

Guide for Families Caring for a **Loved One with Dementia**



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Guide for Families Caring for a Loved One with Dementia

Check in with how you are feeling, talking, behaving

- Those with dementia will respond to the mood of others. If you are frustrated/overwhelmed ...then leave the room, get your mood straightened out and then return. Even sitting quietly and breathing slowly can help calm them down.
- They may not be able to understand what you are saying, but will respond to you attitude, facial expression, body language, and tone of voice. Try different ways of saying something if they don't understand what you are saying.
- Do not ask open ended questions - give them 2 options, or do you want this first or second, or possibly even yes/no questions.
- Break down commands into single steps, cueing.
- If they are nonverbal, follow their demeanor, facial expressions, behavior. Look them directly, in front, and speak slowly. If hard of hearing, lower the pitch of the voice.

Safety

Tips for managing wanderers: position locks on doors higher or lower than usual, put a barrier on the floor (caution tape) or 'Stop 'sign or 'Do Not Enter' sign on the door, Paint a black space or black mat on the porch.

- Apply child-safe plastic covers to doorknobs
- Remove knobs from the stove
- Don't leave them alone
- Have them wear an ID bracelet or necklace
- Disable the car, hide the keys, sell the car and say it is in the shop

Managing Behavior

- Keep a routine - sleep, eat, toilet (½ hour after meals - gastrocolic reflex, every 2 hours)
- If they insist of doing something or going somewhere, agree but that it will be done a little later.
- Accommodate the behavior, not control the behavior. Try giving them a simple but purposeful task (sorting laundry)
- Manage restlessness with activity.
- Reduce overstimulation and distractions.
- Work with where the person is at - if they insist something happened, find a way to move the conversation to a preferable outcome.
- Do not argue. You do not need to be right.
- Join their reality and move it in a preferred direction.
- Distract and redirect is the easiest way to overcome stubbornness, resistance, agitation

Agitation and Anxiety

- Agitation and anxiety may be due to pain, infection, lack of sleep, medication, hunger, thirst.
- Anxiety may be precipitated by confusion, loss of control, doesn't know what to do or where to be.
- Aggression may be precipitated by an inability to express themselves
- Decrease stimulation - noise, clutter, number of people in the room
- Keep everything in the same place
- Keep a routine.
- Avoid stimulants and alcohol
- Their preferred music, whole tones, soothing or classical music even at very low levels,
- Aromatherapy/essential oils (Lavender, lemon)
- Gentle massage of hands or feet.
- Avoid restraining
- Walk or activity
- Acknowledge what they are saying
- Distract and redirect is the easiest way to overcome stubbornness, resistance, agitation, can offer a snack

Repetitive Speech, Questions

- Give simple response, don't need to explain
- Engage them in an activity or song
- Don't discuss plans until immediately before the event
- Make a sign that addresses frequently asked questions
- Recognize behaviors that indicate a need (i.e. pulling on clothing to go to bathroom)

Paranoia

- Don't take it personally
- Only let them keep a small amount of money or play money, an expired credit card
- Look for their hiding places for objects, discuss the missing object then distract
- Don't argue
- Prepare other family members or caregivers for suspicious accusations
- Try nonverbal reassurances like gentle touch, and verbal

Sundowning

- Increase daytime activities, physical exercise
- Keep napping to less than 15 minutes
- Light meal with protein or healthy fat before bedtime
- Structured quiet time during the later hours
- Turn lights on before sunset, close curtains at dusk to minimize shadows

Eating

- Routine eating patterns

- If they are continually 'hungry' they may actually be thirsty, give ½ meal so can give the other ½ later
- Reduce distractions during meal time
- Give them as much independence in feeding as possible - finger foods, sippy cup
- Choose nutritious foods, not empty calories, they usually eat less at night so the big meal is at breakfast or lunch

Hygiene

- Need cueing for activities
- Routine
- Try to keep previous preferred bathing routines, may only need it twice a week
- May not like to be naked, can get clothing to bathe with or use a towel
- Monitor temperature of the room, lighting, safety features (non-slip, grab bars, shower seat)
- Hand held shower
- Never leave unattended
- If hair washing is difficult, do it separately or use a dry shampoo
- Can do a towel bath

Clothing

- Loose fitting, comfortable with easy zippers or snaps
- Set out one set of clothing and remove dirty clothing
- If they want to wear the same outfit - buy several of the same
- Use clothing that closes in the back if they have a tendency to undress

Take Care of Yourself

- Martyrdom helps no one.
- Take care of yourself, then your loved one.
- Get help.
- Join support groups.
- Eat. Sleep. Exercise.
- Alone time.
- Have a good sense of humor.

Get the Legal Papers in Place

- Durable Power of Attorney, Advance Directives, and discuss this with other pertinent family members.
- Designate a spokesman.
- Make copies of these documents and be prepared to show them at each hospital visit

Resources

- The 36 Hour Day by Mace & Rabins
- Area Agency on Aging
- Local chapter of the Alzheimer's Association
- California Caregiver Resource Center
- Family Care Navigator (www.caregiver.org/family-care-navigator)