

A Family Caregiver Handbook

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Introduction to Dementia

Dementia is a general term for changes in memory, thinking, communication, and daily functioning. General dementia symptoms can include:

- Memory loss
- Communication difficulties
- Visual and spatial issues
- Reasoning and problem-solving challenges
- Disorientation and confusion
- Personality changes
- Poor coordination and motor skills

Dementia affects each person differently. Symptoms can change day-to-day, and can worsen with stress, illness, pain, dehydration, poor sleep, or medication side effects.

Each person with dementia is more than their diagnosis - they are still the person you know and love.

It is also important to remember that caregivers need support, and that asking for help is not only okay, but encouraged.

Common Stages of Dementia and Suggestions for Support

While each person's experiences with dementia differ, most people move through four major stages.

1. Asymptomatic

A person experiences brain changes but does not yet show any cognitive symptoms.

2. Mild (Early Stage)

A person functions mostly on their own, but may experience memory problems. Individuals can remember most of their past and recognize loved ones.

Common Signs:

- Forgetting recent conversations, appointments, or information they just read
- Misplacing items
- Having trouble finding the right words or names
- Feeling overwhelmed in busy places
- Getting lost in familiar places
- Experiencing changes in mood (anxiety, irritability, frustration)
- Taking longer to complete familiar tasks
- Facing difficulties planning or organizing

How families can help:

- Keep routines simple and consistent and do not add many new tasks.
- Use reminder systems like calendars, notes and pill organizers to help maintain independence.
- Speak calmly and patiently.
- Give one-step directions or instructions.
- Respect personal space and encourage independence, but be available to offer support if needed
- Monitor for safety concerns, like driving, using a stove, using power tools, etc.
- Be honest with other family members about the diagnosis so they know what is going on and how to support them.
- Begin researching transportation services to medical appointments and other places so they are comfortable when it's time to use these services.

When to ask for more help for your loved one:

- Concerns about unsafe driving
- Mistakes taking medication
- Missed appointments

3. Moderate (Middle Stage)

A person has noticeable symptoms that cause more issues with daily life. People in this stage will need greater care and might act in unexpected ways.

Common Signs:

- Experiencing increased confusion about time, place, or what's happening
- Forgetting personal history and information about themselves
- Having more difficulty managing money, medications, or cooking
- Needing help choosing clothes or dressing appropriately
- Repeating information, questions, or stories frequently
- Seeing changes in sleep patterns, i.e. awake at night, sleeping more during the day
- Experiencing personality changes, including suspicion, agitation, or delusion
- Having greater risk of wandering or getting lost
- Forgetting familiar faces
- Having a harder time understanding what someone is saying to them

How families can help:

- Increase supervision and support with daily tasks.
- Do a home safety check, including removing tripping hazards, installing accessible locks, unplugging ovens, and other potential dangerous home items.
- Speak slowly and clearly so your loved one can process what you are saying.
- Use short sentences and offer simple choices ("tea or water?").
- Redirect conversations if they're upset or confused rather than arguing with them.
- Ensure adequate caregiving help, such as family support, respite, adult day, or home care.
- Avoid talking in front of the person as if they are not there.
- Avoid pointing out memory difficulties.
- Provide support to caregivers so they do not feel overwhelmed. They should seek help from friends, family members, and local respite and senior care services.
- If appropriate, consider utilizing adult day care services or moving family members to a memory care community.

When to ask for more help with your loved one:

- Wandering
- Aggression
- Falls
- Caregiver burnout

4. Severe (Late Stage)

A person experiences major personality changes and needs 24-hour care. People in this stage are completely dependent on the care of others.

Common signs:

- Needing help with most or all daily activities
- Losing awareness of surroundings and ability to recognize familiar people
- Decreasing ability to verbally communicate
- Having more difficulty swallowing or eating safely
- Experiencing greater risk of infections and falls
- Experiencing a decline in physical mobility and increased frailty, with necessity for devices like a walker or wheelchair
- Sleeping more

How families can help:

- Focus on loved one's safety and comfort.
- Use a calming tone and touch (depending on comfort level) to demonstrate care.
- Express love through activities like listening to music, looking at old photos, or sitting outside together.
- Discuss safe food and drinks with medical personnel, especially if there is difficulty swallowing.
- Follow medical personal protocols for skin care, medication and movement.
- Seek advice from medical professionals on next steps, such as hospice care.
- Take caregiver breaks and take care of caregivers' emotional and physical needs.
- Avoid distractions and be fully present in the moment with loved ones.
- Make sure loved ones are comfortable.
- Be alert to any physical and nonverbal signs of pain.

When to ask for more help with your loved one:

- Swallowing concerns
- Weight loss
- Decreased mobility
- Frequent infections

Common Behavioral Changes and Helpful Responses

Your loved one with dementia may exhibit any or all of the following behaviors:

- Repetition
- Wandering
- Sundowning
- Agitation
- Hallucinations
- Refusing care
- Sleep changes
- Hoarding or hiding items

It can be difficult to know how to respond to these behaviors. Here are a few tips that might be helpful:

- Avoid arguing or correcting
- Redirect instead of confronting
- Offer reassurance first.
- Focus on feelings rather than facts

And here are some helpful, reassuring phrases for caregivers that can help in a variety of situations:

- You are safe.
- I am here with you.
- Let's do this together.
- Tell me more.
- Here are two choices
- It sounds like you are upset.

Safety Checklist for Caregivers:

- Remove tripping hazards
- Lock up medications
- Consider stove safety devices
- Add grab bars in the bathroom
- Keep emergency numbers visible
- Use ID bracelets or GPS devices if wandering is a concern

Tips for Children and Teens in Dealing with a Family Member's Dementia

Children need simple and clear explanations on what is happening, as well as ongoing encouragement and support in their interactions and relationship with their loved one. The following reminders can be really helpful and can keep the lines of communication open:

- It is okay if your loved one forgets your name.
- You did not cause dementia in your loved one.
- You can spend time together through music, games, pictures, and walks.
- You can always ask an adult if you feel scared or sad.

Caregiver Burnout

Many families do not realize they are overwhelmed until they are already in crisis. You should seek help if you are a caregiver and are exhibiting any of the following signs:

- Feeling constantly exhausted

- Feeling angry or resentful
- Having trouble sleeping
- Withdrawing from others
- Feeling guilty taking breaks
- Experiencing anxiety or sadness

Multigenerational Activity Suggestions for People with Dementia and their Caregivers

Try out these activities to see what works for you and your family. Remember that connection does not have to be perfect or complicated! Sitting outside together, listening to music, looking at old photos, or holding hands can still be meaningful.

1. Exercise:

- a. Ball tossing/rolling
- b. Chair yoga
- c. Dancing to music
- d. Sweeping or raking
- e. Batting balloons
- f. Taking a walk
- g. Seated chair exercises (with music)
 - i. Marching
 - ii. Bend to touch toes
 - iii. Waving a scarf
 - iv. Reaching arms to the sky
 - v. Shrugging shoulders
 - vi. Wiggling fingers and toes

2. Games:

- a. Cards – playing simple games like Go Fish, or sorting cards by color.
- b. Dominoes
- c. Building with any blocks like Jenga tiles,
- d. Large jigsaw puzzles
- e. Word games – Naming categories (fruit, colors, animals, etc.)

3. Reading:

- a. Flipping through/reading catalogs, magazines, picture books and talking about what you see.

- b. Audiobooks
- c. Reading books aloud
- d. Cartoons or comics

4. Memory or Themed Boxes: collecting items from around the house, going through them talking about their significance.

- a. Photos
- b. Kitchen items
- c. Jewelry
- d. Fabrics, ribbons, yarn
- e. Old postcards or greeting cards
- f. Other collections

5. Chores:

- a. Folding laundry
- b. Sorting socks
- c. Setting the table
- d. Clearing the table
- e. Preparing simple foods (sandwiches, mashing, mixing, decorating, etc)

6. Nature/Outdoors:

- a. Raking
- b. Watering plants
- c. Birdwatching
- d. Planting seeds in pots
- e. Listening to nature sounds (rain, ocean waves, birds, etc)
- f. Collecting leaves or pinecones

7. Arts/Creative:

- a. Painting by number or with water
- b. Using stamps
- c. Modeling with clay
- d. Coloring

- e. Writing notes, if they are able
- f. Collage making
- g. Sticker art

8. Meeting with Friends: Encouraging social interactions

9. Physical Touch:

- a. Hand massage
- b. Manicure
- c. Warm towel for hands
- d. Guided hand-over-hand drawing

10. Music:

- a. Sing-a-longs to familiar music
- b. Name the Tune
- c. Move to the rhythm with shakers, scarves, tambourine, other instruments
- d. Let them play an instrument they've played before

11. Animals:

- a. Cuddling with pets
- b. Soft stuffed animals

12. Sorting:

- a. Buttons
- b. Coins
- c. Beads
- d. Pasta shapes
- e. Junk drawer cleanout

Conversation Starters for Caregivers of Individuals with Earlier Stages of Dementia

Reminiscence

- Tell me about the neighborhood you grew up in.
- Share a memory of a teacher or mentor who meant something to you.
- Describe a family tradition you always enjoyed.
- What was your first car like?
- Who were some of your closest friends when you were younger?
- What is a childhood game you remember enjoying?
- What was a place you loved to visit?
- What was a part of your job that you were especially good at?
- What is one of your favorite holiday memories?
- What pets did you have growing up?

Music & Entertainment

- What songs always lift your mood?
- Have you ever gone to concerts or dances?
- What TV shows do you enjoy?
- Who is an actor or comedian you like?
- What is a movie you've watched many times?
- Who is a performer you always liked?

Nature & Outdoors

- What outdoor activities did you enjoy?
- Do you prefer the beach, mountains, city, or country?
- Which season feels most enjoyable to you?

- Have you ever kept a garden or grown plants?
- What is your favorite place to walk or sit outside?
- What is a natural sound you enjoy – birds, winds, bees, rain?
- What kinds of flowers or plants do you like?

Food & Cooking

- What are some foods you loved as a child?
- What special recipes were made in your family?
- What is a food you would happily eat every day?
- Do you prefer sweet or savory snacks?
- What is a meal you enjoyed cooking?
- What food reminds you of home?
- What are your favorite desserts?
- What kitchen smells bring back memories?
- What restaurants have you liked going to?

Careers

- What did you do for a career?
- What did you enjoy most about your work?
- What was a typical day like?
- Is there something that you accomplished in your work that made you proud?
- What advice would you give to someone starting out in that career?

Hobbies & Interests

- What hobbies have you enjoyed throughout your life?
- What kinds of projects have you liked doing?
- What is something you always wanted to learn?
- What is a skill you learned that you are proud of?
- What kinds of book or magazines have you enjoyed reading?

- What kinds of games or puzzles do you enjoy?

Home & Comfort

- What makes a place feel cozy to you?
- What do you like to do in the morning?
- What is your favorite spot to relax?
- What would you enjoy doing this afternoon?
- Would you like to sit somewhere quiet?
- Does music, a walk, or a warm drink sound nice right now?
- Would you like company or quiet?
- Would you enjoy sitting outside in the warm sun, or staying inside?
- What kind of drink or snack sounds good right now?

Conversation Starters for Caregivers of Individuals with Later Stages of Dementia

NOTE: These questions are intended to engage, not test memory or put pressure on the person to answer.

Daily Conversations:

- What part of today has felt the nicest so far?
- Would you rather sit somewhere bright or somewhere a bit darker?
- Do you enjoy having someone nearby while you relax?
- Do you feel more like resting or doing something else?
- What colors do you enjoy looking at right now?
- Do you feel like chatting or just sitting together?
- Would you like me to read something to you?
- Do you enjoy hearing stories or listening to music more?
- What small things make you feel calm and cozy– soft light, warm blankets, or music?

Music:

- Would you like to tap your hands or feet along or just listen?
- What instruments sound pleasant to you?
- How does this song make you feel?
- Do you like music that's slow or lively?
- Does this tune remind you of anything?

Pictures: (Use with photos or magazines)

- Which picture catches your eye first?
- What do you notice first in this picture?
- What do you think the people in this picture are doing?
- Does this scene feel calm, busy, or cheerful?
- Which colors in this picture stand out to you?
- Which of these pictures do you like best?

Food:

- What drink or snack sounds good right now?
- Do you enjoy sweet flavors, salty ones, or both?
- Do you like crunchy foods or soft foods?
- What smells do you enjoy — coffee, vanilla, citrus?
- Do you enjoy warm drinks or cool ones?

Nature & Outdoors:

- Do you like watching birds, clouds, or people passing by?
- How does the weather feel today?
- Do you like watching the trees or the sky?
- What outdoor sounds do you enjoy?
- Does sunlight or shade feel better?
- What colors of flowers do you enjoy looking at?
- Do you prefer big blossoms or tiny ones?
- Do you like watching plants grow?

Reminiscence:

- What activities made you feel happy?
- What places felt comforting or familiar to you?
- Did you enjoy being around people or having quiet time?
- What kinds of things made you feel proud?
- What places made you feel peaceful?