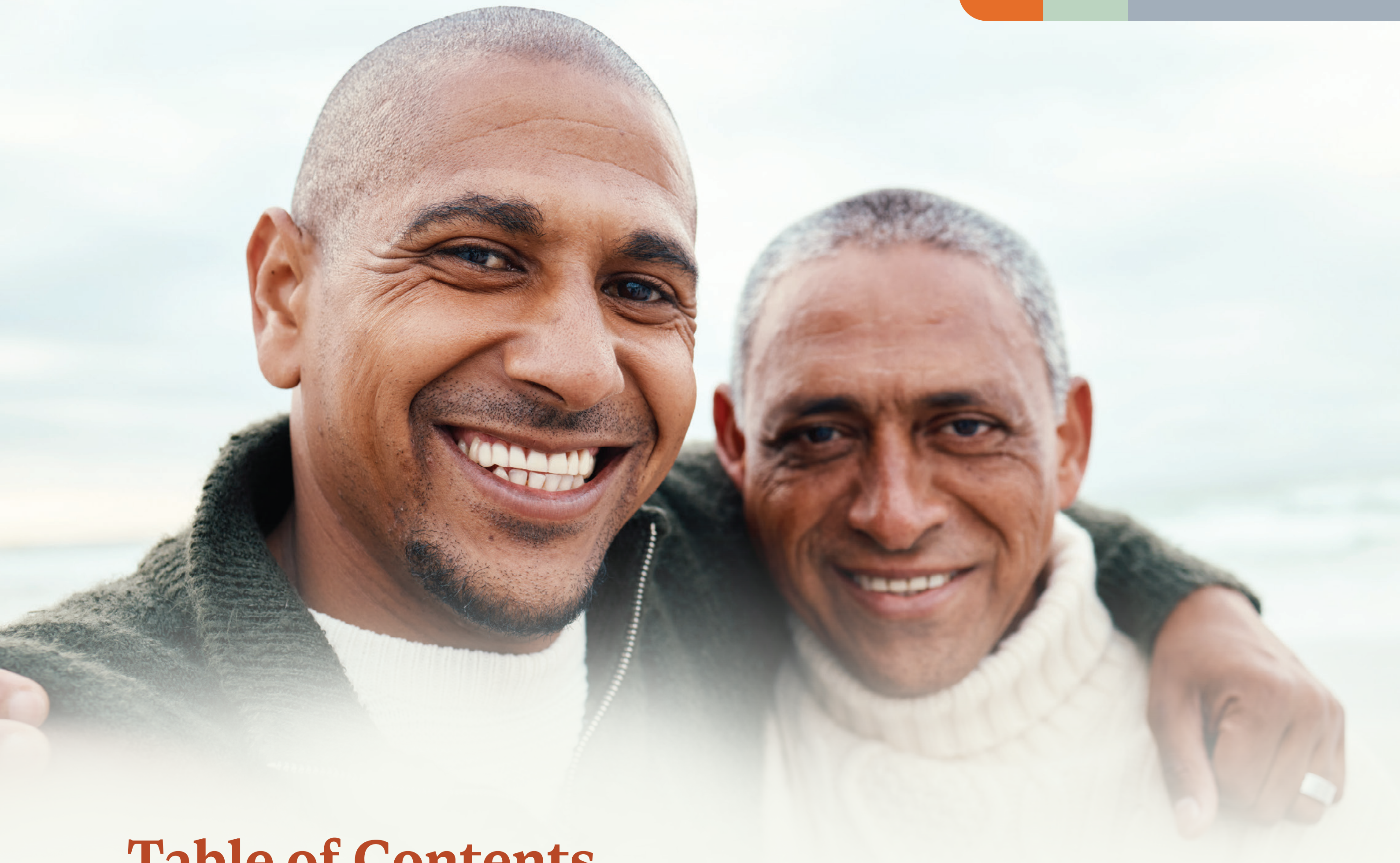
National Institute on Aging

Caring for a Person With Alzheimer's Disease

A family and friends' guide to everyday care, coping with challenging behaviors, and finding help when you need it



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CHAPTER 1

Getting Started

Millions of people living in the United States take care of a family member or friend with Alzheimer's disease or a related dementia. For many families, caring for an individual with Alzheimer's isn't just one person's job. Rather, it's a role for many people who share tasks and responsibilities. Each day may bring new challenges, and you may feel like you don't know what to do.

This guide can help you learn about the realities of caring for someone with dementia. It includes tips for providing care, resources for caregiving support, and guidance on how to take care of yourself.

Being a Caregiver for Someone With Alzheimer's

Do you remember the moment you learned of your loved one's diagnosis? Many people are not surprised — the symptoms of memory loss and trouble thinking were already noticeable — yet the news is still shocking. They wonder: What's next?

Alzheimer's is a brain disorder that causes large numbers of nerve cells to not work properly. It's the most common form of dementia, a term used to describe conditions that cause people to lose their ability to remember, think, and use good judgment.

In the early stages of the disease, many people do not need full-time caregiving. As the disease worsens, people with Alzheimer's may have trouble taking care of themselves and need more help. Often a spouse or partner, other family member, or close friend will assist with everyday activities, medicines, appointments, or other tasks. At all stages of Alzheimer's, it is extremely helpful to have compassionate and well-informed people providing care.

While caregiving can be rewarding and meaningful, it can also be challenging. It can help to have a team or network of caregivers so that all the responsibilities do not fall on one person, but this is not always possible. Self-care is also very important in helping caregivers stay physically and emotionally healthy. The tips and strategies in this booklet are guidelines for effective and compassionate dementia caregiving, and as the disease changes over time, approaches to care will also need to change.

Helping Friends and Family Understand

When you learn that someone close to you has Alzheimer's, deciding when and how to tell your family and friends may be difficult. You may be worried about how others will react to or treat your loved one. It's okay to wait until you feel emotionally ready to share the news or to only tell your closest family members and friends. By knowing what's happening, the people you trust the most can help support you and the person with Alzheimer's. The following suggestions can help get you started.

> **“Friends and family don't get it. It's hard trying to explain it to them because they think that Alzheimer's is just memory loss. They don't understand the full magnitude of it.”**

Tips for Sharing the Diagnosis

It may be hard to share a loved one's Alzheimer's diagnosis with others. Here are a few suggested approaches:

- Realize that family and friends often sense that something is wrong before they are told.
- Be honest with them about the Alzheimer's diagnosis. Explain that Alzheimer's is a brain disease that can have wide-ranging symptoms. Memory loss is a common symptom but it's not the only one. Changes in behavior and communication are also common.
- Share resources (including this guide) to help them understand what you and the person with Alzheimer's are experiencing.

- Give examples of ways they can help, such as visiting, providing meals, or helping with home safety modifications. Let them know you need breaks.

Family and friends may not know how to interact with someone who has Alzheimer's. Share tips to help them feel more comfortable. You can:

- Tell people who visit how much your loved one can understand. For example, if the person is still in the early stage of Alzheimer's, you might say that they can still have a conversation over dinner or play a favorite board game.
- If your loved one has difficulty remembering people, suggest that visitors start a conversation with the person by briefly introducing themselves. For example, "Hello George, I'm John. We used to work together."
- Offer ways to make the conversation easier and more respectful, such as not correcting or arguing with the person with Alzheimer's if they make a mistake or forget something.
- Remind visitors to be patient when the person with Alzheimer's has trouble finding the right words or putting feelings into words.
- Suggest activities beyond talking that they can do together, including listening to music or looking through a photo album.

Helping Children Understand

When a family member has Alzheimer's, it affects the whole family, including children and grandchildren. It's important to talk to young people and help them understand what is happening. For example:

- Answer their questions simply and honestly. You might tell a young child, "Grandma has an illness that makes it hard for her to remember things."
- Reassure them that feelings of sadness and anger are normal.
- Comfort them. Explain that no one caused the disease. Young children may think they did something to hurt their grandparent.

Younger children may watch how you act around your loved one with Alzheimer's. Do not use "baby talk" or adopt a harsh tone with your loved one. Children may pick up on this behavior and act similarly. Try to be mindful of the tone of voice you're using and the way you're interacting with them. It's important to show children they can still talk with the person and do things with them. Activities children and people with Alzheimer's might do together include:

- Simple arts and crafts
- Playing music or singing
- Looking through photo albums
- Reading stories out loud

If you and your children are living in the same house as someone with Alzheimer's, it's important not to let the caregiving responsibilities overshadow the children's day-to-day needs. For example:

- Avoid having a young child help take care of or "babysit" the person with Alzheimer's. This may not be safe for the child or that person.
- Make sure the child has time for their own interests and needs, such as playing with friends, school activities, or doing homework.
- Spend quality time with your child so they don't feel that all your attention is on the person with Alzheimer's.

Some children may not talk about their feelings but may act out at school or at home. Older children and teens might be embarrassed by the behavior of the person with Alzheimer's. Let children know they can always talk to you about what they're feeling. School counselors and social workers also can help children develop healthy ways to process their feelings.

Advance Care Planning

When someone is diagnosed with Alzheimer's, it's important to plan for the future, preferably with help from the person while they can still participate in decisions about their future. Advance care planning involves discussing and preparing for decisions about the person's medical care if they become seriously ill or unable to communicate their wishes. Having meaningful conversations with the person living with Alzheimer's to learn about their values and preferences is the most important part of advance care planning.

It can be helpful to store an older person's official records and legal documents together in one place so you can access them quickly when you need them. Keep these materials somewhere safe and easy to find, such as in a fireproof lockbox.

For more information on planning for health, legal, and financial matters, visit **www.nia.nih.gov/advance-care-planning**.

Prepare and Plan

Having documentation in place can help ensure that future health care decisions align with the person’s preferences. Be sure to review all of their health, legal, and financial information to make sure it reflects their wishes. Check to see that you have the following documents and that they are up to date. Note: These forms can often be found on your state’s Department of Aging website.

- **Durable Power of Attorney for Finances:** Provides someone with the power to make legal and financial decisions for the person with Alzheimer’s.
- **Durable Power of Attorney for Health Care:** Gives a person — called a health care proxy — the power to make medical decisions for the person with Alzheimer’s.
- **Living Will:** Informs doctors how the person with Alzheimer’s wants to be treated if they cannot make their own decisions about emergency treatment.
- **Do Not Resuscitate (DNR) Form:** Informs health care staff that the person does not want CPR or other life-support measures to be attempted if their heartbeat and breathing stops.
- **Will:** Provides legal guidance for the distribution of a person’s property, belongings, and money after they die.
- **Living Trust:** Informs an individual — called a trustee — about how to distribute the property and money of the person with Alzheimer’s while that person is still living but no longer able to manage their own affairs.

CHAPTER 2

Coping With Challenging Behaviors and Symptoms

Alzheimer's affects a person's ability to remember things and think clearly. People with this disease become forgetful and easily confused. They may have a hard time concentrating and become distressed, agitated, or withdrawn.

In addition to thinking and memory problems, people with Alzheimer's may experience symptoms such as agitation, trouble sleeping, and hallucinations. They may wander, pace, and behave in unusual ways. These problems can make your job as a caregiver harder. It's important to remember that the disease, not the person with Alzheimer's, causes these changes. Read on to learn about common challenges and how to cope.

Are There Medications for Alzheimer's?

While there is currently no cure for Alzheimer's, there are medicines available that may temporarily improve or stabilize memory and thinking skills in some people. There are also medicines available that may help manage certain symptoms and challenging behaviors. Talk with a doctor about medication options.

For more information about Alzheimer's treatments, visit **www.nia.nih.gov/alzheimers-treatment**.

Changes in Communication

People with Alzheimer's may struggle with:

- Finding the right word when speaking
- Understanding what words mean
- Paying attention during long conversations
- Organizing words logically
- Keeping their train of thought when talking
- Blocking out background noises from the radio, TV, telephone calls, or conversations in the room

Alzheimer's causes some people to get confused about language. For example, the person might forget or no longer understand English if it was learned as a second language. Instead, they might understand and use only their first language, such as Spanish.

> **“Our doctor said, 'Just think of what it would be like every day to wake up and not know where you're at, not really know who you are, and not know what you need to do. That's what she experiences every day.' That was the most valuable information. It put me in her shoes so I was not just focused on how I felt or what I thought she should be doing.”**

Helping a Person Who Is Aware of Memory Loss

Alzheimer's is being diagnosed at earlier stages. This means that many people are aware of how the disease is affecting their memory and may feel anxious or upset. If this is the case, take time to listen. The person may want to talk about the changes they are noticing. Try to be open, empathetic, and nonjudgmental.

Tips to Cope With Communication Challenges

Keep the following suggestions in mind to make communication easier:

- Make eye contact and call the person by name.
- Be aware of your tone, volume, facial expressions, and body language. Try to avoid appearing angry or tense. Show a warm, loving, and matter-of-fact manner.
- Encourage a two-way conversation if the person is able.
- Be open to the person's concerns, even if they are hard to understand or address.
- Be patient with angry outbursts. Try a distraction, such as offering a favorite snack or a walk outside. If you become frustrated, take some time to calm down.
- Allow more time for the person to respond. Be patient and try not to interrupt.
- Don't talk about the person as if they are not there.
- Don't talk to the person using "baby talk" or a "baby voice."
- Use methods other than speaking to help the person, such as gentle touching to guide them. Hold the person's hand while you talk.

Here are some general tips for helpful communication:

- Always thank the person for helping, even if the results aren't perfect.
- Ask questions with a yes or no answer.
- Use different words if they don't understand what you say the first time.
- Try to stay positive and encouraging.

Avoid saying	Say this instead
What do you want for dinner?	Do you want fish or chicken for dinner?
That's not how you do it.	Let's try it this way.
How do you feel?	Are you feeling sad?
Are you hungry?	Dinner will be ready in five minutes.

Changes in Behavior

Alzheimer's changes the brain in ways that can affect how a person acts. Some days, the person with the disease might seem like themselves, and other days they might act in unusual ways. This variation from one day to the next is common for people with Alzheimer's.

Other reasons for changes in behavior can include the person's mood, medical causes (such as an infection or pain), the environment around them, and expectations of other people. A caregiver needs to consider whether changes in behavior are from the disease itself or from the person's environment. For example, too much noise or too many people in a room with the person with Alzheimer's can result in behavior changes. Determining the cause of behavior changes is not always an easy task. Keeping track of common behavioral changes can help the person's caregivers and health care providers recognize a pattern and determine the cause.

Common behavior changes in Alzheimer's include:

- Showing signs of anxiety or fear
- Getting upset, worried, and angry more easily
- Acting depressed or not interested in things
- Hiding things or believing other people are hiding things
- Imagining things that aren't there

- Feeling suspicious of or threatened by others, for little to no reason
- Pacing a lot of the time
- Showing unusual sexual behavior
- Wandering away from home
- Hitting other people
- Misunderstanding what they see or hear
- Having difficulty sleeping through the night

You may also see changes in behavior that the disease didn't cause. Sometimes certain medicines, pain, poor eyesight or hearing, and fatigue can cause behavior changes. In many cases, a doctor can help you figure out what is causing the problem.

Sudden or rapidly fluctuating changes in behavior, especially if the person has had an infection or recent medication changes, should be immediately brought to a doctor's attention.

Agitation and Aggression

Agitation means that a person is restless and worried, and they aren't able to settle down. Agitated people may pace a lot, not be able to sleep, or act aggressively toward others. They may verbally lash out or try to hit or hurt someone. Here are some tips that may help:

- **Be patient and try not to show frustration.** Speak calmly. Listen to the person's concerns and avoid arguing. Reassure the person that they are safe, and that you are there to help. Use other communication methods besides speaking, such as gentle touching, to help them calm down. Take deep breaths and count to 10 if you get upset.
- **Create a comforting home setting.** Try to keep to a routine, such as bathing, dressing, and eating at the same times each day. Reduce noise and clutter. Play soothing music and keep well-loved objects and photos around the home. Let in natural light during the day. Slow down and try to relax if you think your own worries may be causing concern.

Companion Cards

Some caregivers carry a card when they're out in public. For example, the card might read, "My family member has Alzheimer's disease. They might say or do things that are unexpected. Thank you for your understanding." The card enables you to let others know without the person hearing and may also ease the need for you to keep explaining things.

- **Try focusing on an object or activity.** Distract the person with a snack, beverage, or activity. You could watch a favorite TV show, listen to music, go for a walk, read a book, or do a household chore, such as folding laundry, together.
- **Protect yourself and others if needed.** Hide or lock up car keys and items that could be used in a harmful way, such as guns and kitchen knives. If your loved one becomes aggressive, stay at a safe distance until the behavior stops. Talk to a doctor if aggressive behaviors worsen and consider medications that may help. In an emergency, call 911 and explain that your loved one has dementia.

To learn more, visit **www.nia.nih.gov/agitation-aggression**.

You can also download or order *Tips for Managing Agitation, Aggression, and Sundowning* from **order.nia.nih.gov**.

Wandering and Getting Lost

Many people with Alzheimer's wander away from their home or caregiver. As the caregiver, you need to know how to limit wandering and prevent the person from becoming lost. Try these tips to help keep someone who wanders safe:

- Make sure the person carries some kind of ID or wears a medical bracelet with their name and address, and your phone number.
- If you think the person might remove an ID bracelet, label their clothes with a name and phone number.
- Many GPS systems are available to track the person's location. These can be a good alternative or addition to the medical bracelet.
- Let neighbors and the local police know that the person with Alzheimer's tends to wander.
- Keep a recent photograph or video of the person to help police if the person becomes lost.
- Keep doors locked. Consider a keyed deadbolt, or add another lock placed up high or down low on the door. If the person can open a lock, you may need to get a new latch or lock. Keep the key nearby in case of emergency.
- Install a smart doorbell or alarm that chimes when a door is opened.

Consider enrolling the person in the MedicAlert + Alzheimer's Association Safe Return Program by visiting **www.medicalert.org/alz** or calling **800-432-5378**. Note that this service is not affiliated with the National Institute on Aging and there may be a charge for this service.

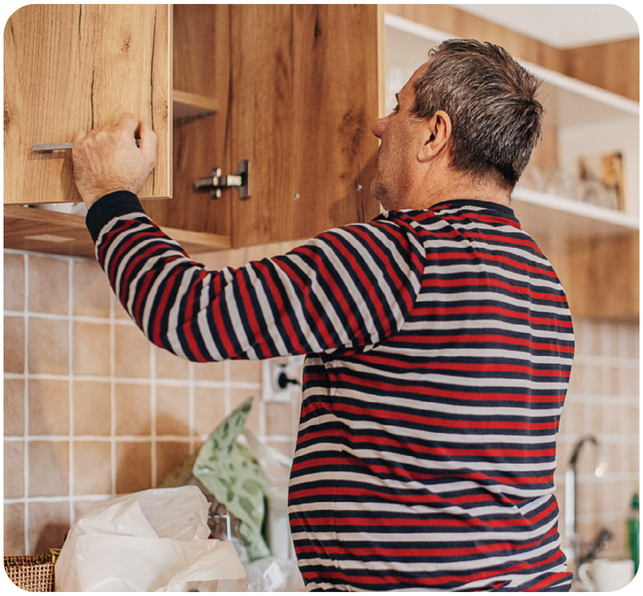
Rummaging and Hiding Things

Someone with Alzheimer's may start rummaging or searching through cabinets, drawers, closets, the refrigerator, and other places where things are stored. They also may hide items around the house.

In some cases, there might be a logical reason for this behavior. For instance, they may be looking for something specific but not able to tell you what it is. They may be hungry or bored. Try to understand what is causing the behavior so you can fit your response to the cause. Here are some other steps to take to keep the person with Alzheimer's safe:

- Lock up dangerous or toxic products or place them out of the person's sight and reach.
- Remove spoiled or expired food from the refrigerator and cabinets. Someone with Alzheimer's may look for snacks but lack the judgment or sense of taste to stay away from foods that have gone bad.
- Remove valuable items that could be misplaced or hidden by the person, such as important papers, checkbooks, credit cards, jewelry, cellphones, and keys.
- People with Alzheimer's often hide, lose, or throw away mail. If this is a serious problem, consider getting a post office box. If you have a yard with a fence and a locked gate, place your mailbox outside the gate.
- Keep the person with Alzheimer's from going into any unused room. This limits their rummaging and hiding things.
- Search the house to learn where the person often hides things. Once you find these places, check them often when out of sight of the person.
- Keep all trash cans covered or out of sight. People with Alzheimer's may not remember the purpose of the container or may rummage through it.
- Check trash containers before you empty them in case something has been hidden there or thrown away by accident.

You also can create a special place where the person with Alzheimer's can rummage freely or sort things. This may be a bag of objects to organize, or a basket of clothing to fold or unfold. You could also give them a personal box, chest, or cupboard to store special objects. You may have to remind the person where to find their personal storage place.



Changes in Intimacy and Sexuality

Intimacy is the special bond we share with a person we love and respect. Sexuality is one type of intimacy. It is an important way that spouses or partners express their feelings physically for one another. If you are a caregiver for your spouse or partner with Alzheimer's, you may notice changes in intimacy and sexuality in both the person with Alzheimer's and yourself.

A person with Alzheimer's may be stressed by the changes in their memory and behavior. Fear, worry, depression, anger, and low self-esteem are common. The person may feel dependent and cling to you. They may not remember your life together and feelings toward one another. Sometimes the person may even fall in love or seek companionship with someone else. Side effects from medications, memory loss, and depression may affect their sexual interest.

You may pull away from the person with Alzheimer's in both an emotional and physical sense. You may be upset or exhausted by the demands of caregiving.

> **“Every once in a while, she would look at me, even from her bed, and she'd say things like, ‘That's my guy.’ But because of the state she was constantly in, you wondered if the next minute she wouldn't recognize you or anyone else.”**

The person's constant forgetfulness and challenging behaviors may make them seem like a stranger. Someone caring for their spouse or partner with Alzheimer's may also feel that it's not okay to have sex with someone who has this disease.

It takes time to learn how to cope with these challenges. It's possible to learn to live with the illness and find new meaning in your relationship with the person with Alzheimer's.

Changes in intimacy and sexuality affect the person with Alzheimer's as well as their spouse or partner. Follow these tips to help cope with these challenges:

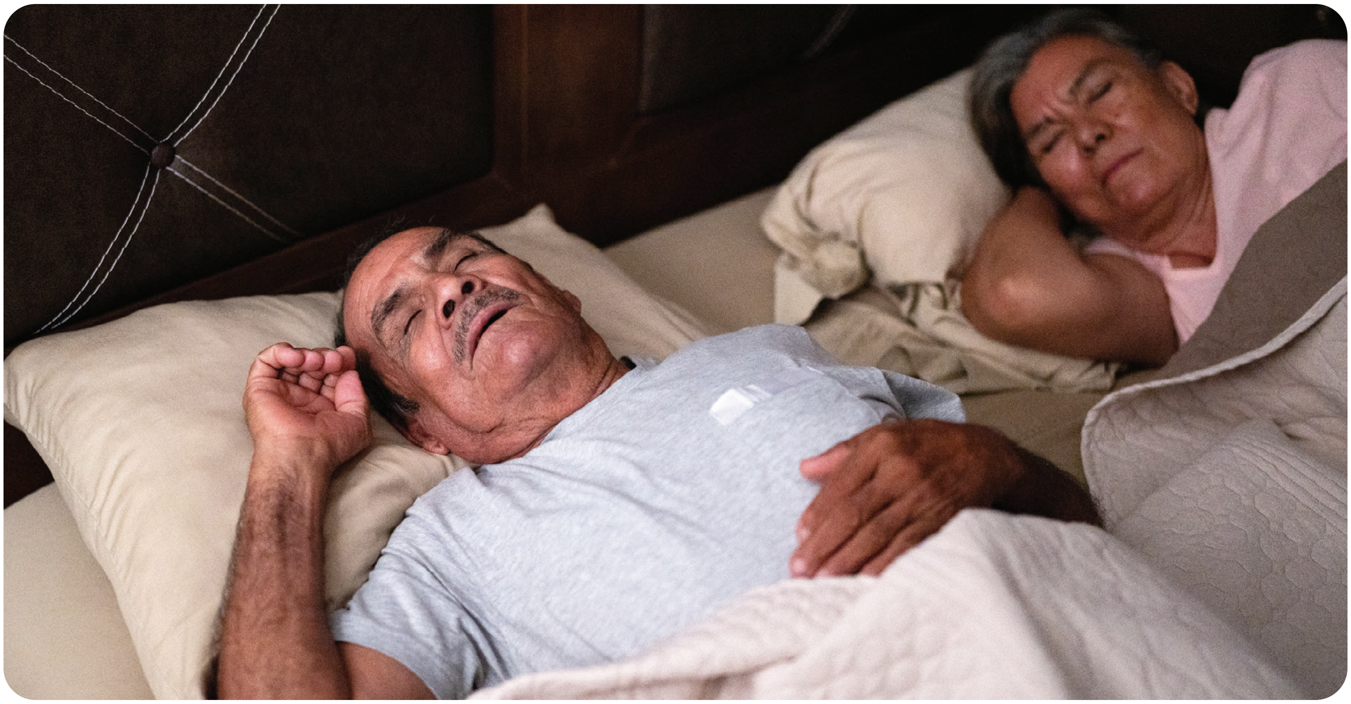
- Reassure the person with Alzheimer's that you love them and will keep them safe.
- Explore new ways of spending time together, such as walking around your neighborhood or playing a game together.
- Focus on nonsexual ways to show affection. Some caregivers find that snuggling or holding hands reduces their need for a sexual relationship.
- Try other nonsexual forms of touching, such as giving a massage, hugging, and dancing.
- Consider meeting your sexual needs yourself.
- Talk with a doctor, social worker, clergy member, or a support group about these changes. It may feel awkward to talk about such personal issues, but it can help.

To learn more, visit **www.nia.nih.gov/alzheimers-relationships**.

Hypersexuality

Sometimes people with Alzheimer's become overly interested in sex. This is called hypersexuality. The person may masturbate a lot or try to seduce others. These behaviors are symptoms of the disease and don't always mean that the person wants to have sex.

To cope with hypersexuality, try giving the person more attention and reassurance. As a caregiver, you should never feel like you must do something you are not comfortable with to appease your loved one. You might gently touch, hug, or use other kinds of affection to meet their emotional needs. Some people with this problem need medicine to control their behaviors. Talk to a doctor about steps to take to manage hypersexuality.



Sleep Problems and Sundowning

Alzheimer's often affects a person's sleeping habits. It may be hard to get the person to go to bed and to stay there. Someone with this disease may either sleep a lot or not sleep enough, and may wake up many times during the night.

People with Alzheimer's also may experience sundowning — restlessness, agitation, irritability, or confusion that can begin or worsen as daylight begins to fade. Being overly tired can increase late-afternoon and nighttime restlessness.

These tips may help ease sleep problems and sundowning:

- Help the person get exercise each day.
- Limit long naps and dozing late in the day.
- Plan activities that use more energy early in the day. For example, try bathing in the morning or having the largest family meal in the middle of the day.
- Set a quiet, peaceful mood in the evening to help the person relax. Keep the lights low, try to reduce the noise levels, and play soothing music if they enjoy it.
- Try to have the person go to bed at the same time each night. A bedtime routine, such as reading out loud, also may help.
- Avoid alcohol and caffeine.
- Use nightlights in the bedroom, hall, and bathroom.

Hallucinations, Delusions, and Paranoia

People with Alzheimer's may experience hallucinations, delusions, and paranoia. All of these symptoms can be fearful and frustrating for both the person with Alzheimer's and their caregiver.

Hallucinations and Delusions

During a hallucination, a person sees, hears, smells, tastes, or feels something that isn't there. For example, the person may see their mother in the room although she is no longer alive. They also may have delusions, which are false beliefs that the person thinks are real. For example, the person may think their partner is in love with someone else.

Here are some tips to help cope with hallucinations and delusions:

- Tell the person's doctor about the delusions or hallucinations. Discuss any illnesses the person has and their medicines. Sometimes they may cause hallucinations or delusions.
- Do not argue about what the person with Alzheimer's sees or hears. Comfort the person if they are afraid.
- Distract the person. Sometimes changing rooms or going out for a walk helps.
- Turn off the TV when violent or upsetting programs are on. Someone with Alzheimer's may think these events are happening in the room.
- Make sure the person is safe and can't reach anything that could be used to hurt themselves or anyone else.

Be Aware of Elder Abuse

Someone with Alzheimer's who is suspicious or distrustful may not have paranoia. They may be a victim of elder abuse. Older adults are often targets for physical, emotional, and financial abuse. Learn the signs of elder abuse and when to get help at **www.nia.nih.gov/elder-abuse**.

Paranoia

People with Alzheimer's may also experience a specific type of delusion called paranoia. People with paranoia may believe — without a good reason — that others are mean, lying, unfair, or out to get them. Your loved one may become suspicious, fearful, or jealous of some people. In a person with Alzheimer's, paranoia is often linked to memory loss.

Paranoia may be the person's way of expressing loss. The person may blame or accuse others because no other explanation seems to make sense.

Here are some tips to help cope with paranoia:

- Try not to react if the person blames you for something.
- Don't argue about what's true.
- Let the person know that they are safe.
- Use gentle touching or hugging to show the person you care.
- Explain to others that the person is acting this way because they have Alzheimer's.
- Search for missing things to distract the person; then talk about what you found. For example, talk about a photograph or keepsake.
- Have extra sets of keys or eyeglasses in case these are lost.

If the person forgets...	**The person may believe...**
Where they put something	Someone is taking their things
You are the caregiver	You are a stranger, and they may not trust you
That they know a family member or friend	The family or friend might cause them harm
Directions you just provided	You are trying to trick them

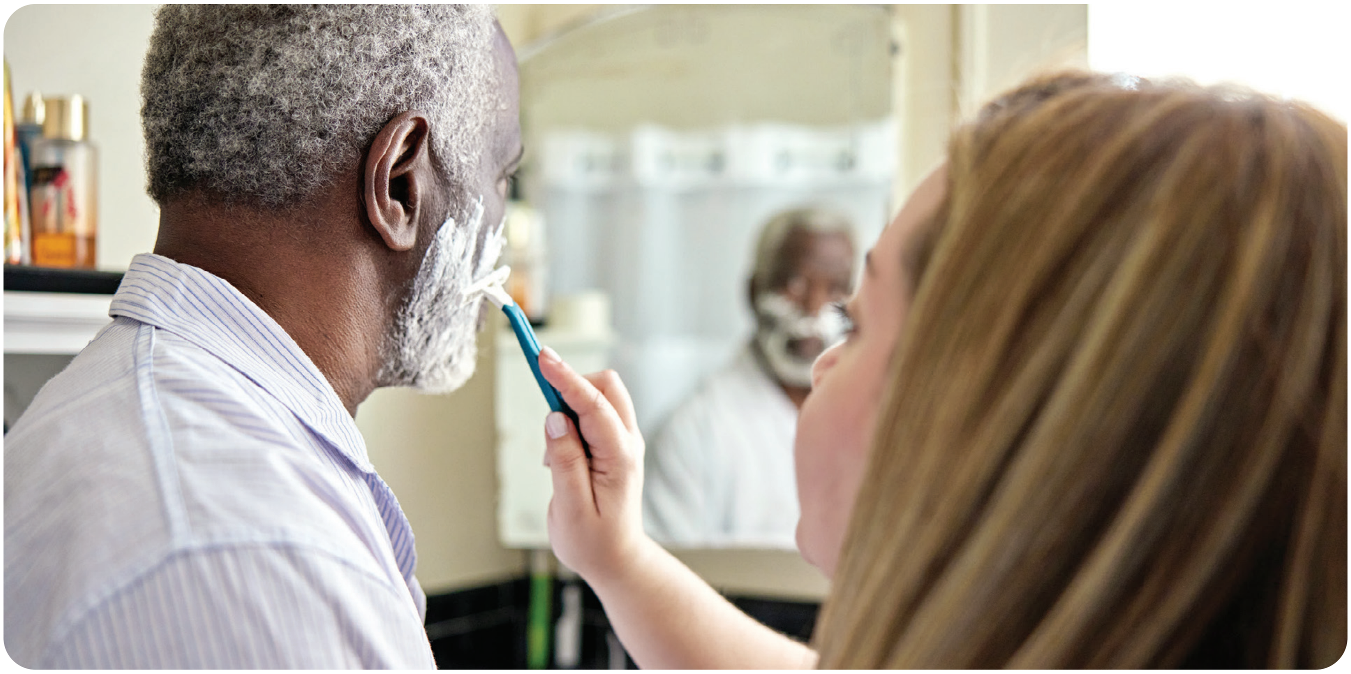
CHAPTER 3

Everyday Care for a Person With Alzheimer's Disease

The ability to perform daily tasks, such as bathing, dressing, and eating, changes when a person has Alzheimer's. During the earlier stages of the disease, they may remain relatively independent, but there will come a point when they need more help with daily activities. For a caregiver, the main goal is to find the balance of letting the person be as independent as possible while providing support when needed. Considering what the person with dementia needs to be successful can be a step toward achieving that balance.

The sections in this chapter offer tips on how to address the needs of someone with Alzheimer's and help them become more comfortable accepting help.

Some of the activities people will need help with, such as bathing and getting dressed, are routines they likely did in private in the past. Your loved one may feel embarrassed and not want help. They may also feel angry about not being able to care for themselves. Try to have patience and consider ways to make the experiences more positive for both of you.



Bathing

Helping someone with Alzheimer's take a bath or shower can be one of the hardest undertakings for caregivers. A person with this disease might regard bathing as scary, embarrassing, or physically unpleasant, and may communicate their discomfort by verbally or physically resisting attempts to help them bathe.

Planning can help make the experience better for both of you. Use the following tips to help keep your loved one safe and comfortable while bathing.

Before a Bath or Shower

- Gather supplies. Get soap, washcloths, towels, shampoo, and a bath chair ready. You can also use a rubber bathmat and safety bars to prevent falls. Do not use bath oils or anything else that could make the tub slippery. If you need additional supplies for yourself, such as gloves, gather those as well.
- Ensure the bathroom is comfortable by keeping the room warm and well lit. Play soft music if it helps to relax the person.
- Make sure the water temperature in the bath or shower is comfortable.
- Be matter of fact about bathing. Say, "It's time for a bath now." If the person doesn't respond, try giving them a choice. For example, ask: "Do you want to bathe now or in 15 minutes?" or "Do you want to take a bath or a shower?"
- Try to schedule bathing at the same time each day.

During a Bath or Shower

- Allow the person with Alzheimer's to have a role in the bathing process. Even if they are unable to wash their body, they could hold the washcloth, sponge, or shampoo bottle.
- If the person can wash their own body, tell them what to do, step by step. Use phrases like "put your feet in the tub," "sit down," "take the soap," or "wash your stomach." You can demonstrate each action or guide the person's hand with your own.
- If you are bathing the person, use a hand-held showerhead. Be gentle and tell the person each step you are going to do before you do it.
- If using a hand-held showerhead, begin by washing hands or feet. These areas are less threatening and can help relax the person before moving to the face, torso, or head.
- Put a towel over the person's shoulders or lap to help them feel less exposed. Then use a sponge or washcloth to clean under the towel.
- Distract the person by talking about something else if they become upset.
- Never leave a person with Alzheimer's alone in the tub or shower.
- If a bath or shower is too upsetting, consider a "wash-up" at the sink. Sometimes washing a person who is sitting in a chair can be a more pleasant experience.

After a Bath or Shower

- Pat the person's skin dry with a towel. Be sure to dry between folds of skin and check for rashes. If you find a rash, try using a moisturizing ointment or cream. See the doctor if the rash doesn't seem to improve.
- If the person has trouble with incontinence, use a protective ointment, such as petroleum jelly, around the rectum, vagina, or penis. To avoid making the person with Alzheimer's uncomfortable, ask them if they would like to do this for themselves if they're able.
- Use lotion to keep skin soft and powder and ointments to prevent chafing, as needed.

> **“My mom was a very strong-willed lady. She absolutely hated the shower — even once a week was difficult. It was a full Saturday morning just trying to convince her that this is what we needed to do. They grew up in a time when you didn't expose your body to anybody. She was not comfortable with that. I get it, but I still had to do it. I just didn't want her to get hurt, so I was trying to be there for her safety.”**

For tips on how to make a bathroom safer for someone with Alzheimer's, check out the home safety section on page 32.

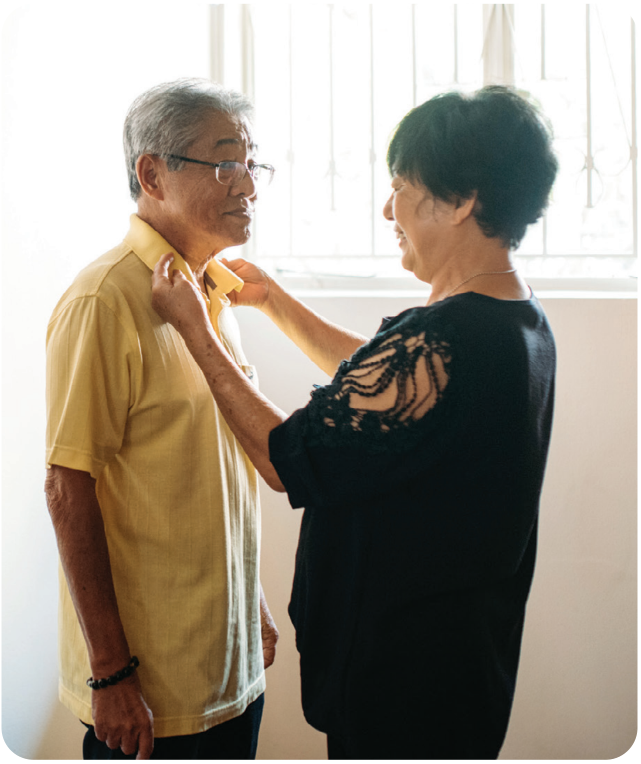
Try to give the person a bath two or three times a week but be open to a more flexible schedule. If possible, consider a sponge bath to clean the face, hands, feet, underarms, and private areas on days when a full bath or shower isn't possible. If shampooing is challenging, try washing the person's hair in the sink, using a hose attachment.

If bathing becomes too hard for you to do on your own, there are professionals who can help. For information on home health care services, see page 47.

Dressing

People with Alzheimer's often need more time to dress. It can be hard for them to choose their clothes, and they might select the wrong clothing for the season. They also might wear colors that don't go together or forget to put on a piece of clothing. Allow the person to dress on their own for as long as possible. Try these tips to make dressing easier:

- Lay out clothes in the order the person should put them on, such as underwear first, then pants, then a shirt, and then a sweater.
- Hand the person one item at a time or give step-by-step dressing instructions.
- Keep only one or two outfits in the closet or dresser at a time to reduce the number of choices.
- Buy three or four sets of the same clothes if the person wants to wear the same clothing every day.
- Buy loose-fitting, comfortable clothing. Short cotton socks and loose cotton underwear are best. Sweatpants and shorts with elastic waistbands are helpful.



- Use fasteners or large zipper pulls for clothing, instead of buttons or buckles. Try slip-on shoes that won't slide off or shoes with hook-and-loop fastener straps instead of shoelaces.

Grooming

For the most part, when people feel good about how they look, they feel better. Helping people with Alzheimer's with their grooming often helps them feel more like themselves. The following tips may help.

Makeup and Hair:

- Encourage the person to wear makeup if they have always worn it. If needed, you can offer to apply makeup and face care products.
- Help them shave as needed if they did this in the past. Use an electric razor for safety. Make sure people with longer facial hair trim it regularly to keep it healthy and make it easier to care for.
- Take the person to get their hair trimmed and styled. Some barbers or hairstylists may come to your home.
- Keep the person's nails clean and trimmed. Consider using a nail file if you or your loved one feel uncomfortable using clippers.

Brushing and Mouth Care:

Good mouth care helps prevent dental problems such as cavities and gum disease.

- Show the person how to brush their teeth. Go step by step. For example, pick up the toothpaste, take the cap off, put the toothpaste on the toothbrush, and then brush. Remember to let the person do as much as possible.
- Try a long-handled, angled, or electric toothbrush if you need to brush the person's teeth for them.
- If the person bites down on the toothbrush or does not want something in their mouth, sometimes using a child's size toothbrush can be helpful.
- Use special tools to make flossing easier. Floss holders, floss threaders, oral irrigators, and interdental brushes can be helpful.
- If the person has dentures, help them keep them clean. Make sure the person uses the denture cleaning material the right way.
- Ask the person to rinse their mouth with water after each meal and use mouthwash once a day.
- Be aware of dry mouth. Some conditions and medications make the mouth feel dry, making it hard to chew, swallow, and talk. If the person you care for has dry mouth, a dentist can help determine the cause. You can also encourage the person to sip water often, avoid caffeine and alcohol, chew sugarless gum, and use a humidifier at night.
- Take the person to see a dentist. Look for a dentist with experience treating people with Alzheimer's. You may need to ask around to find a dentist with experience treating people with Alzheimer's. Be sure to follow the dentist's advice about how often to make an appointment. Consider mobile dentistry, in which patients are treated by trained professionals in comfortable, familiar surroundings.

Healthy Eating and Mealtimes

It's important for people with Alzheimer's to maintain a healthy diet, but some people may have a poor appetite due to medication, lack of physical activity, or a decreased sense of taste and smell.

Follow these suggestions to help keep the person nourished:

- Offer healthy foods such as vegetables, fruits, and whole-grain products. Be sure to buy foods that the person likes and can eat.
- Consider taking advantage of meal kit services, or provide foods that are easy to prepare, such as pre-made salads and microwaveable meals.
- If the person is still living alone, call to remind them to eat.
- Offer smaller but more frequent meals, calorie rich snacks, and sweetening food with honey or syrup if you are concerned the person is not eating enough.
- Use a service such as Meals on Wheels, which will deliver meals to the person's home. For more information, contact Meals on Wheels America at **888-998-6325** or visit **www.mealsonwheelsamerica.org**.

Mealtimes can be hard for someone with Alzheimer's, especially if they have lost some independence. Try these tips to make meals easier:

- If the person has always eaten meals at specific times, continue to serve meals at those times.
- Serve meals in a consistent, familiar place and way whenever possible.
- Make the eating area quiet. Turn off the TV or radio if they distract the person from eating.
- View mealtimes as opportunities for social interaction. You can set the mood with a warm and happy tone of voice.

- Don't rush and don't push. Be patient and give the person enough time to finish their meal.

Over time, people with Alzheimer's may have difficulty eating. Here are some ideas to help make it easier for them to eat:

- Offer just one food at a time instead of filling the plate or table with too many options.
- Cut the food into small pieces and make it soft enough to eat, which will help with chewing and swallowing.
- Enable your loved one to feed themselves if they are able. It may require gentle prompting and patience.
- If your loved one is unable to move the food to their own mouth, try putting your hand on their hand while they hold the fork and guide the food to their mouth.
- Consider pureeing food if the person has difficulty swallowing.
- Avoid over-feeding or force-feeding. Keep in mind that in late stages of Alzheimer's, appetite declines.

Exercise and Physical Activity

Physical activity helps keep the muscles, joints, and heart of someone with Alzheimer's in good shape. Exercise can also improve mood and sleep. Check with their doctor before starting a new fitness routine.

Here are some tips for helping a person with Alzheimer's stay active:

- Take a walk together each day. Exercise is good for caregivers, too!
- Make sure the person with Alzheimer's has an ID bracelet with your phone number if they walk alone.
- Find exercise videos for older adults online.
- Add music to the exercises if it helps the person with Alzheimer's.
- Make sure your loved one wears comfortable clothes and shoes that fit well and are made for exercise.
- Make sure the person drinks plenty of water or juice during and after exercise.
- Be realistic about how much activity can be done at one time. Several short "mini workouts" may be best.

> **She was fantastic at balloon volleyball. We would knock the balloon back and forth, and I would say, 'Way to go, mom,' and that's when she'd smile. I'd go for that moment when you see her smile as she hits the balloon. It was very, very good for her.**

Some people with Alzheimer's may not be able to get around well. Even if people have trouble walking, they may be able to:

- Do simple exercises or yoga while seated in a chair.
- Play games while seated, such as bean bag toss or horseshoe.
- Help with tasks around the home, such as sweeping and dusting.
- Use a stationary bike or pedal exercisers.
- Use soft rubber exercise balls or balloons for stretching or throwing back and forth.
- Use stretching bands, which you can buy in sporting goods stores or online. Be sure to follow the instructions.
- Lift light weights or household items such as soup cans.

Get more tips for providing everyday care to a person with Alzheimer's at **www.nia.nih.gov/alzheimers-care**.

CHAPTER 4

Medical Problems and Going To the Doctor

A person with Alzheimer's may develop other medical problems over time, as we all do. These problems can cause more confusion and behavior changes. The person may not be able to tell you what is wrong. Watch for signs of illness and tell the doctor about what you see.

Pain Alert

Keep in mind that the person with Alzheimer's may not be able to tell you when they are in pain. Watch the person's face to see if it looks like they are in pain or feeling ill. Take note of sudden changes in behavior such as increased yelling or striking out, which may indicate the person is uncomfortable. If you are unsure of what to do, call a doctor for help.

To learn more about causes of pain in older adults, visit **www.nia.nih.gov/pain**.

Common Medical Problems

Some common medical problems to watch for in people with Alzheimer's include:

- Flu, pneumonia, and other respiratory illnesses
- Dehydration
- Constipation
- Diarrhea
- Incontinence
- Urinary tract infection
- Hearing and vision loss

Make sure the person with Alzheimer's sees a health professional on a regular basis. This is the best thing you can do to help prevent medical problems or manage them before they become serious.

In addition to talking with a doctor, there are things you can do at home to help avoid some common medical problems:

- Make sure the person stays up to date on all recommended vaccinations, including their yearly flu and COVID shots. For current recommendations for older adults, visit **www.cdc.gov/vaccines/adults**.
- Be aware of how much fluid the person is drinking. Try to get the person to drink at least six glasses of liquid a day. If the person doesn't want to drink water, try juice, flavored water, broth, milk, or decaffeinated coffee or tea.
- Encourage the person to eat foods high in fiber, which can help ease both constipation and diarrhea. Foods such as dried apricots, raisins, prunes, some dry cereals, and whole-grain bread are high in fiber.
- If possible, ensure the person gets some exercise, such as walking, each day. See page 26 of this guide for tips.

Visiting the Doctor

It's important that the person with Alzheimer's gets regular medical care. Here are some tips to help you get ready for a visit to the doctor's office:

- Make an appointment during the person's best time of day and when the doctor's office is less likely to be crowded.
- Let the office staff know before the visit about the person's Alzheimer's. Ask the staff for help to make the visit go as smoothly as possible.
- Share any information with the staff before the visit which might be difficult to discuss in front of the person with Alzheimer's.

- If visiting the doctor makes the person with Alzheimer's nervous, don't tell them about the doctor's appointment until the day of the visit or even right before it is time to go. Be positive and matter of fact.
- Pack something they like to eat or drink and any materials or activities the person enjoys.
- Have a friend or family member go with you so that one of you can stay with the person while the other speaks with the doctor.
- Have a brief summary listing the person's medical history, primary care doctor, and current medications easily available.

You may also consider telehealth, a service that uses video calling and other technologies to help the person see a doctor from home instead of at a medical facility. Telehealth may be particularly helpful for older adults with limited mobility and for those living in rural areas. Ask your health care provider about telehealth options.

Going to the Emergency Room

A trip to the emergency room (ER) can be very stressful for both the person with Alzheimer's and you. Here are some ways to cope with ER visits:

- Take a list of medicines, insurance cards, contact information for the person's health care providers, and any advance directives. Advance directives are signed documents, such as a living will, that spell out a person's wishes for end-of-life care.
- If you can, ask a friend or family member to go with you or meet you in the ER. They can stay with the person while you complete forms and respond to medical staff's questions.
- Be ready to explain the symptoms and events leading up to the ER visit. You may need to repeat this more than once to different staff members.
- Tell ER staff that the person has Alzheimer's. Explain how best to talk with the person.
- If the person with Alzheimer's must stay overnight in the hospital, try to have a friend or family member stay with them. Talk with the staff about other options for support overnight.

Incontinence

Incontinence means a person can’t control their bladder and/or bowels. Most people with Alzheimer’s will experience incontinence at some point. Incontinence can happen at any stage of this disease, but it is more often a problem in the later stages. Sometimes people with Alzheimer’s can have accidents because they have trouble finding the bathroom or recognizing the toilet as a toilet. Incontinence may cause the person to feel shame or embarrassment.

Incontinence can be particularly challenging for caregivers, who may have to change clothes, underwear, or bedsheets frequently. A doctor can help figure out why incontinence is happening. In some cases, incontinence is caused by certain medications, a urinary tract infection, an enlarged prostate, diabetes, or drinking caffeine. In these cases, the doctor may be able to treat the incontinence. In other cases, the incontinence cannot be treated.

Here are some tips to cope with incontinence:

- Limit fluids after 6 p.m. if problems happen at night. Give the person fresh fruit before bedtime instead of fluids if they are thirsty.
- Do not give the person caffeinated drinks such as regular coffee or tea.
- Remind the person to go to the bathroom every two to three hours and show them the way.
- Mark the bathroom door with a big sign that reads “Toilet” or “Bathroom.”
- Make sure the person wears loose, comfortable clothing that is easy to remove.
- Use a stable toilet seat that is at a good height. A colorful toilet seat may help the person identify the toilet.
- Buy adult disposable briefs or underwear, washable bed protectors, and waterproof mattress covers to make accidents easier to clean up.
- Clean the skin after every leak or accident to avoid irritation and infection. Use a mild soap, rinse, and allow to air dry, if possible. After cleaning, apply moisturizer or petroleum jelly to protect the skin.

CHAPTER 5

Keeping a Person With Alzheimer's Safe

It is essential to ensure the person with Alzheimer's is safe at home, when taking medications, and in the car. Taking measures to improve safety can not only prevent injuries, but may also help the person with Alzheimer's feel more at ease and help to maintain their independence longer.

Home Safety

Over time, people with Alzheimer's will become less able to manage things around the house. For example, they may forget to turn off the oven or faucet, or even how to use the phone in an emergency. People with Alzheimer's may not see, smell, touch, hear, or taste things as they used to. As a caregiver, you can do many things to make a house safer for people with Alzheimer's. Here are some tips:

- Mark the edges of steps with brightly colored tape so the person can see the steps as they go up or down stairs.
- Use brightly colored signs or simple pictures to label the bathroom, bedroom, and kitchen.

- Limit the size and number of mirrors in your home and be specific about where you put them. Mirror images may confuse a person with Alzheimer's.
- Set your water heater to 120°F to prevent burns.
- Label hot-water faucets red and cold-water faucets blue or write the words "hot" and "cold" near them.
- Put signs near the oven, toaster, iron, and other things that get hot. The sign could say, "Stop!" or "Don't Touch — Very Hot!" Be sure the sign is not so close that it could catch fire.
- Pad any sharp corners on your furniture or replace or remove furniture with sharp corners.
- Install automatic lights to light up the path to the bathroom when it's dark to help prevent falls.
- Use smoke detectors and natural gas detectors. People with Alzheimer's may not be able to smell smoke or an unlit gas stove.
- Check foods in the refrigerator often. Throw out any that have gone bad.
- Put away or lock up items such as toothpaste, lotions, shampoos, rubbing alcohol, soap, perfume, and laundry detergent pods. They may look and smell like food to a person with Alzheimer's. Keep the Poison Control number, **800-222-1222**, by the phone, on speed dial, or in "favorites" in your phone contacts.
- Learn basic first aid in case the person gets sick or injured. Learn the Heimlich maneuver and CPR, and when to use each. Check with your local hospital or Red Cross chapter about health and safety classes.

Go through the house room by room to identify potential problems and safety issues. First, correct any immediate dangers, such as loose stair railings and poor lighting, and then work on other ways to ensure the person will be as safe as possible at home.

Visit **www.nia.nih.gov/safety-checklist-alzheimers** for room-by-room suggestions to help you identify and remove hazards around the house.

Paying for Safety Updates

Are you worried that making changes will be expensive? You may be able to get help paying for repairs and safety updates to an older adult's home. Check with your state housing finance agency, social services department, community development groups, or the federal government for financial aid programs and discounts. You can also contact the Eldercare Locator for assistance in finding resources at **eldercare.acl.gov** or by calling **800-677-1116**.

Preventing Falls

Because bones generally get weaker as people age, a fall is more likely to cause a fracture in older adults. People with Alzheimer's are at even greater risk of falling because they often experience changes in depth perception, which is the ability to judge how close or far away objects are. For example, a person with Alzheimer's may think that a change in floor pattern (carpet to tile, for example) is a step, causing them to stumble or trip.

You can make changes in the home of the person with Alzheimer's to better ensure their safety. Check out **www.nia.nih.gov/falls-prevention** for more information about falls and an infographic about how to help prevent them.

Medication Safety

Taking medicines the wrong way or mixing certain drugs and supplements can be dangerous. Older adults often have multiple medical conditions and may take many medicines. People with Alzheimer's often need help taking their medicines. See the tips below for ways to take medications safely.

- Be aware of all prescription medications, over-the-counter drugs, vitamins, dietary supplements, and herbal remedies the person takes.
- Keep a list of all medications. Include the time the person should take each medicine, how much they should take, and the reason it was prescribed.
- Set phone alerts or use a chart, calendar, or timer to remind you when it is time for the person to take medicines.
- Use a weekly pill organizer to help keep track of the person's medications.
- If the person lives alone, call to remind them to take their medicine.
- If the person has trouble swallowing, talk with a doctor or pharmacist about whether the medication is available in liquid form. In some cases, you can crush pills and mix them with food, such as applesauce or yogurt, which may make them easier to swallow. However, some pills must be taken whole to work properly, so ask a health care provider before trying this.
- If the person is experiencing uncomfortable side effects from a medication, talk with the doctor or pharmacist. They may be able to prescribe a different medicine or help you deal with side effects in other ways. Remember that the person should not stop taking any medication without checking with their health care provider first.

To help you keep track of medicines for someone with Alzheimer's, fill out the *Managing Medications and Supplements* worksheet at **www.nia.nih.gov/caregiver-worksheets**.

Driving Safety

Good drivers are alert, think clearly, and make good decisions quickly. When someone with Alzheimer's is not able to do these things, they should stop driving. If the person with this disease keeps driving when it is no longer safe, someone could get hurt or be killed.

Signs that the person should stop driving include:

- New dents and scratches on the car
- Taking a long time to run a simple errand and not being able to explain why, which may indicate the person got lost
- Two or more traffic tickets, minor accidents, or increased car insurance premiums
- Comments from friends and neighbors about the person's driving
- Speeding or sudden lane changes
- Confusing the brake and gas pedals

People with some memory loss may be able to drive safely sometimes, but they may be unable to react quickly when faced with a surprise on the road. If the person's reaction time slows, then they should stop driving. Other people with memory loss may be able to drive short distances on local streets during the day but unable to drive safely at night or on a freeway. If this is the case, limit the person's driving timeframes and distances.

When driving becomes unsafe, the person will need to stop driving. Try these tips:

- Explain your concerns to the person.
- Take them to get a driving test or risk screening for older adults at your state's department of motor vehicles.
- Ask the person's doctor to tell the person to stop driving. The doctor can write, "Do not drive" on a prescription pad, and you can show this to the person. If necessary, hide the car keys, disable the car, move it out of sight, or consider selling it.

Find out about services that help people with disabilities get around their community. These may include free or low-cost buses, taxi and similar private transportation services, or carpools for older people. Some churches and community groups have volunteers who take seniors wherever they want to go.

Contact your local Area Agency on Aging office or Eldercare Locator at **800-677-1116** or **eldercare.acl.gov**. You also can try searching Rides in Sight at **ridesinsight.org** or by calling **855-607-4337** for transportation options for older adults in your area.

For more information, visit **www.nia.nih.gov/driving-alzheimers**.

CHAPTER 6

Adapting Activities for People With Alzheimer's Disease

People with Alzheimer's need to be active and do things they enjoy. However, activities they used to enjoy may become challenging for them as the disease worsens. They may have trouble deciding what to do or starting tasks. Learn how to adapt activities to make them easier and more enjoyable. Start with these tips:

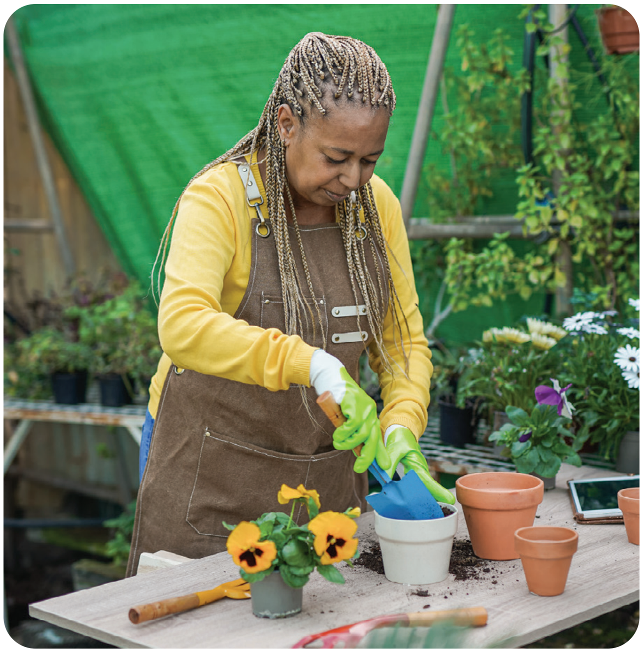
- Match the activity with what the person with Alzheimer's can do.
- Choose activities that can be fun for everyone.
- Help the person get started with the activity.
- Decide if they can do the activity alone or need help.
- Watch to see if the person gets frustrated.
- Make sure they feel successful and have fun.
- Let them simply watch if they seem to enjoy that more.

> **"I try to make it possible for her to do what she can do and enjoy and have a good quality of life. I don't want her just locked in the house. I want her out and about so life still has meaning, life still has a purpose for her."**

At Home

To help keep days interesting and engaging for people with Alzheimer's, try coming up with different activities to do each day. Here are some daily activities people with Alzheimer's may enjoy:

- **Cooking and baking:** Gather materials, measure ingredients, mix and pour, or tell someone else how to prepare a recipe.
- **Exercise:** Take a walk together, use a stationary bike, use stretching bands, throw a soft ball or balloon back and forth, lift weights or household items such as soup cans, or follow along with exercise videos or programs for older adults.
- **Music and dancing:** Play music, talk about the music and the artist, ask what the person with Alzheimer's was doing when the song was popular, sing or dance to well-known songs, or attend a concert or musical program in the community.
- **Pets:** Feed, groom, walk, or sit and hold a pet.
- **Gardening:** Take care of indoor or outdoor plants, plant flowers and vegetables, water the plants when needed, or talk about how much the plants are growing.
- **Household chores:** Wash dishes, set the table, prepare food, sweep the floor, dust, sort mail and clip coupons, sort socks and fold laundry, or sort recycling materials or other items.



- **Visiting with children:** Play a simple board game, read stories or books, visit family members who have small children, walk in the park or near schools, or go to school events. If you don't have children to visit, talk about fond memories from childhood.

> **“My daughter did not know my mother at all like I knew her, and that breaks my heart, because she would have been the best grandma. But they still had an amazing bond, even though she couldn't communicate with my daughter. She would light up when she would see my baby.”**

Going Out

Early in the disease, people with Alzheimer's may still enjoy the same kinds of outings they enjoyed in the past. Keep going out as long as you are comfortable. Plan outings for the time of day when the person is at their best. Keep your time away from home from becoming too long so the person with Alzheimer's doesn't get too tired. Some places your loved one might enjoy visiting include:

- Favorite restaurant
- Zoo or aquarium
- Park or nature trail
- Shopping mall
- Swimming pool (during a slow time of day at the pool)

- Museum, theater, or art exhibits for short trips

The person with Alzheimer's may also enjoy going to a senior center. This type of "going out" could also be considered a form of respite care because it provides an activity for the person with Alzheimer's and gives the caregiver a break. Learn more about respite care on page 49.

Eating Out

Going out to eat can be a welcome change, but it also poses some challenges. Below are some tips for eating out with a person who has Alzheimer's:

- Choose a restaurant that the person likes, is quiet, and has quick service and understanding staff.
- Visit restaurants during "off hours" when they're less likely to be crowded.
- Consider going to the restaurant earlier in the day so the person is not too tired. Bring supplies such as utensils, a towel, and wipes that the person uses at home.
- At the restaurant, ask for a table near the bathroom.
- Help the person choose their meal, if needed. Read parts of the menu or show the person a picture of the food. Suggest food you know the person likes.
- Ask the server to fill glasses half full or leave the drinks for you to serve.
- Order some finger food or appetizers before the main meal to hold the attention of the person with Alzheimer's.

Traveling

Taking a person with Alzheimer's on a trip can be a challenge because it may make the person more worried and confused. Below are tips that you may find helpful.

- Before you leave, talk with the person's doctor about medicines to calm someone who gets upset while traveling.
- Think about the person's unique needs and preferences when choosing transportation, such as a plane, train, or car. Go with the option that provides the most comfort and least anxiety.
- Pack an extra set of clothing and items they enjoy looking at or holding in a carry-on bag.
- Talk to the person about travel plans in advance, but not too far ahead if traveling makes them feel anxious.
- Do not plan too many activities, and plan rest periods.
- During the trip, follow a routine like the one you use at home. Try to have the person eat, rest, and go to bed at the same time as usual.
- Be prepared to cut your visit short if necessary.
- In case the person with Alzheimer's gets lost, make sure they wear or have something with them that tells who they are, such as an ID bracelet.

Managing Finances

Problems managing money may be one of the first noticeable signs of dementia. To provide support while also respecting the person's independence, a family member or trusted friend can help by:

- **Watching for signs of money problems.** Trouble paying for a purchase or a pile of unopened bills may indicate money issues. Start a conversation about available services to help the person with Alzheimer's with their expenses. Giving the person small amounts of cash to have on hand and limiting credit cards may help manage spending.
- **Setting up automated bill payments.** Arrange for their utilities, mortgage, rent, or other expenses to be paid through automatic deductions from a bank account. Automated payments can ensure that bills are paid correctly and on time. Review the automatic payments to make sure all the transactions are accurate.
- **Protecting against scams or fraud.** To lower the risk of telemarketing schemes, place the person's phone number on the National Do Not Call Registry at **www.donotcall.gov**. Consider signing up the

person for fraud alerts through their bank, credit card company, a national credit bureau, or other credit monitoring service.

- If you think the person may be a victim of a scam, contact your local police department. You can also contact the National Elder Fraud Hotline at **833–372–8311**. Your state consumer protection office or Area Agency on Aging office may also be able to help. Look online for these agencies at **www.usa.gov/state-consumer** or **www.usaging.org**.

To learn more about legal and financial planning for someone with Alzheimer's, visit **www.alzheimers.gov/life-with-dementia/planning-for-future**.

Spiritual Activities

Being part of a faith community may help someone with Alzheimer's feel connected to others and remember pleasant times. Here are some ideas to help:

- Involve the person in spiritual activities that they have known well. These might include worship services, religious or other readings, sacred music, prayer, meditation, and holiday rituals.
- Tell people in the preferred faith community about the person's Alzheimer's. Encourage them to talk with the person and show they still care.
- Find worship services or readings online if the person is more comfortable at home.

> **“My mother loves gospel music. We still attend church every Sunday and sing together. She chimes in and sings at the top of her lungs. She loves going to church. Despite her challenges, she has a wonderful personality. She comes in hugging everybody, and she makes light of the fact she doesn't remember who they are. They love her and have been a wonderful support to me.”**

Holidays

Caregivers of people with Alzheimer's may worry about the extra demands that holidays make on their time and energy. Here are some suggestions to make holidays easier:

- Understand that things will be different and be realistic about what you can do.
- Incorporate the holiday traditions of the person with Alzheimer's.
- Create a quiet space in case the individual with Alzheimer's needs a break. Have their favorite activities or calming music in that space.
- Ask friends and family to visit. Limit the number of visitors at any one time.
- Avoid crowds, changes in routine, and strange places that may make the person with Alzheimer's feel confused or nervous.
- Remember to enjoy yourself. Find time for the holiday activities you like to do. Ask a friend or family member to spend time with the person while you're out.

For more tips on how to manage holidays as a caregiver, visit **www.nia.nih.gov/alzheimers-holidays**.

Visitors

Visitors are important to people with Alzheimer's. The person may not always remember who the visitor is, but they often enjoy the company. Remind visitors to:

- Be calm and speak in a normal tone. Don't use a loud voice or talk to the person as if they were a child.
- Consider bringing along some kind of activity to share with the person, such as a well-known book or photo album.
- Respect the person's personal space and don't get too close.
- Make eye contact and call the person by name to get their attention.
- Try not to take it personally if the person doesn't recognize them, is unkind, or gets angry.
- Avoid asking, "Don't you remember?" or correcting or arguing with the person if they say something wrong or unusual.
- Respond to the feelings that the person expresses. If the person seems confused, try to distract them by talking about something different instead of arguing.

To learn more about adapting activities for a person with Alzheimer's, visit **www.nia.nih.gov/activities-alzheimers**.

CHAPTER 7

Caregiver Support and Self-Care

Taking care of yourself is one of the most important things you can do as a caregiver. This could mean asking family members and friends to help out, making time to do things you enjoy, using adult day care services, or getting help from a local home health care agency. Taking these actions can bring you some relief. It also may help keep you from becoming ill or depressed. Here are some ways you can take care of yourself:

- Ask for help when you need it.
- Join a caregiver support group.
- Take breaks each day.
- Spend time with friends.
- Keep up with your hobbies and interests.
- Eat healthy foods.
- Exercise as often as you can.
- See your doctor on a regular basis.
- Keep your health, legal, and financial information up to date.

Clinical Trials for Alzheimer's Caregivers

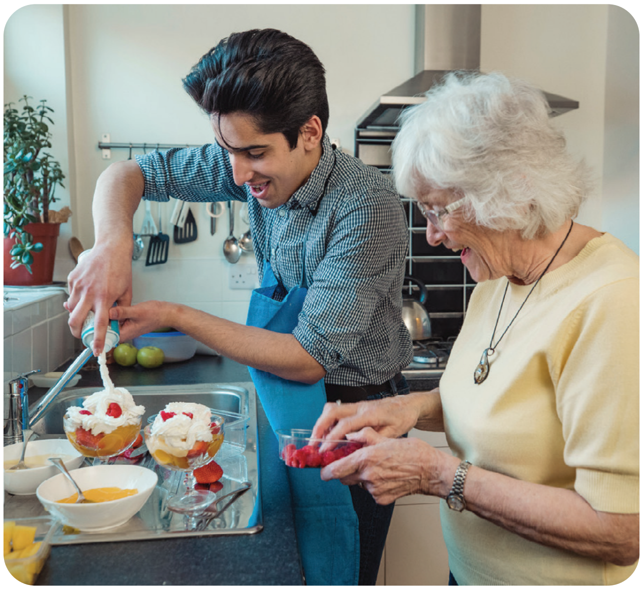
Researchers are testing strategies to reduce stress and improve overall well-being for Alzheimer's caregivers. By participating in a clinical trial, you can help future generations of Alzheimer's caregivers and get access to the latest approaches to reduce caregiver burden.

To find a clinical trial near you, visit **www.alzheimers.gov/clinical-trials**.

Getting Help From Friends and Family

It's okay to ask for help and to take time for yourself. However, many caregivers find it hard to ask others for assistance. You may feel that you should be able to do everything yourself, that it's not okay for you to leave the person with someone else, or that none of your friends and family would help if you asked. **It's important to remember that you're not alone and asking for help is okay.** If you have trouble asking for support, try using some of these tips:

- Ask people to help out in specific ways, like making a meal, visiting the person, or taking the person out for a short time.
- Join a support group in person or online to share advice and understanding with other caregivers.
- Get help from home health care or adult day care services when you need it.
- Use national and local resources to find out how to pay for professional help or get respite care services.



Everyone needs help at times. Recognize that the care of a person with Alzheimer's often exceeds what one person can provide on their own. Consider what "Plan B" looks like if your loved one's care needs increase and you need extra support.

To make dividing up caregiving duties easier, use the Coordinating Caregiving Responsibilities worksheet at **www.nia.nih.gov/caregiver-worksheets**.

> “ **My sister lives further away, but we're still a team. We often wonder whether it's harder for the person who lives close or for the person who lives far away, who only gets to see them occasionally and for a short time. The bottom line is: It's all hard. But having family support is incredibly important, because if you're doing it all on your own, you can really get lost in the everyday and become overwhelmed.** ”

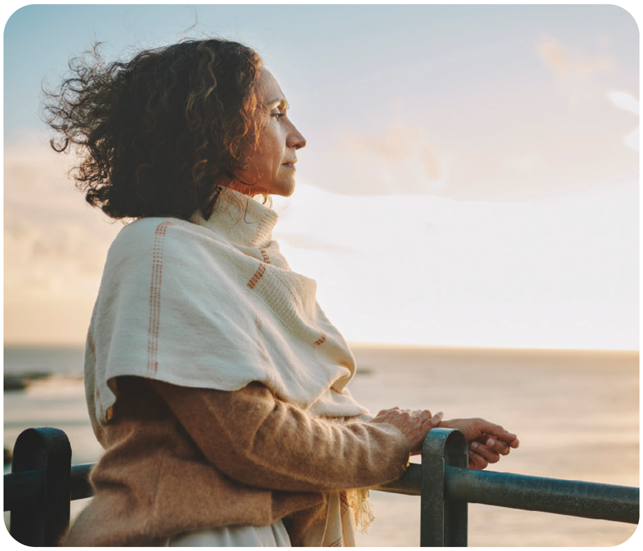
Your Emotional Health

Caring for a person with Alzheimer's takes a lot of time and effort. Your job as caregiver can become even harder when the person you're caring for gets angry with you, hurts your feelings, or forgets who you are. Sometimes you may feel really discouraged, sad, lonely, frustrated, confused, or angry. These feelings are normal.

Here are some things you can say to yourself that might help you feel better:

- I'm doing the best I can.
- What I'm doing would be hard for anyone.
- I'm not perfect, and that's okay.
- I can't control everything that happens.
- Sometimes, I just need to do what works for right now.
- Even when I do everything I can think of, the person with Alzheimer's will still have problem behaviors because of the illness.
- I will enjoy the moments when we can be together in peace.
- I will seek help from professionals if caregiving becomes too much for me.

Some caregivers find that going to a church, temple, or mosque helps them cope with the daily demands placed on them. For others, simply having a sense that larger forces are at work in the world helps them find a sense of balance and peace.



More tips for self-care:

- Understand that you may feel sad and hopeless about what's happening to the person you care for.
- Remind yourself why you've chosen to take care of the person with Alzheimer's. Ask yourself if you made this choice out of love, loyalty, a sense of moral or religious duty, or a desire to help family.

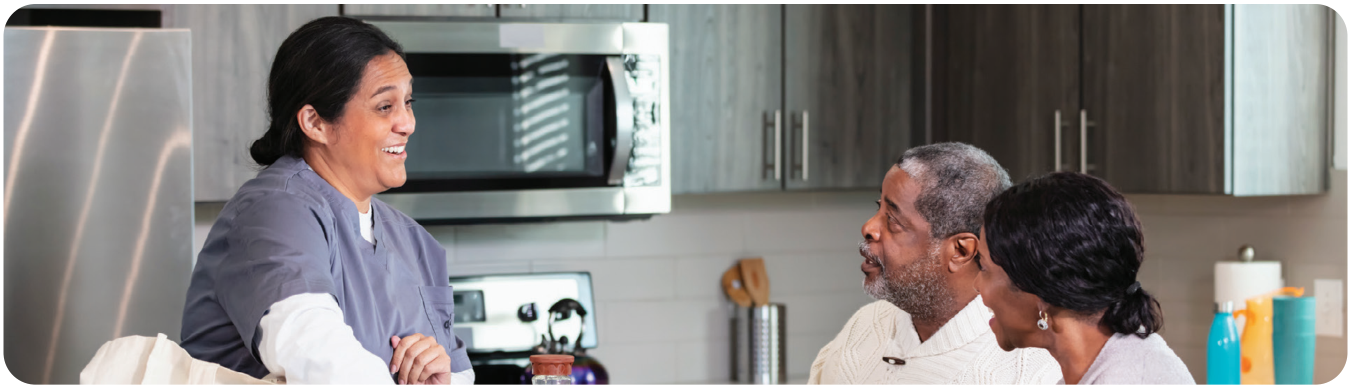
> **"Start building a support network. Get some people in place to help you, because it's a journey that you really can't do solo. It doesn't matter how strong you are, you're going to need help. Do what it takes to take care of your mental health."**

Getting Professional Help

Mental health professionals and social workers can help you deal with stress you may be feeling. They can help you understand difficult feelings, such as anger, sadness, or feeling out of control. They can also help you make plans for unexpected or sudden events.

Mental health professionals charge by the hour. Medicare, Medicaid, and some private health insurance plans may cover some of these costs. Ask your health insurance provider about which mental health services your plan covers. Then check with your doctor, local family service agencies, and community mental health agencies for referrals to counselors.

- Let yourself feel day-to-day “uplifts.” These might include good feelings about the person you care for, support from other caring people, or time to spend on your own interests and hobbies.
- Experiment with relaxation techniques such as meditation, tai chi, or yoga. Download a smartphone app with guided meditations or relaxing music. Many of these apps are free.
- Find a connection to something “higher than yourself.” This may be a belief in a higher power or religious faith or believing that something good comes from every life experience.



Finding Help With At-Home Caregiving

Some caregivers need help when the person is in the early stages of Alzheimer's. Other caregivers look for help when the person is in the later stages of the disease. It's okay to seek help whenever you need it.

While there are medicines available to treat symptoms and slow the disease in some people, there is currently no cure for Alzheimer's. This means that symptoms such as memory loss and confusion will get worse over time, leading to the person with Alzheimer's needing more care.

You may feel that asking for help shows weakness or a lack of caring, but the opposite is true. Asking for help shows your strength. It means you know your limits and when to seek support.

According to many caregivers, building a local support system is a key way to get help. Your support system might include a caregiver support group, nonprofit and community organizations, family, friends, and faith groups.

The following is a list of services that can help you care for the person with Alzheimer's at home, including ways to find out if these services are offered in your area.

Should the Person Move in With Me?

In some cases, it may make sense for a person with Alzheimer's to move into your home so you can take care of them. If you're considering whether that's the right arrangement for you, check out the *Questions To Consider Before Moving an Older Adult Into Your Home* worksheet at **www.nia.nih.gov/caregiving-worksheets**.

Home Care Services

Home care services — not to be confused with home health care services — send an aide to your home to help you care for a person with Alzheimer's. These aides provide personal care and/or company for the person. They assist with daily activities such as bathing and dressing and may help with light housekeeping, transportation, and errands. They do not provide skilled medical care, and aides are usually not medical professionals. Home care aides may come for a few hours or stay for a full day and overnight.

What to know about costs:

- Home care services generally charge by the hour. Some services charge a flat rate for staying overnight.
- Medicare and private health insurance may cover some home care costs, though nonmedical care is generally not covered. Check with your health care provider.
- Long-term care insurance may cover personal care and housekeeping services.

How to find these services:

- Ask the person's doctor or another health care professional, family, and friends to recommend home care services in your area.
- Use an online tool such as the Home Care/Hospice Agency Locator tool from the National Association for Home Care & Hospice, available at **nahc.org/services**.

Home Health Care Services

These are typically part-time medical services ordered by a physician for a specific condition. These may include in-home nursing care to help a person recover from surgery, an accident, or an illness. Home health care may also include physical, occupational, or speech therapy. The provider may come for a few hours each day or stay 24/7.

What to know about costs:

- Home health services charge by the hour.
- Medicare has limited coverage of home health service costs.
- The services must be short-term and provided by agencies certified by Medicare. Medicaid also provides coverage for home health service costs, but these benefits vary by state.
- Most private health insurance plans do not cover these costs.

You must pay all costs not covered by Medicare, Medicaid, or insurance.

How to find these services:

- Ask the person's doctor or another health care professional for a list of agencies that serve your area.
- Use the Home Health Compare tool from **Medicare.gov**, available at **www.medicare.gov/care-compare**.
- Search the Eldercare Locator at **eldercare.acl.gov** or call **800-677-1116**.

Tips for Finding and Hiring In-Home Care Services

Some care services are very good; others are not. Ask providers for references from people who have used their services. If possible, check for any complaints filed against a service. You can check with community, county, or state agencies that regulate health services or contact the Better Business Bureau in your area.

Before signing an agreement for a care provider, gather as much information as you can about services, fees, terms, and restrictions. Use the Questions To Ask Before Hiring a Care Provider worksheet at **www.nia.nih.gov/caregiver-worksheets**.

If you are a veteran or caring for one, the Veterans Administration might be of help to you. To learn more, visit its caregivers' website at **www.caregiver.va.gov**. You might also call their toll-free support line at **855-260-3274**.

Meal Services

Meal services deliver healthy, nutritious meals to a person's home on a daily or weekly basis. Many of these services offer options for special diets and can handle dietary restrictions. However, the delivery staff do not assist with making meals at home or feeding the person.

What to know about costs:

- In some cases, a person must qualify for the service based on certain guidelines. These can include age, mobility, and economic need.
- Medicare does not generally cover meal delivery services, although under certain circumstances, it will provide this benefit for a short time. Medicaid may pay for some meal delivery services if the person is eligible.
- Some meal delivery services do not require payment. Others charge a fee or accept donations.

How to find these services:

- Use the Eldercare Locator at **eldercare.acl.gov** or call **800-677-1116**.
- Call Meals on Wheels America at **888-998-6325** or visit their website at **www.mealsonwheelsamerica.org**.
- Some local governments provide low- or no-cost meals to older adults. Call or check their websites for details.
- Your health care provider or local senior center may also be able to recommend a service.
- There are many subscription services that deliver ready-to-eat meals and meal kits. These can be arranged online and generally involve a regular weekly or monthly charge.

Adult Day Care Services

Adult day care services can provide a much-needed break for caregivers at home. These programs provide a safe environment for older adults with trained staff in a nearby facility. An adult day care center may offer social activities, exercise, meals, personal care, and basic health care services. Some will provide transportation — facility staff or contractors may pick up the person, take them to day care, and then return the person home.

What to know about costs:

- Adult day care tends to be less expensive than in-home or nursing home care.
- Charges can be hourly or by the day.
- Medicare will not pay for adult day care, but Medicaid and other government programs may provide coverage.
- Most private health insurance plans don't cover the costs of adult day care. Some long-term care insurance plans pay a portion of the costs.

You must pay all costs not covered by a government program or insurance.

How to find these services:

- Call the National Adult Day Services Association at **877-745-1440** or visit its website at **www.nadsa.org/consumers/choosing-a-center**.
- Use the Eldercare Locator at **eldercare.acl.gov** or call **800-677-1116**.

Respite Care

Respite services provide short-term care for an older adult at home, in a health care facility, or at an adult day care center. The care may last anywhere from a few hours to several weeks at a time. These services provide regular caregivers with a break to rest, travel, or spend time with other family and friends.

What to know about costs:

- Respite services charge by the hour or by the number of days or weeks that services are provided.
- For a person receiving hospice care, Medicare will cover most of the cost for up to five consecutive days of respite care in a hospital or skilled nursing facility. Medicaid also may provide payment assistance. For more information on Medicare and Medicaid, see page 55.
- Most private health insurance plans do not cover these costs.
- Some long-term care insurance plans may help pay for respite care.

You must pay all costs not covered by insurance or government programs.

How to find these services:

- Visit the ARCH National Respite Locator at **archrespite.org/respitelocator**.
- Use the Eldercare Locator at **eldercare.acl.gov** or call **800-677-1116**.

Geriatric Care Managers

A geriatric care manager, also called an aging life care expert, is usually a licensed nurse or social worker who specializes in geriatrics, which is health care for older adults. Geriatric care managers work with older adults and their families to identify needs, make a care plan, and find services in the community. They can be especially helpful when a caregiver lives far away.

What to know about costs:

- The cost of an initial evaluation varies and may be expensive.
- Geriatric care managers charge by the hour.
- Medicare and Medicaid do not pay for this service.
- Most private health insurance plans don't cover these costs. Long-term care insurance may pay for some of the costs; check the plan to see if it includes coverage.
- Most people must pay for some or all of this service themselves.

How to find them:

- Call the Aging Life Care Association at **520-881-8008** or visit their website at **www.aginglifecare.org**.

Hospice Services

Hospice services provide care for a person who is near the end of life and no longer receiving treatment to cure their serious illness. Hospice services keep the person who is dying as comfortable and pain-free as possible in the person's home or a hospice facility. They also support the family by providing end-of-life care. A person can stop hospice services at any time if they wish to receive life-prolonging treatments again.

What to know about costs:

- Medicare, Medicaid, the Veterans Health Administration, or private insurance plans may cover all hospice costs.
- If you receive hospice services in an assisted living facility or nursing home, you may need to pay for room and board. You must pay all costs not covered by insurance.
- Some nonprofit organizations and hospice providers help cover hospice costs on a sliding scale for low-income patients.
- Once you've chosen to receive hospice services, any medicines intended to treat Alzheimer's will not be covered.

How to find these services:

- Call the National Association for Home Care & Hospice at **202-547-7424** or visit **nahc.org/services**.
- Call the Hospice Foundation of America at **800-854-3402** or visit **www.hospicefoundation.org**.
- Call the National Hospice and Palliative Care Organization at **800-658-8898** or visit **www.nhpco.org/find-hospice**.

Choosing a Long-Term Care Facility

There may come a time when you can no longer care for the person with Alzheimer's at home. When that happens, you will need to find another place for that person to live. You may feel guilty or upset about this decision, but as the disease worsens, it could be the best or even the only way to provide the optimal level of care that your loved one needs. Remember that many caregivers reach this point. Moving the person to a care facility may give you greater peace of mind.

Even after you decide the person needs to relocate, choosing the right place can be challenging. The process involves learning about long-term care facilities, arranging visits, and asking the right questions.

Different Types of Long-Term Care Facilities

Long-term care facilities are not one-size-fits-all. Facility-based long-term care services include assisted living facilities, group homes, and nursing homes.

Some facilities offer only housing and housekeeping, but many also provide personal care and medical services. Many facilities offer special programs for people with Alzheimer's or other types of dementia. Learn about the different types of places to determine where your family member will feel most comfortable.

Assisted living facilities. Assisted living facilities have rooms or apartments. They're for people who may need some help with daily tasks but do not need around-the-clock care. Some assisted living facilities have special Alzheimer's units with staff who check on and care for people with dementia. You must pay for the cost of the room or apartment, and you may need to pay extra for any special care. Some assisted living facilities are part of a larger organization that also offers other levels of care. For example, continuing care retirement communities also offer independent living and skilled nursing care.

Group homes. A group home is a home for people who can no longer care for themselves. Several people receiving care live in the home. At least one caregiver is on site at all times.

> **“My mom said she wasn't keen on living with my sister or myself. She didn't want to be, as she called it, ‘a burden.’ So, we found an assisted living home in a residential neighborhood. It was a home, not a larger facility. To choose a place, you just have to go with how the place makes you feel. The place we ended up choosing, from the moment I walked in, I felt like I was at home. It just felt right.”**

The staff takes care of the people living there by making meals, helping with grooming and medication, and providing for other needs. These homes may not be inspected or regulated but may still provide high-quality care.

Nursing homes. Nursing homes are for people who can't care for themselves anymore and may need ongoing medical care. Some nursing homes have special Alzheimer's care units. These units are often in separate sections of the building where staff members have special training to care for people with dementia. Some units are designed with the goal of making the person feel more like they are at home. They provide special activities, meals, and medical care. Nursing homes are inspected and regulated by state governments.

Visiting Facilities

Once you decide what kind of long-term care facility works for your loved one's needs, choose a few places to visit. Talk with friends, relatives, social workers, or your religious community to find out what places they suggest. Check with health care providers about which nursing homes they feel provide good care. Call the facilities to learn more and to schedule visits.

Visit at different times of day and meet with the facility's leaders to get a full understanding of how the facility works and treats the people who stay there.

Ask yourself:

- How does the staff care for the residents?
- Is the staff friendly?

Resources for Choosing a Long-Term Care Facility

There are many sources of information about long-term care facilities. Visit **LongTermCare.gov** to learn more about long-term care options and find local services. You can also call your local Area Agency on Aging or department of human services from your state or local government. Search the Eldercare Locator at **eldercare.acl.gov** or call **800-677-1116** to find contacts in your area.

Medicare offers a tool to find and compare nursing homes and other health care facilities in your state: Visit **www.medicare.gov/care-compare**.

To check the quality of nursing homes and other health care facilities, visit the Joint Commission at **qualitycheck.org**.

- Does the place feel comfortable?
- How do the people who live there look? Are they clean and well cared for?
- Are mealtimes comfortable for people living there?
- Is the facility well-maintained? Does it look and smell clean?
- Do staff members speak to residents with patience and respect?

Ask the staff:

- What activities are planned for residents?
- How many staff members are at the facility? And how many of them are trained to provide medical care if needed?
- How many residents in the facility have Alzheimer's?
- Does the facility have a special unit for people with Alzheimer's? If so, what kinds of services does it provide? Are the costs for this unit different than the rest of the facility?
- Is there a doctor who checks on residents on a regular basis? How often?
- What is a typical day like for the person with Alzheimer's?
- Is there a safe place for the person to go outside?
- What is included in the fee? What services or options would cost extra?
- How would my loved one get to medical appointments?

Talk with other caregivers who have a loved one at the facility. Find out what they think about the place. Ask about the total costs of care. Each facility is different, so you want to find out if long-term care insurance, Medicaid, or Medicare will pay for any of the costs.

If you're asked to sign a contract, ensure you understand what you are agreeing to.

Making Moving Day Easier

Moving a person with Alzheimer's to an assisted living facility, group home, or nursing home is a big change for both the person and their caregivers. You may feel many emotions, from a sense of loss and sadness to guilt or even relief. It is okay to have all these feelings. A social worker or someone from a private service may be able to help you plan for and adjust to this big change. It's important to have support during this difficult step.

Here are some things that may help:

- Know that the moving day can be very stressful.
- Talk to a social worker about your feelings about moving the person into a new place. Find out how to help the person with Alzheimer's adjust.
- Get to know the staff before the person moves into a facility.
- Talk with the staff about ways to make the change to the assisted living facility or nursing home go smoothly.
- Don't argue with the person with Alzheimer's about why they need to be there.

Be an Advocate

Once the person has moved to their new home, check in to see how they are doing. As the caregiver, you probably know the person best. Look for signs that they may need more attention, are taking too much or not enough medication, or may not be getting the care they need. Build a relationship with staff so that you work together as care partners.
For more information about choosing a long-term care facility, visit **www.nia.nih.gov/ltc**.

Paying for Care

How people pay for long-term care — whether delivered at home or in a hospital, assisted living facility, or nursing home — depends on their financial situation and the kinds of services they use. Some people believe that their current health or disability insurance will pay for their long-term care needs, but most of these insurance policies include limited, if any, long-term care benefits. Often, people must rely on a variety of payment sources, including personal funds, government programs, and private financing options.

Personal Funds (Out-of-Pocket Expenses)

Initially, family and friends may provide personal care and other services, such as transportation, for free. But as a person's needs increase, paid services may be needed.

Many older adults also pay out of pocket to participate in adult day service programs, receive meals, and get other community-based services provided by local governments and nonprofit groups. These services help them remain in their homes.

Professional care given in assisted living facilities and continuing care retirement communities is almost always paid for out of pocket, though in some states, Medicaid may cover some costs for people who meet financial and health requirements.

> **“My mother was an entrepreneur. She had assets. But it's hard to predict how much money you'll need because with this disease you don't know if it's going to go quick or if it's going to be a long thing. I would tell people to figure out what that's going to look like from a financial perspective. It will all work out, but it's extremely nerve-wracking trying to figure out how you're going to pay for care every month.”**

Government Programs

Older adults may be eligible for some government health care benefits. Caregivers can help by learning more about possible sources of financial help and assisting older adults in applying for aid as appropriate.

Several federal and state programs provide help with health care-related costs. Over time, the benefits and eligibility requirements of these programs can change, and some benefits differ from state to state. Check with the individual programs directly for the most recent information.

Medicare. This federal government health insurance program helps pay some medical costs for people age 65 and older, and for people younger than 65 with certain disabilities and serious health conditions. Covered services include hospital stays, doctor visits, some home health care, hospice care, and preventive services such as vaccinations. The program does not cover assisted living or long-term care. Medicare components include Part A (Hospital Insurance), Part B (Medical Insurance), and Part D (Drug Coverage). Medicare Advantage is another option for obtaining Part A and Part B coverage.

Call Medicare at **800-633-4227** or visit **Medicare.gov** for more information.

Medicaid. Medicaid is a combined federal and state program for low-income people. This program covers the costs of medical care and some types of long-term care for people who have limited income and meet other eligibility requirements. Eligibility and covered services vary from state to state.

To learn more about Medicaid, call **877-267-2323** or visit **Medicaid.gov**.

Program of All-Inclusive Care for the Elderly (PACE). Some states offer PACE, which is a combined Medicare and Medicaid program that provides care and services to people who otherwise would need care in a nursing home. PACE covers medical, social service, and long-term care costs. It may pay for some or all of the long-term care needs of a person with Alzheimer's. PACE enables most people who qualify to continue living at home instead of moving to a long-term care facility. Participants receive coordinated care from a team of health care professionals.

You will need to find out if the person who needs care qualifies for PACE and if there's a PACE program near you. There may be a monthly charge. PACE is available only in certain states and locations within those states.

To find out more about PACE call **877-267-2323** or visit **www.medicare.gov/pace**.

Social Security Administration Programs. Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs provide financial assistance to people with disabilities. SSDI is for people younger than age 65 who are

Private Financing Options for Long-Term Care

In addition to personal funds and government programs, there are several private payment options for long-term care, including long-term care insurance, reverse mortgages, certain life insurance policies, annuities, and trusts. Which option is best for a person depends on many factors, including the person's age, health status, personal finances, and likelihood of needing care.

Learn more about these options at **www.nia.nih.gov/paying-long-term-care**.

disabled according to the Social Security Administration's definition. To qualify, you must be able to show that:

- You worked in a job covered by Social Security.
- You are unable to work because of your medical condition.
- Your medical condition will last at least a year or is expected to result in death.

Processing an SSDI application can take three to five months. However, Social Security has "compassionate allowances" to help people with certain serious medical conditions, such as early-onset Alzheimer's and other forms of dementia, get disability benefits more quickly.

SSI is another program that provides monthly payments to adults age 65 and older who have a disability. To qualify, your income and resources must be under certain limits.

To find out more about Social Security Disability Income, call **800-772-1213** or visit **www.ssa.gov**.

State Health Insurance Assistance Program (SHIP). SHIP is a national program offered in each state that provides one-on-one counseling and assistance with Medicaid, Medicare, and Medicare supplemental insurance (Medigap). SHIP can help navigate eligibility, coverage, appeals, out-of-pocket costs, and can answer questions about your family's unique situation and needs.

To contact a SHIP counselor in your state, visit **shiphelp.org** or call **877-839-2675**.

Department of Veterans Affairs. The U.S. Department of Veterans Affairs (VA) provides coverage for long-term care at a facility or at home for some veterans. If your family member or relative is eligible for veterans' benefits, check with the VA or get in touch with the VA medical center nearest you. There could be a waiting list for VA nursing homes.

To learn more about VA health care benefits, call **877-222-8387** or visit **www.va.gov/health**.

National Council on Aging (NCOA). The National Council on Aging, a private group, has a free service called BenefitsCheckUp. This service can help you find federal and state benefit programs for older adults. After providing some general information about the person who needs care, you can see a list of possible benefit programs to explore. These programs can help pay for prescription drugs, utilities, housing, meal programs, and legal services. You don't have to provide a name, address, or Social Security number to use this service.

To learn more about BenefitsCheckUp, call **571-527-3900** or visit: **www.benefitscheckup.org**.

Benefits.gov. For more information about federal, state, and local government benefits, call **800-FED-INFO (800-333-4636)** or visit **Benefits.gov**.

Can I Get Paid to Take Care of My Family Member With Alzheimer's?

Family caregivers make a lot of sacrifices to care for older, sick, or disabled relatives. Some even quit their jobs to care for the person full time. There are many costs involved in caregiving, for example, covering travel expenses, paying bills, and buying household essentials. These costs can add up to create a significant financial burden for caregivers.

Many states offer some form of payment for family caregivers, but the laws, eligibility, and funding for this support vary by state. The most common source of assistance is Medicaid, which offers several state-based programs to people who are eligible based on income or disability. These programs include home and community-based services, adult foster care, and Medicaid personal care services. Contact your state Medicaid agency to learn more.

Long-term care insurance usually provides coverage for care at home. However, policies differ regarding who can deliver that care. In some cases, only a professional service will be paid for long-term care. In other cases, the policy will pay for a family member to provide care. Contact your long-term care insurer to learn about the details of your policy.

CHAPTER 8

Care in the Last Stages of Alzheimer's

The last stages of Alzheimer's can bring different challenges for caregivers. In this stage, the person with Alzheimer's may not be able to move or talk and may require around-the-clock care. This chapter offers caregiving suggestions to help during this time.

> **There was one time Mom put her finger on my nose and said, 'Who are you?' I knew that was coming, from reading books, but it was still very difficult. I just said, 'Well, I'm someone that really enjoys being with you.'**

Caring for a Person With Late-Stage Alzheimer's

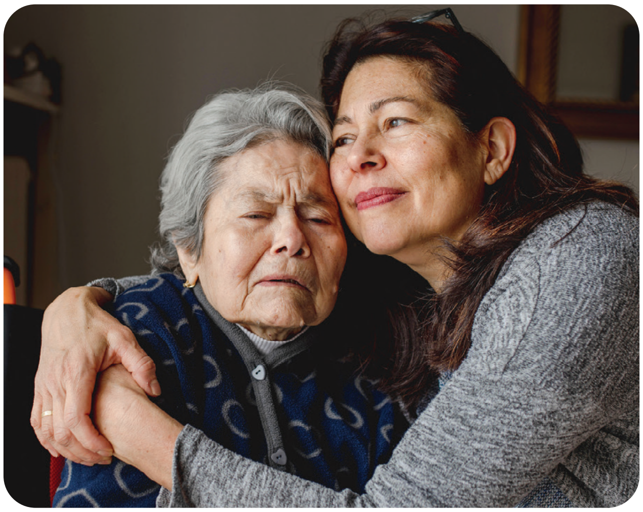
When a person reaches the later stages of Alzheimer's, everyday caregiving may become even harder. This section suggests ways to cope with changes that take place during late-stage Alzheimer's.

When the Person With Alzheimer's Can't Move

If the person with Alzheimer's can't move around on their own, ask their doctor or the hospice or palliative care team for a referral or for resources to help you. A physical or occupational therapist, home health aide, or nurse can show you how to move the person safely, such as changing their position in bed or in a chair.

Also, a physical therapist can show you how to move the person's joints using range-of-motion exercises. During these exercises, you hold the person's arms or legs, one at a time, and move and bend them several times a day. Movement prevents stiffness of the arms, hands, and legs. It also prevents bedsores, which are open sores that can develop when a person stays in one position for a long time.

How to make someone with late-stage Alzheimer's more comfortable:



- Buy special mattresses and wedge-shaped seat cushions that reduce pressure sores. You can purchase these at a medical supply store, drugstore, or online. Ask the home health aide, nurse, or physical therapist how to best use them.
- Move the person to a different position at least every two hours.
- Use a lap board to rest the person's arms and support the upper body when they are sitting up.
- Give the person something to hold, such as a washcloth, while being moved. The person will be less likely to grab onto you or the furniture. If they are weak on one side, stand on the weak side to help the person change positions.

To avoid hurting yourself when moving someone with Alzheimer's:

- Know your limits when lifting or moving the person; don't try to do too much. Also, be aware of how you position your body. If you need additional supports, such as a back brace, have that in place before moving the person.

- Bend at the knees and then straighten up by using your thigh muscles, not your back.
- Keep your back straight, and don't bend at the waist.
- Hold the person as close to you as possible to avoid reaching away from your body.
- Place one foot in front of the other, or space your feet comfortably apart for a wide base of support.
- Take small steps to move the person from one seat to another. Don't twist your body.

How To Make Sure the Person Eats Well

People with Alzheimer's often lose interest in food. This may start in the earlier stages of the disease and worsen over time. You can help the person eat well by following the suggestions on page 25 and trying these tips for preparing food for someone with late-stage Alzheimer's:

- Give the person small amounts of food at a time.
- Describe to them the food they are eating.
- Sit to the side of the person while helping them eat because sitting in front may be intimidating.
- Encourage eating by switching between a bite of the meal and a bite of something sweet.
- Make sure the person has swallowed before introducing more food. Sometimes food can be pocketed in the cheeks.
- Give the person high-calorie, healthy foods to eat or drink, such as protein milkshakes or foods prepared with healthy fats. If the person is still not getting enough calories, talk with their doctor about a dietary supplement.
- Ask the doctor whether the person would benefit from a multivitamin — a tablet, capsule, powder, liquid, or injection that adds vitamins, minerals, and other important nutrients to a person's diet.

Helping a person with Alzheimer's eat can be exhausting. Planning meals ahead and having the food ready can make this task a little easier for you. But remember that people with Alzheimer's may not eat much at certain times and then feel more like eating at other times. No matter how well you plan, the person may not be hungry when you're ready to serve food.

What To Do About Swallowing Problems

In the later stages of Alzheimer's, the person may no longer be able to chew and swallow easily, which increases their risk of choking. If the person chokes on a bite of food, there is a chance that the food could go into the lungs. This can cause pneumonia, which can lead to death.

The following suggestions may help with swallowing:

- Consider using a thickener, such as xanthan gum, corn starch, or maltodextrin, in liquid foods and drinks. Thicker liquids move down the throat more slowly, making it less likely that fluid gets into the lungs. Brand name and generic thickening agents are available at most pharmacies.
- Cut food into small pieces and make sure the food is soft enough for the person to eat.
- Grind or blend food to make it easier to eat.
- Offer soft foods, such as yogurt, applesauce, mashed avocado, sweet potatoes, and bananas.
- Don't use a straw, which may cause more swallowing problems. Instead, have the person drink small sips from a cup.
- Offer drinks of different temperatures — warm, cold, and room temperature — to see which might be easiest for the person to drink.
- Don't hurry the person. Give them time to chew and swallow each mouthful before taking another bite.
- Encourage the person to feed themselves as much as possible during meals. If the person needs support, try using overhand, underhand, or direct hand feeding approaches.
- Don't feed a person who is drowsy or lying down. They should be in an upright, seated position during the meal and for at least 20 minutes after the meal.
- Say "swallow" to remind the person to swallow.

If you think the person with Alzheimer's may have swallowing problems, talk with the person's doctor or home health care team. Doctors can test the person's swallowing and give professional advice for how to reduce the risk of choking.

Body Jerking

Some people with Alzheimer's develop myoclonus, which is sudden muscle spasms or jerks in the arms, legs, or whole body. This can look like a seizure, but the person doesn't pass out. Tell the doctor right away if you see signs of myoclonus. The doctor may prescribe one or more medicines to help reduce symptoms.

Skin Problems

Once a person stops walking or stays in one position too long, they often develop sores or other skin issues. Skin problems can be extremely uncomfortable for someone in the last stages of life. Barrier products such as creams and ointments can help keep the person's skin clean and moisturized. Massaging the skin with unscented lotion can provide pain relief and comfort in addition to protecting the skin. You can also try these tips:

- Apply a balm or petroleum jelly to the lips.
- Gently dab an eye cream or gel around the eyes.
- Try placing a damp cloth over the person's closed eyes.

- If the inside of the mouth seems dry, giving ice chips (if the person is conscious) or wiping the inside of the person's mouth with a damp cloth, cotton ball, or specially treated swab might help.

Sitting or lying in one position can put constant pressure on sensitive skin, which can lead to painful bedsores (sometimes called pressure ulcers). When a bedsore first forms, the skin gets discolored or darker. Watch carefully for these discolored spots, especially on the heels, hips, lower back, and back of the head. Ask the person's doctor what to do if you find redness or sores. Reaching out to the doctor early can help prevent more serious damage to the skin. To help prevent skin or pressure sores, you can:

- Move the person at least every two hours if they are sitting up.
- Move the person at least every hour if they are lying down.
- Put foam, gel, air, or a water pad on top of the mattress. The pad should be comfortable and fit snugly around the person's body.

Foot Care

It's important for the person with Alzheimer's to take care of their feet. If the person can't, you will need to do it. Here's what to do:

- Soak the person's feet in warm water; wash the feet with a mild soap; and check for cuts, corns, and calluses.
- Put lotion on the feet so that the skin doesn't become dry and cracked.
- Cut or file their toenails.
- Talk to a foot care doctor, called a podiatrist, if the person has diabetes or sores on the feet.

End-of-Life Care

Planning for the end of a person's life and knowing what to expect can make this time easier for everyone. Often, hospice and palliative care programs can help coordinate care, get referrals, and provide additional resources.

Both palliative care and hospice care are intended to improve quality of life for the patient and their family. Palliative care is specialized medical care for people living with a serious illness, including Alzheimer's, that provides relief from the symptoms and stress of the illness. This type of care can be helpful at any stage of illness. Hospice care is designed to relieve symptoms, such as pain and discomfort, at the end of life. Palliative or hospice care teams may be able to help identify when someone with dementia is in the last days or weeks of life.

In the final stages of Alzheimer's, a person may not be able to tell you that they are in pain.

Instead, people with Alzheimer's may express pain with groans or sighs and may grimace when touched. They may become upset or aggressive and may sit in unusual positions to guard the part of their body that hurts. If you think the person with Alzheimer's is in pain, talk with the health care team about pain medication and other forms of pain management.

You may find it hard to provide emotional or spiritual comfort at this stage of the disease. However, even in advanced stages of dementia, a person may benefit from such connections. Try telling the person a story or showing them photos. Being touched or massaged can also be soothing. Listening to music, white noise, or sounds from nature seems to relax some people and lessen agitation. Just being present can be calming to the person.

Caring for people with Alzheimer's or another form of dementia at the end of life can be physically and emotionally demanding.

When a person with Alzheimer's dies, their caregivers can experience a range of emotions. These may include sadness, loss of purpose, guilt, and relief. It is important to realize such feelings are normal.

Hospice care experts can provide support to family caregivers near the end of life as well as help with their grief. For more information about these services, see pages 46–50 of the "Finding Help With At-Home Caregiving" section of this guide.

For more information on end-of-life care, visit **www.nia.nih.gov/end-of-life**.

Summary

Alzheimer's is challenging for both the person diagnosed with the disease and for those with caregiving responsibilities. It's impossible to anticipate every situation or challenge. When unexpected issues arise, remember that family and friends, health care providers, support groups, and community organizations may be able to help. You can also refer back to this guide for ideas and resources to help you along the way.

For More Information

Alzheimer's and related Dementias Education and Referral (ADEAR) Center

800-438-4380
adear@nia.nih.gov
www.nia.nih.gov/alzheimers

The NIA ADEAR Center offers information and free print publications about Alzheimer's and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resources.

Alzheimers.gov

www.alzheimers.gov

Visit Alzheimers.gov for information and resources on Alzheimer's and related dementias from across the federal government.

Eldercare Locator

800-677-1116
https://eldercare.acl.gov

The Eldercare Locator is a nationwide service from the U.S. Administration on Aging and U.S. Administration for Community Living that connects older Americans and their caregivers with trustworthy local support resources.

Alzheimer's Association

800-272-3900
info@alz.org
www.alz.org

The Alzheimer's Association offers information, a help line, and support services to people with Alzheimer's and their caregivers. Local chapters across the country offer support groups, including many that help with early-stage Alzheimer's. Call or go online to find out where to get help in your area. The Association also funds Alzheimer's research.

Alzheimer's Foundation of America

866-232-8484
info@alzfdn.org
www.alzfdn.org

The Alzheimer's Foundation of America provides information about how to care for people with Alzheimer's as well as a list of services for people with the disease. It also offers information for caregivers and their families through member organizations. Services include a toll-free hotline, publications, and other educational materials.

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