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## INTRODUCTION

Most people with dementia undergo behavioral changes during the course of the disease. They may become anxious or repeat the same question or activity over and over. The unpredictability of these changes can be stressful for caregivers. As the disease progresses, your loved one's behavior may seem inappropriate, childlike or impulsive. Anticipating behavioral changes and understanding the causes can help you deal with them more effectively.

### What is the behavior telling you?

Persons with dementia often lose their ability to express themselves before they lose their ability to understand. Behavior becomes a means of communication. Ask yourself why your loved one is behaving this way. Then you can take steps to manage the behavior.

### Tips for managing behavioral changes

When your loved one exhibits an undesirable behavior, your reaction may be to try to stop or change the behavior. But remember, you can't reason with or teach new skills to a person with dementia. Instead, try to decrease the intensity or frequency of the behavior. Consider these approaches:

- **Remember that your loved one isn't acting this way on purpose.** Try not to get angry or upset or take it personally.
- **Speak calmly** and softly to the person.
- **If the behavior is aggressive, back away.** Give your loved one space. Then calmly approach him or her. **Don't argue.**
- **Consider the potential cause of the behavior.** Is your loved one tired, hungry, in pain, frustrated, lonely, bored? Could it be a side effect of medication?
- **Respond to the emotion,** not the behavior. If your loved one keeps asking about a certain family member, he or she may need reassurance that this person is healthy and safe. Avoid trying to reason with the patient, this may often lead to frustration for both of you, because he or she may be unable to follow lengthy explanations.

If a behavior continues, keep a journal to identify patterns (time of day and possible triggering events), and this may provide clues regarding ways to intervene.

### Validate, Join and Distract

One effective method for managing a difficult or annoying behavior is to validate, join and distract. For example, if your loved one constantly heads to the door asking to go home, efforts to try to distract him may not work. By simply interrupting the behavior, you don't gain an understanding of why the behavior is occurring.



A more effective approach is to try to validate the emotion that you think is underlying the behavior. For example, say something like, "I know you miss your family." Then sit down and look through family photo albums. This way, you haven't just distracted the person but you've first joined in and validated the person's emotions. Validating, joining and then using distraction may be most effective with people who are in the early to middle stages of the disease.

### **You know your loved one best**

Let your knowledge of your loved one who has dementia guide your choices for distractions. For example, if she was a homemaker, stirring cookie dough or folding laundry may be meaningful activities. Responding to challenging behaviors takes creative solutions, patience and a willingness to be flexible.

## **USING ROUTINES**

Although persons with dementia typically lose recent memory skills, habits are a part of a different memory structure in the brain that tends to remain intact longer. By sticking to the same routine, your loved one doesn't have to stop and think about what to do next. The routine becomes automatic. Components of a routine may include eating breakfast before getting dressed, sitting in the same recliner in the living room each morning, attending elder care in the afternoon and taking a bath in the evening.

Although organizing your own day may take little conscious effort, giving structure to the day of a person with dementia may pose special challenges. Thinking for two takes sensitivity, ingenuity and patience.

### **Using routine as a tool**

As a caregiver, you know your loved one's daily rituals better than anyone else. And, you're in a unique position to customize and refine your loved one's routine so that it includes meaningful activities for as long as possible. These daily activities, which may seem insignificant, honor the life of your loved one and provide him or her with a sense of purpose.

Keep in mind that just because your loved one is changing doesn't mean other things must change. Where objects are located in your home, and when and where routine activities happen can stay the same even as your loved one's disease progresses.

Other aspects of daily life should remain the same and be strengthened. These may include:

- Personal hygiene routines
- Mealtime routines such as preparation, serving, eating and cleanup
- Household chores such as doing laundry, sweeping and dusting

You can use each one of these activities to reinforce routine and capitalize on your loved one's strengths and interests.



These daily tasks also take advantage of procedural or habit memory. By capitalizing on the memory your loved one retains the longest, namely habit memory; you can involve him or her in meaningful, purposeful activities for longer.

The progressive nature of LBD, Alzheimer's, and other forms of dementia requires that you re-examine your routine frequently — especially if you notice your loved one is agitated, unsettled or depressed. There will come a time when you can't sustain even basic routines. At this point, flexibility is important. Maybe your loved one used to read the paper each morning but no longer can read. He or she may still be able to hold the paper and turn the pages, and if this is an activity that he or she enjoys and is meaningful to them, then it should be allowed to continue.

It is important for caregivers to step down expectations as the disease advances. Routine is a tool. Because no two people respond the same to a routine, it's up to caregivers to decide what works best for them and the loved ones in their care.

### **Here are some tips for maintaining a routine:**

- Identify the routine. Routine tasks are those performed on a daily basis. Dressing for the day or walking the dog are routine tasks. Taking an annual trip to a cabin with extended family is not, and your loved one may now find it unsettling.
- Retain important rituals. Maybe your wife preferred to eat the evening meal at a television tray in the living room. By continuing this habit in the same environment, you may cue your wife to eat and serve as a bridge to positive memories.
- Remove distractions and limit choices. This may mean narrowing the clothing choices in the closet, offering two possible outfits to wear (or asking if your loved one would care to wear one particular outfit). It also may mean relocating an item in the house that may otherwise cause your loved one to lose interest in the task at hand.
- Recognize that change may be necessary. Maybe your husband always helped set the table. As the disease advances, you can continue this routine with some changes. Perhaps your husband can continue to just put the spoons on the table, or maybe he can hold the spoons for a while before you put them on the table yourself. Educate your family and friends about the disease. Too many people visiting at one time may overwhelm your loved one and upset your routine. Before your friends visit, give them communication tips, such as not asking your loved one too many questions. (See "The Importance of Maintaining a Support Network.")
- Stay flexible. You can't schedule every activity and event in advance. When an unexpected or unforeseen change occurs in the routine, just restart your routine the next day.



## COMMUNICATING EFFECTIVELY WITH THE PERSON WHO HAS DEMENTIA

As a person's condition progresses, his or her ability to communicate diminishes. Understanding the effects of the disease will help you communicate as effectively as possible for as long as possible

Your loved one may:

- Be unable to remember names, thoughts or memories
- Use the wrong words or invent words
- Mispronounce or repeat words
- Have difficulty organizing thoughts
- May be easily distracted
- Use more nonverbal gesture
- Lose ability to reason and understand
- Use language that is more direct or accusatory
- May become withdrawn and speak very little

Medications and other health problems also may affect communication. If you notice significant or abrupt changes in your loved one's ability to communicate, talk to his or her physician.

**Tips for better communication.** Although you may find these changes frustrating and even alarming, you can counter them. Consider using these tips to improve communication with your loved one:

- **Make the effort.** When communicating becomes difficult, your first response may be to stop. Recognize that communicating effectively may take more time and energy. Making the effort will help you sustain this vital aspect of your relationship with your loved one as well as preserve your loved one's dignity.
- **Try to understand.** Rather than correcting mispronunciations or inaccurate statements, recognize that your loved one may no longer be able to consistently come up with the right words, or may have trouble comprehending what you're saying. Be patient and use phrases such as "I'm sorry, could you repeat that?" or keep the flow of conversation going by providing the elusive word.
- **Speak slowly, calmly and quietly.** This will allow the person time to process what you are saying. People with dementia often watch our non-verbal cues (facial expression, body language, tone of voice) to interpret what we are saying and may mirror our mood.



- **Avoid quizzing, testing or trying to teach the person to remember.** These techniques won't work and will only serve to embarrass and humiliate. Imagine the feelings associated with not being able to recall a child's name during such a test. Instead of saying, "Do you know who this is?" try "Here is your granddaughter Susan who has come to visit."
- **Reassure and comfort. Do not reality-orient.** The person may be worried about the children, parents, going "home" even if living at home or going to work even if long retired. Trying to convince them of the truth is generally fruitless and can be frustrating or even frightening. Jump into their world and help to make it less frightening by providing lots of reassurance. For example, if your loved one is worried because the children are not home from school yet, provide an explanation that might be acceptable and reassuring such as, "the children are staying at a friend's house tonight, they are having a nice time". If your loved one does not recognize you, go along with it or try stepping out of the room and announce your identity upon your return.
- **Be aware of your nonverbal communication.** Speak slowly, calmly and in a normal volume. People with dementia can be sensitive to changes in mood, voice, posture or facial expression. You can do wonders to ease tension by smiling at a frustrating moment. If you have difficulty understanding what your loved one is saying, listen for the feelings behind what he or she is trying to communicate and validate those feelings. For example, say, "I know that you're frustrated right now" or "I'm glad you're so happy today."
- **Forgive yourself when you don't always respond appropriately.** You may find it difficult to communicate with as much understanding and patience as you'd like to. Keep in mind that because of the memory loss, your loved one is unlikely to remember everything you say.
- **Simplify your communication.** Stand directly in front of your loved one and make eye contact. Communicate one idea at a time and use simple instructions. Try breaking even simple tasks into one-step commands. If you're helping with a task, let your loved one know what you're going to do next. If possible, demonstrate what you want your loved one to do — such as brushing teeth or putting on a jacket. If you must repeat things, try to use the same words. If your loved one doesn't understand a second time, then try rewording. Avoid abstract concepts, which your loved one may find difficult to grasp. For example, phrases such as "jump into bed" can be confusing. Instead, use direct statements such as "it's time to get into bed."
- **Validate the feeling behind the words.** Even if you are unable to understand what is being communicated, look at the non-verbal signs of emotion. Is she upset? Joyful? Afraid? Respond accordingly providing lots of affection and comfort.
- **Reminiscence can be very useful and validating.** Persons with dementia usually retain their memories from long ago. Discussing these memories and prior accomplishments often provide a sense of security.



- **Do not try to argue or reason with the person.** Their ability to reason is no longer there, and the person will not be able to remember your reasoning or rationally weigh your points. Do not argue with the person over what they see, hear or feel. If the person is seeing things you don't see, reassure him and respond to his or her feelings about it. Remember that these ideas or hallucinations are very real to the person who is experiencing them. Rather, offer reassurance and validation (e.g., "I know this is troubling for you, let me see if I can help").
- **Reduce clutter, extraneous noises or confusing aspects in the environment.** Check out any real basis to the person's fear. For example, the person may "hear people" in the next room because the TV is on.
- **If the person misplaced something and thinks you or someone else "stole it," offer to help look for the item.** Keep track of frequent hiding places, and if possible keep duplicates of the item.
- **Accept changes.** Keep in mind that the changes you see and hear in your loved one are a result of the disease, not of your loved one trying to be difficult or hurtful. When your loved one says inappropriate things, remember it's the disease talking. Try not to take it personally.

Even when your loved one no longer responds in the way he or she once did, your efforts to communicate will help to keep him or her engaged in life for as long as possible.

### WANDERING

People with dementia are likely to walk or pace aimlessly at some point during the disease. This wandering behavior can occur both indoors and outdoors, and it may have several causes. It may be the result of memory loss and disorientation. It may be a sign of curiosity, restlessness or boredom. Or it may be an attempt to express an emotion, such as fear or loneliness, or basic need, such as hunger or thirst. Here are some tips to help cope with this challenge, determine which ones work best for you and adapt them to your specific situation.

To help reduce or manage your loved one's tendency to wander:

- **Understand the disease process.** People with dementia often have deteriorating communication skills. When language is gone, behaviors may be the only way your loved one can communicate. By wandering, your loved one may be trying to share feelings of fear, isolation, loneliness or confusion. Provide comfort with a hug and a reminder that he or she is safe and in the right place.
- **Make sure your loved one is getting enough food, drink, rest and opportunities to use the bathroom.** If your loved one has trouble expressing wants, wandering may be the only way he or she can tell you that these basic needs aren't being met.



- **Take a daily walk or engage in exercise with your loved one, if possible.** This may reduce anxiety, agitation and restlessness and reduce the tendency to wander.
- **Allow your loved one to wander in safe areas, such as a fenced yard or looping set of hallways, with supervision.** This can be a natural way to explore and adapt to surroundings.
- **Maintain a quiet environment.** Wandering can occur when there's too much stimulation, such as multiple conversations or a loud television.
- **Keep your loved one engaged in daily chores and activities.** Restlessness and boredom can lead to wandering.
- **Make your living space safer by removing throw rugs, moving electrical cords and possibly rearranging furniture.** Use night lights and install gates at stairwells in case your loved one wanders at night.
- **Install childproof doorknobs or latches mounted high on doors or post a stop sign on your home's exit doors.** This may deter outdoor wandering.
- **Keep a family photo album handy.** Your loved one's wandering may indicate a desire to look for family members or something familiar.
- **Post signs that say "Bathroom," "Bedroom" and "Kitchen" on the corresponding doors in your home.** Your loved one may forget where he or she is and may have difficulty finding these rooms without guidance.
- **Keep car keys out of sight.** Wandering doesn't always occur on foot.
- **If your loved one tries to leave the house, do not stop him.** Forcefully trying to restrain a person set on leaving can result in injury and a catastrophic reaction (severe distress). Rather, go with him or her for a "walk", go on an outing (even if it just for a drive around the block), or let them go and then follow them to ensure safety. Even if it is the middle of the night, the few minutes you go for a walk is better than the hours of distress (and possibly injury) associated with trying to stop a person with dementia from leaving
- **Enroll your loved one in the Alzheimer's Association's "Safe Return" program.** This is a nationwide identification system designed to assist in the safe return of people who become lost when wandering. Caregivers pay about a \$40.00 registration fee. In return, they receive an ID bracelet, name labels for clothing, ID cards for a wallet or a purse, registration in a national database with emergency contact information, access to a nationwide alert system and a 24-hour toll-free number for reporting lost persons. To register someone, contact a local chapter of the Alzheimer's Association or call 800-272-3900.



## PREVENTING OR DEFUSING AGGRESSION OR CATASTROPHIC REACTIONS

When people with dementia become frustrated, scared or unable to communicate, they may become irritable or angry. Sometimes a person may experience a catastrophic reaction. This may occur in response to variety of occurrences including: loud noise (radio, TV, person), multiple questions, “why” questions, feeling insecure, feeling left out, small accidents, being reprimanded, arguments, a tense or irritable caregiver, or tasks that are too difficult. Try to see the situation from the patient’s point of view.

- **Make sure your loved one gets enough sleep.** Fatigue can cause combativeness.
- **Reduce loud noises and physical clutter in your home.** Loud noises and clutter can over stimulate your loved one. Limit guests to one or two at a time, and use television sparingly.
- **Don’t expect too much.** Don’t try to teach new information or ask your loved one to perform tasks he or she has been unable to complete in the past. This only results in frustration.
- **Include exercise** and light housekeeping chores in your loved one’s daily routine. This may reduce the restlessness that can lead to agitation and aggression.
- **Don’t argue with or quiz your loved one to test his or her memory.** This can lead to agitation. If you need to ask your loved one questions, make them easy to understand and ask them one at a time.
- **Keep your loved one’s routine and environment consistent and simple.** Changes — even small ones — can cause agitation. If you need to make changes, make them gradually.
- **Try to be pleasant.** If you’re feeling angry, stressed, irritated or impatient, try not to let it show. Respond to your loved one in a calm, reassuring way. That doesn’t mean you should deny your feelings, however. Just try to deal with them at a later time, and it may be a cue that it is time to obtain additional assistance, so you can have some respite from caregiving responsibilities.
- **If your loved one becomes frustrated, provide reassurance and distract him or her with another activity.** After some time has elapsed, you can return to the original activity if necessary.
- **Don’t panic.** If your loved one becomes agitated or aggressive, don’t resort to physical force. Try instead to soothe your loved one by holding hands, gently patting his or her back. Some people do not like to be touched when they are feeling agitated, and for those individuals it may be best to leave the room or to sit quietly a safe distance from him or her.
- **Consider the 5 “R”s in handling catastrophic reactions: Remain calm, respond to feelings, reassure the person, remove yourself, return later.**
- **Check out the reality of a situation;** maybe what the person says or thinks is true.





- **Remember that whispering or laughing around the person may be misinterpreted.**
- **Consult a physician.** Sometimes agitation is caused or aggravated by physical symptoms of pain, discomfort, physical illness or a co-occurring depression.

### BENEFITS OF EXERCISE FOR PEOPLE WITH DEMENTIA

Exercise may not be high on your list of caregiving priorities. But you should consider it. There are many well-documented benefits of exercise for people who have dementia — benefits that also may make it easier for you to cope.

#### Benefits of exercise

Helping your loved one stay active may:

- Improve strength, endurance and cardiovascular health
- Reduce risk of falls and fractures
- Improve energy, circulation, stamina and mood
- Improve sleep
- Promote regular bowel and bladder function
- Help maintain flexibility and balance, reducing the risk of serious injury from falls
- Help sustain the ability to perform self-care activities, such as grooming and dressing
- Impart a sense of belonging, purpose and contribution
- Create a calming effect through familiar activity.

#### Getting started:

If you're interested in making exercise part of your loved one's daily routine, consider these tips:

- **Consult your loved one's doctor first.** Other medical conditions that your loved one may have, such as high blood pressure or heart disease, may affect the type of program you can establish.
- **Offer support and encouragement but not pressure.** Pushing your loved one beyond what he or she is comfortable doing may cause frustration.
- **Go with the familiar.** Plan safe, supervised activities your loved one has enjoyed in the past, such as walking, swimming, golf or tennis. These offer the best chances for success.
- **Exercise with your loved one.** This may even help you manage the stress of caregiving.
- **Adapt activities to your particular situation.** If your loved one was once an avid golfer, for example, hitting chip shots in the backyard still may provide enjoyment.



- **Establish a regular routine.** Exercise at the same time each day, if possible, and keep the sequence of activities the same each time. If you and your loved one walk together, for example, use the same walking path each time to minimize confusion. When it rains, walk inside a mall or in your home.
- **Ask your loved one to follow your lead while exercising.** Offer simple instructions or directions. Or use an exercise videotape as a guide for some light stretching or calisthenics.
- **Look to outside resources.** If your loved one enjoys exercising with others, contact your local senior citizen's center for information about group exercise programs.
- **Look for creative options.** Walk outdoors and watch birds as you go, or dance to music that your loved one enjoys. If outdoor gardening is no longer an option, plant and tend an indoor container garden or take a walk in a local nursery.
- **Wear loose-fitting clothes and comfortable shoes.** If you're exercising outdoors in cool weather, wear layers of clothing appropriate to the temperature. This is especially important if your loved one has lost the judgment required to solve everyday problems, such as knowing what to do if he or she gets too cold.
- **Remember to warm up.** Before any activity, walk for a few minutes and then do gentle stretching exercises for the upper and lower body.
- **Watch for changes in your loved one's capacity for exercise.** As dementia progresses, his or her capacity for exercise decreases. If you see this happening, cut back or try less strenuous activities so that your loved one can stay active as long as possible.
- **Never ignore comments about pain, dizziness or shortness of breath.** Consult a doctor if your loved one complains of these symptoms.

### Keep it fun

When factoring exercise into your care giving goals, aim to help your loved one remain as independent as possible while providing exercise options that offer purpose, meaning, pleasure and fun. In the process, exercise may even enhance your relationship.

## MANAGING SLEEP PROBLEMS

Nearly 90 percent of adults older than 65 who live at home have complaints about sleep. However, among people with dementia, the problem is even more severe. In fact, sleep problems are one reason people with dementia end up in nursing homes.

Stress, alcohol use, poor sleep habits, certain medications and an additional illness can all contribute to disturbed sleep among people with dementia, as can an underlying sleep disorder.



## What is "sundowning"?

Many people with dementia experience periods of increased agitation, confusion and restlessness beginning at dusk and continuing through the night. This late-day phenomenon has sometimes been called sundowning. Nighttime agitation can make it impossible for the person under your care to get the sleep he or she needs to function well. How to cope: To help prevent nighttime agitation in your loved one with dementia, try these tips:

- **Don't serve your loved one alcohol.** It contributes to confusion and can increase anxiety. If the person insists on having a drink, try serving a nonalcoholic drink in a familiar cocktail glass, or serve nonalcoholic beer or wine.
- **Limit caffeine-containing foods and beverages (sodas, coffee, chocolate) to mornings only.** Consuming caffeine later in the day can cause sleeplessness.
- **Plan to go outside, or have your loved one sit near natural light.** Exposure to sunlight helps to set the body's internal clock and may also improve mood.
- **Plan days to include plenty of interesting activities.** Involvement in daytime tasks, such as walks, car rides or exercise help to keep the day filled with meaningful activities. However, avoid overstimulation. This can lead to exhaustion and disorientation. Taper activities off as the day winds down.
- **Establish set times for getting up and going to bed.** Try not to deviate from those times. If possible, set the same sleep and wake schedule the person maintained during his or her working years. If you feel your loved one is sleeping too late, wake him or her up earlier.
- **Limit daytime napping.** If your loved one needs a nap, make sure it's short and not too late in the day. Have him or her take the nap on the couch or in a recliner rather than in bed. Reserve the bed for nighttime sleep.
- **Feed your loved one a light snack before bed.** If he or she awakens during the middle of the night, try warm milk or herbal tea.
- **Establish a bedtime routine of relaxing activities, such as listening to soft music or giving your loved one a backrub.** Do the same things in the same way every night (including using the bathroom before bed). The structure and routine may be comforting to the person with dementia.
- **Avoid upsetting activities near bedtime.** If bathing or dressing for bed is difficult, do it earlier in the day. Let your loved one use the couch or recliner if he or she refuses to go to bed.
- **Create a comfortable, familiar place for sleeping.** Make sure the bedroom is cool and quiet. Have extra blankets available, if needed, especially a favorite blanket, pillow or soft object. Make sure that the person's bed linens and pajamas aren't too restrictive or full of uncomfortable wrinkles and folds. Use a night light in the room.



- **Make sure the bedroom is safety-proofed.** Keep the area around the bed uncluttered, and make sure the path to the bathroom is clear and softly lit.
- **If your loved one has a tendency to act out his or her dreams, make sure there are no breakable objects nearby and check with your doctor about treatment.**
- **If your loved one awakens during the middle of the night and is upset, stay calm.** Ask what he or she needs, and reassure that everything is all right. A reminder of the time of day may be helpful. Don't argue or demand explanations. If you find your loved one wandering in the house, gently guide him or her back to bed or ask if there is a need to go to the bathroom or a desire for a drink of water, and then a gentle reminder that it is time to go to bed.
- **Your doctor can help.** If these tactics don't work, call your doctor. Physical ailments such as bladder or incontinence problems could be interfering with your loved one's sleep. Your loved one may have an underlying sleep disorder, such as Sleep Apnea or Periodic Limb Movement Disorder that may benefit from evaluation and treatment. Your doctor may also be able to prescribe medication to help the person relax at night or may be able to change a medication if it's disturbing sleep.

### SMOOTHING THE TRANSITION ON MOVING DAY

Moving from one house to another can spur anxiety in almost anybody. For people with dementia, however, changes in routine and an unfamiliar environment can be especially stressful. Here's some advice for making the transition to a new home or care facility as comfortable as possible for the person with dementia.

#### Add familiar touches

Even before you bring a loved one to a new home; it's important that the room or space where the person will be is made to look and feel as familiar as possible.

When your loved one sees his or her things, it triggers that it's your loved one's own space — which is important. Some things you can do before the person moves in include:

- Add a favorite quilt or piece of furniture, such as a chair, perhaps a shelf with special items, and other meaningful possessions belonging to the person.
- Bring pictures of family and friends, memory books or photo albums. These are particularly important.

Reminiscing about the past is especially important for people with dementia, and items that enable them do this help create comfort and reduce anxiety. Label the pictures so staff will know the names of the people in them and can talk more knowingly about them.



## **Make a moving day plan**

Plan for the day that you will have to move your loved one. Talk to your loved one — while he or she can still make choices — about what he or she wants. Where does your loved one want to live? Explore all your housing options. Start talking before a move is imminent.

On the actual day, move your loved one during the "best" time of his or her day — whether morning or afternoon. This can also make the transition go more smoothly.

In addition, spend time during moving day reminiscing with your loved one, looking at photo albums or memory boxes. This activity is helpful not only for relieving anxiety in the person with the disorder but also for you.

## **FINDING IN-HOME CAREGIVERS**

As primary caregiver for your loved one with dementia, you know what an overwhelming and time-consuming job it can be. Even with help from extended family, you may reach a point where you need to enlist the help of others — whether church volunteers or home health aides — to allow you to take short breaks or to provide ongoing help.

It's important to know what options are available in your community for caregiving assistance. The key is to identify these options before you need them because it may take some time to implement them. Here's how to get started.

### **Consider what kind of help you need**

As primary caregiver, you know your loved one's routines, medical concerns and personality. Does your loved one need:

- Consistent companionship and socialization?
- Supervision during certain hours of the day for safety reasons?
- Help with dressing, bathing or eating?
- Medical assistance with injections, a catheter or a medical device, such as an oxygen tank?

Also, take into consideration your own needs. Do you need regular help with certain household chores or short breaks from your caregiving responsibilities? Your answers to these questions will help guide you to the appropriate individuals and agencies.

### **Examine your options for help**

Depending on your need, you have several options for help:



- **Volunteer assistance.** You may find willing volunteers in your neighborhood, church or workplace. Volunteers can provide companionship for your loved one as well as assist you with tasks such as running errands, driving to and from doctor's appointments or making meals. The Area Agency on Aging's Elder Locator may be able to help you find a volunteer. Call 800-677-1116 to find the agency nearest you.
- **Homemakers.** They provide home management services, including vacuuming, grocery shopping, laundry and meal preparation.
- **Home health aides and personal care attendants.** These people assist with personal care, such as bathing, dressing and grooming. They work under the supervision of a professional nurse or physical or speech therapist.

Your local Alzheimer's Association chapter can help you identify volunteer programs, trained individuals and the names of agencies that provide other supportive and health care services. To locate your local chapter of the Alzheimer's Association, call 800-272-3900.

To help you narrow your caregiving-assistance options, consider the following:

- **Specialized skills required.** Does your loved one have difficulty communicating or walking, have safety concerns or need help in the bathroom?
- **Time needed.** How much help do you need? A few hours a week, a couple of days a week, every day, overnight or weekends? Also, factor in your own need for time to do errands and to rest.
- **Best location.** Where can care be provided? At home or at an elder care facility, a residential setting or a medical care facility?
- **Payment options.** How will you pay for the care? Check what your loved one's insurance will cover. Consult with physician for prescriptive in-home help, such as visiting nurses. Contact an elder attorney for assistance with determining what your state allows for financial assistance and medicare/medicaid assistance. Does your loved one qualify for government assistance? If you're planning to pay out-of-pocket, how much are you able to spend?

### Hiring help

Develop a list of questions to guide your inquiries and interviews with job candidates. Here are several questions to get you started:

- What training have you had?
- What past in-home care experience have you had?
- What is your past experience working with someone who has dementia?
- Why are you interested in this type of work?



- What special skills do you have, such as singing, playing the piano, doing activities?

Some additional tips:

- **Ask the candidate to respond to a particular hypothetical situation.** For example, "If my father insists that he can leave the house and drive the car, what would you do?"
- **Get recommendations and check references.** You can get recommendations from local home health care agencies, your local Office on Aging, the American Association of Retired Persons or your local Alzheimer's Association chapter. Always check the candidate's references.

Entrusting your loved one to the care of others is a big step. But don't be afraid to ask for help when you need it. By taking the time to pinpoint your needs and identify the appropriate type of help, you can rest assured that you're doing the best thing for yourself and your loved one.

### CARE FOR THE CAREGIVER

As a caregiver, it is very important that you make sure your own needs are met and that you take care of yourself as well.

- Identify the stressors in your caregiving role. What tasks or behaviors are most frustrating or anxiety-producing? Think through and plan your responses to these stressful situations.
- Access all the information you can about the disease and educate yourself as much as possible about its progression.
- Get adequate rest.
- Try to keep incidents in perspective.
- Write feelings or thoughts in a journal. Writing things down will often help put them into better perspective and will be a way of releasing emotions.
- Set realistic goals regarding what and how much you can do for your loved one.
- Be good to yourself. Give yourself frequent praise and rewards for your patience and endurance. Continue to find ways to have fun.
- Use your sense of humor – it relieves stress and is a positive emotional release for both of you.
- Identify and be willing to use your support system. Avoid isolation. Have someone available to vent.
- If family or friends offer help, accept it.
- Set aside certain days or parts of certain days for yourself, and find a companion or day program for your loved one for that period of time.



- Forgive yourself for not being perfect and stop trying to be perfect. Don't be hard on yourself when you experience impatience, frustration, sadness or anger.
- Take care of yourself physically and emotionally. Eat well balanced meals, get regular checkups and exercise.
- Find sources for personal satisfaction.

### **SUPPORT GROUPS: SHOULD I JOIN ONE?**

Caring for a person with dementia can be an overwhelming experience. The physical demands can be exhausting. In addition, there is the emotional stress of trying to balance caregiving with your job, family and other relationships. It's not uncommon to feel angry, guilty, frustrated, discouraged, worried, grief-stricken, isolated and taken for granted.

A dementia support group provides you with an opportunity to share these feelings, learn new caregiving techniques and identify resources.

#### **Benefits of support groups**

- Provide you with up-to-date information and ongoing education about dementia and caregiving
- Provide practical suggestions regarding challenging behaviors
- Allow you to verbalize your thoughts and feelings about caregiving
- Teach you various methods of coping with the stress of caregiving
- Identify additional caregiving options and resources
- Help prepare you for future planning and decision making
- Give you the opportunity to meet other people who can empathize with your situation

#### **Do you have to join a group?**

Support groups aren't for everyone. Some people find that friends and family are sufficient. However, support groups can be beneficial if you find you're emotionally drained in spite of support from your family and friends. You may feel less alone when talking with others who face similar dementia challenges.

#### **Types of groups**

In general, support groups fall into two main categories: those led by professional facilitators (doctor, nurse, social worker) and those led by group members, which are often called peer or self-help groups.

Some groups are more educational and structured. Members may invite a doctor to talk about a specific challenge of dementia or a new experimental treatment. Other groups emphasize emotional support and shared experience.





In addition to traditional support groups, the Internet offers virtual dementia support groups and communities. There are LBD support groups listed on the Lewy Body Dementia Association website ([www.lbda.org](http://www.lbda.org)).

The Alzheimer's Association's caregivers' community ([www.alzconnected.org/](http://www.alzconnected.org/)) allows you to connect with other caregivers and share artwork, poetry and short stories related to your experience.

### **Finding a group**

To find a dementia support group near you:

- Visit the Lewy Body Dementia Association website and click on Find Support for local and online LBD support groups.
- Visit the Alzheimer's Association website and click on In My Area. Type in your ZIP code or search by state.
- Contact the Area Agency on Aging in your area.
- Ask a health care provider for assistance. A doctor, nurse, social worker, clergy member or psychologist may be able to refer you to a local dementia support group.
- Check your local telephone book and newspaper for a listing of dementia support resources.
- Contact community centers, libraries, churches or synagogues in your area. Some offer support groups.
- Ask others you know for suggestions.

Most support groups are free, collect voluntary donations or charge only modest membership dues to cover expenses.

### **Choosing a support group**

Choosing a group that's right for you depends on several factors. The key is finding one that matches your needs - and personality.

You may find that you prefer a structured, moderated group. Or you may feel more at ease meeting less formally with a small group of people. The anonymity of going online may be appealing, but the trade-off may be that you don't know who else is online with you or whether you can believe everything you read.

If you decide to take part in a group (real or virtual), try it out a few times. If you don't find it useful or comfortable, you don't have to continue. Trust your gut feeling. If you're nervous or hesitant about sharing personal issues with a group of people you don't know, consider attending one meeting. You don't have to talk, and you may gain from just listening.





## Understanding Behavioral Changes in Dementia

You may have to experiment with different kinds of support groups before you find one that meets your needs. But keep at it. You may learn new things and form new friendships. And you just might find that a support group helps you cope more effectively with the demands of dementia caregiving in your everyday life.





## Understanding Behavioral Changes in Dementia

**To learn more about LBD,  
visit [www.lbda.org](http://www.lbda.org)**

LBD Caregiver Link:

1-800-LEWYSOS

1-800-539-9767

[lbda@lbda.org](mailto:lbda@lbda.org)

By supporting the work of LBDA, you too will be

**Increasing Knowledge**

**Sharing Experience**

**Building Hope**

Lewy Body Dementia Association

404-935-6444

[www.lbda.org](http://www.lbda.org)

The information set forth in this material is intended for general informational use only. It is not intended to be medical, legal or financial advice or to take the place of competent medical, legal or financial professionals who are familiar with a particular person's situation. Each individual is advised to make an independent judgment regarding the content and use of this information.

