

# DEMENTIA

## *Care Guide*



# TABLE OF CONTENTS

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## THE EARLY STAGES

10 Alzheimer's Warning Signs	—	5
The Stages of Dementia	—	7

## STRATEGIES FOR COMMUNICATING WITH COMPASSION AND UNDERSTANDING

Communication and Dementia: 10 Simple Tips	—	10
Best Music for Dementia Patients	—	11
12 Activities to Foster Connection with Loved Ones Who Have Alzheimer's	—	13
Dementia Care Dos and Don'ts: Dealing with Dementia Behavior Problems	—	15

## LEARNING ABOUT MEMORY CARE

Top Questions about Memory Care	—	19
Person-Centered Memory Care	—	20
Memory Care Checklist	—	22
Recommended Books	—	26

## TAKE ACTION: GET EMPOWERED

How We Can Reduce the Alzheimer's Stigma	—	28
7 Things You Can Do to Help End Alzheimer's Disease	—	30

# *Introduction*

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If you or a loved one is dealing with a dementia diagnosis, you're far from alone. The latest estimates from the Alzheimer's Association indicate that nearly 5 million Americans are currently living with an Alzheimer's diagnosis, and Alzheimer's patients account for only 60-80% of total dementia patients.

With so many people affected, Alzheimer's prevention has become a national priority, as demonstrated by initiatives such as the National Alzheimer's Project Act, which Congress passed unanimously in 2010. Among other things, this act requires a national plan for overcoming Alzheimer's to be updated annually. Yet even as the search for a cure gains momentum, it's widely acknowledged that early diagnosis and proper care can greatly affect the general health and happiness of those who already have the disease.

Whether you've been newly diagnosed or have a loved one in the mid-to-late stages of dementia, this guide is intended to help you and your family enjoy your lives to the fullest, while getting the best possible care.

## THE EARLY STAGES

“ You have to shift the paradigm of defeat by ‘flipping the pain.’ Alzheimer’s disease is going to win. It will take my husband, but it will not take me. I’m going to fight for the next generation. ”

- Meryl Comer

## 10 ALZHEIMER'S WARNING SIGNS

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When it comes to identifying early symptoms of dementia, there's often no clear-cut line between the typical memory changes associated with aging and warning signs that something more serious may be developing. To help differentiate between normal and potentially problematic memory function, the Alzheimer's Association developed the following checklist:

1. ***Short Term Memory Loss***

Forgetting new information is one of the most common early signs of dementia. Forgetting important events and asking for the same information over and over are also common symptoms of early stage Alzheimer's disease. What's typical? Forgetting names or appointments occasionally and remembering them later.

2. ***Difficulty Performing Familiar Tasks***

People with dementia often find it hard to plan or complete everyday tasks. Individuals may lose track of the steps involved in preparing a meal, placing a telephone call or playing a game. What's typical? Occasionally forgetting why you came into a room or what you planned to say.

3. ***New Problems with Writing or Speaking***

People with Alzheimer's disease often forget simple words or substitute unusual words, making their speech or writing hard to understand. They may be unable to find the word "toothbrush," for example, and instead ask for "that thing for my mouth." What's typical? Occasionally having trouble finding the right word.

4. ***Confusion with Time and Place***

People with Alzheimer's can become lost in their own neighborhood, forget where they are and how they got there, and not know how to get back home. What's typical? Momentarily forgetting the day of the week or where you were going.

5. ***Poor or Decreased Judgment***

Those with Alzheimer's may dress inappropriately, wearing several layers on a warm day or little clothing in the cold. They may show poor judgment, like giving away large sums of money to telemarketers. What's typical? Making a questionable or debatable decision from time to time.

6. ***Problems with Abstract Thinking***

Someone with Alzheimer's disease may have unusual difficulty performing complex mental tasks, like forgetting what numbers are for and how they should be used. What's typical? Finding it challenging to balance a checkbook.

7. ***Misplacing Things and Losing the Ability to Retrace Steps***

A person with Alzheimer's may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl. What's typical? Misplacing keys or a wallet, but being able to retrace steps to find it later.

8. ***Changes in Mood or Behavior***

Someone with Alzheimer's disease may show rapid mood swings - from calm, to tears, to anger and aggression - for no apparent reason. They may become extremely confused, anxious, suspicious or dependent on a family member. What's typical? Occasionally feeling sad or moody.

9. ***Trouble Understanding Visual Images and Spatial Relationships***

For some people, a change in visual processing may be a sign of early Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast, which may cause problems with driving. What's typical? Vision changes related to cataracts.

10. ***Withdrawing from Social Activities***

A person with early stage Alzheimer's disease may avoid being social because of the changes they've experienced. They may remove themselves from sports, social events and hobbies. They may become passive, sitting in front of the TV for hours, sleep more than usual or not want to perform daily living activities. What's typical? Sometimes feeling weary of work or social obligations.

In addition to these signs, keep in mind that it's always a good idea to check with a doctor if a person's level of function seems to be changing rapidly. The earlier you recognize that dementia is developing, the sooner you can mitigate its effects.

## THE STAGES OF DEMENTIA

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How does dementia progress? At what stage will you likely start to notice warning signs? Because dementia involves physical changes in the brain, it generally begins long before there are noticeable symptoms. Most clinical providers describe dementia using the seven-stage Reisberg Scale developed by New York University physician and noted expert on aging, Dr. Barry Reisberg. Here are the stages:

### STAGE 1: *No Cognitive Impairment*

Though it may seem odd, the lowest dementia stage on the scale is normal mental functioning, or no cognitive impairment. There are no signs or symptoms of dementia, memory loss, behavioral problems or other changes associated with the onset of dementia.

### STAGE 2: *Very Mild Cognitive Decline*

Where the heck did I put my keys? What was that person's name? According to the Fisher Center for Alzheimer's Research, at least half of the over-65 population reports some minor age-related forgetfulness. Caregivers or medical providers may not even notice such mild impairment, and it is not considered to be actual dementia, though it is part of the scale of dementia stages and may precede more noticeable cognitive decline.

### STAGE 3: *Mild Cognitive Decline*

When memory and cognitive problems become more regular, as well as noticeable to caregivers and loved ones, a person is said to be suffering from mild cognitive impairment (MCI). Since mild cognitive decline can herald more severe stages of dementia in the future, it is important to recognize the signs of this stage in order to alleviate stress in the patient, as well as initiate a medical course of action in the event that the dementia is treatable. Though MCI does not generally have a major impact on day-to-day functioning, some common signs include:

- Impaired work performance
- Memory loss and forgetfulness
- Verbal repetition
- Impaired organization and concentration
- Trouble with complex tasks and problem solving
- Difficulties with driving

**STAGE 4: *Moderate Cognitive Decline***

At this point, a person has clearly visible signs of mental impairment that point to early-stage dementia or Alzheimer's disease. In addition to worsening of the symptoms discussed above, caregivers should stay alert for signs of:

- Social withdrawal
- Emotional moodiness
- Lack of responsiveness
- Reduced intellectual acuity
- Trouble with routine tasks
- Denial of symptoms

**STAGE 5: *Moderately Severe Cognitive Decline***

This stage marks the onset of what many professionals refer to as mid-stage dementia. At this point, a person may no longer be able to carry out normal day-to-day activities, such as dressing or bathing, without some caregiver assistance. Other symptoms that manifest during this stage include:

- Pronounced memory loss, including memory of personal details and current events
- Confusion and forgetfulness
- Further reduced mental acuity and problem solving ability

**STAGE 6: *Severe Cognitive Decline***

Stage 6 is characterized by a need for a caregiver help to perform even basic daily activities, such as dressing, eating, using the toilet and other self-care. Further symptoms may include sleep difficulties, incontinence, personality changes including paranoia or delusions, anxiety, pronounced memory loss and inability to recognize loved ones.

**STAGE 7: *Very Severe Cognitive Decline***

In severe Alzheimer's disease or late-stage dementia, people are essentially unable to care for themselves, and suffer from both communication and motor impairment. They may lose the ability to speak, walk or smile without help.



# COMMUNICATION TIPS AND COPING STRATEGIES

“ *Though those with Alzheimer’s might forget us, we as a society must remember them.* ”  
- *Scott Kirkschenbaum, Filmmaker*

## COMMUNICATION AND DEMENTIA: 10 SIMPLE TIPS

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*Here are 10 tips on how to effectively communicate with someone who has moderate-to-severe dementia:*

**1. RECOGNIZE WHAT YOU'RE UP AGAINST.**

Dementia inevitably gets worse with time. People with dementia will gradually have a more difficult time understanding others, as well as communicating in general.

**2. AVOID DISTRACTIONS.**

Try to find a place and time to talk when there aren't a lot of distractions present. This allows your loved one to focus all their mental energy on the conversation.

**3. SPEAK CLEARLY AND NATURALLY IN A WARM AND CALM VOICE.**

Refrain from “baby-talk” or any other kind of condescension.

**4. REFER TO PEOPLE BY THEIR NAMES.**

Avoid pronouns like “he,” “she,” and “they” during conversation. Names are also important when greeting a loved one with dementia. For example: “Hi, Grandma. It's me, Jeff,” is to be preferred over, “Hi. It's me.”

**5. TALK ABOUT ONE THING AT A TIME.**

Someone with dementia may not be able to engage in the mental juggling involved in maintaining a conversation with multiple threads.

**6. USE NONVERBAL CUES.**

For example, maintain eye contact and smile. This helps put your loved one at ease and will facilitate understanding. Keep in mind that when dementia is very advanced, nonverbal communication may be the only option available.

**7. LISTEN ACTIVELY.**

If you don't understand something your loved one is telling you, politely let them know.

**8. DON'T QUIBBLE.**

Your conversations are not likely to go very far if you try to correct every inaccurate statement your loved one makes. It's okay to let delusions and misstatements go.

**9. HAVE PATIENCE.**

Give your loved one extra time to process what you say. If you ask a question, give a moment to respond. Don't let frustration get the better of you.

**10. UNDERSTAND THERE WILL BE GOOD DAYS AND BAD DAYS.**

While the general trend for those living with dementia is a downward decline, people with dementia will have ups and downs just like anyone else.

## BEST MUSIC FOR DEMENTIA PATIENTS

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### 1. MOOD ENHANCING MUSIC: Personally Meaningful Songs and Familiar Old Favorites

Listening to old favorites can enhance mood and make potentially troublesome daily living activities such as bathing or dressing go more smoothly for all involved. Kim Warchol, a licensed occupational therapist says that the music should be something familiar to your loved one, “Music can be used in so many ways and for so many purposes in Dementia Therapy. Get creative and get personal. Find the specific songs that were special to your relative and awaken their interest and attention.” Play songs that have some importance to your loved one. This could range from a favorite hymn to “All Shook Up” by Elvis Presley. For ideas about what songs to include, rely on your own recollection of your loved one’s tastes in addition to asking your loved one about his or her favorite songs. Older family members may also be able to recall tunes that were special to your loved one in their youth.

### 2. STIMULATING MUSIC: Pop Songs From Their Salad Days

Stimulating big band, swing and salsa music often inspires dance and movement in dementia sufferers, giving them much needed physical exercise. Ann Napoletan, whose mother suffered from Alzheimer’s disease says, “My mom enjoyed just about any music,” adding that her mother’s housemates “loved the oldies station – Frank Sinatra, Dean Martin. There’s lots of singing along.” Look at the top pop songs from the years when your loved one was a young adult. If your loved one was born in 1930, look at the music charts for the late 1940s and the 1950s. Wikipedia maintains a list of top American pop songs from 1940 onward.

### 3. SOOTHING MUSIC FOR AGITATION MANAGEMENT

Soft classical music, lullabies or non-rhythmic instrumental background music can reduce agitation and anxiety during periods of sundowning. Music therapists also suggest redirecting agitated patients to participate in a rhythmic activity such as singing, tapping or shaking percussion instruments, drumming or clapping.

### 4. CONNECTING AND COMFORTING MUSIC: Sing-Along Classics

To create a sense of comfort and safety as well as engagement, look for classic American folk songs with easy to remember lyrics that most of us learned as children. Think “She’ll Be Comin’ Round the Mountain” and “I’ve Been Working on the Railroad.” Certified musical therapist, Rachel Rambach, wrote “12 Songs Every Music Therapist Should Know.” Some of the songs she’s found most successful in her work include: “Over the Rainbow” and “You Are My Sunshine,” even “American Pie” by Don McLean. She adds that “Amazing Grace” has been a favorite song of elderly patients she’s worked with.

### *Sample Song Playlist: Music for Dementia Therapy*

Dementia patients vary in their response to music depending on which stage of the disease they're experiencing, but it can also change from day to day. What music should you play for your loved one? Bottom line – whatever works.

- “You Are My Sunshine”
- “She’ll Be Comin’ Round the Mountain”
- “This Land is Your Land”
- “Amazing Grace”
- “Over the Rainbow” – Judy Garland
- “Pennies from Heaven” – Bing Crosby
- “Moonlight Serenade” – Glen Miller
- “A-Tisket A-Tasket” – Ella Fitzgerald
- “Moon Glow” – Benny Goodman
- “Nature Boy” – Nat King Cole
- “Memories are Made of This” – Dean Martin
- “Wheel of Fortune” – Kay Starr
- “Five Minutes More” – Frank Sinatra
- “Look for the Silver Lining” – Chet Baker
- “The Goldberg Variations” – J.S. Bach

## 12 ACTIVITIES TO CONNECT WITH A LOVED ONE WHO HAS DEMENTIA

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In addition to having good strategies for dealing with common communication and behavioral issues, there are many activities that will foster a closer connection with those who have dementia. The next time you visit with your loved one, try one or more of the following activities to create a connection with them:

### 1. CREATE A MEMORY BAG

Fill the bag with items reminiscent of their late teens/early twenties. Scented products work well for this, as scents are strongly tied to memory. Try including soap, perfumes and aftershave, or holiday scents like gingerbread, pine and peppermint.

### 2. LOOK THROUGH FAMILY PHOTO ALBUMS

Photo albums with pictures from their childhood or young adulthood are best for this. Old periodicals are another good option, particularly those that include many photos such as *Life* or *Time* magazines.

### 3. READ OUT LOUD

If your loved one has a favorite book, read it out loud to them and let them hold the book and feel the pages. Encourage them to enjoy the distinctive “old book smell.” Reading aloud works especially well with poetry, as the cadence of the words are familiar and calming.

### 4. LISTEN TO A PLAYLIST OF FAVORITE MUSIC

Download songs or set up radio to stream that features music from their teenage years. Many internet radio stations include everything from classic rock to big band sounds, their favorite music should be easy to find.

### 5. SING OLD SONGS

If they grew up going to church, sing old hymns with them. If it’s around the holidays, sing holiday carols or other special songs. Class sing-a-longs and music classes were much more common in schools prior to the electronic age. You might be surprised at what songs your loved ones know and remember from elementary school.

### 6. WATCH OLD MOVIES AND TV SHOWS

Did your parents grow up watching westerns like “Gunsmoke” or family dramas such as “My Three Sons?” Perhaps they were more interested in musicals like “The King and I” or “Singing in the Rain.” You can find many favorite movies and shows from the 40s, 50s and 60s on Netflix or other streaming services.

### 7. GO ON A NATURE WALK

Use nature to integrate sensory experiences into conversation. Listen to birdsong, touch the wet grass, smell the roses and feel the sunshine on your shoulders. Ask what their favorite outdoor activities were during their youth and try to safely recreate similar scenarios if possible.

#### 8. LOOK THROUGH OLD COOKBOOKS

In the past, women spent a great deal of their teenage years learning to cook and young adult years cooking for their families. Discuss origins and variations on old family recipes, or better yet, cook with those old family recipes and share the results with your loved ones.

#### 9. ENJOY FAVORITE TREATS

Look for candy or other indulgences that were commonplace when your loved one was young. Many companies specialize in nostalgic candy where you can buy old favorites like horehound candy and soft peppermint sticks. Even simple things, like an orange, can be a treat to someone who remembers when you only had them during holidays.

#### 10. VISIT AND CONNECT WITH ANIMALS

People who grew up on farms may enjoy an outing to a petting zoo or family farm where they can touch and talk to horses and other farm animals. Ask questions about animals, old pets, or what it was like to grow up on a farm. This is a great activity to involve grandchildren in, since many kids today are not familiar with farms

#### 11. REMINISCE OVER CHILDHOOD TOYS

Nothing elicits childhood memories like familiar old toys. Erector sets, kewpie dolls, sock monkeys and marbles were some of the most popular toys during the 40s and 50s. There are many websites dedicated to antique toys. If you have any old toys available, bring them when you visit, ask questions about how they were played with, or, in the case of construction toys, build something together.

#### 12. REVISIT OLD HOBBIES AND SKILLS

Did your loved one quilt, crochet or knit? Put a homemade quilt or skein of yarn in their hands and let them feel the weight of the quilt and the scratchiness of the yarn. You may be surprised to find that your loved one can still crochet or knit a little bit, even though they have serious memory or cognitive deficits. Often, the muscles remember what the brain has forgotten.

## DEMENTIA CARE DOS & DON'TS: DEALING WITH DEMENTIA BEHAVIOR PROBLEMS

Communication difficulties can be one of the most upsetting aspects of caring for someone with Alzheimer's disease or other types of dementia. Here are some common situations that arise when someone has dementia, and suggestions for ways to handle them:

### *Common Situation #1: Aggressive Speech or Actions*

**EXAMPLES:** Statements such as "I don't want to take a shower!," "I want to go home!," "I don't want to eat that!" may escalate into aggressive behavior.

**EXPLANATION:** The most important thing to remember about verbal or physical aggression, says the Alzheimer's Association, is that your loved one is not doing it on purpose. Aggression is usually triggered by something - often physical discomfort, an unfamiliar environment or even poor communication. "A lot of times aggression is coming from pure fear," says Tresa Mariotto, Family Ambassador at Silverado Senior Living in Bellingham, Washington. "People with dementia are more apt to hit, kick or bite" in response to feeling helpless or afraid.

Writer Ann Napoletan emphasized the unpredictable nature of late stage Alzheimer's, "As my mom's disease progressed, so did the mood swings. She could be perfectly fine one moment, and the next she was yelling and getting physical. Often, it remained a mystery as to what prompted the outburst. For her caregivers, it was often getting dressed or bathing that provoked aggression."

**DO:** The key to responding to aggression caused by dementia is to try to identify the cause - what is the person feeling to make them behave aggressively? Once you've made sure they aren't putting themselves (or anyone else) in danger, you can try to shift the focus to something else, speaking in a calm, reassuring manner.

"This is where truly knowing your loved one is so important," says Napoletan. "In my mom's case, she didn't like to be fussed over. If she was upset, oftentimes trying to talk to her and calm her down only served to agitate her more. Likewise, touching her - even to try and hold her hand or gently rub her arm or leg - might result in her taking a swing. The best course of action in that case was to walk away and let her have the space she needed."

**DON'T:** "The worst thing you can do is engage in an argument or force the issue that's creating the aggression," Napoletan says. "Don't try to forcibly restrain the person unless there is absolutely no choice." Mariotto agrees: "The biggest way to stop aggressive behavior is to remove the word 'no' from your vocabulary."

### *Common Situation #2: Confusion About Time or Place*

**EXAMPLES:** Statements such as "I want to go home!," "This isn't my house.," "When are we leaving?" "Why are we here?"

**EXPLANATION:** Wanting to go home is one of the most common reactions for an Alzheimer's or dementia patient living in a memory care facility. Remember that Alzheimer's causes progressive damage to cognitive functioning, and this is what creates the confusion and memory loss.

There's also a psychological component, says Mariotto: "Often people are trying to go back to a place where they had more control in their lives."

**DO:** There are a few possible ways to respond to questions that indicate your loved one is confused about where he or she is. Simple explanations along with photos and other tangible reminders can help, suggests the Alzheimer's Association. Sometimes, however, it can be better to redirect the person, particularly in cases where you're in the process of moving your loved one to a facility or other location.

"The better solution is to say as little as possible about the fact that they have all of their belongings packed, and instead try to redirect them – find another activity, go for a walk, get a snack, etc.," says Napoletan. "If they ask specific questions such as 'When are we leaving?' you might respond with, 'We can't leave until later because...' the traffic is terrible / the forecast is calling for bad weather / it's too late to leave tonight."

"You have to figure out what's going to make the person feel the safest," says Mariotto, even if that ends up being "a therapeutic lie."

**DON'T:** Lengthy explanations or reasons are not the way to go. "You can't reason with someone who has Alzheimer's or dementia," says Ann. "It just can't be done." In fact, says Mariotto. "A lot of times we're triggering the response that we're getting because of the questions we're asking."

This was another familiar situation for Ann and her mother. "I learned this one the hard way. We went through a particularly long spell where every time I came to see my mom, she would have everything packed up ready to go – EVERYTHING! Too many times, I tried to reason with her and explain that she was home; this was her new home. Inevitably things would get progressively worse."

### ***Common Situation #3: Poor Judgment or Cognitive Problems***

**EXAMPLES:** Unfounded accusations: "You stole my vacuum cleaner!" Trouble with math or finances: "I'm having trouble with the tip on this restaurant bill." Other examples include unexplained hoarding or stockpiling and repetition of statements or tasks.

**EXPLANATION:** The deterioration of brain cells caused by Alzheimer's is a particular culprit in behaviors showing poor judgment or errors in thinking. These can contribute to delusions, or untrue beliefs. Some of these problems are obvious, such as when someone is hoarding household items, or accuses a family member of stealing something. Some are more subtle, however, and the person may not realize that they are having trouble with things that they never used to think twice about.

According to Napoletan, "There came a time when I began to suspect my mom was having problems keeping financial records in order. At the time, she was living independently and was very adamant about remaining in her house. Any discussion to the contrary, or really any comment that alluded to the fact that she may be slipping, was met with either rage or tears. It was when she asked me to help with her taxes that I noticed the checking account was a mess."



**DO:** First you'll want to assess the extent of the problem. "If you're curious and don't want to ask, take a look at a heating bill," suggests Mariotto. "Sometimes payments are delinquent or bills aren't being paid at all." You can also flip through their checkbook and look at the math, or have them figure out the tip at a restaurant.

The Alzheimer's Association says to be encouraging and reassuring if you're seeing these changes happen. Also, you can often minimize frustration and embarrassment by offering help in small ways with staying organized.

This is what Napoletan did for her mother: "As I sifted through records to complete her tax return, I gently mentioned noticing a couple of overdraft fees and asked if the bank had perhaps made a mistake. As we talked through it, she volunteered that she was having more and more difficulty keeping things straight, knew she had made some errors, and asked if I would mind helping with the checkbook going forward. I remember her being so relieved after we talked about it." From there, over time, Napoletan was gradually able to gain more control over her mother's finances.

**DON'T:** What you shouldn't do in these circumstances is blatantly question the person's ability to handle the situation at hand, or try to argue with them. "Any response that can be interpreted as accusatory or doubting the person's ability to handle their own affairs only serves to anger and put them on the defensive," says Napoletan.

# LEARNING ABOUT MEMORY CARE

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*To care for those who once cared for us  
is one of the highest honors.*

*- Tia Walker*

## TOP QUESTIONS ABOUT MEMORY CARE

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### *What is the difference between memory care and assisted living?*

Today's assisted living and memory care communities offer residents everything from gourmet meals and social events to creative singing, art and writing classes; in addition to help with bathing, dressing and medication management. Both memory care and assisted living offer person centered care programs that are designed to enrich the lives of residents emotionally, socially and physically. However, the cost of memory care can be twice as expensive as assisted living for a single resident due to the therapeutic programming. In a full-scale memory care program, a team of health care professionals create individualized programs to help each resident function at the highest possible level for as long as possible.

### *What are typical memory care features?*

Memory care is often located in a separate unit of a larger assisted living facility, or a dedicated wing of a community offering a continuum of care. Key features include the following:

1. A secure safe, environment
2. A high staff-to-resident ratio
3. Sensory-based programming
4. Color-coded hallways and design features to facilitate easy navigation and reduce anxiety for residents
5. Accommodations for residents in the early, middle and late stages of Alzheimer's and dementia

### *Can memory care cure dementia symptoms?*

While there is no cure for Alzheimer's, communities with memory care programs have reported a higher quality of life for its residents in a number of different areas, including reduced medication and medication side effects; fewer falls, injuries, and hospital visits; increased nutrition and wellness; and greater independence and social interaction. As many as 75% of memory care residents even experience improvement or maintenance of mental functioning and the ability to walk.

### *How can you find a good memory care facility?*

Any high quality memory care community will provide education and outreach for families, however families must do their due diligence in researching whether a particular facility is right for their loved one. Before you make a final decision, consider your loved one's individual needs, as well as features and treatments available at the community, their policies, their security and safety, what on-site staffing is available, and whether you and your loved one have an overall positive impression of the place. See our Memory Care Checklist below for more questions to ask.

## PERSON-CENTERED MEMORY CARE

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Memory care providers, like the rest of the senior living industry, have moved away from institutional, one-size-fits-all approach to care. Instead they have adopted an almost Zen-like approach to memory care. Person-centered care means adapting everything about the care to the person being cared for rather than attempting to make people with dementia conform to preconceived notions or standards. It means going with the flow rather than trying to make the river flow uphill.

We spoke with Lesley Yanak of Koelsch Senior Communities, who related a good, real-life example of a person centered approach to dealing with difficult behaviors. During a visit to one of their communities she recalled passing through a hallway and witnessing a resident who was refusing to get dressed. Instead of the incident turning into a tantrum or battle of wills, the caregiver in the room began to sing one of the elderly resident's favorite songs, and she quickly calmed down and agreed to get dressed. "You will see moments like this at our community every day," Yanak said.

### *Know Thy Resident: Promoting Person-Centered Care*

A person-centered approach to care requires caregivers to know who they are caring for. The story Yanak related could not have happened if the caregiver did not know the resident. The caregiver had learned not only that the resident liked songs, but the particular song that would be most calming to her.

One common technique for helping caregivers and community members get to know residents is to decorate the entryway to each resident's unit with photos and mementos of his or her past life. For example, a proud retired police officer might have her badge on her studio door along with some photos of her in uniform. This not only helps caregivers and other staff get to know the residents better – it also helps the residents find their rooms. (Try remembering a room-number with dementia.)

### *Empowering Memory Care Staff to Improve Lives*

Tom Alaimo, Vice President of Life Guidance for Atria Senior Living, said that, at Atria communities, staff are called on to bring their unique and authentic personalities and talents to their job. For example, a staff member with a gift for the piano might be encouraged to play a Mozart sonata for the residents, even if that staff member's regular duties are completely unrelated to the activities program.

Alaimo said that just as all staff are expected to get to know memory care residents, they are also expected to engage them in impromptu activities whenever feasible. For example, a resident who was a devoted and proud homemaker might be encouraged to spend some time with the staff who are, say, folding laundry. Participating in familiar tasks gives residence the pleasure of feeling useful, while enabling caregivers to give them one-on-one attention.

### ***Personalized Activities***

At Lifehouse Health Services senior communities, the Montessori method that was originally developed for the education of children has been successfully adapted to the memory care program. Elicia Van Ark, the Montessori Program Directory for Lifehouse told us, “The Montessori program allows for individual’s personalities to shine. Part of the Montessori program involves having activity baskets and stations available at all times. This allows for the staff and families to grab a basket and do an activity with a resident at any time. The instructions are on the front of the basket with three steps or less.”

We also spoke with Eva Arant, Memory Care Specialist at Koelsch Senior Communities, who described how their homes have at least two (and more often three) separate memory care activity groups. The groups cater to the residents’ level of functioning. For example, the group that is higher functioning is composed of seniors who have early dementia. They may play cards while the group of residents of with mid-stage dementia is doing a sing along; residents with advanced dementia may engage in simple tactile activities like playing with Play-Doh.

Similarly, Koelsch communities and some other memory care providers offer multiple dining environments for memory care residents. Higher functioning residents who like restaurant-style dining have one area – where they can see into the kitchen, hear plates clinking and the grill sizzling, and are served by wait-staff. The second dining area is calmer and more peaceful, and it’s reserved for residents who could become over-stimulated in the restaurant dining area, who need assistance eating, or just prefer a more relaxed atmosphere.

### ***How Person-Centered Care Promotes a Good Life***

If you agree that “the good life” can be made of happiness, kindness, and laughter, then the good life is certainly possible for residents of memory care communities. Even if you find the term “the good life” grandiose, we can call it a good life. By taking an approach to care that involves maximizing happiness and comfort while minimizing discomfort and pain, residents have the opportunity to enjoy wonderful moments and positive experiences with an overall degree of happiness you might not associate with Alzheimer’s patients.

# MEMORY CARE CHECKLIST

## *Questions to Ask When Considering a Memory Care Community*

When you are considering a memory care community for a parent or loved one, you should try to make sure that the care that's provided is closely aligned with their needs. You should find the answers to these questions before you make a final decision about memory care:

## *Questions to Ask Yourself About Your Loved One's Needs*

- YES  NO Does your loved one wander or seek exits?
- YES  NO Does your loved one need help eating?
- YES  NO Does your loved one require diabetic care?
- YES  NO Does your loved one need 24/7 supervision?
- YES  NO Does your loved one show aggression or other behavior issues?
- YES  NO Does your loved one need help toileting or experience incontinence?
- YES  NO Does your loved one require assistance with mobility, using a walker or wheelchair?
- YES  NO Does your loved one need any ongoing medical attention or treatments?  
(for example, dialysis or colostomy care)

## *Additional Comments*

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## QUESTIONS TO ASK THE COMMUNITY

### *Safety and Staffing*

How many hours of training does the staff receive? \_\_\_\_\_

What is the staffing ratio during the day? (number of residents per caregiver) \_\_\_\_\_

What is the staffing ratio at night? \_\_\_\_\_

What medical services are available? \_\_\_\_\_

Can outside (visiting) care be arranged? If so, who coordinates that care? \_\_\_\_\_

Is a nurse on duty 24 hours per day? If not, how many hours is a nurse on duty, and what are those hours? \_\_\_\_\_

- YES  NO Does the community have secure buildings and secure grounds?
- YES  NO Does the staff have sufficient and current training?
- YES  NO Does each resident have an individual care plan?
- YES  NO Is there a visiting physician?
- YES  NO Can you care for wheelchair bound or bedridden residents?
- YES  NO Are you able to care for residents who are physically aggressive or who exhibit disruptive behaviors?

### *Additional Comments*

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### *Memory Care Features and Treatments*

What are the living arrangements? Memory care cottages? Neighborhood style? \_\_\_\_\_

- YES**  **NO** Do they have an assisted living to Alzheimer's care bridge program for early stage patients?
- YES**  **NO** Do they have walking paths or circular walking paths for residents?
- YES**  **NO** Snoezelen rooms? Or other light treatment?
- YES**  **NO** Do they have a special memory care dining program?
- YES**  **NO** Do they group residents by cognitive level?
- YES**  **NO** Do they offer pet therapy?
- YES**  **NO** Music therapy?
- YES**  **NO** Reminiscence therapy?
- YES**  **NO** Parkinson's care?
- YES**  **NO** Vascular dementia care?

### *Community Policies*

What types of care are they not able to provide? How do they transition residents from memory care to skilled nursing? \_\_\_\_\_

- YES**  **NO** Do they provide a thorough assessment before admission?
- YES**  **NO** How often do they update families about resident's well-being?
- YES**  **NO** Do you understand their policy for handling a medical emergency?
- YES**  **NO** Do you understand how the fee structure works?
- YES**  **NO** Is there one flat fee, or separate fees for housing and care?
- YES**  **NO** Do you understand the discharge policy?

### *Your Gut Check*

- YES**  **NO** Does the staff appear to be knowledgeable and caring?
- YES**  **NO** Do residents have free access to outdoor areas?
- YES**  **NO** Is the community easy to navigate?
- YES**  **NO** Does their philosophy of care resonate with you?





## RECOMMENDED READING FROM A PLACE FOR MOM'S CAREGIVER COMMUNITY

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We compiled this list of memoirs, novels and practical guides on the topic of Alzheimer's and dementia that were frequently mentioned by the families we work with as being particularly insightful, compassionate and useful .

“Alzheimer's: A Caregiver's Guide and Sourcebook” by Howard Gruetzner

“Creating Moments of Joy for the Person with Alzheimer's or Dementia: A Journal for Caregivers”  
by Jolene Brackey

“Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease”  
by Joanne Koenig Coste

Still Alice by Lisa Genova

“Ten Thousand Joys & Ten Thousand Sorrows: A Couple's Journey Through Alzheimer's”  
by Olivia Ames Hoblitzelle

“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

“The Alzheimer's Action Plan: The Experts' Guide to the Best Diagnosis and Treatment for Memory Problems” by P. Murali Doraiswamy; Lisa Gwyther

“The Common Sense Guide to Dementia for Clinicians and Caregivers” by Anne Lipton and Cindy Marshall

## TAKE ACTION: GET EMPOWERED

“ *Share the best moments of your life  
with your children as often as you can.*

*Someday when your memory fails  
they will be happy to share them with you!* ”

*- H. Tuller*

## HOW WE CAN REDUCE THE ALZHEIMER'S STIGMA

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### *Understand the Facts*

There is a common misconception that upon receiving a dementia diagnosis, one loses all decision making abilities as well as independence. Most people do not understand the full range of dementia symptoms, conditions and stages, all of which vary widely.

Did you know that about 30-40% of senior patients who go to the emergency room are cognitively impaired, but do not have a diagnosis of dementia?

### *Think of the Person Behind the Disease*

Richard Taylor, who was diagnosed with Alzheimer's about 10 years ago, experienced Alzheimer's stigma firsthand. After reflecting on what he could do to change it, Taylor dedicated himself to speaking out and advocating for a different way for society to look at those with dementia.

Some senior living communities are already looking at the disease and those behind it in a different light. "Dementiaville," a pioneering dementia and Alzheimer's care community, has increased quality of life for dementia sufferers by allowing them to experience life as they once had before the onset of their illness.

Taylor says that he and other dementia sufferers want to be understood. They want others to know, "I am still a whole person. I am not fading away. I am not half-empty or a soulless individual. I'm changing, but I still have the same needs as everyone else. What's ebbing is not myself, but merely the capacity to meet those needs by myself."

### *Place a Priority on Socialization*

From his experience speaking to senior living communities, Richard Taylor learned that the only time many Alzheimer's residents interacted with others was when the staff served them food or administered their medication. "Interaction was not encouraged because it was not seen as a real need. It's not always that we need to be loved; we have a desire to give love, to develop friendships." Recent studies show that socialization actually reduces symptoms of dementia.

### *Don't Hide: Go Public*

In 2014, actor Seth Rogen spoke to the Senate Appropriations Subcommittee on Labor, Health & Human Services about the urgent need for more Alzheimer's funding. He shared how his mother-in-law's long struggle with Alzheimer's disease impacted his family, and told Congress he needed to speak out because "People need more help. I've personally witnessed the massive amount of financial strain this disease causes...[and] to show people they are not alone, so few people share their personal stories."

Rogan was shocked that his mother-in-law, who was diagnosed in her mid-50s, suffered from the disease at such a young age. He thought Alzheimer's was "something only really, really old people got" and involved "forgetting your keys and mismatched shoes."

Rogan hopes that sharing his story, raising awareness about the disease and raising funds for Alzheimer's research through his Hilarity for Charity foundation, will change the stigma associated with dementia.

“Americans whisper the word ‘Alzheimer’s’ because their government whispers the word ‘Alzheimer’s,’ and although a whisper is better than silence that the Alzheimer’s community has been facing for decades, it’s still not enough. It needs to be yelled and screamed to the point that it finally gets the attention and the funding that it deserves and needs.”

Renowned travel guide author, radio and TV host, Rick Steves, lost his mother to Alzheimer's disease in 2013 and spoke to the Washington Post about how to reduce the stigma of dementia. “We’re proud people, there are a lot of social expectations, and we have a loved one who is not able to perform in public. So what do you do? I think it’s important to take them into public and let them sit there and let them make noise... let it shine that there is a loved one here who is enjoying this concert.”

***Thank you for reading our Dementia Care Guide.*** We wish you comfort and hope as you care for your loved one with dementia. You are not alone. For guidance finding memory care, you can get help from an A Place for Mom Senior Living Advisor in your area at 877-311-6099. For additional resources for your caregiving journey, please check out our Caregiver Toolkit at [www.aplaceformom.com/senior-care-resources/caregiver-toolkit](http://www.aplaceformom.com/senior-care-resources/caregiver-toolkit).

– *A Place for Mom Senior Living Advisors*

We value your feedback. Please send your suggestions to [content@aplaceformom.com](mailto:content@aplaceformom.com).



alzheimers.net

## 7 THINGS YOU CAN DO TO STOP ALZHEIMER'S BY 2025



### 1. JOIN A CLINICAL TRIAL

Are you a healthy adult or know of someone who has been recently diagnosed? Everyone is highly encouraged to participate in a clinical trial.

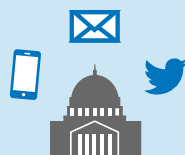
[www.nia.nih.gov/alzheimers/clinical-trials](http://www.nia.nih.gov/alzheimers/clinical-trials)



### 2. GET GENETIC TESTING

Assess your risk of having any amount of genetic predisposition for Alzheimer's by getting yourself genetically tested.

[www.alz.org/national/documents/topicsheet\\_genetic\\_testing.pdf](http://www.alz.org/national/documents/topicsheet_genetic_testing.pdf)



### 3. EMAIL, CALL, AND TWEET YOUR STATE SENATE & CONGRESS

Get them to increase funding for Alzheimer's research and FDA to approve more drugs that impede Alzheimer's, just as they did with cancer.



### 4. GET EDUCATED ABOUT ALZHEIMER'S & DEMENTIA

Learn more about Alzheimer's risk factors, treatments, myths and clinical studies.

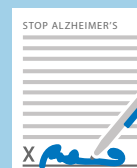
[www.aplaceformom.com/blog/category/memory-dementia-care](http://www.aplaceformom.com/blog/category/memory-dementia-care)



### 5. SPEAK UP IF YOU SEE SYMPTOMS

Help to de-stigmatize and get the conversation going about symptoms and other important facts.

[www.aplaceformom.com/senior-care-resources/articles/alzheimers-warning-signs](http://www.aplaceformom.com/senior-care-resources/articles/alzheimers-warning-signs)



### 6. SIGN THE STOP ALZHEIMER'S PETITION

Get the word out about Alzheimer's by signing the petition.

[www.alzfdn.org/AFAServices/napa\\_survey.html](http://www.alzfdn.org/AFAServices/napa_survey.html)



### 7. JOIN THE FIGHT AGAINST ALZHEIMER'S

Volunteer or donate to your favorite Alzheimer's research or Alzheimer's awareness organization

[www.alz.org/join\\_the\\_cause\\_volunteer.asp](http://www.alz.org/join_the_cause_volunteer.asp)