



Living with Dementia

A CAREGIVER GUIDE TO MEMORY CARE



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Introduction

It can be very difficult to care for someone with dementia. You may feel sad and not sure about the future. You might feel stressed and alone. You may wonder, “How many more memories will be lost? How much will this person change today? How much longer will I be caring for this person?”

Being the caregiver for a person with dementia is a huge — and many times thankless — job. This booklet lets you know what to expect. It also offers helpful care tips for each stage of the illness.

Call us if you need help. We are here to support you. When you have support, you can give better care.

“Those with dementia are still people and they still have stories ... they still have character ... they are all individuals, and they are all unique. And they just need to be interacted with on a human level.”

— Carey Mulligan, actress

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What Is Dementia?

“Dementia” is a term that covers a wide range of symptoms. It is caused by damage to brain cells. These changes in the brain can cause problems with thinking, memory, behavior, and physical abilities.

The most well-known cause of dementia is Alzheimer’s disease. Dementia can also be caused by:

- Other diseases of the brain, like Parkinson’s or Huntington’s
- Stroke, blood clots, tumors, or infections
- Some thyroid, kidney, or liver diseases
- A long history of depression, major sleep problems, or heavy alcohol/drug abuse

Early signs of dementia may seem like normal signs of aging. Some people showing signs of dementia may not seek help. They may be in denial or embarrassed about their symptoms.

It may help to keep in mind that dementia is an illness. Instead of affecting the heart or lungs, this illness affects the brain. It is nothing to be ashamed of.

There is no cure for dementia. It is a terminal illness. Some people don’t know this because it might take many years for dementia to reach end stage. This is another reason why caregiving can be so hard.

Remember, the dementia patient is
not *giving* you a hard time.
The dementia patient is *having* a hard time.

Symptoms and Stages of Dementia

Dementia affects each person in a different way. The timeline and symptoms will vary for everyone. Some people take years to reach late stage. Others decline quickly. Those who are getting worse may seem better at times. Those who have progressed slowly may suddenly get worse.

People with dementia will lose skills as their disease affects certain parts of the brain. Ask us what you might expect in your case. It is normal to focus on what skills have been lost. Try instead to focus on the skills the person has left. Working with the person from this mindset may help.

Memory loss is the most common sign of dementia. Other symptoms may come first. What symptoms show — and when — depend on what part of the brain the person's disease has damaged. Below are things to look for at each stage. Not everyone will show all symptoms. **Contact us if symptoms disrupt daily life.**

Early stage

The person can live on their own and make small talk. But symptoms disrupt daily life. They may struggle with planning or complex tasks. Some people are aware they need help and count on others for reminders. Some people are not aware.

The person might:

- Have trouble recalling names, words, or recent events
- Be confused about time or place
- Lose things often and for long spans of time; not be able to retrace steps to find lost items
- Have trouble speaking or writing in a way that makes sense
- Have trouble doing familiar tasks; show poor judgment

Middle stage

This stage can last many years. Symptoms are more obvious. The person needs help with daily tasks. Many cases of dementia are not caught until this stage or later.

The person might:

- Forget family members or big life events
- Be more confused about time or place and get lost easily
- Not understand what is being said to them
- Not be able to see, hear, talk, or write clearly
- Withdraw from activities
- Not be able to drive
- Not be able to cook, clean, or do other household tasks
- Need help eating, toileting, bathing, dressing, or walking
- Have personality changes, have mood swings, become more aggressive, or lose self-control
- Be more anxious at night (“sundowning,” see page 12)

Late stage

Symptoms are the worst at this stage. The person relies on others to do daily tasks and will need full-time care.

The person might:

- Not know where they are, who they are, or who the people around them are
- Have very big changes in personality; be easily upset or angered
- No longer be able to stand, walk, speak, or swallow
- Use gestures or facial expressions instead of talking
- Be very weak and frail

Caregiving Tips

The goal is to keep the person calm and as active as possible during each stage of dementia. Many of these tips can be used in all stages. They may need to be adapted for each person's ability at each stage. Using these guidelines may help slow symptoms in some cases. Contact us if you have questions.

Safety and setting

The goal is to keep the person's space safe and calm:

- Avoid overstimulation (when sights, sounds, smells, or touch are too much for the person). Switch out bold linens for simple patterns and soft colors. Keep the person's space neat and free of clutter. Keep the room at a temperature that the person prefers.
- Label cabinets and doors to remind the person where things are. Secure items such as medicines, cleaning supplies and other toxins, sharp or dangerous objects, etc.
- Falls are common and can cause serious harm. Check the person carefully for injuries if they fall. To prevent falls:
 - Keep floors clear; remove area rugs and secure cords.
 - Keep a cane/walker near the person, if needed.
 - Make sure the person wears their hearing aid and glasses, if needed.
 - Keep the home well lit; use night lights after dusk.
 - Check stairs and steps for safety. Put bright, non-skid tape at the edge of steps. Use safety gates, if needed.
 - Install grab bars and put non-skid mats in the bathroom. Use a bath chair. Put soaps and washcloths within reach.
- Limit or block access to cramped areas or storage rooms, like attics or basements.

Communication

The communication style will vary by person and will need to change at each stage:

- Do not speak to the person as if they are a child. Never speak in front of the person as if they are not there.
- Limit distractions when you talk to the person. Ask to turn TVs, phones, and other devices down or off.
- Approach the person from the front. Get eye-level with them and make eye contact. Introduce yourself and call the person by the name they prefer. Consider wearing a name tag with large print.
- Speak slowly and calmly. Use short, simple words. Keep your tone light and soothing. Be aware that your energy can change the person's mood.
- Practice good listening skills. Give the person more time to respond. Ask a question, then count to 5 before you talk again. Don't interrupt the person, but let them interrupt you. They might forget what they are trying to say. Do not "quiz" the person or ask them to remember things they can't recall.
- Keep your body language open and relaxed. Avoid crossing your arms. Gentle touch helps some people. Rest your hand on the person's shoulder or hold hands. Do not rub or pat. This could cause more anxiety. Some people do not like to be touched. Do what makes the person comfortable.
- Try not to take angry outbursts to heart. The person is only trying to cope with their own sense of fear and loss. **Do not argue with the person.** Try to validate their feelings: "I see you are upset. How can I help you?"
- Look for nonverbal cues in the late stage. Watch the person's face and body movements. Use pictures or gestures when talking to them.

Dignity

Protecting dignity (a person's self-esteem) is important in *all* stages of dementia. Try to always keep the person clean and comfortable. Keep them covered during care tasks.

- **Put yourself in the person's shoes.** Think about how it feels to not know where you are or who the people around you are. You might feel scared or upset. The person may also be trying to cope with loss of freedom and control.
- Think of the phrase, "Do with, not for." Be present, but let the person do tasks on their own for as long as they can. If the person has trouble, offer to help.
- Try to stay patient and flexible. Be calm and kind in order to get things done. The person may not remember you, but they might know you make them feel safe and at ease.

Daily tasks

Daily tasks such as eating, dressing, bathing, and grooming can be a struggle. Contact us for more detailed guidance on daily tasks. Each person may have unique needs.

- Write out a daily plan. Tasks should be done around the same time each day. Be flexible, based on how the person feels. Fit the schedule to the person's habits. For example, let the person sleep in if they are a late riser.
- Look for **nonverbal signs of pain** if the person resists your help. **People who can't talk might wince, gasp, moan, shift around, rub spots on their body, or grab your hand** to let you know they are in pain. Call us if you think the person is in pain.
- Talk about what you are going to do before you do it. Break tasks down into clear steps. Guide the person through one step at a time. This can help lessen confusion even in later stages. Use the communication tips on page 7.

- Tips for meals:
 - Give plenty of time for meals. Limit distractions. Keep the table setting simple.
 - Sit and eat with the person. Watching you eat may remind them what to do.
 - Fix food the person likes. Serve small portions of one or two items. Use plates in colors that contrast with the food. For example, use a white plate for pasta with tomato sauce or a red plate for mashed potatoes.
 - Serve snacks throughout the day if the person can't sit through a meal. Finger foods (like sandwiches) may be better for patients who have trouble holding forks and spoons.
- Feeding in the late stage:
 - Contact us if the person struggles to swallow. We may suggest giving thicker liquids or careful hand feeding.
 - We may suggest “comfort feeding only,” also known as pleasure feeding, at this point. Pleasure feeding does not maintain weight. The goal is to improve quality of life through social connection. Small amounts of favorite foods are given. Feeding is stopped if there is gagging or choking.
 - It may be tempting to use a feeding tube when the person loses weight. Feeding tubes and IVs (known as artificial nutrition and hydration) are not usually suggested for people in the late stage of dementia. **Feeding tubes do not extend life for dementia patients.** They also may cause harm, such as infection or ulcers. Call us if you have questions.
- Ease into care tasks like dressing, bathing, and toileting. Imagine if someone you didn't know started to undress you. You might be very confused, scared, or angry.

- Bathing can be a big challenge. Some tips that may help:
 - Show the person the tub/shower beforehand. Start the water before you help them undress.
 - Be sure the room and water temperature are comfortable to the person. If a bath chair is used, cover it with a towel for comfort.
 - Protect the person’s privacy. Use large towels to cover them as they enter and exit the tub/shower.

Activities

Try to keep the person’s mind as active as possible. Exercising the brain each day may help slow symptoms in some cases.

- Social connection is important. Hold hands, talk, and share meals with the person (for as long as the person can eat). Think of things that might comfort the person. Do not ask them about the past, but tell stories about good times. Look through old photos. Play music from when they were young. Use familiar smells from their past, like perfume they used to wear.
- Make “activity kits” to stimulate the mind. Ideas for each stage are listed below.
 - **Early stage:** Puzzles, coloring books for adults, cards, checkers, word finds, matching games, beading
 - **Middle stage:** Sorting games with marbles, buttons, paper clips, colored blocks, or larger beads
 - **Late stage:** Textured balls, large blocks, soft blankets
- Some people find comfort in dolls or stuffed animals. Having a “baby” or “pet” to care for can help the person feel needed. Pet therapy may also help some people.
- If the person is religious, prayers, readings, music, religious objects, and rituals can bring comfort. Reciting familiar prayers might inspire the person to speak more. Contact the person’s spiritual counselor to see if they can visit.

Difficult Behaviors

Difficult behaviors tend to happen in the middle and late stages of dementia. They can be very hard to handle. Difficult behaviors are a form of communication. Not eating could mean the person can't swallow well. Not getting dressed might mean they are in pain.

Common difficult behaviors are listed below. Let us know if the person shows any of these behaviors. We can check medicines or see if other treatments might help. In some cases, we might suggest a geriatric psychiatrist. These doctors specialize in helping with difficult behaviors in dementia patients.

Agitation and aggression

People with dementia who can't express themselves may get agitated, or upset. This can lead to aggression. They may hit, bite, or lash out. There are many causes of agitation. Finding and treating its cause can help prevent it. **Untreated pain is often the cause of aggressive behavior or changes in mood.**

- Other causes of agitation/aggression could be:
 - Lack of sleep
 - Changes in medication
 - Constipation, being soiled, or urinary tract infection
 - Depression, loneliness, or feelings of grief and loss
 - Stress (sudden changes in place/routine/people)
 - Overstimulation, discomfort (too loud, too cold, etc.)
 - Loss of control or feeling forced to do things
- Try to find and avoid causes of agitation. Change the setting as needed, like reducing noise or adjusting the thermostat. Call us if this doesn't help. We may have more tips or treatment options.

- **“Reset” the event with distraction. Take the person for a walk, get a snack, or start a new activity.**
- Never hold the person down. This can upset them more.
- Reach out for help if the person becomes physically or emotionally abusive. No matter how sick the person may be, you should never have to take abuse.
- **The person may get more nervous or upset at night. This is known as “sundowning.”** Try to keep nights calm to help lessen the effects. Call us if you need help. Experts aren’t sure what causes this common behavior. Some factors could be:
 - A long day for the person and caregiver can leave both tired and moody.
 - Changes in sleep patterns from damage to the brain; the person’s “internal clock” could be mixing up night and day. The person also might not be able to tell dreams from reality.
 - Shadows and darkness at night can cause fear and confusion for the person.

Wandering

Wandering and getting lost — even in familiar places — is common. It can happen at any stage if the person can still walk. Try to limit wandering to keep the person safe.

- Make sure the person feels secure and cared for. Never leave them alone at home, in a car, or in public.
- Some people with dementia need to pace or walk. They could be bored, anxious, uncomfortable, or confused. If the person walks a lot, give them a safe space to walk. Try to plan for time to take walks with them each day.
- Stick to a daily routine. Always see to the person’s basic needs (bathroom, food, drink). Note the times of day the person wanders. Plan activities for those times, if possible.

- Limit liquids a couple hours before bed. Make sure the person uses the bathroom just before bed.
- Consider getting medical ID jewelry. Bracelets, necklaces, and tags are sold online or through most drug stores.
 - If the person can make choices, involve them in picking out the jewelry. Choose a piece they'll enjoy.
 - Make sure it fits well, not too loose or too tight.
 - Engrave the jewelry with an "In Case of Emergency" (ICE) phone number.
 - Add short phrases to describe the person's needs, such as "Memory Loss," "Diabetes," "Pacemaker," etc.
 - A paid medical alert safety service might be helpful but is not required. These services charge a fee for 24-hour emergency response.
- Secure all exits. Move locks higher or use childproof knobs. Mask doors with wall paint or curtains. Place bells (or install alarms) by doors and windows to alert you if they are opened.
- Hide car keys and park the car where the person can't see it.
- Know the area around the house. Be aware of hazards such as bodies of water, thick woods, construction sites, or busy roads.
- Make an emergency plan in case the person wanders:
 - Write down names and phone numbers of friends, family, and neighbors to call for help.
 - List places the person might try to go. Think of places they used to visit often, like past jobs or former homes. Many times wandering isn't aimless.
 - Have the person's up-to-date medical information and a recent photo at hand.

- **If the person gets lost:**

- Search inside the house. Check closets and under or behind furniture. Carefully search cramped areas or storage rooms that have not been blocked off.
- If you can't find the person inside, start your search outside right away.
- If you're not sure which way to go, turn right if the person is right-handed and left if they are left-handed.
- Search for no more than 10–15 minutes before calling 911. Let them know the person has dementia.

Delusions and paranoia

Delusions are false beliefs that the person thinks are real. Paranoia is a type of delusion where the person thinks others are “out to get them.”

- Remember, no matter how strange the person's thinking may seem to you, it is very real to them. Do not try to correct them.
- Validate the person's feelings: “It must upset you to feel like there is a stranger in your room.”
- Try to comfort the person. Let them know you are there to care for them and keep them safe.
- If comforting the person doesn't work, try distraction (see page 12). The right approach will depend on the person.

Hallucinations

The person might see, hear, smell, taste, or feel something that is not there.

- Treatment may not be needed if the person is not distressed. Watch for changes in behavior. Contact us if you have concerns. We can adjust medicines or suggest other treatment.

Palliative Care and Pain Management

The focus of palliative care is on comfort, pain relief, and emotional support. Palliative care treats the *whole* person, not just the disease. It can be provided at any stage of an illness.

The goal of palliative care is to increase quality of life. It is well-suited for the special needs of someone with dementia. A team of doctors, nurses, social workers, therapists, and other staff works to reduce pain and symptoms. Medicines and treatments are tailored to each person's unique needs.

What you can do:

- Ask us about palliative care and pain management options.
- Try to keep notes about the person's behavior if you think they might be uncomfortable or in pain. Note the times of day they seem more upset or anxious.
- The person may use nonverbal signs (see page 8) to tell you that they are in pain or uncomfortable.
- Check the person each day for bruises, wounds, fever, or red/swollen spots. These can be signs of injury or infection.
- Contact us if the person is bedbound. We can give you tips on how to avoid bed sores.
- **Always give medicine as prescribed.** Do not skip doses, even if it seems like the symptoms are gone. The goal is to stay *ahead* of pain and discomfort.
- Avoid harmful drug interactions. Give us a full list of medicines and supplements the person takes.
- Be aware that strong pain medicines (like opioids) may need to be used in the late stage of dementia. These will not shorten the person's life. If you have concerns about pain medicines, call us.

Honoring Wishes

It is never too soon to discuss end-of-life care choices. It's hard for many people to talk about death. But the desire for most of us is to die in the way and place that we choose.

The challenge of having end-of-life care talks with someone with dementia is that they can't express their wishes. It's often too late to have a clear conversation by the time dementia is diagnosed. Even if the person can talk about it, they may forget everything the next day.

Common care choices include the use of feeding tubes, IVs, ventilators (breathing machines), CPR, hospitals, palliative care, and hospice. Below are tips to keep in mind at each stage when talking about the person's wishes. It may help to have a nurse or doctor there to answer questions about treatment.

Early stage

The person can still express their wishes. Patients, caregivers, and doctors should talk about what to expect and what the patient wants.

What you can do:

- **Talk about the person's wishes for end-of-life care now.** For many kinds of dementia, the person's mental state will never be better than it is now.
- Contact us if you need help starting the conversation. We are here to help. Decide what needs to be done today. Make plans for the future. Write down notes.
- Ask us about advance directives, such as a living will or healthcare power of attorney. We can help you fill out the forms based on state laws. Having wishes in writing will make sure everyone is aware of what the person wants.

- Make it a two-way conversation. Some people might not want to talk about their wishes. Talking about what you would want for yourself may help start the conversation.
- Ask the person these questions to start:
 - What is most important to you? What are your goals?
 - Who would you want to make healthcare decisions for you?
 - If you could choose, who would you want to care for you? A professional or a family member?
 - If you could choose, would you want to receive care at home or in a hospital?
 - Which treatments do you want? Which treatments do you *not* want?
 - What kind of pain management do you want?
 - Do you ever want to be on life support?
 - If you could choose, where would you want to spend your last days?

Middle stage

There is more confusion and memory loss — and fewer chances to talk about the person's wishes — at this stage. Look for moments of clarity to get information in small bits.

What you can do:

- Wait for the right time. Talk to the person at times of the day when they are most calm.
- Do not have these talks if the person is upset. If the person starts to get upset during the talk, stop and try again later.
- Ask the person one question at a time. Use the communication tips on page 7 when talking to them.

Late stage

Most people with end-stage dementia cannot express their end-of-life care choices. Caregivers must make the decisions.

What you can do:

- Use the person's advance directive to guide choices.
- If the person does not have an advance directive, make choices based on what you know about the person's values.
- **Answer questions as the person would answer them.** Have a family meeting, if you feel it would be helpful.
- Be aware that in-home nursing, memory care, or a nursing home may need to be considered. Full-time care is often too much for one caregiver to handle alone.
- **Be gentle with yourself as you make healthcare decisions for the person. Do the best with the information you have. Whatever decision you make will be the right one.**

“Caregiving often calls us
to lean into love we didn’t know possible.”

— Tia Walker,
*The Inspired Caregiver:
Finding Joy While Caring for Those You Love*

When It's Time for Hospice

Many people with dementia may not be able to talk about their wishes. But the wish to die with dignity is the same for most of us. Every dementia patient will need to shift to end-of-life care at some point. It may be time to call hospice when the person starts showing late-stage symptoms (see page 5).

Hospice can help dementia patients experience a more peaceful and natural death by:

- **Providing services that include palliative care**, which addresses physical, emotional, social, and spiritual needs.
- **Managing the patient's pain, anxiety, and other symptoms.** The focus is on pain relief and comfort.
- **Meeting the special needs of the patient** and providing support for their caregivers.

Hospice is for people with 6 months or less to live, if the disease runs its normal course. It can be hard to tell how long a person with any disease has to live. It's even harder with dementia patients.

Anyone can refer a person to hospice, but a doctor will need to confirm that they are eligible. Services can be continued after 6 months if the doctor believes that the patient is still near the end of life. Services also can be cancelled at any time.

We know it can be hard to talk about hospice. It may seem like "giving up." But the goal of hospice is to give patients comfort and hope, even in the last stage of life.

What you can do:

- Ask the doctor if it might be time to consider hospice.
- Contact hospice directly for information. The hospice care team can help you confirm if the person can receive services.

Care for the Caregiver

Many caregivers of people with dementia expect there will be memory loss. But many don't expect the big changes in personality that can make caring for someone with dementia so hard. Below are normal feelings that caregivers may have.

Sadness and grief

It's common for caregivers to feel sad when the person doesn't remember them. Feelings of grief can affect caregivers, even if the person is still alive. Caregivers might grieve the loss of the person they once knew or the life they had before. There may also be anticipatory grief, a kind of "pre-grief" that comes before an expected loss.

Depression

Caregivers of people with dementia have a higher chance of being depressed. The risk grows if caregivers do not feel like they have support.

Frustration and anger

Caregivers may feel angry when the person does not seem to value all they do. Difficult behaviors and communication issues can make things worse.

Guilt

Caregivers may feel like all they're doing is not enough. They might feel guilty for losing their patience or feeling angry. There may also be guilt if the person needs to go into a nursing home. Many caregivers may feel guilt for wishing the person would die to end their suffering and the heavy burden of care.

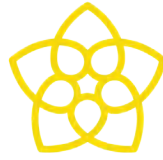
What you can do:

- Accept all of your feelings. It is okay to be sad, frustrated, angry, or guilty. Contact us if you feel depressed. We can help you get the support you need.
- Manage your own stress. Try to exercise, eat well, and get sleep. Try yoga or deep breathing to help you relax.
- Ask us about respite care. Trained staff can watch the person while you take a break. If there is a facility, the care team may bring the person there for a short stay.
- Try to stay positive. Take it one day at a time. Forgive the person and yourself. You are doing the best you can.
- Reflect on good memories when you feel overwhelmed.
- **Reach out for help when you need it.** Contact family, friends, support groups, or faith groups. Or contact us for support. We are here for you.



Questions and Notes:

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