

Caring For A Loved One With Dementia

a practical
guide
for family
caregivers
4

Dementia Stages, Signs & Symptoms



Introduction



Researchers have learned that dementia begins to develop years before it is diagnosed. A caregiver may notice subtle changes in cognition or behavior in a loved one that may seem like normal aging. But is it? Read on to learn what comprises normal aging, the signs of Alzheimer's disease, and what to expect as the condition progresses.



Signs of Alzheimer's Disease

When memory loss is due to a neurological progressive condition, such as Alzheimer's disease, there are several warning signs to help you detect the problem and seek treatment as soon as possible. The signs include:

1. Memory Loss

This often presents itself as someone having problems with short term memory loss. This may be forgetting names of people you know well, appointments, instructions, or conversations. The person may misplace items and be unable to locate them or retrace steps. In some cases, the "forgetfulness" interferes with life, such as preventing a person from attending events or appointments due to forgetting.

2. Disorientation

Individuals who are experiencing signs and symptoms of dementia may have trouble navigating new and familiar environments. They may have significant difficulty reading a map, following directions, and may become lost or disoriented in familiar environments. For example, someone may become lost while taking a walk in a familiar neighborhood, or may be disoriented to person, place, time, or situation.

3. Language

Changes in language can appear in the form of having word finding difficulties. A person may have trouble finding the right word, or may use a word that doesn't quite fit. For example, instead of "shut the light off" they may say "close the light off".

Instead of "napkin" they may say "Kleenex". Problems with language may be a sign or symptom if it is a new change, or if new problems surface related to speaking or writing. Any changes in language and speech should be evaluated immediately since they can also be symptoms of strokes or other neurological damage.



4. Mood

Often times, people who are experiencing memory loss are aware changes are happening. They are often worried and may try and hide it from others. Persistent worry and fear often leads to anxiety and depression. If you see changes in mood, personality, withdrawal from work or social activities, poor judgment or increased impulsivity (such as shop lifting), schedule a checkup and include a memory test to help determine what might be causing the change in mood and behavior.

Normal aging

There are a number of changes that occur as people age that are normal. Remember, however, that “normal” changes will not interfere with life. Normal changes include the following:

1. Slower processing

It takes longer, and a lot more effort to learn. Our brains take longer to organize and store new information.

2. Distraction

As we age, we are much more susceptible to distractions. The lack of attention slows down our learning and makes it more difficult to learn and store information efficiently.

3. Slower Recall

What was that person’s name? It’s on the tip of my tongue... Normal aging includes slower recall- our brains take longer to bring information to the surface, especially recently learned information, such as a new acquaintance. Our ability to recognize is unaffected however. This is a good tip- if you recognize someone but can’t recall their name immediately, that is normal. If you just met them and don’t recognize them, that may be a sign of a problem.

4. Switching Gears

As the brain ages, the ability to transition between tasks takes a hit. Younger brains think and organize in one mode, and can

quickly switch to a new task with a different set of organizational rules. Consider the brain shift you might have to make if you were writing a technical manual for a computer one minute and a children’s book about barnyard kittens the next. The skills, words, planning and organization would take longer as we age.

Normal Age-Related Forgetfulness

Sometimes misplaces keys, eyeglasses, or other items.

Momentarily forgets an acquaintance's name.

Occasionally has to "search" for a word.

Occasionally forgets to run an errand.

May forget an event from the distant past.

When driving, may momentarily forget where to turn, quickly orients self.

Jokes about memory loss.

Mild Cognitive Impairment

Frequently misplaces items.

Frequently forgets people's names and is slow to recall them.

Has more difficulty using the right words.

Begins to forget important events and appointments.

May forget more recent events or newly learned information.

May temporarily become lost. May have trouble understanding and following a map.

Worries about memory loss.

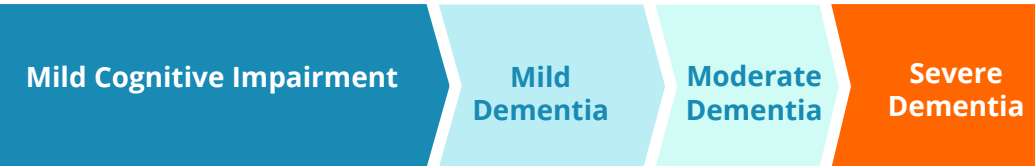
Stages

There are generally four stages of dementia; mild cognitive impairment, mild, moderate, and severe. Each stage has its own signs, symptoms, and challenges.

Pre-dementia Stage

Dementia Stage

2



Impairment does not interfere with activities of daily living.

Impairment in two or more cognitive functions, and such impairment does interfere with activities of daily living.

Preclinical

In the preclinical stage, before impairments are evident to others, individuals may complain of problems with recent memory (names, where they placed things, appointments, etc). They may have some trouble concentrating, and there may be some mood changes as they may be aware of the changes but using denial to put off addressing them. A person may receive a memory screening in this stage and score in the normal range. This stage is sometimes known as “A stage where the person knows, but the doctor doesn’t”.

Mild Cognitive Impairment (MCI)

In this stage, a person may have mild symptoms of memory loss, however the impairments do not interfere with daily functioning. This stage may last up to 7 years.

7

	Mild	Moderate	Severe
Cognitive	Increased forgetfulness, word-finding difficulties, disorientation, and impaired judgment.	Severe short-term memory deficit, failure to recognize others. Short attention span. Severe naming and fluency problems. Getting lost easily.	Severe short and long-term memory deficits. Loss of speech, mutism. Neurological changes (e.g., swallowing and walking problems). Inability to recognize spouse and self easily.
Behavioral	Depression, apathy, withdrawal, irritability, denial.	Increased anxiety, restlessness, apathy, and isolation. Wandering, delusions, and hallucinations. Anger and frustration with impairments. Changes in sleep and appetite.	High levels of passivity, agitation, and egocentrism. Non-responsiveness. No awareness of others.
Functional	Increased difficulty with routine tasks, increased difficulty with higher order tasks such as driving or balancing a checkbook, more difficulty and risk in living independently.	Difficulty with basic activities (e.g, grooming, eating). Cannot be left unsupervised.	Total dependence on others for all activities. Bladder and bowel incontinence.

What to expect

Alzheimer's disease and other dementias are progressive diseases, meaning that the person will likely progress over a number of years through all the stages. Several factors may influence how fast or slowly progression takes place, including genetics, diet, exercise, type of dementia, other health conditions, medications, education, and staying socially active. Depression and anxiety can have a negative impact on cognitive health, and a positive attitude and approach can make a significant difference. Early intervention will have the most profound effects, so addressing problems early and seeking treatment is very beneficial.



It is important to remember that this condition has likely been present for a number of years - 10 or more - before being diagnosed. Despite that, making lifestyle changes in diet and exercise and engaging in social and cognitively challenging activities has been shown to have significant effects on patients well into their 80's, and can help slow the progression of many types of dementia. In the event that you or a loved one is diagnosed, being active advocates for care, intervention, and medication will help you live your best, longest, and highest quality of life with dementia.

Caregiving

A caregiver who provides daily care and interaction with a person with dementia may want to identify possible changes leading to the next stage. Anticipating what may be coming next will help you cope and prepare to meet the challenges of a changing disease. If you are not sure what stage your loved one is in, ask your doctor for an assessment, or work with the patient's neurologist to determine the stage.

As changes occur, it can be difficult to adapt to meet a person's new needs, and you may need to adapt both your strategies for interactions, and also the environment. A regular environmental assessment is recommended to help keep the patient safe.

Environmental Considerations

1. Emergency Response

Is the person safe to be alone? Would they know what to do in case of an emergency?



To check, perform monthly emergency response checks by asking them the following questions:

What would you do if there was a fire? (Leave the house or call 911)

What number do you call for an emergency? (911)

Can you show me? (Points to correct numbers)

What is your home address? (Can recite address)

If your loved one is not able to perform these tasks, they are likely not safe to be left alone, even for short periods of time. Place 911 stickers at phones if reminders are needed.

2. Driving

If the person is not safe to drive, determined either by them or their physician (or both), remove access to the car keys, or unplug the car battery. If they have been involved in an accident, exhibit a lack of judgment, or confusion behind the wheel, inform their physician immediately. The doctor will make a determination to notify the DMV.

3. Hygiene

Monitor to be sure the person is using the restroom, has good hygiene and handwashing, and is showering regularly. Do they have increased confusion while doing these activities or need assistance?



4. Financial Risk

Monitor phone and computer use for potential fraud risk. Consider restricting access to credit cards or cash if the person's judgment is too impaired to keep information safe.

5. Environmental/Home Safety

a. Monitor cooking and kitchen activity. Consider unplugging the stove.

b. Remove hazardous objects that may be mistaken for food or candy, including laundry detergent pods or other objects that could be swallowed.

c. Assess carpets and rugs. Remove dark colored rugs that may appear to be “black holes”.

As a caregiver, you may notice changes including increased resistance, difficulty, or confusion. Other changes may be temporary, then the person returns to their normal functioning. This is quite common, and while we can say everyone has “good days” and “bad days”, occasionally changes in a person's presentation may be due to factors, such as pain or an infection. Cognitive functioning may be negatively affected by stressful events, hospitalizations, or illness.

To help navigate the changes and gain skills and tools for being an adaptable caregiver, find a local support group and attend as regularly as possible. Caregiver support groups are attended by other people who have the same challenges, frustrations, guilt, and worry, but they have some solutions and tools to share too. This is an invaluable resource for helping you cope, and the research shows that caregivers who attend support groups are much healthier and better adjusted as well.

As a caregiver, you have a big job to take care of yourself, your loved one, and make the best and often times difficult choices. If you are unable to do this, for whatever reason, there are resources available.

1. Adult Protective Services (APS) Agencies. An APS is an agency to help elder adults (65 and older) when these adults are not able to meet their own needs, or are victims of abuse, neglect, or exploitation. APS also provides referrals and coordination to other agency, and may involve a social worker who can provide resources to improve the situation.

2. Caregiver Resource Center (CRC) serves families coping with the physical, emotional, and financial responsibilities of caregiving. By providing families with individualized, supportive services CRC focuses specifically on the needs of caregivers, who are coping with a loved one's chronic illness. Services include family consultation, assessment, care planning, counseling, referrals for resources, psycho-educational seminars, respite planning and community education. CRC is a not-for-profit organization and services are free to caregivers.

Conclusion

Knowing what to expect and how to prepare for the various stages of a loved one's dementia are key to coping with the condition. So is knowing where to get help. Be sure to take time for yourself, and be willing to reach out when you need assistance.

Resources

- **Adult Protective Services (APS)**

To get your Adult Protective Services (APS) County contact information, visit:

www.cdss.ca.gov/inforesources/Adult-Protective-Services

- **Caregiver Resource Center (CRC)**

www.caregiveroc.org

¹Johns Hopkins Medicine. *Guide to Understanding Dementia.*

www.johnshopkinshealthalerts.com

²Orange County Vital Brain Aging. *MCI and Dementia.*

www.ocbrain.org

The series of Caregiver Books "Caring For A Loved One With Dementia - A Practical Guide for Family Caregivers" was developed by Alzheimer's Family Center in Huntington Beach, California thanks to the generous support of the Arthur N. Rupe Foundation.

Contributors to the series are:

Cheryl Alvarez, PsyD; Marie Oyegun, MA; Corinne Enos, LCSW; Traci Roundy, RN; Patrick Wallis, MSG; Irma Marin, CNA; Judy Osuna; Becky Barney-Villano; as well as the program team, nursing team, activities team, and social work team at *Alzheimer's Family Center* in Huntington Beach, CA. Special thanks to Judy Culhane.

www.AFSCenter.org