DEMENTIA CAREGIVING

Dressing

The individual may have difficulty with buttons, snaps or zippers; he/she may not remember the order of putting on clothes, or recognize seasonal changes; and sometimes he/she may not want to change clothes at all.

Helping the person you're providing care to dress appropriately helps him or her maintain dignity and self-esteem.

- For as long as possible, allow the individual to dress him/herself.
- Reduce the number of choices. Empty the closet of unnecessary or impractical clothing.
- When self-selection become difficult, offer a choice between 2 outfits.
- Allow enough time to dress.
- Sneakers or crepe-soled shoes can help prevent falls.
- Velcro closings and elastic waistband are easier to manage than buttons and zippers. Cardigans and front-buttoning shirts are easier than pullovers.
- It may become necessary, to assist in dressing by handing the articles of clothing, one at a time.

Bathing and Grooming

Bathing can be frightening, or become a time of confrontation. Refusal to bathe is not unusual.

- Encourage the individual to participate as fully as possible, for as long as possible.
- Make bathing and grooming part of the daily schedule and incorporate a much of the person's former personal care routines as possible.
- Schedule the bath at the same time every day. Plan it for the time of day when the individual is likely to be more agreeable and cooperative.
- Ensure that the room and water temperature are comfortable.
- Allow plenty of time, so as not to rush the individual.
- Stay calm, gentle and reassuring throughout the bath.
- If the person needs hand-on assistance, tell them what you are going to do before doing it.

- Provide as much privacy as possible while maintaining safety. Grab bars, non-skid treads in the tub, a handheld shower head and a shower bench may be helpful.

Incontinence

It is common for the person with Alzheimer's disease to experience loss of bladder and/or bowel control in the mid to later stages of the disease.

- A toileting schedule can be helpful to the person with dementia. Take the individual to the bathroom every 2-3 hours throughout the day. Don't wait to be asked.

- Watch for signs that the person needs the bathroom, such as restlessness or pulling at clothes. Respond quickly.

- Be understanding when accidents occur. Stay calm and reassure the person if they are upset.

- Try to keep track of when accidents happen in order to plan ways to reduce their occurrence.

- If you and your care receiver are going to be out, plan ahead. Know where restrooms are located. Take an extra set of clothing along, in case of an accident.

- Purchase clothing that is easily washable. Easy to remove clothing with elastic waistbands or Velcro can help prevent accidents.

- Adult diapers are helpful.

- Limit fluid intake before bedtime.

- Putting pictures of a toilet on the bathroom door can help identify the right room.

Sleep Problems

Coping with nighttime wakefulness in a person with dementia can be exhausting for the caregiver.

Medications should be pursued only after these approaches have been tried.

- Try to keep the care receiver on a regular schedule for going to bed and waking up.
- Create a comfortable sleep environment, regulating room temperature.
- Establish regular meal times. Avoid caffeine and alcohol.
- Soothing music or massage may induce relaxation.
- Encourage regular daily exercise.
- Limit daytime napping.
- Use night lights if the darkness is frightening or disorienting.
- Consider hiring help for the night shift or share night-time supervision with others so you can get your own rest.

Wandering

Wandering among people with dementia is dangerous. They may easily become lost and unable to communicate adequately.

- Have the individual wear an identification bracelet or necklace, or sew identifying information into their clothes.
- Join MedicAlert, through the Alzheimer's Association Safe Return Program link to (https://www.medicalert.org/safereturn) or Caring Kind's NYC Wanderer Safety Program link to (https://caringkindnyc.org/medicalertnyc-apply/). The program activates a community support network when a person with dementia is reported lost or found in a community.

- Maintain a current photo in the event you need to report your care receiver missing.

- Alert neighbors about the individual’s wandering behavior. Make sure they have your phone number(s).

- Consider a slide bolt installed at floor level or above eye level.

- A barrier such as a curtain or colored streamer can mask the door. A familiar “stop” or “do not enter” sign also may help.

- A dark or solid color mat or 2-foot painted threshold in front of the door may keep the individual from going out, or may create the illusion of a hole to be avoided.

- Safety door knob covers may prevent the individual from opening the door.

- Be sure to secure or put away anything that could cause danger, both inside and outside of the house.

Agitation

Agitation can be caused by a number of things, but it almost always results in an upset care receiver and caregiver. Sometimes the cause is easily remedied and other times it’s not.

As the person with Alzheimer’s progresses through the disease, behaviors associated with agitation may be more pronounced at different times. Remember that the person’s behavior is symptomatic of the illness. They are not intentionally doing things to annoy, anger or frighten you.

A little patience, flexibility and good humor will go a long way.

- Try to identify the precipitant to the agitation. What sort of change occurred in the routine? Were you feeling rushed or less patient in your interactions with individual?

- Recognize that the time of day may affect behavior. 'Sundowning,' a behavior that includes wandering, pacing, agitation or depressed mood occurs for many individuals with dementia later in the day or early evening. Being aware may help you to better select or reduce activities.

- Too much stimulation, such as exposure to crowds, loud noise, or unfamiliar places or events, may cause agitation or withdrawal.

- Certain behaviors such as fidgeting, rocking, or pacing may reflect the person's attempt to cope with stress or tension. Try to redirect the individual's energy toward manageable, supervised activities.

- Restraining a person with dementia in response to agitation is NEVER advised. Physical restraints disregard the individual's dignity and increase the level of agitation.

- Community services such as adult day services can provide a structured environment for activities.

- While a non-pharmacological approach is preferable, medication can have a significant role in reducing agitation. Medication should be used only under the supervision of a physician. Unless monitored, adverse reactions can occur.

Repetition

It requires lots of patience when a person with Alzheimer's says, does or asks something over and over. Through repetition, he or she may be seeking comfort, familiarity or reassurance. It is also possible the individual is doing his/her best to keep a conversation going.

- Respond to the question or confirm the statement. Try to redirect the individual.

- Discus plans such as doctor appointments closer to the time to prepare to leave, rather than days ahead.

- Try placing signs such as "dinner is at 6:30" on the kitchen table, to remove anxiety and uncertainty about anticipated events.

- Provide safe and simple activities such as folding towels, or matching socks.

Hallucinations and Delusions

Hallucinations and delusions are perceptual disorders with no basis in reality. Hallucinations include hearing, seeing, smelling, or feeling things are not actually present.

Delusions are firmly held beliefs in false ideas, despite contradictory evidence.

Both hallucinations and delusions are fairly common in Alzheimer's disease. They are very real to the person experiencing them and can present quite a caregiving challenge.

Be aware that hallucinations and delusions can be indications of a physical illness or a reaction to medication. Contact the doctor and report what the care receiver is saying, doing or reporting.

Rather than trying to convince the individual that what they perceive to be real is not, respond to what they are expressing, provide reassurance, and ensure their safety.

Introducing a new activity as simple as moving to another room or going outside for a walk may refocus the individual.

For free publications with additional helpful information:

National Institute on Aging
Link to (https://www.nia.nih.gov/health/caregiving)

National Institute of Health
Link to (https://nihpublications.od.nih.gov)

Alzheimer's Association
Link to https://www.alz.org/alzheimers_disease_publications.asp

CaringKind, The Heart of Alzheimer's Caregiving
Link to (http://www.caringkindnyc.org/)