Dementia Care

For Caregivers of Persons with Dementia
Introduction

The goal of this booklet is to help educate caregivers. This includes family, friends and staff who provide daily care for persons with dementia. We honor those who give such care. We believe that knowledge helps caregivers find the joy in caring for a person with dementia.

CONTENTS

Tips for Communicating 3

Stages of Dementia 4

Activities for People with Dementia 6

Handling Common Behaviors 8

Safety and Comfort 10
Tips for communicating

When you speak to a person with dementia:

• Present one idea or step at a time. Use short sentences with simple messages.

• Speak slowly and simply. Do NOT expect a quick response. Give the person time to process what you said. At stage 6 and 7, it can take up to 90 seconds for a response.

• Speak calmly in a normal tone of voice. Do NOT express excitement.

• Use statements to get the person to do something. Example: “It is time to take a bath” or “Let’s get dressed now.”

• Avoid asking questions. Do NOT quiz the person about family member names and so on. This will embarrass him or her.

• If you need to repeat something, use the same words. Do NOT rephrase it. Ask the person to repeat what you said; this may aid understanding.

• Stand in front of the person. Touch an arm or shoulder gently to keep his or her attention. Maintain eye contact.

• Approach from the front so you don’t startle the person.

• Communicate with more than one of the senses, for example: touch and talk.

• Use gestures or visual aids to get your message across. Do not use gestures that may be seen as threatening. If you use signs, write in neon green and use the person’s words for things.

A person with dementia:

• May say one word and mean another. You may have to guess the meaning. Try to confirm with the person that your guess is correct.

• May repeat or prolong a thought or action. The person may get distracted, forget what he or she was doing, and start over.

• May not be able to voice the pain he or she feels. Watch for body language and expressions and adjust your actions.

• May be sensitive to your tone of voice or the look on your face. Your voice and your face can say as much as your words.
# The Stages of Dementia

<table>
<thead>
<tr>
<th>Stage</th>
<th>Traits and Behaviors</th>
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<tr>
<td><strong>Normal, forgetful aged adult</strong></td>
<td>- Slight memory loss. The person may complain of being forgetful.</td>
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<td>- May struggle to remember names or words, or where he or she has placed something.</td>
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<td>- May have trouble recalling recent events or appointments.</td>
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<td><strong>Early level of confusion:</strong></td>
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<tr>
<td><strong>Mild decline in thinking</strong></td>
<td>- May have problems with memory at work or trouble remembering what was read moments earlier.</td>
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<td>- May have problems when traveling or driving to unfamiliar places.</td>
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<td>- May have anxiety along with denial.</td>
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<td><strong>Late level of confusion:</strong></td>
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<tr>
<td><strong>Moderate decline in thinking</strong></td>
<td>- Memory loss is longer-term: May forget social events or news.</td>
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<td>- Confused about time, not person or place.</td>
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<td>- Knows that his or her memory is not what it used to be and can give examples.</td>
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<td>- Several days per month will get confused or lost.</td>
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<td>- Not as able to pay bills, manage finances, grocery shop, prepare meals, or safely use the stove.</td>
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<td>- Not as able to drive safely.</td>
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<td>- Needs help with complex tasks.</td>
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<td>- May withdraw from stressful situations.</td>
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| Early dementia:   | • Person no longer knows they have dementia.  
                   • New learning stays with person for 5 minutes. He or she will tend to repeat questions.  
                   • Living alone is unsafe. He or she must have help and may benefit from day programs.  
                   • Unable to recall major aspects of their current lives. Has trouble recalling names, especially of grandchildren.  
                   • Confused about time or place, but still remembers major facts about themselves.  
                   • Relies on familiar routines and surroundings.  
                   • Unable to remember 3-item list or 3-step directions.  
                   • May need help with basic tasks such as choosing clothes that fit the season or bathing regularly. But able to complete most self-care if given cues. |
| Middle dementia:  | • Person is largely unaware of all recent experiences. Memory of past life may be vague.  
                   • Needs help with all basic activities: dressing, bathing and toileting.  
                   • Cannot do two actions at the same time. For example, the person will tend to stop walking and turn their whole body to look at you rather than turning just their head.  
                   • Peripheral vision and depth perception will slowly fade, often leading to falls.  
                   • Eye gaze tends to shift downward to just 20 to 30 inches above the floor.  
                   • May have lost control over urine and bowel movements. |
| Late dementia     | • Brain is no longer able to tell the body what to do.  
                   • Tends to be controlled by the senses and what feels good.  
                   • Usually bedridden, incontinent, unable to feed self. Speech or communication is very basic; may have about a half dozen words.  
                   • The ability to smile is gone. |
Activities for people with dementia

People need to feel they have a purpose. Staying active will stimulate the mind and keep up physical well-being. The best activities are those that relate to the person's former work or interests.

- **Find out some facts about the person.** Ask yourself and others who know the person: Where did he or she work? What about jobs, hobbies, interests, likes and dislikes, favorite music, movies, or TV shows? What are the names of family members and pets? Did the person do military service or live through the depression?

- **Learn the person's routines and habits by observing him or her at various times in different settings.** Imagine what the person may be thinking or doing. This will help give you context for setting up activities that suit the person.

- **Color affects people with dementia.** Use bright colors with high contrast for the background. Yellow/neon green is the easiest to see. Green is restful. Blue is calming. Red increases brain activity. Red dinnerware may increase eating and drinking in later dementia.

- **In the early stages, exercise is an option.** In the later stages, give him or her tasks with a purpose.

- **In the early confused stages, help the person with complex tasks.** These would include managing finances, driving or taking medicines on schedule.

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**Early-stage dementia**

- Keep up familiar activities whether social, physical or mental.
- Talk about the day of the week and weather.
- Encourage the use of a watch, calendar and schedule.
- Talk about current events in brief terms.
- Teach the person new skills that may be used in later stages of dementia: how to use memory aids before asking for help or how to use an assistive device for balance.
- Break down weeks, days and events into smaller parts.
- Involve the person in seasonal activities and current events.
- During holidays be creative. Have the person help with special foods and decorating.
- He or she might help with household tasks. This might include having the person:
  - Make sandwiches
  - Stir food
  - Gather supplies
  - Hang up clothes
  - Unload the dishwasher and sort silverware
  - Care for the garden or house plants.
- Play well-known games such as Scrabble or Yahtzee. Involve grandchildren with Candyland or Chutes and Ladders. Play card games like Solitaire and Crazy Eights.
- Do easy crossword puzzles or word finds.
- Play a color word game: Name something that is blue. Name some orange vegetables.
- Do large jigsaw puzzles of 24 to 50 pieces.
**Middle-stage dementia**

- Provide a calendar and schedule. Break it down into small parts: one morning, one day, one week.
- Develop a memory book with a focus on family. Include details on spouse, children, friends, birth dates, and important events.
- Look at the memory book.
- Set up self-care supplies. Give cues like sit or stand; help move the body or hold a hairbrush; help the person do tasks in the right order.
- Do seasonal activities.
- Do household tasks: Fold clothes, use a feather duster, or have a chest of drawers for rummaging.
- Pick silk off a cob of corn.
- Knead thawed frozen bread dough with raisins and cinnamon. Pick the raisins out of the dough.
- Play at rolling dice. No need to have a goal.
- Sort and match items or colors. Colors need to be strong – socks, large buttons or beads, spools of thread or ribbon, silk flowers.
- Organize a toolbox.
- Set up area for shuffling papers and stuffing envelopes.
- Set up assembly line projects.
- Roll up silverware in napkins.
- Paint with watercolors or pudding.
- Play color word game: What color is a sunflower?
- Play with jigsaw puzzles of 24 pieces.
- Use bright lights in the morning. This tends to decrease sundowners in the afternoon. Sundowners is a term for increased confusion as the light changes.

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**Late-stage dementia**

- Ask the person to take part in feeding, washing or dressing self. Say, “Would you help me do…?” instead of, “Can I help you?”
- Recall happy memories and look at pictures of family, friends and places.
- Stimulate the senses using color, smells or sound.
- Stimulate sense of smell with plug-ins, popcorn, cooking or baking smells.
- Move colorful objects for them to follow with their eyes, like a colorful beach ball, pinwheel, scarves or flowers.
- Roll golf ball or other balls back and forth on a table.
- Toss or roll balloons with beads inside (put craft beads in a balloon and inflate it).
- Sing familiar songs.
- Listen to music that is well known to them.
- Toss or kick a ball, hit a balloon.
- Fill bird feeders. Watch for birds.
- Use a lava light.
Handling common behaviors

*People with dementia may:*

- Appear anxious
- Wander
- Steal things
- Have trouble staying quiet
- Demand attention all the time
- Repeat words or actions
- Have trouble using the toilet
- Take off their clothes at the wrong time
- Act out sexually
- Have emotional outbursts
- Scream or curse
- Have trouble sleeping and waking at regular times
- Show anger
- Get frustrated easily
- Refuse to cooperate
- Hit, kick or bite
- Have paranoid ideas
- Resist or refuse care
- See things that aren’t there
- Have mood swings
- Feel sad or hopeless
- Show extreme reactions when excited; may shut down.

*Tips for caregivers*

- Respect their “space.”
- Respect routines.
- Approach from the front so you do not startle the person.
- Always explain what you are doing before you do it.
- Allow simple choices, for example: the red or blue dress?
- Be aware of the person’s body language or expression.
- Encourage social activity.
- Make changes in routine or surroundings slowly.
- Take time to listen.
- Do not excite the person too much (with questions, information or activity).
- Keep surroundings calm and quiet.

*If the person is confused:*

- Spend time with the person.
- Keep the same daily routine.
- Avoid questions that require problem solving.
- Use simple sentences or single words when speaking to the person.
- Know the person’s past habits.
- Spend time recalling family stories (use pictures).
- Be gentle with the person.
- Allow the person time to respond.
If the person is anxious:

- Get rid of sights, sounds or textures that irritate the person.
- Try soothing music.
- Let him or her walk.
- Provide a safe place for him or her to cry or be angry.
- Try humor, but take care the person does not think you are laughing at him or her.

If the person is hostile or aggressive:

- Try to distract the person.
- Offer gum (Extra brand is good).
- Offer a favorite food.
- Allow the person to express feelings.
- Allow a cooling down period.
- Get away as needed.

If the person tends to wander:

- Check to see if he or she is hungry or in pain.
- Take him or her to the bathroom.
- Take the person for a walk.
- Don’t pull or use force.
- Make “dead end” signs for doors.
- Set up a safe place to wander.
- Allow time to rest if tired.

If the person is paranoid (distrusts everyone):

- Don’t disagree.
- Observe the look on his or her face.
- Watch closely but be discreet.
- Offer to help find stolen items.
- Be aware of hiding places.

If the person has trouble sleeping:

- Play a tape with crickets chirping.
- Do not let him or her get overtired; give afternoon naps.
- Provide calm surroundings.
- Give a soothing bedtime snack (warm milk is calming).
- Avoid drinks with caffeine after dinner.
Safety and comfort

• A new location, routine, or caregiver can overwhelm the person. If a person’s care or place of care must change, make the changes slowly. Introduce yourself each time you arrive.

• Decorate the walker in a way he or she may enjoy. For example, a farmer liked it when his walker was decorated like a John Deere tractor.

• A person may get out of bed when it is unsafe. If this happens, push the side of the bed that he or she tends to use against the wall.

• If there is trouble with walking, tripping, or short stride, avoid tennis shoes. Shoes with leather soles work well.

• As vision and depth perception decrease, bifocals may cause more falls. Try having lenses corrected for distance only. Reveal light bulbs may help.

• As posture changes, your loved one’s visual focus may change.
  – Focus shifts lower to about 30 inches from the floor.
  – You may need to move some items to where the person can see them.
  – Get down on the floor or kneel when talking to the person.

• Things that bring comfort:
  – Full body pillows
  – Pillowcases with the person’s own scent or that of a family member.
  – Dolls or stuffed animals. Replace the inside with a bag of rice and heat in the microwave. This is warm and soothing.
Web resources

Alzheimer’s Association
www.alz.org

The Alzheimer’s Store
www.alzstore.org

“The Forgetting: A Portrait of Alzheimer’s”
(Also search for caregiver Alzheimer’s)
www.pbs.org

MindStart: Offers books, games, puzzles and information on activities for people with dementia
www.mind-start.com

Reminisce: Online magazine about recalling the past.
www.reminisce.com

Occupational therapist’s website. Resources for geriatrics, including Still Giving Kisses, about her mother’s Alzheimer’s. How to adapt the environment, create activities, and navigate legal, medical and insurance issues.
www.barbarasmithoccupationaltherapist.com