

Enhancing quality of life for those affected by Alzheimer's and their care partners



As a caregiver, you give much needed help and support.
We know that your work is difficult, and we hope that this book will help you provide the best care possible.

You may not need certain parts of this book now because the person you care for is not in that stage of the illness. But please keep this book in an easy-to-reach spot. As the person changes, read new sections.

You make a difference in the life of a person with dementia. We salute the understanding and compassionate care that you give.

For more information about the Oklahoma Healthy Brain Initiative, please turn to the back cover.

Adapted with permission from materials created by the Alzheimer's Association.



Contents

01	Wh	at is Dementia?	22	Making Daily Care Easier		
03	What is Alzheimer's Disease?			22	For All Activities of Daily Living	
03	Stages of Alzheimer's Disease			22	Dressing & Grooming	
	03 Early Stage			22	Bathing	
	04	Middle Stage		23	Medication Management	
	05	Late Stage		23	Eating	
	05	Late Stage		23	Toileting	
07		rice From a Family Member h Alzheimer's Disease		23	Bedtime & Sleeping	
08	For People Living With Dementia		25	Phy	Physical Care	
				25	Skin Care & Prevention of Pressure Sores	
09	Communication			26	Lifting or Moving a Person with Dementia	
	09 10	Listening Tips for Communicating		26	Moving From a Sitting Position to Another Sitting Position	
11	When the Person with Dementia			26	Rolling Over in Bed	
	is H	aving a Difficult Day		27	Helping a Person Sit Up	
12	Especially for Caregivers				on the Edge of the Bed	
13	Ideas for Everyday Routines		27	Der	mentia Risk Reduction	
				28	Healthy Habits for Brain Health	
15	Common Behaviors & What You Can Do to Help		29	Car	Care Notes	
	15	Repetitive Actions	31	Not	Notes to Take to a Doctor's Appointment	
	15	Suspicious Thoughts	31			
	15	Aggressive Behaviors				
	15	Hallucinations & Delusions	33	Resources		
	16 Sundowning16 Wandering & Pacing					
	16	16 Driving Retirement				
	18 Recognition Difficulties					
	18 Social Inappropriateness					

What is Dementia?

Years ago, older people who were confused were thought of as senile, or had hardening of the arteries. These days, we use the word dementia. Dementia is a general term for the loss of memory and other intellectual abilities serious enough to interfere with daily life. Persons with dementia may also have a more specific diagnosis like Alzheimer's disease.

Dementia is not a normal part of the aging process. It can be hard to know the difference between age-related changes and dementia. Below are ten warning signs for Alzheimer's disease or related dementias:

- · Memory loss that disrupts daily life
- · Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, at work or at leisure
- · Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- · Decreased or poor judgment
- Withdrawal from work or social activities
- · Changes in mood and personality

If these symptoms occur frequently and interfere with the person's daily life, then dementia is likely. At this point, it is very important for the person to see a doctor who knows about gerontology, aging, and dementia. The doctor will do some tests to see why the person has these symptoms. The tests include blood and urine tests, questions and answers, and a complete physical.

Just because a person has dementia-like symptoms does not always mean they have Alzheimer's disease. Many things can cause these symptoms and physicians look at these causes first:

- Medication side effects
- · Infection, such as urinary tract
- Depression
- Untreated diabetes or thyroid problems
- Poor diet
- · Excess alcohol use
- · Thyroid problems
- · Vitamin deficiencies

These conditions can be treated and often cured. But most of the time dementia comes from a disease or condition that cannot be cured, such as Alzheimer's disease.

Alzheimer's disease is the most common type of dementia. Nearly seven million Americans have Alzheimer's disease. About 11% of people over the age of 65 have Alzheimer's disease, and nearly 32% of those 85 or older.

There is currently no cure for Alzheimer's disease. There are many tests and evaluations doctors may perform to diagnose Alzheimer's, and new methods are being developed all the time. Some medications are available to treat Alzheimer's and it's symptoms. Talk with your doctor about risks and benefits of all medications.

Other Types of Dementia

Alzheimer's disease is one type of dementia. When a doctor states that a person has dementia, your next question should be, "What kind of dementia?" Some other types of dementia are:

- Dementia with Lewy Bodies
- Vascular dementia
- · Frontotemporal dementia
- · Parkinson's disease
- · Huntington's disease
- Creutzfeldt-Jakob disease (CJD)
- · Normal pressure hydrocephalus
- · Physical injury to the brain
- Mixed Dementia (more than one type of dementia at once, i.e. Alzheimer's and Vascular dementia)

<u>Click here</u> to learn more about the different types of dementia.



What is Alzheimer's Disease?

Alzheimer's is a progressive, degenerative brain disease. Alzheimer's disease causes brain cells to die, which results in tissue loss and eventual shrinkage of the brain. These changes to the brain cause dementia symptoms such as memory loss, trouble thinking, and behavior changes.

False beliefs about Alzheimer's disease:

- Alzheimer's disease is a normal part of aging.
- · Aluminum pans or foil cause it.
- · Alzheimer's disease is not fatal.
- · A person can catch it like a cold.

Truth about Alzheimer's disease:

- Alzheimer's disease kills brain cells.
- · It is the most common kind of dementia.
- It cannot be prevented.
- · Once a person has it, it does not go away.
- It makes a person unable to think, remember, solve problems, and make decisions.
- It makes a person forget and lose judgment about safety.
- It makes thinking harder and everyday tasks more difficult.
- In the end, it takes away the ability to talk or do simple tasks like bathing or brushing teeth.

A higher quality of life can be had if the person receives help and support from the community, family members, and caregivers.

Stages of Alzheimer's Disease

Most of the time, a person with Alzheimer's disease is described as going through three stages: early, middle, and late. It is important to keep in mind that stages are general guides, and symptoms vary greatly. The disease affects each person differently. Each person travels through the stages at their own pace.



Healthy Brain



Mild Alzheimer's



Severe Alzheimer's

Early Stage

- Problems remembering the most recent events.
- · Forgets what he or she was just told.
- · Loses interest even for important things.
- · Has trouble concentrating.
- Takes longer with routines like getting dressed.
- Has trouble doing familiar tasks/chores such as paying bills, following a recipe, driving, or going on a walk.
- Has trouble finding the right word to use:
 "The writing thing" instead of "the pencil."
- May become frustrated or rude.
- Does not begin an activity alone lacks motivation to get going.
- · Seems bored or tired.
- May follow you around.
- Personality changes less energy, impatient, more angry, or withdrawn.
- May lose sense of humor or seriousness.
- Cannot learn new things.
- Shows no interest.
- Upset by change.

How You Can Respond

- Try to understand the person's anger and confusion.
- · Offer support in times of frustration.
- Organize and simplify daily routines.
 Do things one step at a time.
- Encourage the person to be as independent as possible.
- · Provide rest and live "in the moment."
- Reach out for support early and often.
 No one can do this alone.



Note: Depression is not uncommon and should be diagnosed and treated.

Middle Stage

- More forgetful.
- Cannot remember visits or activities right after they occur.
- Forgets own name and names of spouse, children, and others.
- · Has trouble thinking clearly.
- · Cannot understand, concentrate, or plan.
- Has trouble reading, writing, or doing simple math.
- · Confused about time and place.
- Cannot remember where he or she is.
- · Cannot locate a room, such as a bathroom.
- · May wander outside and get lost.
- Shows poor judgment.
- · Wears the wrong clothing for the season.
- · Forgets to turn the stove off.
- · Has a problem with language.
- · Cannot find the right word.
- · Cannot remember objects' names.
- · May not recognize family or friends.
- Needs help with everyday tasks like bathing or dressing.
- · Wets and soils clothing.
- May need someone to watch or help all the time.
- · Shows behavioral changes.

- May forget the proper place to dress or undress.
- May say inappropriate things or show sexually unsuitable behavior.
- Restless, especially in late afternoon and at night.
- May have problems judging distances and heights.
- Has a hard time getting into a chair, climbing stairs, or getting in and out of a car.
- May imagine hearing or seeing things that really are not there (hallucinations).
- May have thoughts or ideas that are not true.
- May think someone is stealing from him or her.
- May think children or work needs him or her.
- May be suspicious, irritable, teary, or silly.
 Mood swings are common.

How You Can Respond

- Use simple memory aids.
- Put a picture of the toilet on the bathroom door.
- Put names of family members under their pictures.
- Label outside of drawers and cabinets with list of contents.

- · Give one-step directions.
- Follow a routine. Do the same things the same way.
- · Encourage strengths and enjoyment.
- If the person can still draw or paint for fun, do that.
- Remind and repeat gently, without sounding angry.
- Accept that the person will not talk or respond at times.
- Limit noise and activity that can be distracting and confusing.
- Attempting a lengthy play might be too much noise and too many people, so try a short concert instead.
- · Speak in a gentle, low, slow voice.

- Do not argue or correct.
- Do not attempt to reason.
- · Come back later and try again.
- · Use distraction and pleasant events.
- Use kind, gently touching for reassurance, like kisses on the cheek, hugs, or holding hands.
- · Maintain a safe, predictable environment.

Strengths That Remain

- · Ability to hold and touch objects.
- Enjoyment of music, poetry, and prayer.
- Relates to routines and reassurance of relationships — may be episodic.

Late Stage

- · Cannot use words: is unable to talk.
- · Needs care all the time.
- Unable to feed self (may have a choking response).
- · Unable to walk.
- Incontinent.
- Needs help with bathing, dressing, eating, and going to the bathroom.
- May put things into mouth or touch everything.
- · Cannot recognize family or self in a mirror.
- May groan, scream, or make grunting sounds.

How You Can Respond

- · Repeat often. Give lots of time to respond.
- · Use props when explaining a task.
- Show him or her the cup when you ask if he or she is thirsty.
- Keep talking even though you may not get a verbal response.

- Touch the person in a kind way. Use touch with words to communicate.
- Tell the person he or she is doing a task well.
- · Use pleasant sights, smells, and sounds.
- · Offer plenty of liquids.
- Read to the person or play low, pleasant music to create a soothing atmosphere.
- · Consider hospice care.



Remember: The person with Alzheimer's disease does not act this way on purpose; the disease causes the person to lose control.



Advice From a Family Member with Alzheimer's Disease

This advice comes from Jeanne Coop, who has early stage Alzheimer's disease. Jeanne lives with her husband, next door to her daughter and her family. Jeanne is a member of the Early Stage Alzheimer Support Group of Marlborough, New Hampshire.

"Do not hurry me. Hurrying me tends to make me forget, and then I tend to get confused.

"If I forget something, remind me gently. If I seem to forget that company is coming or that we are due to be somewhere, help me realize that it is OK if we are a little late or that everything needed is not ready.

"Do not keep asking me questions. This frustrates me and makes me feel I am being tested.

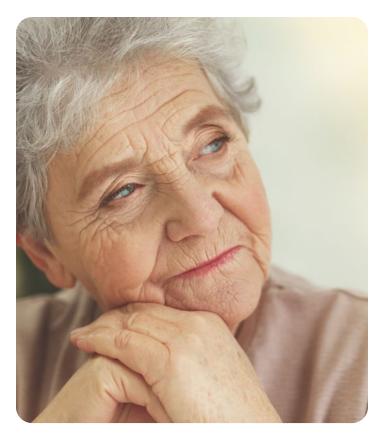
"When I forget, either laugh with me or hug me, but please do not try to make excuses for me.

"When you do that, it makes me very angry and I feel that you do not understand what I am feeling inside.

"When I say, "I do not know how to turn the oven on," just come up and help me. No words are needed and chances are, tomorrow I will be able to do it on my own.

"When I tell you something "dumb" that I did, please listen and try to understand what I am really trying to tell you is that I am scared and hurting. I need to be loved and given time to talk about what is happening to me.

"When I am silent and unable to sleep, chances are that I am struggling with my own fears about how this is going to hurt you as time goes on. I am asking myself what is going to happen to me and how we as a family are going to cope and survive.



"Try to understand that some days I almost convince myself that there is nothing wrong with me... and then there are days when I have no doubt that my head is not working normally.

"These latter days are the ones when you are most apt to find me down in spirit. Try to understand I am really finding it difficult to believe that this is really happening to me. The big questions, "Why?" and "How long" keep going around in my head."

And a note to medical staff . . .

"I need medical personnel who are willing to take the extra time to talk with me, allowing me to share my fears, frustrations, and my many emotional ups and downs. I do not need medical staff that treats me like I am a textbook case... and on occasion need a hug and someone who encourages me in my struggle to keep going."

This piece first appeared in the support group newsletter, "The Gift of Hope." Reprinted with permission from Jeanne Coop and Irene Keating of Marlborough, New Hampshire Support Group.

For People Living with Dementia

If you have been diagnosed with Alzheimer's or another dementia, you are not alone. There are people who understand what you are going through, and help is available. In this section, we'll highlight local and nationwide resources you can access.

Alzheimer's Association | I Have Alzheimer's Webpage

 This webpage offers comprehensive advice from experts and people living with dementia about many aspects of life with the disease. Topics include disease progression, changes in social dynamics, planning for the future, treatments and research, overcoming stigma, and tips for living well with dementia.

Alzheimer's Association: Oklahoma Chapter

- Offers programs and services for families dealing with dementia in our state, including education programs, support groups, social engagement programs, and other helpful resources.
- You can find more information about these programs by visiting the <u>Alzheimer's</u> <u>Association Community Resource Finder</u> and clicking on "Alzheimer's Association Programs and Events." You can also call the 24/7 Helpline at 800.272.3900 for assistance or ask to be connected to the local Chapter.

National Council of Dementia Minds

- National Council of Dementia Minds (NCDM) is the first national 501(c)(3) nonprofit organization founded and governed by persons living with dementia.
- NCDM stands out by challenging stigma and offering hope-filled strategies and resources to support living well with dementia. In addition to peer support, they provide education led by persons living with dementia and create resources that empower individuals by demonstrating that life with dementia can be lived with meaning, purpose and connection.

Memory Cafés

- A memory café is a social gathering for individuals living with dementia and their care partners. Guests are welcome whose dementia is due to any underlying condition, and at any stage of disease progression. Care partners can include spouses, children, friends and professional caregivers.
- Cafés meet in accessible community locations. They strive for an atmosphere that's more like a coffee house or a neighborhood party than a clinical program. While information about resources and services is available for those who seek it, cafés provide a break from focusing on disease and disability.

Clinical Trials

- Many people with dementia are interested in joining clinical trials. Clinical trials are a way for people living with dementia to help researchers advance our understanding of dementia and eventually develop effective treatments. There may be additional benefits for those who choose to participate in clinical trials, such as financial compensation, access to close medical care, and access to experimental treatments. Of course, there are also risks associated with participation in clinical trials. Be sure to talk with your doctor before about the risks and benefits before participating in a trial.
- Learn more about clinical trials and find studies you can participate in at Alzheimers.gov.
- The Alzheimer's Association also offers a clinical trial matching service called TrialMatch.
- The National Institute of Health also maintains a <u>database of clinical trials</u> which you can filter by condition, treatment type, and location.

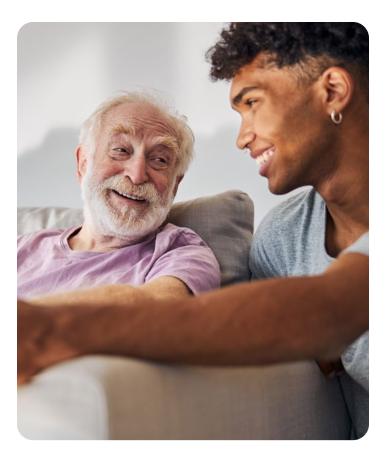
Communication

Communicating with a person who has dementia can be hard. Many times, the person cannot find the words to say what he or she wants or may have trouble understanding what you are saying.

A person with dementia wants to communicate. Often, he or she will use actions rather than words, letting the face or body tell you something. This is because the person does not know the right words anymore.

To help a person with dementia, you need to be a good listener. Watch eyes and body language, then respond.

You can help the person with dementia in many other ways. Touch and smile at the person. Go slow. Use props to help him or her understand what you are saying. Give the person a hug.



Listening

- Limit noise. Find a quiet place, so you won't be interrupted and the person with dementia can focus on his or her thoughts.
- Let the person know you are listening and trying to understand what he or she is saying.
- When you greet someone with dementia, shake hands to get eye contact. Bend down and get on eye level with the person.
- If someone is having problems expressing thoughts, let him or her know it's OK.
 Encourage the person to keep trying.
- Let the person think about and describe what he or she wants. Do not interrupt. Be patient and understanding.
- Do not say what he or she is saying is wrong.
 Listen and try to understand.
- If you do not agree with what is being said, let it go. You cannot win an argument with a person who has dementia because he or she cannot understand reasons or explanations.

- If the person cannot find a word or uses a word that confuses you, try helping. If you understand what he or she means, do not correct wrong words.
- Think about feelings, not words. Feelings can be more important than words. Tone of voice and actions may help you understand how the person is really feeling and what he or she may need from you.
- If you do not understand what is being said, ask the person to point or make a sign.

09

Tips for Communicating

- Approach from the front and tell the person who you are, even if you are a family member.
- · Address the person by name.
- Smile and use other friendly facial expressions.
- Try not to surprise the person. Avoid sudden movements, and do not walk up behind him or her.
- · Look into his or her eyes when you speak.
- · Speak slowly and in a low, gentle tone.
- Use simple words and sentences. Offer kind, factual statements such as, "You look well today," instead of "How are you feeling?"
- Ask one question at a time. Ask questions that he or she can answer with "yes" or "no." Limit the number of questions, which might make the person feel bombarded or defensive.
- Wait for an answer. If he or she doesn't answer, wait and ask again. Use the same words as before.
- If there is still no answer, ask in a different way.
- Remain calm and reassure if he or she gets upset. Do not become impatient.
- Give one-step directions. Break tasks and instructions into simple steps. Wait for the first step to be complete before you give the next instruction.
- Show your request by pointing, touching, or beginning the task. Use lots of props.
- Avoid directions like, "Hop in the car."
 The person may try to hop! Also, avoid slang because it is hard for the person to understand.
- Sometimes, it may be better to say what to do instead of giving a choice. For example, instead of asking, "Do you need to use the restroom?" you might say, "Let's go to the restroom."
- Limit choices. Ask, "Do you want to wear the plaid shirt or the blue shirt?" Point to the choices.

- Be specific. Instead of saying, "Here it is," try "Here is your hat."
- Smile, nod, pat, point, touch, hug, hold hands, and use other signals to aid understanding.
- Include the person in conversations. Do not talk down or talk as if he or she isn't there.
- Be careful with jokes. He or she may not understand you. If the person does understand humor, enjoy the joke and a good laugh.
- Be aware of your feelings and attitudes. The person can sense your feelings. You show your feelings in your tone of voice, how you stand, and your facial expressions.
- · Avoid noise, distractions, and interruptions.
- Be aware of your own stress. An Alzheimer's Association support group is a great place to express yourself and gain knowledge.



10 — COMMUNICATION

When the Person with Dementia is Having a Difficult Day

Tips for Difficult Times

- · Stay calm.
- · Be patient and flexible.
- · Look for reasons for each difficult behavior.
- Respond to the emotion, such as fear or loneliness, instead of the action.
- Confusion causes fear, which may make the person with dementia want to fight or run away.
- · Do not argue or try to convince.
- Let the person know you have heard and understand his or her requests.
- · Accept the actions as part of the dementia.
- · Try different solutions.
- Use distraction.
- Have lots of items you can use to distract the person: look at magazines or family pictures, watch TV, go for a walk, have a snack.
- Remember that when the person is acting difficult, he or she would act this way with any caregiver, not just you.
- Talk to others about your situation.
- · Find time for yourself.
- Call the Alzheimer's Association 24/7 Helpline at 800.272.3900.





Remember: Caregivers caring for the same person should talk with one another about the way the person with dementia is acting. Share this book with all caregivers, too. In this way, you make sure you each are handling situations in the same way (one that works). Consistency and routine are important. If difficult behaviors become more difficult, talk about them with his or her doctor or call the Alzheimer's Association Helpline at 800.272.3900.

Especially for Caregivers

You, the caregiver, have many challenges. It's important to take care of yourself so that you can take care of the person with dementia.

- · Take regular times for fun and exercise.
- Use deep, slow breaths to calm yourself and to help you focus.
- Give yourself credit for each little step, even if it's not successful.

When you are with the person with dementia:

- · Use a calm, kind tone of voice.
- Use kind touching like hugs or holding his or her hand.
- Allow lots of time. People with dementia sense your impatience and may be upset by it, and that makes things worse.

Understanding Behaviors & Responding

Alzheimer's disease and other dementias can cause a person to act differently. He or she can become anxious or aggressive and might repeat certain questions or gestures. These changes can cause frustration and tension.

Please remember that the person is not acting this way on purpose! It's the disease.

Causes for Changes in Behavior:

- Illness, infection, medication, or physical problems.
- Loud noises or too much activity.
- Not recognizing new places or changes in the home.
- · Activities or chores that are too complicated.
- Frustration with not being able to communicate.
- Change in the routine of the day or new activities.

Ask Yourself

When there is difficult behavior, ask yourself these questions. The answers may give you ideas that might prevent the problem next time.

- · What happened?
- Where did it happen?
- · When?
- · Why?
- · How?
- Who was around?

Think of Different Ways to Solve the Problem

- · Are the person's needs being met?
- Can changing surroundings stop the difficult behavior?
- How can you change how you react? For example, are you reacting calmly and gently, with a warm tone of voice?
- If the behavior change is sudden, it may be a medical problem. Check with the doctor.

Try to Do Something Different Next Time

- · Did your new response help?
- · What can you do differently?
- Keep a journal or diary.
- Ask for ideas at your support group or call the 24/7 Helpline at 800.272.3900.

Ideas for Everyday Routines

Routines are good for people with dementia. Let the person help with simple tasks like setting the table and folding laundry.

Continue the bathing routine the person is used to. If the person normally showers in the morning, do not switch it to the evening. If the person bathes every two days, do not force him or her to bathe every day.

Morning Activities

- · Wash face and hands.
- · Brush teeth.
- · Get dressed.
- · Prepare and eat breakfast.
- Coffee and talking.
- Talk about the newspaper, read out loud, make a craft, or look at old photos.
- · Get some exercise.
- · Take a walk or play a game.

Afternoon Activities

- Make and eat lunch, read mail, clear the table and wash dishes.
- Have a friend over for a brief coffee or tea break (caffeine free if necessary).
- Listen to music, fold laundry together, water plants, or watch television.
- Do some gardening, take a walk, or visit a neighbor.
- · Take a short break or a nap.

Evening Activities

- · Make and eat dinner. Clean up the kitchen.
- · Talk over warm milk and dessert.
- Look at favorite magazines, listen to music, watch a movie, or give a gentle massage.
- Get ready for bed and quietly read to him or her.

Make an Activity Bag

Caregivers can organize an activity bag or box that you can use when the person is restless or bored. Prepare the bag ahead of time so it is ready when you need it. Use a cloth bag, a drawer, a plastic bucket, a box, or a laundry basket filled with things like these:

- Old holiday or birthday cards, postcards, photographs, and photo albums.
- · Picture books, favorite magazines, catalogs.
- Building blocks, balls, pieces of fabric, socks or towels for folding.
- Safe kitchen tools like a wooden spoon or plastic spatula.
- Nerf balls, tennis or rubber baseballs and catcher's mitt.
- Tool box with plastic or rubber tools (Fisher Price).





Common Behaviors & What You Can Do to Help

Repetitive Actions

The person with dementia may do or say things over and over again. He or she may pace and undo what you just did, like unmaking the bed. These actions are often harmless, but can be stressful for you.

How You Can Respond

- · Avoid scolding. This is part of the disease.
- Turn the action into a useful task. If he or she is rubbing hands across the table, provide a dish cloth.
- Give the person the answer being sought, even if you have to repeat it several times.
- Reassure by saying, "It's OK. I love you. I'll take care of it."
- Give the person something to do as a distraction. Use memory aids. If the same questions are repeated, remind with notes, clocks, calendars, or pictures.
- · Ignore the behavior and let it go.
- Talk to a doctor. Some medicines may cause repetitive actions.

Suspicious Thoughts

People with dementia may be paranoid or suspicious. He or she may lose a wallet, then accuse you of stealing it. The person may not understand what you are saying or doing and be upset by it.

How You Can Respond

- Listen to what is bothering the person and try to understand.
- · Do not argue. Go with the flow.
- · Offer a simple answer.
- · Switch attention to another activity.
- Replace lost items. If he or she is looking for something specific, have several around. For example, have two empty wallets, or wallets with play money or only a few dollars.

Aggressive Behaviors

Aggressive behaviors may include shouting, name-calling, hitting, or pushing. It is important to try to figure out what is causing a person with dementia to become angry or upset. For example, it could be a sudden noise or the need to go to the bathroom.

How You Can Respond

- Try to remember how frustrating dementia can be.
- Do not get angry and upset yourself. Be calm and kind.
- Stick to the routine for meals and bathroom trips.
- · Offer an activity or item as a distraction.
- Try to figure out what started the upset and work to change the situation.
- Try a relaxing activity such as music or massage.
- Walk away if it is safe to do so. Come back later.
- Develop an emergency plan for violent episodes.

Hallucinations & Delusions

Hallucinations occur when a person hears or sees things that are not there. Delusions are false ideas such as the person believing he or she is still at work.

How You Can Respond

- Hallucinations and delusions are very real to the person with dementia. Avoid arguing or correcting.
- Go with the flow. Talk about what it is that the person sees or hears.
- · Provide a distraction.
- Make sure glasses and hearing aids work correctly.
- · Reduce clutter and shadows.
- Talk to the doctor if you or the person with dementia is extremely upset by these episodes.

Sundowning

A person with dementia may get more anxious later in the day, as the stress of the day builds up and the shadows get long.

How You Can Respond

- Make sure the person gets a good balance of exercise and rest during the day.
- Plan a quiet activity and calming interactions for this time of day (i.e. listening to quiet music, massaging hands with lotion, aromatherapy, etc.).
- Reduce stimulation as much as possible.
 Turn down the TV and minimize social stimulation.
- Rearrange the person's daily schedule so that fewer major activities take place later in the day (i.e. have bath, main family meal, and appointments during earlier part of the day).

Wandering & Pacing

A person with dementia may pace, wander, or be restless. Looking for something or someone familiar, boredom, or feeling uneasy may cause this behavior.

How You Can Respond

- Make the area safe by removing clutter, area rugs, and other obstacles such as footstools.
- Give him or her something to do help you with cleaning, vacuuming, or sweeping.
- Put away items that may make the person want to leave the house, such as car keys or coats.
- Lock doors and windows. Put a gate across stairs.
- Put a bell on doors to warn you that he or she is leaving.
- Place locks at the top of doors where he or she probably won't notice them.
- Disguise the door/doorknob.
- Consider signing up for MedicAlert, or using another GPS tracking system.

Driving Retirement

Having the Conversation

Plan to discuss how retirement from driving will be handled before it becomes an issue. Be sympathetic as you address the topic because retirement from driving and the perceived loss of independence is difficult for many. It is important to acknowledge a person's feelings and preserve his or her independence, while ensuring the person's safety and the safety of others.

Starting the Conversation

- Initiate a dialogue to express your concerns.
 Stress the positive and offer alternatives.
- Address resistance while reaffirming your unconditional love and support.
- Appeal to the person's sense of responsibility.
- Ask your physician to advise the person not to drive. Involving your physician in a family conference on driving may be more effective than trying to persuade the person not to drive by yourself. Ask the physician to write a letter or prescription stating that the person with Alzheimer's must not drive. You can then use the document to remind your family member what's been decided.
- Consider an evaluation by an objective third party.
- Understand that this may be the first of many conversations about driving.

When the Conversation Does Not Go Well

Some people give up driving easily, but for others this transition can be very difficult. Be prepared for the person to become angry with you, due to the memory and insight issues that are part of Alzheimer's.

- Be patient and firm. Demonstrate understanding and empathy.
- Acknowledge the pain of this change and appeal to the person's desire to act responsibly.
- Ask a respected family authority figure or your attorney to reinforce the message about not driving.

- If the conversation does not go well, do not blame yourself. The disease can impair insight and judgment, making it difficult for people to understand that their driving is no longer safe. The disease can cause mood and personality changes that make reactions more pronounced.
- As a last resort, take away the car keys, disable the car, or consider selling the car. When you do any of these things, be sure to provide safe, reliable alternative transportation.
- If the person refuses to give up driving and you are forced to take away the car, consider using a "therapeutic fib" to give a reason the car needs to go away while preserving the person's dignity. An example of this would be saying something like, "Your grandson who is away at college got into an accident and totaled his car, now he won't be able to get to class. Why don't we give him your old car?"

Planning Ahead

For people in the early stages of Alzheimer's, it is never too soon to plan ahead for how you get around when you can no longer drive. Putting a plan in place can be an empowering way to make your voice heard.

Tips for Planning Ahead

- Remember that each situation is unique. What works for one person may be different from what works for another. You can get the information and support you need from the Alzheimer's Association 24/7 Helpline at 800.272.3900.
- · Involve family and close friends in the plan.
- Confront resistance. Empathize with those who are uncomfortable having the conversation and stress the importance of preparing for the future.
- When the person is still in the early stage
 of Alzheimer's, ask them to sign a <u>driving</u>
 <u>contract</u> that gives you his or her permission
 to help them stop driving when the time
 comes.

Transportation Options

Driving is not the only transportation option available. There are many options people can explore that will allow them to continue to travel independently and remain in control of their mobility.

- Transition driving responsibilities to others.
 Arrange for family members and friends to provide transportation.
- · Arrange a taxi service.
- Use special transportation services for older adults. <u>The Oklahoma Mobility</u>
 <u>Management Program</u>'s primary goal is to increase mobility management services to rural residents in Oklahoma counties.
 Access other local resources using our free <u>Community Resource Finder</u> or <u>Eldercare Locator</u> to search for transportation services.
- Reduce the need to drive by having prescription medicines, groceries or meals delivered.

Learn more: National Transportation Resources.

Signs of Unsafe Driving

Determining when someone can no longer safely drive requires careful observation by family and caregivers. The following list provides warning signs that it's time to stop driving:

- Forgetting how to locate familiar places
- · Failing to observe traffic signs
- · Making slow or poor decisions in traffic
- Driving at an inappropriate speed
- · Becoming angry or confused while driving
- Hitting curbs
- · Using poor lane control
- · Making errors at intersections
- · Confusing the brake and gas pedals
- Returning from a routine drive later than usual
- Forgetting the destination you are driving to during the trip.

Reference: <u>Alzheimer's Association, Dementia</u> and Driving

Recognition Difficulties

At times, a person with dementia may not recognize familiar people, places, or things. He or she may forget relationships, call family members by other names, or become confused about where he or she lives. The person may also forget the purpose of common objects such as a pen or fork. These times are very hard for caregivers. Try to have patience and understanding.

How You Can Respond

- Stay calm.
- · Tell the person who are. Avoid quizzing.
- Show photos of people and places important in his or her life.
- Give corrections as a suggestion without scolding.
- Remember, the person is not doing this on purpose. The disease causes him or her to forget.
- Name things as you give them to the person.
- Make a memory book. Put one photo of each important person on each page, with the person's name and relationship in big letters.

Social Inappropriateness

Socially inappropriate behaviors may happen because the person with dementia forgets what privacy or modesty means. He or she may not remember manners or how to act and talk in public. It might also be the case that the person can no longer control impulses.

How You Can Respond

- · Ignore the behavior if you can.
- If you know that certain places or people make him or her act incorrectly, avoid them.
- Distract the person. Keep a list of activities that are enjoyed, such as walking, music, or a special treat. Use these if you feel a problem coming on.
- Guide to a more appropriate behavior.
 Do not scold.



- Remember, the person is not doing this on purpose.
- · The disease causes this behavior.
- Be prepared. Think ahead of time what you will do if he or she makes inappropriate comments or removes clothing in public.
- Carry a card (included on the following two pages) stating that your companion has dementia or a memory illness. When inappropriate behavior occurs, you can show the card to bystanders if it isn't convenient to explain.

Please Be Patient

This person with me has

Alzheimer's disease and may require a few
extra moments.

Thank you for understanding.

ALZHEIMER'S () ASSOCIATION

Please Be Patient

This person with me has

Alzheimer's disease and may require a few
extra moments.

Thank you for understanding.

ALZHEIMER'S (ASSOCIATION

Please Be Patient

This person with me has
Alzheimer's disease and may require a few
extra moments.

Thank you for understanding.

ALZHEIMER'S () ASSOCIATION

Please Be Patient

This person with me has

Alzheimer's disease and may require a few
extra moments.

Thank you for understanding.

ALZHEIMER'S () ASSOCIATION

Please Be Patient

This person with me has Alzheimer's disease and may require a few extra moments.

Thank you for understanding.

ALZHEIMER'S () ASSOCIATION

Please Be Patient

This person with me has
Alzheimer's disease and may require a few
extra moments.

Thank you for understanding.

ALZHEIMER'S \\\ ASSOCIATION'

Please Be Patient

This person with me has
Alzheimer's disease and may require a few
extra moments.

Thank you for understanding.

ALZHEIMER'S (ASSOCIATION

Please Be Patient

This person with me has
Alzheimer's disease and may require a few
extra moments.

Thank you for understanding.

ALZHEIMER'S () ASSOCIATION

Please Be Patient

This person with me has
Alzheimer's disease and may require a few
extra moments.

Thank you for understanding.

ALZHEIMER'S (ASSOCIATION

Please Be Patient

This person with me has
Alzheimer's disease and may require a few
extra moments.

Thank you for understanding.

ALZHEIMER'S OS ASSOCIATION

Nearly 7 million Americans are living with Alzheimer's. 1 in 3 seniors dies with Alzheimer's or another dementia.

- 24/7 Helpline
- Educational Presentations
- Support Groups
- Multicultural Outreach
- Early-Stage Support
- Multicultural Outreach

We are here to help. Visit us at alz.org or call 800.272.3900.

ALZHEIMER'S \\ \ ASSOCIATION'

Nearly 7 million Americans are living with Alzheimer's. 1 in 3 seniors dies with Alzheimer's or another dementia.

- 24/7 Helpline
- Educational Presentations
- Support Groups
- Multicultural Outreach
- Early-Stage Support

We are here to help. Visit us at alz.org or call 800.272.3900.

ALZHEIMER'S Q'S ASSOCIATION'

Nearly 7 million Americans are living with Alzheimer's. 1 in 3 seniors dies with Alzheimer's or another dementia

- 24/7 Helpline
- Educational Presentations
- Support Groups
- Multicultural Outreach
- Early-Stage Support

We are here to help. Visit us at alz.org or call 800.272.3900.

ALZHEIMER'S (ASSOCIATION'

Nearly 7 million Americans are living with Alzheimer's. 1 in 3 seniors dies with Alzheimer's or another dementia.

- 24/7 Helpline
- Educational Presentations
- Support Groups
- Multicultural Outreach
- Early-Stage Support

We are here to help. Visit us at alz.org or call 800.272.3900.

ALZHEIMER'S (ASSOCIATION'

Nearly 7 million Americans are living with Alzheimer's. 1 in 3 seniors dies with Alzheimer's or another dementia.

- 24/7 Helpline
- Educational Presentations
- Support Groups
- Multicultural Outreach
- Early-Stage Support

We are here to help. Visit us at alz.org or call 800.272.3900.

ALZHEIMER'S (ASSOCIATION'

Nearly 7 million Americans are living with Alzheimer's. 1 in 3 seniors dies with Alzheimer's or another dementia.

- 24/7 Helpline
- Educational Presentations
- Support Groups
- Multicultural Outreach
- Early-Stage Support

We are here to help. Visit us at alz.org or call 800.272.3900.

ALZHEIMER'S () ASSOCIATION

Nearly 7 million Americans are living with Alzheimer's. 1 in 3 seniors dies with Alzheimer's or another dementia.

- 24/7 Helpline
- Educational Presentations
- Support Groups
- Multicultural Outreach
- Early-Stage Support

We are here to help. Visit us at alz.org or call 800.272.3900.

ALZHEIMER'S OS ASSOCIATION'

Nearly 7 million Americans are living with Alzheimer's. 1 in 3 seniors dies with Alzheimer's or another dementia.

- 24/7 Helpline
- Educational Presentations
- Support Groups
- Multicultural Outreach
- Early-Stage Support

We are here to help. Visit us at alz.org or call 800.272.3900.

ALZHEIMER'S () ASSOCIATION

Nearly 7 million Americans are living with Alzheimer's. 1 in 3 seniors dies with Alzheimer's or another dementia.

- 24/7 Helpline
- Educational Presentations
- Support Groups
- Multicultural Outreach
- Early-Stage Support
 - ALCOHOL SERVICE CONTRACTOR CONTRA

We are here to help. Visit us at alz.org or call 800.272.3900.

ALZHEIMER'S () ASSOCIATION

Nearly 7 million Americans are living with Alzheimer's. 1 in 3 seniors dies with Alzheimer's or another dementia.

- 24/7 Helpline
- Educational Presentations
- Support Groups
- Multicultural Outreach
- Early-Stage Support

We are here to help. Visit us at alz.org or call 800.272.3900.

ALZHEIMER'S () ASSOCIATION



Making Daily Care Easier

As the dementia continues, the person will not be able to take care of him- or herself. Eventually, the person will need help with all activities of daily living such as bathing, dressing, and brushing teeth.

As a caregiver for a person with dementia, your job may be to help with grooming, dressing, dining, bathing, or toileting. You need to know the tasks the person can still do and encourage him or her to do as much as possible. Use these guidelines to help you know how much the person can do. The person you care for may take longer to do the task. That's OK. This encourages independence and makes him or her feel good.

As time goes by, he or she will depend more on other people for their total care. As you read these ideas for daily living, remember that you may use some of them now and others as the disease progresses. Always treat the person with dignity and respect.

For All Activities of Daily Living

- Tell him or her what you are going to be doing.
- Break the task into small steps.
- Show the person and explain what you want him or her to do.
- Offer few choices. Do not force the person to make a decision.
- · Be positive. "I will help you take a bath."
- · Allow him or her to do as much as possible.
- Plan much more time for the person to do the task. Take your time. Do not rush him or her. It may upset both of you.
- · Get rid of noises and distractions.
- Protect the person's privacy.
- Keep things simple. Repeat steps one at a time if needed.
- Do not try to do too many activities in one day.

Dressing & Grooming

- Set a time for grooming when the person is most relaxed. Help him or her brush teeth and clean dentures every day. Do the activity alongside, and he or she may copy you.
- Choose clothing that is easy to get on and off and is comfortable. Sweat suits are good.
- For the person who keeps taking off clothes, choose clothes that fasten in the back.
- Keep accessories simple.
- Lay out clothes in the order they will be put on.
- Give the person one piece of clothing at a time.

Bathing

- · Check the bathroom for safety:
 - » Be very careful about throw rugs. Remove them or be sure they have a non-skid surface.
 - » Make sure the floor is dry.
 - » Keep hair dryers and electric razors out of reach.
 - » Avoid using bath oil because it can make the tub or shower slippery.
- Bath time can be frightening for a person with dementia. For many, it is the most common time for troublesome behavior.
- Follow old routines. Consider the time of day and type of bathing, such as shower or bath.
- Don't tell the person about the bath hours before it is time. Wait until the bath or shower is ready.
- Don't force him or her to bathe. Wait and try later if you are refused.
- The person may not want to get into the tub but may be willing to have a sponge bath on a chair.
- Have everything ready before you bring him or her into the bathroom. Make sure the bathing area is warm and smells nice.
- Check the temperature of the water not too hot or too cold.
- · Use only a few inches of water in the tub.

- A bath is generally safer and not as frightening. If a shower is necessary, use a hand-held.
- Many adults are embarrassed to have someone help them with bathing.
- · Close doors and curtains for privacy.
- Wrap a warm, fluffy towel around his or her shoulders while bathing.

Medication Management

- Lock up all medications and cleaning supplies. People with dementia can mistake them for food or drinks.
- · Use a pill box to organize medications.

Eating

- Set a routine for when and where meals are served.
- Remove distractions fancy tablecloth, place mats, table decorations.
- Serve one item at a time, using only basic utensils such as a fork and the plate.
- Use the bathroom before sitting down at the table.
- Use dark cups for milk and light cups for coffee so the person can see the liquid.
- Finger foods such as cheese, fruit or sandwiches are easy to manage.
- If there is difficulty swallowing, grind the food or use soft foods such as applesauce or cottage cheese.
- Make food that smells good to stimulate the appetite. Pop microwave popcorn.
- · Give clear and simple one-step directions.
- Remind him or her to chew.
- If a person will not open his or her mouth, alternate bits of warm and cold items.
- The taste of "sweet" is lost last. Sweeten any foods with sugar, honey, or sweetener to stimulate eating.
- Do not keep anything around that looks like food but isn't, such as artificial fruit or dog treats. People with dementia may mistake them for real food and eat them.

Changes in visual perception and confusion might also make other non-food items, like a napkin, seem like food.

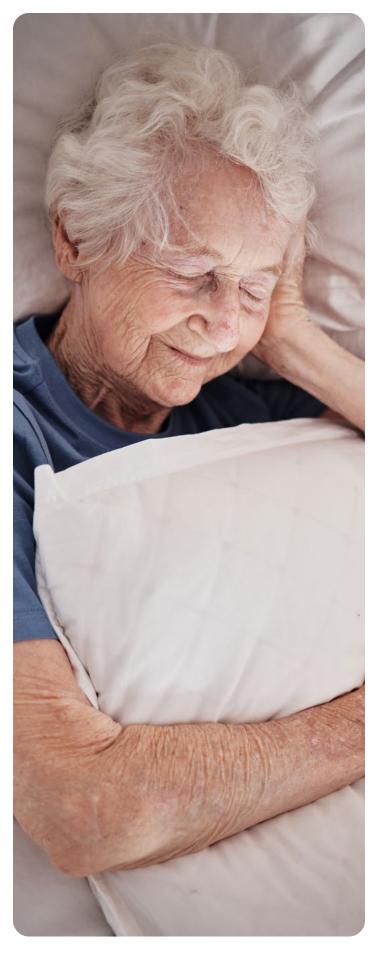
Toileting

- A person with dementia may not know when he or she has to go to the bathroom, or where it is, or what to do there.
- Set a regular schedule for going to the bathroom.
- Look for patterns and signals such as making a face, pulling on his or her pants, or acting restless.
- Make sure the bathroom and hallway have good light, especially at dusk and dark.
- · Put a sign or picture on the bathroom door.
- If the bathroom is all one color, get a different color toilet seat to make it easier to find.
- · Assist with removing or adjusting clothing.
- Help the person relax. He or she may be embarrassed. Take it slow. One step at a time.

Bedtime & Sleeping

Sleep disturbances may be caused by dreams, lack of exercise, or night-day confusion.

- · Make it safe for night wandering.
 - » Clear the area around the bed.
 - » Make sure the way to the bathroom has soft, but clear, light.
 - » Put a commode next to the bed if finding the bathroom is a problem.
 - » If you sleep in a different area of the house, consider a room monitor or a bed alarm (like for a baby) so that you can hear the person if he or she gets up.
 - » Block stairs with a gate.
 - » Lock all outside doors and windows.
 - » Put scissors, knives, and other dangerous items in a locked place.
- · Limit alcohol and avoid caffeine.
- Use warm milk and turkey to encourage sleepiness.



- Keep a good routine of exercise and naps during the day.
 - » Make sure he or she is comfortable:
 - » Adjust the room temperature. Have extra blankets available.
 - » Make sure the bed, pillows, and nightclothes are comfortable.
 - » Make sure the person isn't hungry or thirsty.
 - » Make sure he or she uses the bathroom before bed.
 - » Try a back rub to relax the person and use calm music or fan for light noise.
- Create a familiar sleeping area by using a favorite pillow or blanket.
 - » Use a nightlight to help the person know where he or she is.
 - » Let the person sleep on the couch or in an armchair if there is refusal to go to bed.
 - » Let the person sleep in his or her clothes if that is a preference.
 - » Help the person relax before bedtime by playing soft music.
- · Avoid upsetting activities before bedtime.
- Be careful about TV programs. They can seem real and may be too upsetting or violent.
- · Give quiet reminders that it is bedtime.
- · Use "white noise" such as a fan.
- If awakened suddenly, he or she may be more confused than usual. Help the person become familiar with surroundings by talking and moving where he or she can see you.

Physical Care

Skin Care & Prevention of Pressure Sores (bedsores)

Pressure sores are blisters or breaks in the skin caused when the body's weight presses blood out of a certain area. The most likely people to get pressure sores are very thin or very overweight, diabetic, dehydrated, malnourished, or those whose bodies retain fluids. Most often these people are bed-bound or cannot turn from side to side. The best treatment for pressure sores is prevention.

Facts

- The most common areas for pressure sores are the tailbone, hips, heels, ears and elbows.
- Sores can appear when the skin rubs repeatedly on a sheet or surface.
- The skin breakdown starts from inside the body and works to the surface. It can occur in just 15 minutes.
- Pressure sores look like a change in skin color, all the way to deep wounds down to the muscle or bone.
- In the first stage in light-skinned people, a pressure sore may change the skin color to dark purple or red in an area that does not become pale when you touch it with your fingertips. In dark-skinned people, the area of a sore may become darker than normal.
- The sore place may feel warmer than the skin around it.
- Untreated pressure sores can lead to hospitalization due to severe infection and can require operations. If left untreated, they can cause death.

Prevention

- Check the skin every day. Bath time is a good time because it can cause the least discomfort.
- Make sure the person with dementia gets healthy foods from all food groups.
- · Keep the skin dry and clean.
- Urine left on the skin can cause sores and infection.

- Keep clothes loose.
- If the person wears splints or braces, make sure they are adjusted properly.
- Use light touch when you massage the person.
- Use skin lotions such as Keri, Uni-Derm, or Vaseline Intensive Care.
- Turn a bedridden person at least every two hours, changing position.
- Keep wrinkles out of sheets every 15 minutes is best.
- Lightly tape foam to bony sections of the body, using medical tape, which will not hurt the skin when you remove it. Check with the pharmacist for which tape to use.
- Use flannel or 100% cotton sheets to absorb moisture.
- Two types of mattress pads give extra comfort: "sheepskin" and "egg crate."
- If possible, rent a ripple bed, an electronically operated special bed. With a doctor's order, a physical therapist or occupational therapist can help you get the right equipment.
- Do not use plastic sheets or bed pads because they cause sweating.
- When the person with dementia is sitting up for a while, have him or her change positions every 15 minutes.
- · Use a foam pad on the chair he or she sits in.
- Provide as much exercise as possible.
- If you see pressure sores, tell the nurse or doctor right away. Follow their orders for treatment and prevention.

This section adapted with permission from The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers, available at booksellers everywhere, from Amazon, or by calling 1.800.565.1533.

Lifting or Moving a Person with Dementia

When caring for a person with dementia, you may have to move him or her from one place to another.

You want to move the person without injuring yourself. These guidelines come from many different books and experts. They should not take the place of advice from your doctor, a nurse, an occupational therapist, or a physical therapist. We also recommend that you contact a home health provider to practice movements before you try them.

Do Not Hurt Yourself

- Never lift more than you can handle comfortably.
- When standing, your feet should be 12 inches apart, with one foot slightly ahead of the other.
- Use your legs to lift. Do not let your back do the heavy lifting.
- Wear a back support belt if you do a lot of lifting.
- · Use a transfer belt (a gait belt) if you can.
- Encourage the person who you are moving to use his or her own strength to help you.
 You can say, "Now I would like you to stand up with me."
- Make sure you and the person have proper footwear. Do not wear slippers or just socks because they can slip and skid.
- Practice the moves with someone else before helping the person with dementia.
- Make sure furniture and tables are not in your way.
- Make sure the floor is dry and not slippery.
- Prepare the person by explaining what you are going to do.
- · Speak clearly and slowly.
- Keep yourself in good shape by getting exercise and eating right.
- Know your limits and ask for help.

Moving from a Sitting Position to Another Sitting Position

- Get close to the person. Straddle one of his or her legs.
- · Put your arms around the waist.
- Before you move the person, count with him or her, "1-2-3-go."
- While lifting, keep your back normally arched, not stiff.
- · Keep your weight balanced on both feet.
- Tighten your stomach and back muscles.
- · Use your legs to lift.
- Pivot both of your feet at once. Do not twist your body.
- · Keep your shoulders relaxed.
- Place the person back down by bending your knees.

Rolling Over in Bed

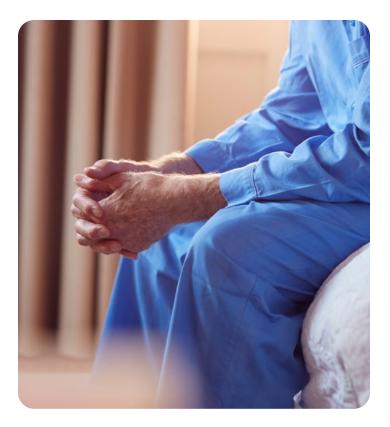
Rolling a person over in bed is a two-stage task.

- 1. Move him or her to one side of the bed:
 - Stand at his or her shoulders.
 - · Place your feet 12 inches apart.
 - · Bend your knees.
 - Slide your arms under the shoulder blades and upper back.
 - Slide him or her toward you by rocking your weight back and forth.
 - Use the same procedure for the hips and leas.
- 2. Roll the person over on his or her side.
 - · Bend his or her knees.
 - Hold at the hip and should blade on the far side of his or her body.
 - Roll the person toward you to make sure he or she does not fall off the bed.

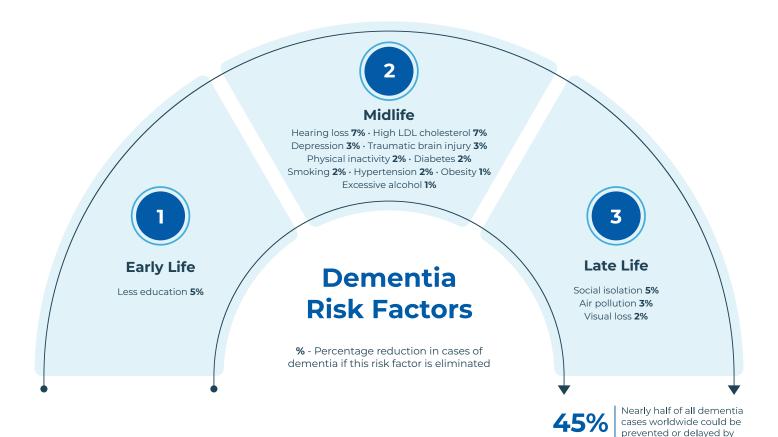
26 — PHYSICAL CARE

Helping a Person Sit Up on the Edge of the Bed

- Roll the person on his side as described above.
- · Bend his or her knees.
- · Stand so the person is facing you.
- Reach one arm under the shoulder blade (the one closest to the bed).
- · Place your other arm in back of the knees.
- Stand close to him or her, with your feet 12 inches apart (one foot behind the other).
- Count 1-2-3-go and rock your weight on your back leg.
- Shift his or her legs over the edge of the bed while pulling his or her shoulders to a sitting position.
- Stay in front of the person until he or she is ready.



Dementia Risk Reduction



risk factors.

addressing 14 modifiable

POTENTIALLY MODIFIABLE

Healthy Habits for Brain Health



Challenge your mind

Put your brain to work. Learn a new skill. Try something artistic. Challenging your mind may have short- and long-term benefits for your brain.

Stay in school



Education reduces the risk of cognitive decline and dementia. Encourage youth to stay in school and pursue the highest level of training possible. Continue your own education by taking a class at a local library or online.



Get moving

Engage in regular exercise. This includes activities that raise your heart rate and increase blood flow to the brain and body.

Protect your head



Help prevent an injury to your head. Wear a helmet for activities like biking, and wear a seatbelt when driving. Protect yourself while playing sports. Do what you can to prevent falls, especially for older adults.

Be smoke-free



Quitting smoking can lower the risk of cognitive decline back to levels similar to those who have not smoked. It's never too late to quit.

Control your blood pressure



Medications can help lower high blood pressure, and healthy habits like eating right and physical activity can help, too. Work with a health care provider to control your blood pressure.

Manage diabetes



Type 2 diabetes can be prevented or controlled by eating healthier, increasing physical activity and taking medication, if necessary.

Eat right



Eating healthier foods can help reduce your risk of cognitive decline. This includes more vegetables and leaner meats/proteins, along with foods that are less processed and lower in fat.

Sleep well



Good quality sleep is important for brain health. Do all you can to minimize disruptions. If you have any sleep-related problems, talk to a health care provider.

Stay socially active



Social engagement is associated with reduced rates of disability and mortality, and may also reduce depression. Among individuals with a genetic risk for dementia, rates of dementia were lower among those who frequently engaged in social activities.

Vision loss



Research has shown that risk of dementia or cognitive decline is greater among those with visual impairment than among those without visual impairment. Treating conditions that cause vision loss may help lower risk of cognitive decline.

Hearing loss



Hearing loss has been strongly associated with increased rates of cognitive decline and dementia risk. Treating hearing loss via the use of hearing aids may help reduce risk of dementia and slow cognitive decline.

Care Notes

Use this section to note concerns, questions, or the occurrence of something out of the ordinary. This type of activity log can be helpful in detecting patterns in difficult behaviors, gradual changes in the person's condition, and notations of successful outcomes.

Date	Time	Notes
02/28/25	All day	Busy, lots of visitors, short-tempered with grandchildren. Paced often, but crackers and milk helped a little.

29 –

Care Notes

Use this section to note concerns, questions, or the occurrence of something out of the ordinary. This type of activity log can be helpful in detecting patterns in difficult behaviors, gradual changes in the person's condition, and notations of successful outcomes.

Date	Time	Notes

30 –

Notes to Take to a Doctor's Appointment

Da	Date:						
1.	How would you describe the overall mental state of your loved one? About the same as the last visit? Better? Worse?						
	Things to consider:						
	• Can your loved one perform the tasks of daily living such as: bathing or showering without help and maintaining personal cleanliness; getting to the bathroom without having an accident; dressing, walking and eating without assistance?						
	Does your loved one remember where everyday items are kept in the house?Does your loved one know what day it is?						
	· Can your loved one use a computer or cell phone?						
	 Does your loved one have trouble finding words when speaking? If your loved one went for a walk in your neighborhood, would he/she get lost? 						
2.	How would you describe the overall physical health of your loved one? About the same as the last visit? Better? Worse?						
	Things to consider:						
	 Does your loved one exercise? How? How often? Has your loved one lost weight? How is his/her appetite? Has your loved one been to Urgent Care or the ER since the last visit? 						
3.	Does your loved one feel connected to the outside world?						
	Things to consider:						

- with interest? Do they read books, magazines or a newspaper?
- · Does your loved one remember the names of close friends and family members?
- · Can your loved one communicate in writing (handwritten, text or email)?
- · Does your loved one get anxious when in new surroundings or with people he/she doesn't know?

4.	Is your loved one still driving?					
	Things to consider:					
	 Has the ability of your loved one to drive changed? Has your loved one ever gotten lost while driving? Do you consider your loved one a safe driver? Have you noticed new dents, scrapes, etc. on the vehicle they drive? 					
5.	Does your loved one seem happy?					
6.	Do you ever fear physical harm from your loved one?					
	COMMENTS/NOTES					

Resources

Alzheimer's Association

communityresourcefinder.org

The Community Resource Finder offers easy access to a comprehensive listing of Alzheimer's and dementia resources, community programs and services.

alz.org/care

The Caregiver Center offers support including message boards and information about all stages of caregiving.

American Medical Association: Caregiver Health Self Assessment

healthinaging.org/resources/ resource:caregiver-self-assessment

The American Medical Association has created a checklist to help caregivers take stock of their own well-being and minimize risks to their health. The Caregiver Health Self Assessment Questionnaire will help caregivers analyze their own behavior and health risks and, with their physician's help, make decisions that will benefit caregiver and patient. It is downloadable in English, Spanish, and Greek.

Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease

nia.nih.gov/Alzheimers/Publication/caringperson-alzheimers-disease/about-guide A caregiver guidebook from the National Institute on Aging, which provides tips on common topics/issues caregivers face (visiting the doctor, sleep problems, incontinence, eating, etc.).

Eldercare Online

ec-online.net

Eldercare Online provides an Eldercare directory, a monthly newsletter, caregiver support chat schedule, tips and updates.

Centers for Medicare and Medicaid

cms.gov

CMS is the federal agency that administers the Medicare program and monitors the Medicaid programs offered by each state. The website has information about Medicare, Medicaid, regulations, research, outreach, and education. Browse by topic or provider type. There is a section for looking up acronyms and an area to submit questions for individualized responses from the CMS support team.

The Medicare Learning Network

cms.gov/MLNGenInfo/20_spotlight.asp

The MLN aims to help Medicare providers understand changes in Medicare policy by breaking down policy into plain language with tips easily translated into actions used in day-to-day work. The "Spotlight" page has the latest MLN product and announcements, such as articles, brochures, fact sheets, web-based training courses and videos, updated regularly.

Family Caregiver Alliance

caregiver.org

Family Caregiver Alliance (FCA) is a national center on caregiving that provides information, education, services, research, and advocacy based on caregiver needs; and offers programs at local, state, and national levels. The award-winning FCA website offers families, professionals, policy makers, employers, and the media information on a wide range of caregiver issues, services, and support. Caregivers have access to online discussion groups and a regularly updated website 24/7. The FCA website also provides a variety of publications, including fact sheets, newsletters, research studies, reports, policy briefs and other materials for families and professional care providers. Additionally, their website has a Family Care Navigator, a guide to help families locate publicly funded caregiver support programs in all 50 states.

Resources

State of Oklahoma Resources

Long Term Care Information

Oklahoma Long Term Care Ombudsman Program

The Ombudsman Program serves residents in Oklahoma's long-term care facilities, including nursing homes, assisted living and similar adult care homes. An Ombudsman helps improve the quality of life and the quality of care available to long-term care facility residents.

Adult Protective Services, Legal and Financial Help for Seniors

Adult Care Facilities Emergency Plan Template

This plan is designed as a resource tool to assist in the development and implementation of an emergency action plan within your organization or agency.

Long Term Care Information, Inspection and Complaints

The Long Term Care Service oversees the health and safety of residents living in licensed long-term care facilities.

Oklahoma Mobility Management

This program aims to enhance transportation for veterans, older adults, people with disabilities, individuals with lower incomes, and many more.

Dementia Friendly Oklahoma

oklahoma.gov/health/dfo

Dementia Friendly Oklahoma is an initiative to bring awareness and education across the state to support those living with dementia and their care partners. Oklahoma is a member of the Dementia Friendly America® Network which is a multi-sector, national collaborative on a mission to foster communities that are equipped to support people with dementia and their family and friend care partners by working to become "dementia friendly."

A dementia friendly community is where those individuals with the disease, their families and care partners feel supported, respected, and included to foster quality of life.

The Oklahoma Caregiver Coalition

OKCares.org

The Oklahoma Caregiver Coalition, OKCares, is a collaboration of over 400 private and public partners who strive to improve the supports and experiences of family caregivers across the lifespan through education, advocacy, and access to resources. Partners meet quarterly to discuss pressing caregiver issues.

The OKCares website houses a wealth of information for Oklahoma family caregivers, including a resource directory, support group locator, recordings of past statewide caregiver conferences, and contact information for statewide respite programs. OKCares.org is a one-stop-shop for relevant resources for Oklahoma family caregivers, whether they are caring for an infant, an older adult, or anyone in between.

If you are interested in joining the Oklahoma Caregiver Coalition, please complete the registration form.

Respite Locator

Respite is planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult. OKCares has gathered all of the respite voucher and waiver provider services across the state. Caregivers can view the eligibility and contact information for each program.

Caregiver Action Network

caregiveraction.org

The network educates and supports the more than 65 million Americans who care for loved ones with a chronic illness or disability, or the frailties of old age. The website provides a variety of resources, online support groups and opportunities to advocate for caregivers' rights.

Resources

Oklahoma Dementia Care Network

www.ouhealth.com/oklahoma-center-for-geroscience/healthy-aging-services/oklahoma-dementia-care-network-okdcn-/

The Oklahoma Dementia Care Network (OkDCN) is a collaborative statewide program to improve the care and health outcomes of older adults living with Alzheimer's disease and other dementias and their family and friend caregivers. Our mission is to enhance the care and support for the growing number of Oklahomans affected by all types of dementia. **Phone: 405.271.8166**

OkDCN's goals are to:

- Promote a statewide network of organizations and people dedicated to improving the care of persons living with dementia and their caregivers;
- Train primary care providers to assess and address the needs of older adults with dementia;
- Transform primary care and long-term care settings to be age-friendly and dementiafriendly; and
- Deliver community-based education and training to improve dementia care and support.

Oklahoma Area Agencies on Aging (AAA)

oklahoma.gov/content/dam/ok/en/okdhs/documents/okdhs-publication-library/91-27.pdf

These agencies assess the needs of seniors and coordinate programs to allow older adults to lead independent, meaningful and dignified lives in their homes and communities.

AAA Caring Assistance Hotline: 1.800.211.2116

Oklahoma Healthy Aging Initiative (OHAI)

<u>ouhealth.com/oklahoma-center-for-geroscience/healthy-aging-services/oklahoma-healthy-aging-initiative-ohai-/</u>

Lifelong health for all Oklahomans. Staying healthy and living safely in your own home and community for as long as possible. That's the goal – and you can do it with help from Oklahoma Healthy Aging Initiative (OHAI). This statewide network through the Section of Geriatric Medicine at the University of Oklahoma Health Sciences Center is designed especially for seniors and their loved ones living anywhere in Oklahoma and offers a wide range of healthy aging educational programs and resources close to home.

OU Health Memory Care Clinic

<u>ouhealth.com/oklahoma-center-for-geroscience/</u> healthy-aging-services/memory-care/

At the OU Health Memory Care Clinic, Oklahoma's first comprehensive memory care service, you benefit from a holistic approach that puts a priority on your physical, emotional and social needs. You and your caregiver or support network will work with an experienced interdisciplinary team of geriatric medicine specialists and related medical experts to accurately diagnose your condition and stage of progression.

35 — RESOURCES



The Oklahoma Healthy Brain Initiative promotes brain health, addresses cognitive impairment and acknowledges the needs of caregivers. We are focused on the improvement of early detection and diagnosis, increased awareness and education, risk reduction and prevention of comorbidities and preventing hospitalizations.

Oklahoma.gov/Health/HealthyBrain | HealthyBrain@health.ok.gov

Adapted with permission from materials created by the Alzheimer's Association Greater Missouri Chapter. This publication was issued by the Oklahoma State Department of Health (OSDH), an equal opportunity employer and provider. A digital file has been deposited with the Publications Clearinghouse of the Oklahoma Department of Libraries in compliance with section 3-114 of Title 65 of the Oklahoma Statutes and is available for download at documents.ok.gov. | February 2025