

The Family Caregiver's Guide to **Alzheimer's & Dementia**



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About this Guide

Dementia can be a frightening diagnosis for a senior and for their loved ones. Across the world, millions of individuals and their families struggle with various symptoms of dementia. These families experience financial struggles, mental exhaustion, and emotional grief as they provide loving care and support.

To understand the worldwide impact of this disease, here are some staggering statistics:

- 1 in 3 seniors dies with dementia
- Alzheimer's disease accounts for 70% of dementia cases in seniors
- 1 in 6 women 55+ will develop dementia
- 1 in 10 men 55+ will develop dementia
- Every 65 seconds someone in the US develops Alzheimer's
- By 2050, there will be 13.8 million Americans with Alzheimer's

As a dementia caregiver, you don't have to care for your loved ones alone. This guide to Alzheimer's and dementia is a comprehensive resource for dementia caregivers to understand how these illnesses change the brain and how you can better care for your loved ones.

Dementia caregiving can be overwhelming, and each day brings new challenges. Refer to this guide often to help anticipate and cope with new challenges.

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The Face of Dementia Caregiving

Family caregivers provide all-encompassing care to their loved ones to keep them as safe and healthy as possible. Their care extends to personal hygiene, meal preparation, housekeeping, transportation, and more. Caregiving takes a physical, mental, and emotional toll. These duties can be made more difficult by a diagnosis of dementia.

Dementia Caregiver Statistics:

- Over 16 million Americans provide unpaid care for individuals with dementia
1 in 3 of these caregivers is 65+
- 40% of dementia caregivers have a college degree or greater education
- Approximately 25% of dementia caregivers are in the “sandwich generation”
- Over 66% of these caregivers are women
- 86% of dementia caregivers have provided assistance for at least a year
- Over 60% of dementia caregivers are expected to continue giving care for the next 5 years

With the numbers of seniors with dementia continue to increase, the need for loving dementia caregivers continues to increase as well.

Getting to Know the Dementia Family

Dementia refers to several different brain disorders, including the following.

Alzheimer's disease: This is the most common form of dementia. It is characterized by forgetfulness, confusion, apathy, depression, judgement impairment, and difficulties in communication.

Parkinson's disease: Parkinson's disease is often accompanied by dementia. This disease is characterized by tremors and shakiness, and later results in dementia.

Vascular dementia: This form of dementia develops with blood flow to the brain is impaired. As such, the brain doesn't get the oxygen it needs. This type of dementia is accompanied by small strokes that block blood vessels. Vascular dementia is found in about 40% of individuals with dementia.

Dementia with Lewy bodies: Seniors with this type of dementia have abnormal clumps of protein deposits called Lewy bodies. The symptoms are very similar to Alzheimer's, but individuals may be extremely tired during the day and experience hallucinations.

Mixed dementia: Alzheimer's disease and vascular dementia at the same time.

Creutzfeldt-Jakob disease: This form of dementia is extremely rare. It is a more rapid form of dementia.

Fronto-temporal lobar degeneration (FTLD): Early symptoms include changes in personality or behavior. Unlike Alzheimer's disease, memory remains intact during the first stage.

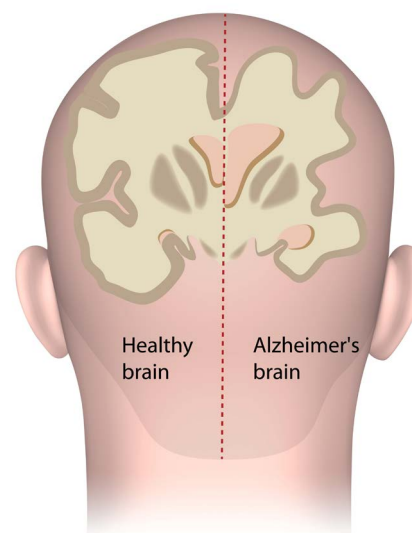
Normal pressure hydrocephalus: This disease is caused by cerebrospinal fluid buildup. Symptoms include memory loss, incontinence, and difficulty walking. It only accounts for 5% of dementia cases.

Each of these dementia-related diseases results in brain damage: brain cell damage or damaged connections between brain cells. This damage is revealed in the form of memory loss, decline in speech and cognition, decline in motor skills, and a decline in the ability to make sound judgements.

It is important to note that dementia physically changes the brain. When German physician Alois Alzheimer studied the brain of a dementia patient after her death, he discovered clumps of tangled proteins at the ends of nerve cells. These protein clumps disrupt brain signals and cause the progressive symptoms seen in dementia patients.

Unfortunately, this process is irreversible. As of today, there are no treatments that can heal Alzheimer's or related dementia.

As a caregiver, understanding that dementia-related diseases physically change the brain can help you as you care for your loved one.



Causes of Alzheimer's & Dementia

Alzheimer's and dementia-related diseases may have a genetic link and may also be triggered by lifestyle factors.

A GENETIC LINK

Early-onset Alzheimer's may be inheritable. The APOE-e4 gene has a strong link with Alzheimer's. 20% to 25% of individuals with Alzheimer's disease have this gene. Additionally, individuals who have amyloid precursor protein (APP), presenilin-1 (PS-1), and presenilin-2 (PS-2) will develop Alzheimer's and can even start to show symptoms in their 30s or 40s. However, research shows that later-onset Alzheimer's disease is less inheritable.

LIFESTYLE FACTORS

While there is no conclusive evidence that links dementia or Alzheimer's with lifestyle choices, there are some compelling arguments.

Because heart health is linked to brain health, anything that damages the heart may increase the chance of developing Alzheimer's. Heart-damaging conditions include:

- Heart disease
- Stroke
- High blood pressure
- Diabetes
- High cholesterol

These conditions are impacted by lifestyle choices like diet, smoking, alcohol and drug use, and lack of exercise.

How These Diseases Progress

Dementia results in loss of functionality. The beginning of the disease is unknown, but most likely, Alzheimer's begins about 10 years before symptoms are noticeable.

As mentioned above, during the progression of Alzheimer's or dementia, deposits of proteins in the brain accumulate and block the flow of information from brain neurons. This effectively keeps memories from being accessed and emotions from being kept in check. As neurons begin to function less efficiently, they lose the ability to communicate altogether. When this happens, the brain tissue shrinks.

Seniors ages 65 or older are at a higher risk of developing Alzheimer's. By 85 years old, seniors are at 50% risk of developing the disease.

There are 3 stages of disease progression:

EARLY

The early stage of disease is characterized by energy loss, frustration, mood swings, and confusion. Seniors may get lost more easily, have difficulty remembering daily tasks, lose items like their glasses or wallet. Some seniors may also develop changes in personality. This stage typically lasts for 2 to 4 years.

During this stage, seniors may be fully aware of what is happening to their minds. This battle for the brain can be difficult for seniors and their caregivers alike.

MIDDLE

The moderate stage of dementia is the longest stage, lasting between 2 and 10 years on average. During this stage, a senior becomes disabled. Seniors lose the ability to perform complex tasks, experience depression, lose control of their emotions, experience withdrawal, and may even become physically violent.

Your loved one might stop taking showers or wander off. But your loved one may still be able to recognize family members and discuss memories.

We recommend managing finances and appointing power of attorney at this stage, although it's never too early to be prepared.

LATE

During the final stage of dementia, a senior may lose the ability to speak, to recognize family members, to control their body, and to recall memories. Seniors in the final stage of dementia need constant care and attention.

Your loved one is at a high risk for falling and for illness. You may notice that your senior has difficulty swallowing, which can put them at risk for aspiration pneumonia. During this last stage, you may become overwhelmed as a family caregiver. Consider bringing in an extra set of hands to care for your loved one.

At Caring Senior Service, our caregivers are trained to assist seniors with dementia to ensure that they remain as comfortable and healthy as possible during this last stage of the disease.

Discussing a Diagnosis with Your Loved One

It can be difficult to approach the topic of Alzheimer's or dementia with your struggling loved one. Some families may be afraid that the diagnosis can cause their loved one to fall into depression. However, it's important that get a diagnosis as soon as possible. An early diagnosis can lead to better medical treatment.

Here are some tips to approaching the conversation about dementia:

- 1 Consider the best approach for your loved one.** Everyone is unique, and as a family caregiver, you have the best knowledge of your loved one's medical condition and of their personality and preferences. Use this knowledge to help guide the conversation.
- 2 Practice how you will bring up dementia.** Role playing with another family member or even just speaking the words aloud can help you figure out the best way to talk about dementia symptoms. By practicing with another individual, you can get feedback on how your words could be perceived.

Here are some conversation starters:

Mom, I have noticed some behavior changes lately, and I wanted to know if you've noticed the same changes.

Would you like me to tell you of any changes I observe in your behavior or health?

- 3 Plan for the worst.** While you may practice the conversation, remember that it might not always go according to plan. Be open and honest even if your loved one gets angry or defensive. But don't force the conversation. If your loved one doesn't want to talk about it now, give it a few days. However, if they refuse to open up, you may need to contact a medical professional.
- 4 During the conversation, offer your loving support and reassurance.** The possibility of Alzheimer's or dementia can be scary for your loved one. Let them know that you will be there every step of the way and that you will help them through the upcoming months and years.
- 5 Point out specific examples of behavior.** Your loved one may not even realize that they exhibit signs of dementia. You should come prepared with specific instances of confusion, withdrawal, aggression, denial, etc.
- 6 And once you have a diagnosis, you should inform your loved one about their situation.** This can be scary for some family caregivers. Your loved one may even be comforted by the diagnosis. Confirming there is something wrong can help them understand the cause of their mood swings, confusion, or forgetfulness. They may be relieved to know that the memory loss isn't their fault.
- 7 Make a game plan together.** After the difficult conversation is over, you and your loved one can begin to create a plan together. You should learn everything you can about the disease, review treatment options, discuss how your loved one wants to be cared for, and remain positive.

Common Symptoms & How to React to Them

As a caregiver, you need to look for the signs of Alzheimer's and other dementia-related diseases to be able to care for your loved one most effectively. To help you out, here are some common symptoms of Alzheimer's and dementia and some ideas for how you can react when you experience these symptoms with your loved one.

Confusion and Forgetfulness

Confusion is one of the first symptoms of Alzheimer's or dementia-related diseases. Seniors may forget how to get to the grocery store. They may call your neighbors by different names. They could even forget how to put on their clothes or take a shower.

This "forgetfulness" can be very agitating to a caregiver, especially if it happens every day and you are constantly having to remind your loved one of the same things over and over.

Tips to Help Deal with Confusion:

- Stay calm
- Remember that the confusion is part of the disease itself
- Offer simple explanations to your loved one
- Try to help your loved one's memory with pictures of places, people, or other important things

Sundowning

Sundowning refers to late-day confusion. You may see sundowning in your loved one due to exhaustion, a disturbed internal clock, or larger shadows and decreased lighting.

Tips to Help Deal with Sundowning:

- Limit caffeine and sweets
- Eat dinner early
- Keep your loved one busy throughout the day
- Keep rooms partially lit to lessen confusion caused by darkened surroundings

Judgement Impairment

Individuals may not be able to make sound judgement choices with Alzheimer's or dementia. They may lie, steal, or make irrational decisions. This behavior could also include eating strange things like paper.

Tips to Help Deal with Judgement Impairment:

- Be patient
- Establish ground rules in simple language
- Safe-proof your home to ensure your loved one can't accidentally harm themselves

Aggression or Agitation

Your loved one may experience aggression or agitation due to lack of communication, physical pain, frustration when trying to recall memories, or other factors. It is common for individuals with Alzheimer's or dementia to experience this aggression, even if it doesn't seem in line with an individual's personality.

Tips to Help Deal with Aggression:

- Look for causes of aggression or agitation
- Make changes to make your loved one more comfortable (turn off the TV, adjust the lights, remove clutter, etc.)
- Go for a walk
- Don't become agitated yourself
- Discuss behavior with a doctor
- Remember that you cannot control behavior, but you can accommodate it

Suspicion

Individuals with Alzheimer's or dementia may become suspicious of you as their caregiver. They may make accusations about you, family members, friends, or other individuals.

Tips to Help Deal with Suspicion:

- Don't argue
- Try to figure out what the root of the problem is
- Offer an explanation
- Try to engage them in an activity to take their mind off their suspicion

Hallucinations

Hallucinations can be extremely scary for you and for your loved one. These hallucinations could be memories from the past or could be completely new experiences. Hallucinations can occur because of dementia or dehydration, pain, medication abuse, or vision and hearing problems.

Tips to Help Deal with Aggression:

- Stay calm
- Change the surroundings or move into another room
- Try to engage them in an activity to refocus their attention

Depression

Many seniors with Alzheimer's or dementia experience depression due to the disease and their decreased comprehension and ability to communicate. They may show signs of isolation, social withdrawal, and hopelessness.

Tips to Help Deal with Depression:

- Remember that the disease is physically changing the brain, resulting in the increase of hormones associated with depression
- Discuss depression treatment options with a doctor
- Help your loved one exercise daily
- Engage your loved one in activities they enjoy
- Provide reassurance

Falling or Tripping

Individuals with dementia or Alzheimer's may experience more falls due to impaired cognitive function and balance. As the disease progresses and motor skills decrease, tripping or falling can become more dangerous. And once a senior falls, they are more likely to fall again.

Tips to Help Deal with Falls:

- Remove fall hazards
- Get your loved one proper footwear
- Provide mobility assistance

As a caregiver, these symptoms can be scary and hard to deal with. At Caring Senior Service, we understand these difficulties, and our caregivers are specially trained to deal with Alzheimer's and dementia-related diseases. If you need additional help to address the needs of your loved one, don't hesitate to reach out!

Caring for Seniors with Alzheimer's or Dementia

Caring for a loved one with Alzheimer's or dementia can be a difficult task. However, loving care can ensure that your loved one maintains their quality of life to the best of their ability. Here are some tips to help you provide care during this difficult period in your loved one's life.

1 Clear communication

Caregivers will find that it is increasingly difficult to communicate with individuals with Alzheimer's or dementia because of the progressive nature of the diseases. Written and spoken language will be impaired along with cognitive functions.

Dementia caregiver communication checklist:

- Use simple words and sentences
- Avoid sarcasm
- Speak in a calm tone of voice
- Avoid arguing
- Do not speak to your loved one like a baby
- Reduce distractions when trying to communicate (TV, radio, etc.)
- Make eye contact
- Set a positive mood with your tone of voice and body language
- Ask simple yes/no questions when needed
- Maintain your sense of humor

In addition, caregivers may have to say "No" a lot. This can be disheartening for the senior and for the caregiver. It's heartbreaking when a loved one can't understand why you are refusing something that they want or that they have done in the past. If this is the case, try making a request more personal and offering a reward.

For example: If you are trying to get your dad to go outside with you, try saying, “Dad, let’s go outside and take a look at your garden. I need your advice on how the tomatoes are doing, since you’ve always been the master gardener. Afterward, we can go in and eat cookies.”

2 Engaging activities

Participating in activities together is a great way for you and your loved one to pass the time. Choose activities that (1) promote movement and exercise, (2) are enjoyable for the senior, (3) help sharpen skills, and (4) are appropriate for the stage of the disease.

When doing activities together, remember to communicate clearly. It’s also a good idea to focus on having fun. Don’t worry about whether your loved one can complete a task or achieve a goal. Just enjoy your time together.

Dementia caregiver activity checklist:

- Bake together
- Do arts and crafts
- Sing songs
- Watch family videos
- Work on a puzzle
- Fold laundry
- Create a memory box
- Untie knots
- Thread pasta with a piece of yarn
- Play with a 2 x 2 Rubik’s cube
- Read aloud

3 Good personal hygiene

Seniors with Alzheimer’s or dementia-related diseases often have a difficult time with personal hygiene, including bathing and grooming. Your loved one may even be afraid of the shower or forget how to get dressed.

Dementia caregiver personal care checklist:

- Stick to a routine
- Add grab bars, non-slip mats, & other safety features in the bathroom
- Tell your loved one what you are going to do before you do it
- Limit clothing selections to avoid clutter
- Choose clothes that are comfortable and easy to put on and take off
- Don't rush
- Enhance feeling of privacy by closing doors and curtains
- In the shower, hold up a towel as a privacy screen if needed
- Have clothes ready to put on after a shower
- Never leave your loved one in the shower unattended
- Consider dry shampoo

4 Proper eating habits

Dementia can impact a senior's eating habits. As mentioned, seniors may want to eat things that are inedible or pair foods together that just don't taste good. Additionally, the disease may decrease appetite and erase all memory of knowing how to use utensils. As a caregiver, it's your responsibility to ensure that your loved one is getting proper nutrition.

Dementia caregiver nutrition checklist:

- Streamline food choices
- Eat at the same time every day
- Remove clutter from the table
- Ensure that food and drinks aren't too hot or too cold
- Be patient
- Make mealtimes special by playing soft music or adding flowers to the table
- Serve foods that are easy to chew and swallow
- Pre-slice foods and don't be too concerned with proper table manners

5 Safety concerns

Safety should be one of your top priorities as a caregiver. You want to make sure that your loved one is safe and that those around them are safe.

Dementia caregiver safety checklist:

- Remove tripping hazards like cords and clutter
- Improve lighting around the home
- Install appliances with an auto shut-off feature
- Remove knobs from the stove and other appliances
- Remove locks from doors so loved ones can't lock themselves in
- Ensure that smoke detectors and other detectors have working batteries
- Use childproof latches on cabinets with sharp objects
- Keep a spare key in an area that you can get to in case your loved one locks you out
- Cover outlets with childproof plugs
- Resolve uneven surfaces

While you can never guarantee safety for any individual, the tips provided can help you reduce the chance of injury at home.

6 Anticipating wandering

Seniors with dementia tend to wander. They may be looking for food, they might be bored, or they might be getting some exercise.

Dementia caregiver wandering checklist:

- Place a GPS locator on your loved one
- Make time for exercise in your routine
- Add “stop” or “do not enter” signs around the house
- Install new locks
- Add child-proof locks to doors
- Install a home security or monitoring system
- Inform neighbors about your loved one's wandering behavior

Potential Treatments

While there is no cure for dementia, there are some treatment options that can help prolong your loved one's life and keep symptoms at bay.

MEDICATION: Doctors can prescribe medications to help manage the symptoms of Alzheimer's or dementia. Typically, doctors will prescribe something to help with depression. Memory pills are also a common treatment. These do not stop dementia but can help boost brain function to temporarily improve symptoms.

ELECTROCONVULSIVE THERAPY: This therapy has been used to help treat depression. The treatment is painless and doesn't take too long. During this therapy, electric current is passed through electrode pads that are placed on the head. Seniors are put under anesthesia during the procedure.

LIFESTYLE: Lifestyle choices can help manage Alzheimer's and dementia as well. Have an established routine that includes daily exercise. Seniors need to feel like they are contributing in some way, so engage them in meaningful activities.

Disease Prevention

While there is no way to ensure that you or a loved one doesn't develop Alzheimer's or dementia, there are some things that you can do that may help.

MAINTAIN A GOOD DIET. Unhealthy diets can cause damage to the brain, but healthy choices in food can help your brain stay healthy. Consider forgoing sweets, pre-packaged foods, fatty foods, and processed meats for healthier alternatives.

INTERACT WITH OTHERS. People who engage with others in conversation results in higher cognitive function. Conversations require stimulation and deep thinking, which is good for your cognitive abilities.

ENGAGE IN COMPLEX THOUGHT. Complex jobs (doctor, social worker, lawyer, engineer, etc.) and work environments are extremely beneficial for the brain and can help you maintain cognition as you age.

EXERCISE. Exercise is great for the body, spirit, and mind. Exercising can help keep your body strong and healthy as you get into your golden years.

Additional Resources for Caregivers

There are many additional resources available for individuals caring for seniors with Alzheimer's or dementia. The internet provides a wealth of information to learn more about your loved one's disease.

There are many online forums or chat groups that you can join to discuss your challenges as a caregiver. It's likely that other caregivers are going through the exact same situation, and you can gain strength from joining a community with them. Search for support groups that meet in person or stick to an online group depending on your needs.

You can also look around your community to find local organizations that can provide support. Check with nursing homes, assisted living facilities, mental health centers, nursing schools, church groups, and other organizations. If you contact an organization who can't help you, ask them for a referral. They probably know where you can turn for assistance.

Finally, consider respite care when you are feeling overwhelmed. Respite care refers to bringing in a professional caregiver so that you can get a break. This type of care doesn't mean that you aren't fulfilling your duties as a caregiver. On the contrary, it allows you to recharge and rejuvenate your spirit so that you can care for your loved one more effectively. Respite care can last for a few hours or a few weeks. Reach out to Caring Senior Service for more information about providing respite care for you!

Resources

<https://www.alz.org/media/Documents/facts-and-figures-2018-r.pdf>

<https://www.seniorliving.org/healthcare/alzheimers-disease>

https://www.helpforalzheimersfamilies.com/wp-content/uploads/HelpForAlzheimersFamiliesGuide_final.pdf

<https://braintest.com/dementia-stats-u-s-worldwide/>

<https://www.caregiver.org/caregivers-guide-understanding-dementia-behaviors>

<https://www.alzheimers.net/how-to-talk-with-a-parent-about-dementia-symptoms/>

