understanding difficult behaviors: some practical suggestions for coping with Alzheimer's disease and related illnesses A. Robinson, B. Spencer, and L. White. Eastern Michigan University, Ypsilanti, MI: 2007
5. Activities to Do with Your Parent Who Has Alzheimer's Dementia by Judith Levy, EdM, OTR. CreateSpace Independent Publishing Platform, 2014





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