

Helping your *loved one* experiencing dementia or memory loss

| FAMILY RESOURCE GUIDE





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OVERVIEW

Recently, your family physician may have diagnosed your loved one with Alzheimer's Disease (AD) or another form of dementia or you may be noticing changes in your loved one's memory loss and behavior patterns. Understanding the disease and navigating the right resources as your family processes this new or existing reality may leave you feeling overwhelmed and stressed. Rest assured, SYNERGY HomeCare can help you navigate through uncharted waters and create peace of mind in caring for your loved one experiencing dementia or memory loss.

Understanding dementia/Alzheimer's disease

It is important to note that dementia and Alzheimer's disease are not the same things. **Alzheimer's is the disease causing the symptoms; dementia represents the symptoms of the disease.**

For example, if you go to the doctor because you are coughing (symptom), your diagnosis is going to be what's causing the coughing (disease or condition). One possible cause of the coughing could be an upper respiratory infection. Similarly, dementia alone is not the diagnosis; something causes dementia.

ALZHEIMER'S | THE DISEASE

Alzheimer's is an irreversible brain disease that causes brain damage. Currently, Alzheimer's disease is not preventable, curable, or treatable

THE DISEASE AFFECTS

- Memory
- Communication
- Thinking skills

- A person's ability to carry out basic activities of daily living skills (i.e. bathing, dressing, eating, brushing teeth, etc)

DEMENTIA | SYMPTOMS OF THE DISEASE

Dementia is a group of symptoms that interferes with a person's ability to carry out daily tasks; it is much more than memory loss

BECAUSE OF THE BRAIN DESTRUCTION ALZHEIMER'S CAUSES, ONE MAY EXPERIENCE:

- Forgetfulness
- Memory loss

- Loss of ability to perform familiar tasks
- Disorientation to time and/or place

*These symptoms are commonly associated with dementia.

MOST COMMON TYPES OF DEMENTIA

1

Alzheimer's disease

2

Vascular dementia

3

Dementia with Lewy Bodies

4

Frontotemporal dementia

In the event your loved one is experiencing dementia, ask their medical professional what type of dementia they have or what is causing their dementia



Stages of memory loss/dementia

As we age, it is normal to forget things now and then. It is common to forget where you put your glasses, cell phone, car keys, etc., but typically you are able to backtrack your steps to recover your lost items. It is when you experience difficulty retrieving lost items more frequently or forgetting what those items are used for that may reveal a larger problem.

As thinking skills in older adults begin to decline, it tends to happen in stages.

EARLY STAGE SIGNS

- Recent memory loss. Unable to recall things that happened yesterday but able to recall things that happened years ago
- Not able to find the right words to say
- Poor judgment and decision making. For example, your loved one is not paying bills on time like he/she used to; bills are now being paid weeks and months late and that behavior is different for your loved one
- Getting times, dates, and places mixed up
- Depression
- Difficulty doing things they used to know how to do. For example, your loved one gets confused on how to cut the grass and they need someone to remind them how to use the lawn mower
- Decreased concentration
- Misplacing items and taking a long time to find the lost items

MIDDLE STAGE SIGNS

- Increased memory loss
- Mood swings
- Increased word-find problems
- Unable to follow along during a conversation
- Reading may stop
- Repetitive behaviors (saying and doing things over and over again)
- Unable to recognize familiar faces

MIDDLE STAGE LATE SIGNS

- Increased agitation
- Increased depression
- Paranoia/hallucination
- Can get lost easily
- Wandering
- Considerable weight loss
- Increased risk for falls
- Wetting themselves
- Unable to control bowels
- Difficulty following simple instructions

LATE STAGE SIGNS

- Unable to perform activities of daily living skills independently, such as bathing, dressing or eating
- Unable to walk
- Swallowing difficulties
- Limited communication skills. Might stop talking all together

Communication

Effective communication is a shared responsibility between two people. But, when someone develops dementia, the caregiver becomes responsible for interpreting the entire conversation and decoding messages for their loved one.

As dementia worsens, your loved one might have trouble understanding what you are saying and may rely more heavily on non-verbal communication. Non-verbal communication can consist of body language, tone of voice, facial expressions, and touch.

In order to communicate effectively with someone with dementia, the following actions are recommended:

- Visually demonstrate what you would like for your loved one to do. For example, if you want him/her to eat, you might rub your stomach
- Speak slowly to give your loved one time to process what you are saying so that he/she can respond
- Assist them with finding the right words when they forget
- Always talk with your loved one before asking him/her to do a task. You don't want to surprise them and catch them off guard
- Be patient and supportive
- Offer comfort and reassurance as much as possible
- Avoid correcting and criticizing them
- Limit distraction so that it won't be overwhelming for your loved one.
- Focus on their feelings as opposed to focusing on the task at hand as it could cause frustration. Focusing on your loved one's feelings allows you the opportunity to connect with them and offer the reassurance and nurturing they need during a tough time

Using these effective communication styles with someone with dementia can help mitigate challenging behaviors.



Behaviors

Behaviors are the way in which a person responds to people, places, and things in their environment. Behaviors can become challenging when they are disruptive or dangerous. There are several causes of what we consider to be “challenging behaviors” and dementia is not one of them.

A few of the most common challenging behaviors when it comes to caring for someone with the dementia are as follows:

- Agitation
- Physical and verbal aggression
- Repetition (doing and saying things over and over again)
- Rummaging (moving things from one area to the next and building clutter)
- Wandering

The behaviors noted above may be caused by several things other than dementia. The list below provides guidance on things that might cause someone with dementia to display challenging behaviors:

PHYSICAL CAUSES

- Pain/discomfort
- Your loved one might be in pain or experiencing discomfort due to a medical condition
- Medications
 - The medications that your loved one is taking might be causing concerning behaviors. Perhaps your loved one is taking too many medications or the medications they are taking are not working well together. The behaviors you might see may suggest that the medications are the problem and you should speak with your loved one’s physician. These behaviors tend to come on suddenly as opposed to gradually:
 - Anger, aggression, irritability, irrational thinking patterns, agitation, confusion, disorientation, wandering, paranoia, hallucinations
- Thirst and/or hunger
- Urinary Tract Infection
 - Your loved one could have a urinary tract infection (UTI) which causes significant behavior challenges, such as delirium; confusion; memory loss; and sometimes aggression and wandering
- Lack of sleep
 - Your loved one could be tired because they are not sleeping well at night

COGNITIVE CAUSES:

- Unable to communicate in a manner that others understand
- Loss of memory
- Not understanding
- Loss of hearing or vision

EMOTIONAL CAUSES:

- Fear
- Agitation
- Confusion
- Need for control
- Loneliness

ENVIRONMENTAL CAUSES:

- Too much noise (stimulation)
- Not enough noise (stimulation)
- New or strange places or people
- Their home is no longer familiar to them, so they might begin to wander away

COMMUNICATION CAUSES:

- Rushing your loved one to do something, such as getting dressed
- Too aggressive in your tone when talking to your loved one, such as saying mean words or sounding mean in your tone of voice
- Not talking slow enough for your loved one to understand what you are trying to say
- Too many people telling your loved one what to do and each of them is using different words, phrases, tones of voice, and body languages; this causes confusion for your loved one



Practical solutions

- Minimize change in routine and people
- Allow your loved one to do things that are familiar, such as help wiping down the table or sweeping the floor
- Use appropriate communication skills by giving your loved one instructions using short phrases one at a time, such as “stand up, walk over here, sit down here, pick up your spoon, put it in the rice, pick up the spoon, open your mouth, put the spoon in your mouth”
- Congratulate your loved one on completing a task, as opposed to criticizing them, even if it is not to the caregiver’s liking. For example, if your loved one puts their shirt on inside out, don’t say that it’s on backwards; say that they did a good job putting on their shirt
- Don’t surprise your loved one when talking to them about doing something. You should communicate with them, first, to establish a connection. A simple conversation about the weather would be fine
- Give them appropriate choices and try not to control their decisions. Making decisions helps to promote independence. The choices that you provide them need to be appropriate choices. For example, if it is 100 degrees

outside, the choice of clothing should be two outfits that are worn in the summertime (i.e. short sleeves) as opposed to the winter (i.e. long sleeves). So, no matter what they choose, it will be appropriate

- Keep the environment simple and calming. Don't overwhelm them with lots of colors and patterns on the floor and walls (i.e. decorative pictures and patterned rugs)
- Establish a predictable routine with them and stick to the routine, so they know what to do next and won't have to ask you over and over again



Nutrition and hydration

As we get older, vitamins that we need in our body tend to diminish over time. Therefore, it is extremely important to ensure that seniors have adequate nutrition and that they are properly hydrated to reduce the risk of a medical emergency and/or hospitalization, as dehydration can cause a Urinary Tract Infection (UTI). Malnourished or dehydrated individuals can experience dementia symptoms (see Stages of dementia); however, these types of symptoms are treatable with proper nutrition, hydration, and sometimes antibiotic medications.

As the disease progresses, people living with dementia tend to change their eating habits. The food items they enjoyed before the disease, they may no longer like. For example, they once loved eating mashed potatoes, but now they frown at the sight of them. This is normal for someone who is living with dementia, because their taste buds change over time. In fact, the last taste to change is sweet; this is why they tend to eat sweets more often than anything salty or savory.

With this in mind, here are a few tips to ensure your loved ones are eating and getting enough liquids:

- First, they must feel hungry. If they don't feel hungry, they are not going to want to eat
- They must like the food they are eating. If they don't like it, they are not going to eat it
- Check for physical problems, such as a toothache

- Ensure your loved one is not eating in a distracting place, such as a dining room with more than one or two people
- Ensure your loved one can see the food that is in front of them and on the plate. Caregivers might try color contrasting the food items. For example, put the green beans on a white plate so that they can see them better
- Make sure the food is at the right temperature for them
- Be sure your loved one understands what food is. It might be helpful to sit down at the table to eat with your loved one so that they can see what you are doing and they might follow what they see. It might also be helpful for you to put your hand over their hand and coach them through the eating process by giving them step by step instructions (i.e. pick up the spoon, put it in the beans, pick up the beans, put it in your mouth)
- Give them double servings of their favorite foods
- Be sure to give them foods they are familiar with. For example, don't give them whole crab legs if they don't know how to eat them. It could cause major frustration and then they might refuse to eat all together
- Turn any meal into finger food so they can eat by themselves
- Cut food into small pieces
- If assisting them with eating, give them one food item at a time so as not to overwhelm them
- Try adding calorie dense foods to their meals such as:
 - Cheese
 - Nuts
 - Granola
 - Avocados
 - Sweet potatoes
- Add food supplements to their diet, with their doctor's approval, such as:
 - Nutritional shakes
- Give them several small meals throughout the day if they are constantly looking and asking for food. Providing them small meals throughout the day will satisfy their desire for food, but without the health risk of overeating
- Give them soft foods and stay away from stringy, sticky foods because they can pose a choking hazard
- Allow them to smell the food, as this might stimulate their appetite
- Allow them plenty of time to eat the way they want to eat. Don't rush them
- Offer fluids throughout the day so that they won't become dehydrated
- Try a frozen liquid on a stick, such as a popsicle, if they refuse to drink liquids
- Be sure to offer them the types of drinks they like, such as sodas, even if the drink is watered down
- Also, having preferred drinks in certain containers could help them identify the drink and make a choice to drink it. For example, they might drink their water in a clear tall cup and they might drink their coffee in a coffee cup. You don't want to confuse the two by putting water in a coffee cup because they might not drink it; in their mind only coffee goes in a coffee cup

Home environment/safety:

The home environment of a person with dementia is very important to their well-being. The environment should be familiar, comfortable, and safe. Here are a few tips to ensure your loved one is safe in their home or living areas:

- Be sure there is adequate and even lighting so that they can see where they are going; also to reduce shadows that can encourage hallucinations and paranoia
- Remove throw rugs, as they can be a tripping hazard
- Child proof the home as much as possible, such as covering outlets with outlet covers so that they cannot plug anything in
- Be sure the following are installed in the bathroom to help prevent falls:
 - Handrails
 - Grab bars
 - Bath chair
 - Non-skid tub bottom (add textured stickers if necessary)
- Regulate water temperature. The recommended temperature is 100 – 120 degrees Fahrenheit
- Be sure the outside steps are textured and or mark the edges of the steps with bright tape or paint





Emotional well-being of the family caregiver

Caring for a loved one with dementia is a very challenging but rewarding experience. The cost of caring for this population can cause emotional, mental, and physical strain if caregivers do not take care of themselves. In fact, approximately 60% of family caregivers report extremely high emotional stress and 40% report developing depression. Due to the emotional and physical strain of caring for an older adult, caregivers have increased medical costs.

In order to reduce the family caregivers’ risk of burn-out, medical complications, and not being able to care for their loved ones, the following healthy habits should be considered:

- Lower blood pressure and/or cholesterol
- Control inflammation
- Do not smoke
- Limit alcohol intake
- Exercise regularly

- Utilize relaxation techniques, such as yoga or meditation
- Maintain a brain-healthy diet, for example, incorporating the following foods into your diet:
 - Blueberries
 - Salmon
 - Dark chocolate
- Take vitamin supplements when necessary
- Challenge your brain through activity and engagement. For example:
 - Playing games, such as Sudoku
 - Learning to play a musical instrument
 - Reading
 - Learning a different language
 - Dancing
- Get plenty of rest. It is recommended that adults get six to nine hours of sleep each night

- Stay social
- Consider building a support team that includes the following doctors and professionals:
 - Primary Care Physician
 - Geriatrician (Cares for those 65+)
 - Neurologist (Specializes in brain conditions)
 - Pharmacist (It is recommended to have one pharmacy to develop a relationship with the pharmacist in order to have quicker access when you have a question about the your loved one’s medications)
 - Geriatric Psychiatrist (Recommended if the your loved one is over the age of 65 AND diagnosed with a mental health condition such as depression and/or anxiety)
 - Geriatric Care Manager (Coordinates all support and medical services on behalf of the your loved one and caregiver)
 - In-home Care Provider (Paid in home caregiver to provide respite to family caregivers by assisting their loved one with companionship, personal care, and activities)
- Care strategies to help family caregivers manage stress:
 - Establish and maintain a predictable routine
 - Cooperate with your loved one’s wishes
 - Demonstrate visually to help with communication
 - Do not force something, try again later if your loved one doesn’t want to do it at that time
 - Be sure to offer choices and try not to control your loved one
 - Remove any distractions so that your loved one won’t get overwhelmed
 - Play the role you’re given. For example, if your loved one thinks you are the mail carrier as opposed to their daughter, then you should ‘play’ the role of the mail carrier until your loved one says otherwise
 - Provide reassurance throughout the disease process through touch, eye contact, calming voice, and positive polite words
 - Incorporate meaningful activities that your loved one remembers and enjoys
 - Answer your loved one’s questions verbally or through written communication each time they ask
 - Understand that behavior is a form of communication (see Behaviors)
 - Understand that behaviors are manageable. You want to focus on your loved one’s emotions as opposed to their behaviors to better understand what they are feeling so that you can offer them reassurance and comfort
 - Do not ignore the signs of dementia (see Stages of memory loss)
 - Reach out for help

RESOURCES

Alzheimer's and Dementia Caregiver Center

1-800-272-3900

<http://www.alz.org/care/overview.asp>

Alzheimer's Disease Education and Referral Center (ADEAR)

National Institute on Aging

Tel: 1-800-438-4380

Fax: 301-495-3334

Email: adear@nia.nih.gov

<http://www.nia.nih.gov/alzheimers>

Family Caregiver Alliance® National Center on Caregiving

1-800-445-8106

<https://caregiver.org/dementia-caregiving-and-controlling-frustration>

Eldercare Locator

1-800-677-1116

<http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx>

Aging Life Care Association

[https://www.aginglifecare.org/
Local Area on Aging](https://www.aginglifecare.org/LocalAreaonAging)

Considering In-home and respite care support

It is important that family caregivers take a break and time away from constantly caring for their loved ones. This is called Respite. The Merriam-Webster Dictionary defines Respite as “to grant a temporary period of relief”; this is where caregivers give themselves permission to take a break and take time away from caring for their loved one in order to practice self-care. When caregivers take advantage of Respite options, stress and depression are reduced; thereby, allowing family caregivers the emotional and physical ability to care for their loved ones in a healthier way.

When considering in-home care and respite support, family caregivers should consider asking the following questions to in-home care providers:

1. What type of dementia training is offered to the staff?
2. How often is this training provided?
3. Do you provide client-specific dementia training?
4. What is the backup plan in the event the primary caregiver is not available?
5. What type of background checks do you perform on your staff?
6. Do you do supervisory visits where someone from your agency would come out unannounced and check on the quality of your staff's work?
7. Will my loved one and I be able to meet the caregivers before they begin working?
8. If I feel the caregiver is not a good fit for my loved one, will I be able to choose someone else?
9. Do you accept insurance, such as Medicaid, Medicare Advantage or Long-Term Care Insurance?
10. How are your services paid? Do you accept cash, check, bank transfer, credit card payment?



We are here to help. SYNERGY HomeCare takes pride in equipping our caregivers with advanced up-to-date dementia care practices that will benefit not only your loved one, but families, as well.

At SYNERGY HomeCare, we believe that every client and their family should be cared for with their individual needs and preferences in mind. There is no one size fits all in-home care support for clients experiencing memory loss; therefore, we offer *A Convergence of Care*. Our philosophy brings together a person-centered approach to dementia care that leverages industry best practices, technology solutions and nationally recognized training

standards in Alzheimer's and dementia. Our memory care program incorporates wholehearted engagement through stimulating activities, conversations and music, along with enhanced companionship through nostalgic entertainment and robotic therapy pets; plus, additional safety precautions are taken to reduce wandering or other associated behavioral concerns.

We can design a customized memory care plan to help your loved one live their best life, wherever they call home, with comfort and purpose. And you can find peace of mind, too.

For more information visit SYNERGYHomeCare.com or call 877-432-2962.



For care cost information, a customized care plan
and a free home assessment, contact us.

877-432-2692

SYNERGYHomeCare.com