

For the Caregiver

Taking Care of Yourself



***You cannot take care of anyone else –
if you do not take care of yourself first.***

Maintain good habits

- Get plenty of rest
- Eat right
- Drink 8 glasses of water per day
- Exercise: take a walk every day and include your loved one

Take care of your health

- Fill your prescriptions
- Take your medications as prescribed
- Keep your doctors' appointments

Make time for yourself!

- Spend at least 8 consecutive hours away from caregiving per week

Don't put your own health on the "back burner"

For the Caregiver

Guidelines for Coping



Be realistic about what you can do

- You can't do everything for everybody
- Take it one day at a time
- DON'T BE AFRAID TO ASK FOR HELP!

Take care of yourself

- Spend at least 8 consecutive hours away from caregiving per week
- Communication is essential
- Tell your family and friends how you feel and what it is like caring for a loved one

Plan ahead

- Anticipate future needs and make plans now to avoid a crisis
- Talk to an elder law attorney to plan for financial and legal needs

For the Caregiver

Looking on the Brightside



Important caregiver responses are:

- JOY
- WARMTH
- SATISFACTION
- LAUGHTER
- HAPPINESS

Many family members feel good about caring for a loved one -

Don't forget to look on the bright side

For the Caregiver

Depression



Depression: Often occurs in individuals with dementia
Is a common response to caregiving

Treating depression can significantly improve quality of life.

If you or your loved one has any of the following signs of depression, call your health care provider for help:

- Sleeping too much or too little
- Eating too much or too little
- Not wanting to do anything
- Hopelessness
- Helplessness
- Difficulty concentrating
- Feeling sad all the time
- Wanting to die

For the Caregiver

Communicating with your Loved One



Choose a good location

- Eliminate distracting noises or activities in the surrounding area
- Move slowly and touch gently on the arm or hand to get your loved one's attention

Identify yourself

Listen

Be positive and calm

- Speak slowly and softly
- Use positive facial expressions
- Express a cheerful, pleasant mood
- Converse in a social and non-threatening manner

Keep it simple

- Use short, specific, familiar words and simple sentences
- Give one direction or ask one question at a time
- Allow plenty of time for your loved one to respond
- If there is no response, repeat exactly what you said

For the Caregiver

Suggestions for Communication



Things to try

- Stand or crouch down face-to-face to maintain eye contact
- If you lose eye contact, take a break and try again later
- Watch for signs of restlessness or withdrawal such as looking away or frowning
- If you're having difficulty with communication, take a break and try again later
- If your loved one can't find the right word, cue his or her associations. For example, if your loved one points to the mouth and says, "it's like I eat with it...in here." You say "Your teeth."

Keep in mind

- Do not take negative things your love one says personally
- People who live in the moment need reassurance in that moment
- People with dementia can read words long after they stop understanding the written thought
- Always treat your loved one with dignity and respect

For the Caregiver

Understanding Nonverbal Messages



Just because your loved one cannot speak doesn't mean he/she is not trying to tell you something.

FACIAL EXPRESSIONS: Your loved one may no longer be as lively in their expressions as they once were. Often their face is rigid, but if you look carefully, you may see small changes that give clues about what they're feeling.

Signs of happiness:

- Lower eyelids are crinkly
- Cheeks are raised
- The mouth smiles

Signs of sadness:

- The face droops
- The mouth may tremble

Look for other nonverbal clues that can help you to determine what your loved one is trying to say.

EYES: The eyes are the window to the soul. The eyes may show that your loved one is still present and aware, a person who deserves caring and respect. Look for widening or narrowing of the eyes, eye movement, tension in the lids and tears in the eyes. Always maintain eye contact when communicating with your loved one.

For the Caregiver

More Understanding Nonverbal Messages



Look for signs that your loved one is not open to communication:

- Backs away
- Turns head or body away
- Walks away
- Frowns
- Avoids eye contact
- Pulls away from you
- Shrinks away from being touched
- Tells you to go away

Continuing to interact with your loved one when he/she is non-receptive may lead to a catastrophic reaction.

INCREASED RESTLESSNESS such as pacing, fidgeting or rubbing body parts may indicate your loved one has to use the bathroom, has an infection or is anxious or upset.

When words fail, listen for clues in the speed, pitch and volume in your loved one's **VOCALIZATIONS**.

- A loud tone is more likely to cause concern than a quiet one
- Speaking quickly indicates that your loved one may be losing self-control or feeling anxious; wait for him/her to calm down before approaching again
- Try to guess what your loved one is saying unless your guesses annoy him/her

If your loved one gets agitated or anxious, **STOP** what you are doing.

For the Caregiver

Activities to Encourage



- Identify and encourage activities that your loved one enjoyed in the past
- Dance with your loved one
- Encourage your loved one to exercise (if approved by the doctor)
- Participate in activities that you and your loved one enjoy doing together
- Encourage your loved one to participate in social outings with family and friends
- Reminisce with your loved one
- Encourage drawing, painting, crafts and other creative activities
- Encourage your loved one to participate in household chores:
 - Preparing a meal
 - Helping with housework
 - Taking care of a pet
- Enroll your loved one in an adult daycare program
- Take your loved one to the local senior center
- Encourage your loved one to listen to music

For the Caregiver

Activities to Avoid



Avoid ...

Leaving the TV or radio on all day, especially:

- Noisy, confusing programs or entertainment
- Long programs

Activities that drastically change your loved one's routine

Activities that may overwhelm your loved one

- Activities that require a lot of preparation and explanation
- Activities that require memory
- Activities that require learning something new

Activities that may irritate or agitate your loved one

- Too much activity or too many visitors
- Busy work
- Childish activities
- Bad or sad news

Activities your loved one disliked in the past

For the Caregiver

Help with Exercise



Being active can improve sleep and can decrease agitation, stress and moodiness for both you and your loved one. Be sure to get the doctor's approval before you and/or your loved one start an exercise plan.

Thing to try

- Turn on your favorite music
 - Dance by yourself or with a partner
 - Try to dance for at least 10 minutes
- Go for a walk in your neighborhood
 - Bring your loved one with you
 - Try to walk for at least 10 minutes
- Ride a stationary exercise bike
 - Be sure to start slowly and gradually build up speed
 - Try to ride for at least 10 minutes
- Attend a local exercise class designed for seniors
- Do stretching, balance and strength building exercises

The National Institute on Aging offers many free resources including exercise books and DVDs. Visit: go4life.nia.nih.gov to order.

For the Caregiver

Personal Care



Create a routine and stick to it

- As much as possible, do not change anything in the routine
- Keep calm
- Don't argue or try to rush your loved one
- Don't try to explain or reason

Remember that light, color and noise may affect your loved one

Help more when the time comes

- Allow your loved one to do as much by himself/herself as possible
- Always treat your loved one with dignity and respect

If your loved one's personal care needs becomes too difficult, ask for help

For the Caregiver

Getting Dressed



Create a routine and stick to it

- Have your loved one get dressed in one location and undressed in another. The location will prompt the appropriate task.
- Lay out clothing in the order your loved one should put them on

Maintain your loved one's dignity and comfort

- Pull curtains and close doors for privacy
- Make sure the room temperature is comfortable. Your loved one may undress if the room is too warm OR may refuse to undress if it's too cold.

Help more when the time comes

- Let your loved one take care of as much as he/she can
- Watch for a sign that your loved one needs help
- Help more when the time comes

Communication

- Talk to your loved one with a reassuring and calm voice
- Give verbal clues and reminders as needed such as:
 - Sit down
 - Put on your shirt
 - Zip your pants
- Give one instruction at a time, speaking slowly and clearly

Helpful Hints

- Don't argue, explain or try to reason
- Don't rush or force your loved one
- Be flexible and ready to try a new way

For the Caregiver

Clothing Ideas



Select clothing that is comfortable and easy to care for

- Soft fabrics
- Loose fitting clothing
- Washable clothing that doesn't need ironing

Select clothing that is easy to put on and take off

- Pants with elastic waist bands
- Pullover tops
- Clothing items without zippers or buttons

Helpful Hints

- Slip-on shoes with rubber on the bottom are safe and easy
- If your loved one removes clothing at inappropriate times, use clothes that fasten in back
- If pullover tops are difficult to put on, use clothes that fasten in front
- Replace buttons with Velcro tape
- Eliminate belts, scarves, sweaters, ties, and other accessories that are often confusing and likely to be put on wrong
- Keep the closet organized
- Store all clothing that is out of season or not being used somewhere else
- Hang all pieces of an outfit in the closet together

For the Caregiver

Bath Time



Create a routine and stick to it

- Keep the same bath time every day or week
- Get everything ready before you bring your loved one to the bathroom
- Don't ask if your loved one is ready for a bath. Say "your bath is ready now."

Keep the bath area safe

- Use non-slip mats and avoid throw rugs
- Use a shower chair if needed to prevent falls
- Provide enough light
- Turn down the temperature on the water heater
- Never leave your loved one alone in the bath
- Place only 2-3 inches of water in the tub
- Install a flexible shower head

Maintain your loved one's dignity and comfort

- Make sure the bath water and the room are warm
- For privacy, close curtains and the bathroom door
- Allow your loved one to do as much as possible; provide help when needed

Communication

- Talk to your loved one with a reassuring and calm voice
- Give one instruction at a time, speaking slowly and clearly
 - Pick up the soap
 - Put soap on the washcloth
 - Wash your face

Be positive and calm

- Don't argue, fight, rush or embarrass your loved one
- If your loved one is resistant, take a break and try again in a few minutes
- Allow time for relaxation

For the Caregiver

Toileting



Preventing accidents

- Try to predict when your loved one will need the toilet
- Have your loved one use the toilet on a regular schedule, for example
 - Every two hours
 - Before and after meals and before bed
- Look for patterns of where and when accidents occur
- Avoid fluids after 7:00 PM
- Choose clothing that is easy to put on and take off
- Provide a bed and a chair that make it easy for your loved one to get up and go to the bathroom
- Consider a commode by the bed at night

Toileting safety

- Use a nightlight in the bathroom
- Provide adequate lighting to and from the bathroom
- Remove throw rugs from the bathroom
- Remove the lock from the bathroom door

Keeping your loved one healthy

- Give your loved one 6-8 glasses of water per day
- Limit caffeine
- Avoid citrus juices and other bladder irritants
- Avoid skin breakdowns; keep your loved one clean and dry

For the Caregiver

Help at Mealtime



Create a routine and stick to it

- Offer meals at regular times
- Allow enough time to eat
- Try soft, relaxing music

Keep it simple

- Remove distractions from the table
- Try one food, one bowl and one utensil at a time
- Don't use plastic utensils
- Serve finger foods

Avoid Messes

- Use a plastic tablecloth or placemat
- Put a smock over your loved one's clothing
- Use bowls(rather than plates) and spill proof cups

Help more when the time comes

- Allow your loved one to feed himself/herself as able
- Give one instruction at a time, speaking slowly and clearly
 - Open your mouth
 - Chew your food
 - Have another bite
 - Drink the water

For the Caregiver

More Help at Mealtime



Maintain your loved one's dignity and comfort

- When planning the menu, keep in mind your loved one's eating habits, likes and dislikes
- Eat with your loved one (or sit with him/her during mealtime)
- Try soft, relaxing music at mealtime
- Always pay attention to food temperature

Keep your loved one healthy

- Give regular drinks to avoid dehydration
- Avoid alcoholic drinks because they can increase confusion
- Check for dental problems and mouth care problems

If there's a problem, look for patterns

- Certain foods causing a problem?
- Chewing or swallowing a problem?
- Someone causing agitation?
- Something a distraction?

For the Caregiver

Dental Care



Oral health is important. Don't neglect it!

- Check regularly for mouth sores
- Check and recheck how dentures are fitting
- Look for a dentist who understands dementia and is willing to work with your loved one
- Schedule regular dental check-ups
- Use mouthwash that can safely be swallowed

Create a routine and stick to it

Keep it simple

- Give simple one-step instructions
- Give verbal clues and reminders as needed such as:
 - Turn on the water
 - Take the cap off the toothpaste
 - Put the toothpaste on the toothbrush
- Give one instruction at a time, speaking slowly and clearly
- Show and tell your loved one the behavior you want
- Avoid electric toothbrushes because they can be confusing

For the Caregiver

Help with Balance and Walking



As memory loss progresses, your loved one is likely to experience difficulty with movement or balance caused by damage in the areas of the brain that control movement. You may notice that your loved one has developed stiffness, awkward movements, a stooped or leaning posture, or a shuffling walk.

Tell your health care provider about any change in walking, posture, stiffness, repetitive motions or falling. This may be due to memory loss or there may be a problem that can be treated.

Prevent accidents and falls

- Remove throw rugs
- Pad steps and corners of furniture
- Get things out of the way
- Simplify traffic patterns in the home

Provide assistance

- Tightly install handrails and grab bars
- Assure that chairs and furniture your loved one may lean on are sturdy
- If your loved one is willing, have him/her take your arm; hold your arm close to your body

Keep in mind

- If your loved one is unable to learn to use a cane or walker properly, then it is safer not to use it
- Consider which works better: Smooth or rubbery shoe bottoms?

For the Caregiver

Help with Driving



Driving is a complex task that requires the ability to plan ahead and react quickly to a variety of conditions and situations. At some point, a person with dementia will be unable to drive safely.

Plan ahead

- Observe your loved one's driving a regular basis as a passenger in the vehicle. Watch for signs that your loved one is having trouble:
 - Slow reaction time
 - Driving too slow
 - Anxiety
 - Getting confused or lost
 - Accidents or "close calls"
- Enroll your loved one in MedicAlert® + Alzheimer's Association Safe Return®
- Have your loved one's driving formally evaluated (e.g. Rehab Hospital of Indiana, Crossroads, DMV).
- Plan how you will talk to your loved one about driving when it becomes an issue
 - Ask the doctor or social worker for assistance in planning what to say
 - Visit the Alzheimer's Association® Dementia and Driving Resource Center (alz.org/driving for helpful information and tools).
- If your loved one is still in the early stage of dementia, talk with him/her about plans for when driving is no longer safe
- Ask yourself if you are comfortable as passenger when your loved one is driving or if you would allow others to be passengers. If the answer is no, it's time to act.

For the Caregiver

More Help with Driving



Reduce the need for your loved one to drive as much as possible

- Arrange for a friend or family member to drive your loved one
- Arrange for a transportation service (CICOA Way2Go, taxi, Uber, Lyft, etc.)
- Have prescriptions and groceries delivered
- Arrange for home-delivered meals

When your loved one can no longer drive

- Share your concerns with your loved one as previously planned
- Ask others for help and support:
 - Involve your loved one's physician in a family conference on driving
 - Ask the doctor to write prescription stating that your loved one must not drive. Use the prescription to remind your loved one what was decided.
 - Ask family and friends to reinforce the message about not driving
- Offer reasons why someone else needs to drive
 - The route has changed
 - Conditions are dangerous right now
 - You deserves an opportunity to rest and enjoy the scenery
- Have your loved one sit in the back seat with someone to provide a distraction

If your loved one refuses to stop driving

- Take away the car keys
- Disable the car
- Give your loved one set of keys that doesn't work
- Move the car out of sight
- Consider selling the car

REMEMBER: Taking away a driver's license does not prevent driving. Your loved one may forget that he/she longer has a license or that a license is required to drive.

For the Caregiver

About Falling and Injuries



Your loved one with memory problems may become clumsy, bump into things, trip or fall out of bed.

If your loved one falls

- Remain calm
- Check for pain and injuries that you can see
- Avoid a negative reaction by assuring your loved one that everything is alright
- Watch for signs of pain, swelling, bruises, agitation or distress

Keep in mind: it is easy to overlook serious injuries

- Older people are more vulnerable to broken bones from what seems to be a minor accident
- Your loved one may continue to use a broken arm or leg
- People with memory loss may not tell you they are in pain or may forget to tell you that they have fallen
- Changes in behavior may be your only clue to an injury
- Routinely check your loved one for cuts and bruises

Take your time!

Accidents happen when caregivers and loved ones rush

For the Caregiver

Help with Wandering



Wandering is a common behavior among people with memory loss. There appear to be two kinds of wanderers:

The Aimless Wanderer: Enjoys moving around and looking at things, much like window shopping.

The Directed Wanderer: Has a “mission” with someone to see or some place to go. This wanderer is usually more difficult to redirect.

Things to try

- Involve your loved one in regular activities and exercise
- Keep your loved one’s surroundings familiar and calm
- Never argue or try to reason
- Put things out of sight that might remind your loved one to leave such as coats, hats, purses and keys
- Make doors less noticeable
- Encourage family and visitors to arrive and leave without being noticed

For the Caregiver

More Help with Wandering



Make sure that your loved one is safe

- Install locks that are out of your loved ones' reach
- Develop safe wandering paths inside and outside
- Consider using monitoring devices that alert you to sound and movement
- Make sure that your loved one is wearing identification
 - Consider a bracelet with his or her name and your phone number that says "memory impaired"

Things to try

- If your home is safe and secure, allow your loved one to wander
- Take wanderers for regular walks
- Have a plan for what you will do when your loved one starts wandering
- Have a back-up plan
- Try to predict what leads to wandering, then try to change the things that lead to it

Is your loved one registered with the Safe Return Identification Program? Contact the Alzheimer's Association for details.

For the Caregiver

Help with Delirium in the Hospital



Delirium: Confusion that comes on very fast, sometimes in just a few hours.

What you should know

- A person with delirium cannot think clearly, has trouble paying attention and is not aware of what is going on around him/her
- A person with delirium can see or hear things that are not really there
- Delirium usually clears up after a few days to weeks
- Delirium can be caused by medications, medical illness and hospitalization for medical procedures
- A person with dementia is at higher risk for developing delirium

What you can do

If your loved one is going to the hospital, the best thing you can do to help is to work together with the doctors and nurses to prevent delirium.

For the Caregiver

More Help with Delirium at the Hospital



If your loved one is going to the hospital...

What can you do to help prevent delirium?

Alert the doctors and nurses if your loved one has been confused because of illness or medications in the past or if you notice:

- Signs of pain or constipation
- Any unusual behavior

Help your loved one to stay oriented to time and place

- Bring glasses and hearing aids to the hospital
- Encourage your loved one to stay awake during the day
- Keep a light on in your loved one's room during daylight
- Gently remind your loved one several times per day of the date, time, where he/she is and the reason for the hospitalization
- Keep a clock and calendar in your loved one's room

Help your loved one feel calmer

- Bring personal items to the hospital
- Sit with your loved one as much as possible
- Offer warm milk or a gentle back rub before bedtime

For the Caregiver

Help with Delirium at Home



If your loved one develops delirium in the hospital, he/she will need special care when returning home.

Your loved one needs at least 4-6 hours of uninterrupted sleep at night.

If your loved one is having trouble sleeping try:

- Decreasing noise at night
- Providing a warm drink of milk before bedtime
- Offering your loved one a back rub for 10-15 minutes before bedtime
- Encourage your loved one to stay awake during the day

Help your loved one to stay oriented to time and place

- Gently remind your loved one several times per day about the date, time and surroundings
- Keep a clock and a calendar inside your loved one's bedroom
- Make sure your loved one has his/her glasses or hearing aids
- Keep a light on in your loved one's bedroom during daylight

For the Caregiver

More Help with Delirium at Home



When your loved one comes home from the hospital:

- Make sure he/she is taking the right medications, in the right dose, at the right time
 - Medications may have been started or stopped when your loved one was in the hospital
 - If you have any questions, contact your loved one's doctor or nurse immediately
- Watch for signs that your loved one is in pain or is constipated
- Notify the hospital staff if your loved one is showing symptoms of pain or constipation or exhibiting any unusual behavior

For the Caregiver

Help with Sleeping



Remember that any change may affect sleep

- Sleeping place
- Caregiver change
- Different visitors

Things to try

- Review medications with your loved one's doctor
- Keep previous sleeping and waking habits in mind
- Increase physical activity
- Provide a calm, predictable setting
- Go to bed at the same time every night
- Create and keep a bedtime routine

Things to avoid

- Napping during the day
- Alcohol, caffeine and heavy or spicy foods prior to bed time

For the Caregiver

Help Verbal Noises



Create calm, predictable, relaxing surroundings

- Use touch, massage and hugs or gently rock your loved one
- Play soft or relaxing music
- Speak in a soothing tone
- Create and keep a daily routine and schedule for your loved one
- Look for things in the area that might frighten your loved one

Assure that your loved one is comfortable

- Provide enough meals, drinks and snacks
- Make sure your loved one is clean and dry
- Make sure clothing is comfortable
- Regularly check the position of your loved one's body

Watch for changes in your loved one's health

- Look for signs of pain or illness
- Ask the doctor or nurse to review your loved one's medications

For the Caregiver

Help with Repetitive Behavior or Words



Repetition may be:

- Caused by the loss of short term memory so your loved one cannot remember they are repeating
- An attempt by your loved one to regain some control
- A method of trying to get attention or to pass on information that your loved one cannot express any other way
- An attempt at being social

Things to try

- Create and keep a daily routine and schedule
- Distract your loved one
 - Keep him or her busy
 - Redirect with music or food
 - Make video or audiotapes of the family available
- Give your loved one a note with the answer to the question he/she is repeating.
- Reassure your loved one with a gentle touch, if he/she is open to being touched
- Answer questions in the same words and in the same tone of voice each time the question is asked

Keep in mind

- Repetition is caused by the disease; your loved one is not trying to annoy you
- Sometimes ignoring the behavior is best, especially if you are getting angry
- Interrupting a repetitious behavior may upset your loved one

For the Caregiver

Sundowning



Catastrophic Reactions: Sudden, unexpected response that seems to be an overreaction to what occurred.

Sundown Syndrome: Increased agitation or aggressive behavior occurring late in the day.

| WHY does my loved one do that? | Things to TRY to avoid or minimize the behaviors |
|---|---|
| Surroundings are too stimulating, confusing or new | Simplify the surroundings |
| Change in the routine or caregiver | Create and keep a daily routine and schedule |
| Caregiver is agitated, frustrated or impatient | Maintain a positive, matter-of-fact, calm approach |
| Too many demands are being made on your loved one | Simplify instructions and do not ask questions that require good memory |
| Brain damage from the disease causes misunderstanding of surroundings | Do not argue or disagree; what seems real to your loved one is different than what is real to you |
| Side effect of medication | Suggest a medication review |

For the Caregiver

Help with Paranoia



Paranoia: Worrying that something bad may happen or that others are out to get you.

Memory loss may cause your loved one to have trouble understanding what is real and what is not.

Remember not to take being accused personally. Paranoia is a part of the disease.

Things to try

- Create a keep a daily routine and schedule
- Maintain calm, predictable surroundings with familiar objects around
- When surroundings must change, try to prepare your loved one
- Do not argue or disagree; what seems real to your loved one is different than what is real to you
- Check out your loved one's suspicions; they may be based on fact
- Use touch to reassure your loved one, if he/she is open to being touched

For the Caregiver

Help with Hallucinations



Hallucination: A hallucination is when a person hears, sees, feels, smells or tastes something that is not really there.

A hallucination is not based on reality.

Delusion: A delusion is false belief not based on a person's surroundings.

Usually the belief is not consistent with what the person knows as fact and has experienced.

Things to try

- Make sure there is adequate lighting
- Do not argue or disagree
- Distract your loved one with other activities

Consider professional medical help

- Request a medication review; some medications can cause hallucinations
- Have a hearing and vision test performed
- Get a medical evaluation
- A psychiatric evaluation may be needed

For the Caregiver

Help with Inappropriate Sexual Behavior



Look for patterns or explanations

- Is the behavior simply an expression of affection?
- Is the room temperature comfortable?
- Is clothing comfortable?
- Does your loved one need to go to the bathroom?
- Are there specific times when the behavior happens? Bath time, bed time?

Things to try

- Keep routine, surroundings and caregiver consistent
- Distract your loved one with food, drink, a walk or other activity
- Ignore the remark or behavior
- Avoid scolding or trying to reason
- Answer in a matter-of-fact tone
- Provide appropriate affection such as a hug or holding hands
- Encourage the family to show affection; this may be what your loved one wants