

Alzheimer's & Dementia Education Materials for Clients and Families



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If you have any questions, please do not hesitate to call the BrightStar Care®
Registered Nurse Director of Nursing:

Name:		
Phone Number:		

1. THE CAREGIVER: WHAT TO EXPECT

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Care Partner Resources

At BrightStar Care®, we understand that taking care of someone living with Alzheimer's or dementia can be overwhelming at times. There are many connections that need to be made to optimize your own and your loved one's peace of mind, safety, and security. We'd like to offer a few ideas for important connections to make and related resources that may help you on this journey.

Legal and Financial Resources/Matters to Consider

lacksquare
> Attorney/Legal resource for the following:
– Power of Attorney for Healthcare
- Power of Attorney for Finance
– Legal Guardianship
- Living Will
> Financial Advisor/Accountant
> Income Tax Preparation
Healthcare Resources/Matters to Consider > Geriatrician
> GeroPsychiatrist
> Neurologist
> Counselor
> Preferred Hospital
> Hospice Agency
> Medicare Home Health
> Assisted Living Community
EMOTIONAL SUPPORT > Alzheimer's Association Support Group
> Area Agency on Aging
> Senior Center
HOME SAFETY SUPPORT > Alzheimer's Association Safe Return Program
> RadioShack: Electronic Door Alarms, Door Locks
> Web-based home monitoring systems

Home Safety and Dementia

People with Alzheimer's or dementia can live in their homes, as long as safety measures are in place. As dementia progresses, a person's abilities change. But with some creativity and problem solving, you can adapt the home environment to support these changes.

How Dementia Affects Safety

Dementia causes a number of changes in the brain and body that may affect safety. Depending on the stage of the disease, these can include:

- > Judgment: forgetting how to use household appliances
- > Sense of time and place: getting lost on one's own street; being unable to recognize or find familiar areas in the home
- > Behavior: becoming easily confused, suspicious or fearful
- > Physical ability: having trouble with balance; depending upon a walker or wheelchair to get around
- > Senses: experiencing changes in vision, hearing, sensitivity to temperatures or depth perception

Home Safety Checklist

Assess your home. Look at your home through the eyes of a person with dementia. What objects could injure the person? Identify possible areas of danger. Is it easy to get outside or to other dangerous areas like the kitchen, garage or basement?
Lock or disguise hazardous areas. Cover doors and locks with a painted mural or cloth. Use "Dutch" (half) doors, swinging doors or folding doors to hide entrances to the kitchen, stairwell, workroom and storage areas.
Be prepared for emergencies. Keep a list of emergency phone numbers and addresses for local police and fire departments, hospitals and poison control help lines.
<i>Make sure safety devices are in working order.</i> Have working fire extinguishers, smoke detectors and carbon monoxide detectors.
<i>Install locks out of sight.</i> Place dead bolts either high or low on exterior doors to make it difficult for the person to wander out of the house. Keep an extra set of keys hidden near the door for easy access. Remove locks in bathrooms or bedrooms so the person cannot get locked inside.
<i>Keep walkways well-lit.</i> Add extra lights to entries, doorways, stairways, areas between rooms, and bathrooms. Use night lights in hallways, bedrooms and bathrooms to prevent accidents and reduce disorientation.
<i>Remove and disable guns or other weapons.</i> The presence of a weapon in the home of a person with dementia may lead to unexpected danger. Dementia can cause a person to mistakenly believe that a familiar caregiver is an intruder.
<i>Place medications in a locked drawer or cabinet.</i> To help ensure that medications are taken safely, use a pill box organizer or keep a daily list and check off each medication as it is taken.
<i>Remove tripping hazards.</i> Keep floors and other surfaces clutter-free. Remove objects such as magazine racks, coffee tables and floor lamps.
<i>Watch the temperature of water and food.</i> It may be difficult for the person with dementia to tell the difference between hot and cold. Set water temperature at 120 degrees or less to prevent scalding.
Support the person's needs. Try not to create a home that feels too restrictive. The home should

encourage independence and social interaction. Clear areas for activities.

What is Dementia?

Dementia is a general term used to indicate that a person has developed difficulties with reasoning, judgment, and memory. Irreversible dementia is chronic and progressive. People who have dementia usually have some memory loss and difficulty with at least one other area, such as:

- > Speaking or writing coherently (or understanding what is said or written)
- > Recognizing familiar surroundings
- > Planning and carrying out multi-step tasks

In order to be considered dementia, these changes must be severe enough to interfere with a person's independence and daily activities.

Dementia can be caused by several diseases that affect the brain. The most common cause of irreversible dementia is Alzheimer's disease. Alzheimer's disease accounts for 60-80% of all cases of dementia. There are many different types of dementia; it's important that you discuss your specific diagnosis with your healthcare provider.

Common Causes of Dementia

Alzheimer's disease

Alzheimer's disease is associated with the death of nerve cells (neurons) in important parts of the brain. Scientists have not yet determined exactly why and how AD develops, but they do know that the brains of patients with Alzheimer's disease develop deposits of a protein called beta amyloid (these deposits are also known as plaques), and that people also develop disorganized masses of protein fibers within the brain cells known as neurofibrillary tangles. For more information on Alzheimer's disease and other dementias, please visit the Alzheimer's Association website at www.alz.org, and be sure to take the interactive Brain Tour.

Vascular dementia

People with vascular dementia have lost or damaged areas of brain because of reduced blood flow. This can happen when the blood vessels in the brain get clogged with blood clots or fatty deposits. This form of dementia is more common among people who have had strokes or are at risk for strokes, especially those with long-standing high blood pressure and diabetes. Vascular dementia can occur together with Alzheimer's disease.

Lewy Body dementia

People with Lewy Body dementia often have memory loss and thinking problems but also tend to have significant challenges with sleep, visual hallucinations, and parkinson-like symptoms such as muscle rigidity.

Early-Stage Caregiving

What to Expect

"Early stage" refers to people, irrespective of age, who are diagnosed with Alzheimer's disease or related disorders and are in the beginning stages of the disease. A person in the early stages may experience mild changes in the ability to think and learn, but he or she continues to participate in daily activities and give-and-take dialogue. To others, the person may not appear to have dementia. The early stages of Alzheimer's can last for years.

Your Role as a Care Partner

In the early stages, you may act more like a care partner, than a caregiver. Your role is one of support, love and companionship. You are there to help with daily life, as needed, and to help the person with Alzheimer's plan for the future. Since no two people experience Alzheimer's alike, the degree of assistance needed from a care partner in this stage varies.

A person with early-stage Alzheimer's may need cues and reminders to help with memory. For example, he or she may need help with:

- > Keeping appointments
- > Managing money
- > Doing familiar tasks
- > Planning or organizing
- > Remembering words or names
- > Recalling familiar places or people
- > Keeping track of medications
- > Spiritual

Tap into the person's strengths and encourage him or her to continue living as independently as possible. You can help the person stay organized with shared calendars, notes, medication schedules and other reminder systems. Establishing a daily routine and maintaining some regularity will be of benefit.

The person also will need emotional support. He or she may feel frustrated, anxious, embarrassed or isolated. You can help by:

- > Encouraging the person to share his or her feelings, and asking how you can be supportive
- > Encouraging the person to stay involved in activities he or she enjoys
- > Helping the person locate a support group for people in the early stages and their care partners

As a care partner, you also will go through many emotions. Know that you aren't alone. Being part of a community of people going through similar experiences can provide you with support, hope and information. Contact your local Alzheimer's Association chapter to find an early-stage care partner support group near you.

OUICK TIPS

- > Encourage the person with Alzheimer's to continue living as independently as possible.
- > Educate yourself about Alzheimer's and caregiver resources. Use Alzheimer's Navigator, our free online tool that helps guide you to answers by creating customized action plans.
- > Make legal and financial care decisions for the future.
- > Nurture your relationship by living in and enjoying the moment.
- > Think of ways to complete tasks as a team.
- > Remember there will be good days and bad days.

Know that support is available. Other care partners and families affected by early-stage Alzheimer's disease can help you & your family. Contact the Alzheimer's Association to locate a support group.

Early-Stage Issues

A diagnosis of Alzheimer's is life changing for both the person with the disease and the care partner. Here are some of the issues you may both face:

- > Telling others about the diagnosis. Telling others about a diagnosis of Alzheimer's or dementia is one of the most difficult steps for people diagnosed in the early stages and their care partners. There may be anxiety surrounding who to tell and worry about social stigma. Be open with friends and family about the changes that are taking place. Educate them on the disease and tell them how they can be supportive.
- > Life changes. Even if changes are small at first, a person with early-stage Alzheimer's will have different needs than he or she did before the diagnosis. Support is critical. As a care partner, you'll need a support system in place, too. You may feel anxiety over how your relationship may change or feel distanced from friends and family. Know that you aren't alone, and that help is available.
- > Planning for the future. It's important to have discussions now about topics that will have to be addressed later. As a care partner, one of the most important things you can do is help the person with early-stage Alzheimer's get legal, financial and care plans in place. Doing so allows the person to share his or her wishes for future decisions, and also allows time to work through the complex issues that are involved in long-term care. This is also the time to talk about future safety topics, such as what to do when driving is no longer an option.
- > Staying engaged. People with early-stage Alzheimer's want to stay as engaged and active as possible for as long as possible. As a care partner, you can help foster this by encouraging involvement in daily life and a healthy lifestyle. Staying engaged and healthy is important for care partners as well. Continue being a part of support systems you have in place. Spend time with friends and family. Be a part of activities you love. And don't forget to eat well, exercise and see the doctor regularly.
- > Living alone. With support and resources, many people in the early stages of Alzheimer's live independently. If you are a family member or caregiver for someone who lives on his or her own, stay involved. Call or visit every day, and make sure the person gets the assistance needed, such as help with housekeeping, meals, transportation, bill paying and other daily chores. Put home safety measures in place, and be aware of any changes that would indicate the need for additional supervision or care.

Middle-Stage Caregiving

What to Expect

During the middle stages of Alzheimer's, damage to the brain can make it difficult to express thoughts and perform routine tasks. You may notice the person with Alzheimer's jumbling words, having trouble dressing, getting frustrated or angry, or acting in unexpected ways, such as refusing to bathe.

While these changes are difficult for everyone involved, resources are available to help both you and the person with dementia as the disease progresses. There will be challenging days, but there also will be good days. As your relationship with the person with dementia changes, you will find new ways to connect and deepen your bond.

Your Role as a Caregiver

Being a caregiver for someone in the middle stages of Alzheimer's requires flexibility and patience. As the abilities of the person with Alzheimer's change and functioning independently becomes more difficult, you will have to take on greater responsibility. Daily routines will need to be adapted, and structure will become more important.

As you gain experience as a middle-stage caregiver, you will develop strategies and ways of coping that work for you and the person with dementia. When abilities diminish further, these will need to be modified. The Alzheimer's Association offers educational workshops and resources that can provide you with the caregiving skills needed to deal with changing needs of someone in this stage of the disease. Sharing information with other Alzheimer's caregivers also can be a great source of information and support. Other caregivers truly understand the complex feelings associated with caring for a person with dementia.

As caregiving responsibilities become more demanding, it's important take care of yourself. Take breaks, even if it is only for a few moments. Make sure not to isolate yourself. Learn what respite services are available in your community, and take friends and family up on offers to help. Since paying for long-term care can be a big concern and source of stress, research all your options, if plans are not already in place.

OUICK TIPS FROM OTHER CAREGIVERS

- > Learn what to expect in the middle stages of the disease so you can be prepared.
- > Use a calm voice when responding to repeated questions.
- > Respond to the emotion, instead of the specific question; the person may simply need reassurance.
- > Use simple written reminders if the person can still read.
- > If you notice changes, check with the doctor to rule out other physical problems or medication side effects.

Middle-Stage Caregiving

Middle-Stage Concerns

- > *Changes in behavior*. Changes in behavior can be some of the most distressing for caregivers and family members. During the middle stages, people may experience depression, anxiety, irritability and repetitive behaviors. As the disease progresses, other changes may occur, including sleep changes, physical and verbal outbursts, and wandering. Understanding what behaviors are common during this stage and how to assist the person with dementia can help.
- > Communication. As people with Alzheimer's gradually lose their ability to find words, express thoughts and follow conversations, they also have more difficulty understanding others. Communication changes during the middle stages include trouble finding the right word, repeating questions, losing the train of thought, reverting to a native language and relying on non-verbal communication. You can help improve communication by making simple changes, such as speaking slowly and distinctly in a gentle tone. If you notice sudden changes in communication, make sure to contact the doctor, since this could indicate other medical issues or side effects of medication.
- > Daily care needs. Eating, dressing and grooming will become more challenging as dementia progresses. This loss of independence and privacy can be a very difficult transition for the person with dementia; your patience and sensitivity will go a long way in helping him or her through it. Once your assistance is needed to complete daily tasks, think about the person's abilities. Encourage the person to do as much as possible, but be ready to help when needed. For example, when dressing, you can give direction indirectly by laying out clothing in the order in which item is put on.
- > Activities that provide meaning. In addition to enhancing quality of life, activities can reduce behaviors like wandering and agitation. You don't need to invent new things to do. Think of activities as things we do as part of our daily living. Activities can be making dinner together, gardening, listening to music or going for a walk.
- > *Driving*. During the middle stages of the disease, a person with Alzheimer's will need to stop driving. When it is clear that driving is no longer safe, try to involve the person with dementia in the decision to stop. Explain your concerns by giving specific examples. Assure the person you will do everything possible to make rides available.
- > Other safety concerns. Early in the middle stages, it will become too difficult or dangerous for a person with Alzheimer's to be left alone. Preventing wandering becomes a crucial part of care, and safety precautions will need to be taken throughout the person's living environment. At this point, if the person is living alone, he or she may need to move in with relatives or to a residential care setting. Go to our free online tool, Alzheimer's Navigator, to receive step-by-step guidance on topics including home safety and driving.

Late-Stage Caregiving

What to Expect

As the disease advances, the needs of the person living with Alzheimer's will change and deepen. A person with late-stage Alzheimer's usually:

- > Has difficulty eating and swallowing
- Needs assistance walking and eventually is unable to walk
- > Needs full-time help with personal care
- > Is vulnerable to infections, especially pneumonia
- > Loses the ability to communicate with words

Your Role as Caregiver

During the late stages, your role as a caregiver focuses on preserving quality of life and dignity. Although a person in the late stage of Alzheimer's typically loses the ability to talk and express needs, research tells us that some core of the person's self may remain. This means you may be able to continue to connect throughout the late stage of the disease.

At this point in the disease, the world is primarily experienced through the senses. You can express your caring through touch, sound, sight, taste and smell. For example, try:

- > Playing his or her favorite music
- > Reading portions of books that have meaning for the person
- > Looking at old photos together
- > Preparing a favorite food
- > Rubbing lotion with a favorite scent into the skin
- > Brushing the person's hair
- > Sitting outside together on a nice day

Late-Stage Care Options

Since care needs are extensive during the late stage, they may exceed what you can provide at home, even with additional assistance. This may mean moving the person into a facility in order to get the care needed.

Deciding on late-stage care can be one of the most difficult decisions families face. Families that have been through the process tell us that it is best to gather information and move forward, rather than second guessing decisions after the fact. There are many good ways to provide quality care. Remember, regardless of where the care takes place, the decision is about making sure the person receives the care needed.

At the end of life, another option is hospice. The underlying philosophy of hospice focuses on quality and dignity by providing comfort, care and support services for people with terminal illnesses and their families. To qualify for hospice benefits under Medicare, a physician must diagnosis the person with Alzheimer's disease as having less than six months to live.

Ideally, discussions about end-of-life care wishes should take place while the person with the dementia still has the capacity to make decisions and share wishes about life-sustaining treatment.

Late-Stage Caregiving

Food and fluids

One of the most important daily caregiving tasks during late-stage Alzheimer's is monitoring eating. As a person becomes less active, he or she will require less food. But, a person in this stage of the disease also may forget to eat or lose his or her appetite. Adding sugar to food and serving favorite foods may encourage eating; the doctor may even suggest supplements between meals to add calories if weight loss is a problem.

To help the person in late-stage Alzheimer's stay nourished, allow plenty of time for eating & try these tips:

- > *Make sure the person is in a comfortable, upright position.* To aid digestion, keep the person upright for 30 minutes after eating.
- Adapt foods if swallowing is a problem. Choose soft foods that can be chewed and swallowed easily. Make liquids thicker by adding cornstarch, unflavored gelatin or food thickeners (available at pharmacy and health care supply stores) to water, juice, milk, broth and soup. Learn the Heimlich in case of an emergency.
- > **Encourage self-feeding.** Sometimes a person needs cues to get started. Begin by putting food on a spoon, gently putting his or her hand on the spoon, and guiding it to the person's mouth. Serve finger foods if the person has difficulty using utensils.
- > Assist the person with feeding, if needed. Alternate small bites with fluids. You may need to remind the person to chew or swallow. Make sure all food and fluid is swallowed before continuing on with the next bite.
- > *Encourage fluids*. Because the sense of thirst diminishes in the late stages of Alzheimer's, the person may not realize that he or she is thirsty. Encourage the person to drink liquids or to eat foods with high liquid content, such as watermelon, peaches, pears or sherbet.
- > *Monitor weight*. While weight loss during the end of life is to be expected, it also may be a sign of inadequate nutrition, another illness or medication side effects. See the doctor to have weight loss evaluated.

Bowel and bladder function

Difficulty with toileting is very common at this stage in the disease. The person may need to be walked to the restroom and guided through the process. Incontinence is also common during late-stage Alzheimer's.

To maintain bowel and bladder function:

- > **Set a toileting schedule.** Keep a written record of when the person goes to the bathroom, and when and how much the person eats and drinks. This will help you track the person's natural routine, and then you can plan a schedule. If the person is not able to get to the toilet, use a bedside commode.
- > *Limit liquids before bedtime*. Limit liquids at least two hours before bedtime, but be sure to provide adequate fluids throughout the day.
- > *Use incontinence products*. Adult briefs and bed pads at night can serve as a backup to the daytime toileting schedule.
- > *Monitor bowel movements*. It is not necessary for the person to have a bowel movement every day, but if there are three consecutive days without a bowel movement, he or she may be constipated. In such instances, it may help to add natural laxatives to the diet, such as prunes or fiber-rich foods (bran or whole-grain bread).

Late-Stage Caregiving

Skin and Body Health

A person with late-stage Alzheimer's disease can become bedridden or chair-bound. This inability to move around can cause skin breakdown, pressure sores and "freezing" of joints. To keep skin and body healthy:

- > *Relieve body pressure and improve circulation*. Change the person's position at least every two hours to help keep him or her mobile.
- > **Learn how to lift the person.** A care provider, such as a nurse or physical therapist, can provide instructions on how to properly lift the person without causing injury. Make sure not to ever lift by pulling on the person's arms or shoulders.
- > *Keep skin clean and dry.* Since skin can tear or bruise easily, use gentle motions and avoid friction when cleaning. Wash with mild soap and blot dry. Check daily for rashes, sores or breakdowns.
- > Reduce the risk of bedsores. Use pillows or pads to protect bony areas such as elbows, heels and hips.
- > Maintain range of motion in the joints. "Freezing" of the joints (limb contractures) can occur when a person is confined to a chair or bed. Ask the doctor if range of motion exercises might be beneficial and, if so, how they should be performed.

Infections and Pneumonia

The inability to move around during late-stage Alzheimer's disease can make a person more vulnerable to infections. To help prevent infections:

- > *Keep the teeth and mouth clean*. Good oral hygiene reduces the risk of bacteria in the mouth that can lead to pneumonia. Brush the person's teeth after each meal. If the person wears dentures, remove them and clean them every night. Also, use a soft toothbrush or moistened gauze pad to clean the gums, tongue and other soft mouth tissues.
- > *Treat cuts and scrapes immediately.* Clean cuts with warm soapy water and apply an antibiotic ointment. If the cut is deep, seek professional medical help.
- > **Protect against flu and pneumonia.** The flu (influenza) can lead to pneumonia (infection in the lungs). It's vital for the person with Alzheimer's as well as his or her caregivers to get flu vaccines every year to help reduce the risk. A vaccine to guard against pneumococcal pneumonia is also available. (Usually only one dose is needed, but in certain circumstances, a second dose may be given five or more years after the first dose.)

Pain and Illness

Communicating pain becomes difficult in the late stages. If you suspect pain or illness, see a doctor as soon as possible to find the cause. In some cases, pain medication may be prescribed. To recognize pain and illness:

- > Look for physical signs. Signs of pain and illness include pale skin tone; flushed skin tone; dry, pale gums; mouth sores; vomiting; feverish skin; or swelling of any part of the body.
- > *Pay attention to nonverbal signs*. Gestures, spoken sounds and facial expressions (wincing, for example) may signal pain or discomfort.
- > Watch for changes in behavior. Anxiety, agitation, shouting and sleeping problems can all be signs of pain.

Communication and Alzheimer's

Alzheimer's disease and other dementias gradually diminish a person's ability to communicate. Communication with a person with Alzheimer's requires patience, understanding and good listening skills. The strategies below can help both you and the person with dementia understand each other better.

Changes in Communication

Changes in the ability to communicate are unique to each person with Alzheimer's. In the early stages of dementia, the person's communication may not seem very different or he or she might repeat stories or not be able to find a word. As the disease progresses, a caregiver may recognize other changes such as:

- > Speaking or writing coherently (or understanding what is said or written)
- > Recognizing familiar surroundings
- > Planning and carrying out multi-step tasks

In addition to changes in the brain caused by Alzheimer's, a number of physical conditions and medications can affect a person's ability to communicate.

Consult a doctor if you notice major changes.

Helping the person with Alzheimer's communicate

People with Alzheimer's and other dementias have more difficulty expressing thoughts and emotions; they also have more trouble understanding others. Here are some ways to help the person with Alzheimer's communicate:

- > **Be patient and supportive.** Let the person know you're listening and trying to understand. Show the person that you care about what he or she is saying and be careful not to interrupt.
- > Offer comfort and reassurance. If he or she is having trouble communicating, let the person know that it's okay. Encourage the person to continue to explain his or her thoughts.
- > **Avoid criticizing or correcting.** Don't tell the person what he or she is saying is incorrect. Instead, listen and try to find the meaning in what is being said. Repeat what was said if it helps to clarify the thought.
- > **Avoid arguing.** If the person says something you don't agree with, let it be. Arguing usually only makes things worse often heightening the level of agitation for the person with dementia.
- > Offer a guess. If the person uses the wrong word or cannot find a word, try guessing the right one. If you understand what the person means, you may not need to give the correct word. Be careful not to cause unnecessary frustration.
- > **Encourage unspoken communication.** If you don't understand what is being said, ask the person to point or gesture.
- > *Limit distractions*. Find a place that's quiet. The surroundings should support the person's ability to focus on his or her thoughts.
- > *Focus on feelings, not facts.* Sometimes the emotions being expressed are more important than what is being said. Look for the feelings behind the words. At times, tone of voice and other actions may provide clues.

Communication and Alzheimer's

Best ways for you to communicate

While a person with later-stage Alzheimer's may not always respond, he or she still requires and benefits from continued communication. When communicating with a person with dementia, it's especially important to choose your words carefully.

- > *Identify yourself.* Approach the person from the front and say who you are. Keep good eye contact; if the person is seated or reclined, go down to that level.
- > Call the person by name. It helps orient the person and gets his or her attention.
- > *Use short, simple words and sentences.* Lengthy requests or stories can be overwhelming. Ask one question at a time.
- > **Speak slowly and distinctively.** Be aware of speed and clarity. Use a gentle and relaxed tone a lower pitch is more calming.
- > Patiently wait for a response. The person may need extra time to process what you said.
- > Repeat information or questions as needed. If the person doesn't respond, wait a moment. Then ask again.
- > *Turn questions into answers*. Provide the solution rather than the question. For example, say "The bathroom is right here," instead of asking, "Do you need to use the bathroom?"
- > Avoid confusing and vague statements. If you tell the person to "Hop in!" he or she may interpret your instructions literally. Instead, describe the action directly: "Please come here. Your shower is ready." Instead of using "it" or "that," name the object or place. For example rather than "Here it is" say "Here is your hat."
- > Turn negatives into positives. Instead of saying, "Don't go there," say, "Let's go here."
- > *Give visual cues*. To help demonstrate the task, point or touch the item you want the individual to use or begin the task for the person.
- > Avoid quizzing. Reminiscing may be healthy, but avoid asking, "Do you remember when ...?"
- > Write things down. Try using written notes as reminders if the person is able to understand them.
- > *Treat the person with dignity and respect*. Avoid talking down to the person or talking as if he or she isn't there.
- Convey an easygoing manner. Be aware of your feelings and attitude you may be communicating through your tone of voice. Use positive, friendly facial expressions and nonverbal communication. For communication tips from other caregivers, join ALZConnected, our message boards and online support community. Every day, caregivers like you share new ideas and encourage one another.

Ongoing communication is important, no matter how difficult it may become or how confused the person with Alzheimer's or dementia may appear.

2. GUIDE TO HEALTH AND WELLNESS FOR PERSONS LIVING WITH ALZHEIMER'S OR DEMENTIA

Create a daily plan and manage daily schedule | p. 16 Activities' role in enhancing quality of life | p. 18 Food, eating, and Alzheimer's | p. 21

Creating a Daily Plan

Daily routines can be helpful for both you — the caregiver — and the person with Alzheimer's. A planned day allows you to spend less time trying to figure out what to do, and more time on activities that provide meaning and enjoyment.

Organizing the Day

A person with Alzheimer's or other progressive dementia will eventually need a caregiver's assistance to organize the day. Structured and pleasant activities can often reduce agitation and improve mood. Planning activities for a person with dementia works best when you continually explore, experiment and adjust. Before making a plan, consider:

- > The person's likes, dislikes, strengths, abilities and interests
- > How the person used to structure his or her day
- > What times of day the person functions best
- > Ample time for meals, bathing and dressing

Regular times for waking up and going to bed (especially helpful if the person with dementia experiences sleep issues or sundowning)

Make sure to allow for flexibility within your daily routine for spontaneous activities.

As Alzheimer's disease progresses, the abilities of a person with dementia will change. With creativity, flexibility and problem solving, you'll be able to adapt your daily routine to support these changes.

> Remember to make time for yourself, or include the person with dementia in activities that you enjoy – for example, taking a daily walk.

Checklist of Daily Activities to Consider

- > Household chores
- > Creative activities(music, art, crafts) > Personal care
- > Intellectual (reading, puzzles)
- > Social

- > Mealtimes
- > Physical
- > Spiritual

Writing a Plan

When thinking about how to organize the day, consider:

- > What activities work best? Which don't? Why? (Keep in mind that the success of an activity can vary from day-to-day.)
- > Are there times when there is too much going on or too little to do?
- > Are spontaneous activities enjoyable and easily completed?

Don't be concerned about filling every minute with an activity. The person with Alzheimer's needs a balance of activity and rest, and may need more frequent breaks and varied tasks.

In general, if the person seems bored, distracted or irritable, it may be time to introduce another activity or to take time out for rest. The type of activity and how well it's completed are not as important as the joy and sense of accomplishment the person gets from doing it.

Daily Plan Example (EARLY- TO MIDDLE-STAGES OF THE DISEASE)

- > Wash, brush teeth, get dressed
- > Prepare and eat breakfast
- > Have coffee, make conversation
- > Discuss the newspaper, try a craft project, reminisce about old photos
- > Take a break, have some quiet time
- > Do some chores together
- > Take a walk, play an active game

AFTERNOON

- > Prepare and eat lunch, read mail, wash dishes
- > Listen to music, do crossword puzzles, or watch TV
- > Do some gardening, take a walk, visit a friend
- > Take a short break or nap

- > Prepare and eat dinner, clean up the kitchen
- > Reminisce over coffee and dessert
- > Play cards, watch a movie, give a massage
- > Take a bath, get ready for bed, read a book

Managing My Daily Schedule

I will do the following to help add structure and meaning to my day:
☐ Get adequate rest
☐ Follow a routine
\square Be patient with myself and others
\square Ask for help and let others help me when needed
☐ Keep a daily calendar
☐ Avoid unnecessary changes to my environment or schedule
☐ Listen to comforting music
\square Do something I enjoy that is not complex
□ Take a walk (weather permitting) with a friend
☐ Avoid going out or driving alone

Activities

A person with Alzheimer's or other dementia doesn't have to give up the activities that he or she loves. Many activities can be modified to the person's ability. In addition to enhancing quality of life, activities can reduce behaviors like wandering or agitation.

Choosing Activities

In the early stages of dementia, the person may withdraw from activities he or she previously enjoyed. It is important to help the person remain engaged. Having an open discussion around any concerns and making slight adjustments can make a difference. For example, a large social gathering may be overwhelming, but the person may be able to interact more successfully in smaller groups. As Alzheimer's progresses, you may need to make other adjustments to the activity. Use the following tips:

- > *Keep the person's skills and abilities in mind.* A person with dementia may be able to play simple songs learned on the piano years ago. Bring these types of skills into daily activities.
- > *Pay special attention to what the person enjoys*. Take note when the person seems happy, anxious, distracted or irritable. Some people enjoy watching sports, while others may be frightened by the pace or noise.
- > Consider if the person begins activities without direction. Does he or she set the table before dinner or sweep the kitchen floor mid-morning? If so, you may wish to plan these activities as part of the daily routine.
- > **Be aware of physical problems.** Does he or she get tired quickly or have difficulty seeing, hearing or performing simple movements?
- > Focus on enjoyment, not achievement. Find activities that build on remaining skills and talents. A professional artist might become frustrated over the declining quality of work, but an amateur might enjoy a new opportunity for self expression. For activity ideas join ALZConnected, our message boards and online support community. Every day, caregivers like you share new ideas and encourage one another.
- > *Encourage involvement in daily life*. Activities that help the individual feel like a valued part of the household like setting the table can provide a sense of success and accomplishment.
- > **Relate to past work life.** A former office worker might enjoy activities that involve organizing, like putting coins in a holder or making a to-do list. A farmer or gardener may take pleasure in working in the yard.
- > Look for favorites. The person who always enjoyed drinking coffee and reading the newspaper may still find these activities enjoyable, even if he or she is not able to completely understand what the newspaper says.
- > **Consider time of day.** Caregivers may find they have more success with certain activities at specific times of day, such as bathing and dressing in the morning.
- > *Adjust activities to disease stages*. As the disease progresses, you may want to introduce more repetitive tasks. Be prepared for the person to eventually take a less active role in activities.

Caregivers Take Note – Music as Therapy: Although music has been with us since the dawn of time, in the last few decades studies have found that music as a therapeutic tool can increase cognitive function in Alzheimer's patients!

Activities

Your Approach

- > *Help get the activity started*. Most people with dementia still have the energy and desire to do things but may lack the ability to organize, plan, initiate and successfully complete the task.
- > *Offer support and supervision*. You may need to show the person how to perform the activity and provide simple, easy-to-follow steps.
- > Concentrate on the process, not the result. Does it matter if the towels are folded properly?

 Not really. What matters is that you were able to spend time together, and that the person feels as if he or she has done something useful.
- > **Be flexible.** When the person insists that he or she doesn't want to do something, it may be because he or she can't do it or fears doing it. Don't force it. If the person insists on doing it a different way, let it happen, and change it later if necessary.
- > Assist with difficult parts of the task. If you're cooking, and the person can't measure the ingredients, finish the measuring and say, "Would you please stir this for me?"
- > Let the individual know he or she is needed. Ask, "Could you please help me?" Be careful, however, not to place too many demands upon the person.
- > Stress a sense of purpose. If you ask the person to make a card, he or she may not respond.

 But, if you say that you're sending a special get-well card to a friend and invite him or her to join you, the person may enjoy working on this task with you.
- > **Don't criticize or correct the person**. If the person enjoys a harmless activity, even if it seems insignificant or meaningless to you, encourage the person to continue.
- > *Encourage self expression*. Include activities that allow the person a chance for expression. These types of activities could include painting, drawing, music or conversation.
- > *Involve the person through conversation*. While you're polishing shoes, washing the car or cooking dinner, talk to the person about what you're doing. Even if the person cannot respond, he or she is likely to benefit from your communication.
- > Substitute an activity for a behavior. If a person with dementia rubs his or her hand on a table, provide a cloth and encourage the person to wipe the table. Or, if the person is moving his or her feet on the floor, play some music so the person can tap to the beat.
- > *Try again later.* If something isn't working, it may just be the wrong time of day or the activity may be too complicated. Try again later, or adapt the activity.

If you notice a person's attention span waning or frustration level increasing, it's likely time to end or modify the activity.

101 Ways to Stay Active

Here are some suggestions for making connections to keep individuals active and feeling productive and successful. Everyone is different, find out what works with each person and be ready to modify to fit interests and abilities. *Remember: they never fail and are never wrong, always be reaffirming, flexible, and aware of safety.*

 Client: ______
 Date: ______

1. Vacuum	35. Sensory Stimulation	69. Finish a famous saying
2. Sweep the kitchen	36. Look at photos	70. Feed the ducks
3. Bake cookies	37. Reminisce – vacations	71. Mold dough
4. Read paper	38. Clip coupons	72. Picture books
5. Invite children to visit	39. Sort poker chips	73. Put a simple puzzle together
6. Read a letter out loud	40. Count things	74. Sand wood
7. Listen to music	41. Fold towels	75. Rub on hand lotion
8. Parachute game	42. Afternoon Tea	76. Decorate place mats
9. Color/Paint	43. Reminisce – inventions	77. Arrange fresh flowers in a vase
10. Make lemonade	44. Play a game	78. Remember famous people
11. Wipe off table	45. Listen to favorite music	79. Rake leaves
12. Weed the garden	46. Cut out paper dolls	80. Make a fruit salad
13. Write out holiday cards	47. Identify states and capitols	81. Sweep the patio or room
14. Spelling bee	48. Make a family tree	82. Talk about famous events
15. Readers Digest	49. Color American Flag	83. Nursery Rhymes. You start.
16. Fold clothes	50. Cook hot dogs	84. Make sandwiches
17. Pet visit	51. Grow magic rocks	85. Dust furniture
18. Cut out cards	52. Water house plants	86. Cut up paper/Tear paper
19. Wash silverware	53. Reminisce – first kiss	87. Take care of bird cage/fish tank
20. Bake bread	54. Play horseshoes	88. Trace/cut leaves
21. Sort objects	55. Dance	89. Simple trivia questions
22. Sing Christmas songs	56. Sing a hymn	90. Pray
23. Life Review	57. Make ice cream	91. Paint with string
24. Put silver away	58. Plant bulbs	92. Send thank you notes
25. Make a Valentine's collage	59. Make cards	93. Read/listen to a short story
26. Sing songs	60. Sort cards by suit	94. Put coins in a jar
27. Take a ride	61. Write a letter	95. Sew sewing cards
28. Make a pie	62. Dress in team colors	96. Put seed in bird feeder
29. Read a poem	63. Pop popcorn	97. Clean out pumpkin
30. Dye Easter eggs	64. Name the U.S. Presidents	98. Roll yarn
31. Sort socks	65. Give a manicure	99. Reminisce – grocery stores
32. Write out birthday cards	66. Skype/FaceTime	100. Make a cake
33. String fruit loops	67. Plant a tree	101. Something unique:
34. String cranberries	68. Make a may basket	

Food, Eating and Alzheimer's

Regular, nutritious meals may become a challenge for people with dementia. As a person's cognitive function declines, he or she may become overwhelmed with too many food choices, forget to eat or have difficulty with eating utensils.

Nutrition tips

Proper nutrition is important to keep the body strong and healthy. For a person with Alzheimer's or dementia, poor nutrition may increase behavioral symptoms and cause weight loss.

The basic nutrition tips below can help boost the person with dementia's health and your health as a caregiver, too.

- > *Provide a balanced diet with a variety of foods*. Offer vegetables, fruits, whole grains, low-fat dairy products and lean protein foods.
- > Limit foods with high saturated fat and cholesterol. Some fat is essential for health but not all fats are equal. Go light on fats that are bad for heart health, such as butter, solid shortening, lard and fatty cuts of meats.
- > *Cut down on refined sugars*. Often found in processed foods, refined sugars contain calories but lack vitamins, minerals and fiber. You can tame a sweet tooth with healthier options like fruit or juice-sweetened baked goods. But note that in the later-stages of Alzheimer's, if loss of appetite is a problem, adding sugar to foods may encourage eating.
- > Limit foods with high sodium and use less salt. Most people in the United States consume too much sodium, which affects blood pressure. Cut down by using spices or herbs to season food as an alternative.

As the disease progresses, loss of appetite and weight loss may become concerns. In such cases, the doctor may suggest supplements between meals to add calories.

Staying hydrated may be a problem as well. Encourage fluids by offering small cups of water or other liquids throughout the day or foods with high water content, such as fruit, soups, milkshakes and smoothies.

People with Alzheimer's or dementia do not need a special diet. As with anyone, eating a well-balanced, nutritious diet is important for overall health.

Possible Causes of Poor Appetite

- > *Not recognizing food*. The person may no longer recognize the foods you put on his or her plate.
- > *Poor fitting dentures.* Eating may be painful, but the person may not be able to tell you this. Make sure dentures fit and visit the dentist regularly.
- > *Medications*. New medications or a dosage change may affect appetite. If you notice a change, call the doctor.
- > *Not enough exercise*. Lack of physical activity will decrease appetite. Encourage simple exercise, such as going for a walk, gardening or washing dishes.
- > Decreased sense of smell and taste. The person with dementia may not eat because food may not smell or taste as good as it once did.

Food, Eating and Alzheimer's

Make Mealtimes Easier

During the middle and late stages of Alzheimer's, distractions, too many choices, and changes in perception, taste and smell can make eating more difficult. The following tips can help:

- > *Limit distractions*. Serve meals in quiet surroundings, away from the television and other distractions.
- > *Keep the table setting simple*. Avoid placing items on the table such as table arrangements or plastic fruit that might distract or confuse the person. Use only the utensils needed for the meal.
- > **Distinguish food from the plate.** Changes in visual and spatial abilities may make it tough for someone with dementia to distinguish food from the plate or the plate from the table. It can help to use white plates or bowls with a contrasting color placemat. Avoid patterned dishes, tablecloths and placemats.
- > Check the food temperature. A person with dementia might not be able to tell if something is too hot to eat or drink. Always test the temperature of foods and beverages before serving.
- > Serve only one or two foods at a time. Too many foods at once may be overwhelming. Simplify by serving one dish at a time. For example, mashed potatoes followed by meat.
- > **Be flexible to food preferences.** Keep long-standing personal preferences in mind when preparing food, and be aware that a person with dementia may suddenly develop new food preferences or reject foods that were liked in the past.
- > Give the person plenty of time to eat. Remind him or her to chew and swallow carefully. Keep in mind that it may take an hour or longer to finish eating.
- > *Eat together.* Make meals an enjoyable social event so everyone looks forward to the experience. Research suggests that people eat better when they are in the company of others.
- > Keep in mind the person may not remember when or if he or she ate. If the person continues to ask about eating breakfast, consider serving several breakfasts juice, followed by toast, followed by cereal.

Encourage Independence

During the middle and late stages of Alzheimer's, allow the person with dementia to be as independent as possible during meals. Be ready to help, when needed.

- > Make the most of the person's abilities. Adapt serving dishes and utensils to make eating easier. You might serve food in a bowl instead of a plate, or try using a plate with rims or protective edges. A spoon with a large handle may be less difficult to handle than a fork, or even let the person use his or her hands if it's easier.
- > **Serve finger foods.** Try bite-sized foods that are easy to pick up, such as chicken nuggets, fish sticks, tuna sandwiches, orange segments, steamed broccoli or cauliflower pieces.
- > Use a "watch me" technique. For example, hold a spoon and show the person how to eat a bowl of cereal.
- > **Don't worry about neatness.** Let the person feed himself of herself as much as possible. Consider getting plates with suction cups and no-spill glasses.

Food, Eating and Alzheimer's

Minimize Eating and Nutrition Problems

In the middle and late stages of Alzheimer's, swallowing problems can lead to choking and weight loss. Be aware of safety concerns and try these tips:

- > *Prepare foods so they aren't hard to chew or swallow.* Grind foods, cut them into bite-size pieces or serve soft foods (applesauce, cottage cheese scrambled eggs).
- > **Be alert for signs of choking.** Avoid foods that are difficult to chew thoroughly, like raw carrots. Encourage the person to sit up straight with his or her head slightly forward. If the person's head tilts backward, move it to a forward position. At the end of the meal, check the person's mouth to make sure food has been swallowed. Learn the Heimlich maneuver in case of an emergency.
- > Address a decreased appetite. If the person has a decreased appetite, try preparing favorite foods, increase physical activity, or plan for several small meals rather than three large ones. If the person's appetite does not increase and/or he or she is losing weight, consult with the doctor. Keep in mind, as the person's activity level decreases, he or she may not need as many calories.
- > Only use vitamin supplements on the recommendation of a physician.

3. ASSESSING AND RESPONDING TO THE EFFECTS OF ALZHEIMER'S & DEMENTIA

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Memory Loss and Confusion

In the later stages of the disease, a person with Alzheimer's may not remember familiar people, places or things. Situations involving memory loss and confusion are extremely difficult for caregivers and families, and require much patience and understanding.

What to Expect

In the earlier stages, memory loss and confusion may be mild. The person with dementia may be aware of and frustrated by the changes taking place, such as difficulty recalling recent events, making decisions or processing what was said by others.

In the later stages, memory loss becomes far more severe. A person may not recognize family members, may forget relationships, call family members by other names, or become confused about the location of home or the passage of time. He or she may forget the purpose of common items, such as a pen or a fork. These changes are some of the most painful for caregivers and families.

Such types of behavior is sometimes incorrectly referred to as "senility" or "senile dementia," which reflects the formerly widespread but incorrect belief that serious mental decline is a normal part of aging.

Causes

The main underlying cause of memory loss and confusion is the progressive damage to brain cells caused by Alzheimer's disease. While current medications cannot stop the damage Alzheimer's causes to brain cells, they may help lessen symptoms for a limited time.

Certain situations — such as a change in living arrangements, switch in routine or certain infections can cause symptoms to worsen. Any time there is a sudden change in behavior, it is important to have a medical evaluation to rule out other causes.

Memory Loss and Confusion

How to Respond

- > **Stay calm.** Although being called by a different name or not being recognized can be painful, try not to make your hurt apparent.
- > **Respond with a brief explanation.** Don't overwhelm the person with lengthy statements or reasons. Instead, clarify with a simple explanation.
- > **Show photos and other reminders.** Use photographs and other thought-provoking items to remind the person of important relationships and places.
- > Travel with the person to where he or she is in time. If the person's memory is focused on a particular time in his or her life, engage in conversation about recollections with an understanding that this is his or her current reality.
- > Offer corrections as suggestions. Avoid explanations that sound like scolding. Try: "I thought it was a fork" or "I think she is your granddaughter Julie."
- > *Try not to take it personally.* Alzheimer's disease causes your loved one to forget, but your support and understanding will continue to be appreciated.
- > **Share your experience with others.** Join ALZConnected, our online support community and message boards, share what response strategies have worked for you and get more ideas from other caregivers.

EVOKING MEMORIES. Use photographs and other thought-provoking items to remind the person of important relationships and places.

Mini-Cog Test

Administration

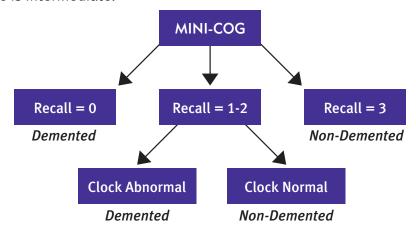
The Mini-Cog test is a 3-minute instrument to screen for cognitive impairment in older adults in the primary care setting. The Mini-Cog uses a three-item recall test for memory and a simply scored clock-drawing test (CDT). The latter serves as an "informative distractor," helping to clarify scores when the memory recall score is intermediate. The Mini-Cog was as effective as or better than established screening tests in both an epidemiologic survey in a mainstream sample and a multi-ethnic, multilingual population comprising many individuals of low socioeconomic status and education level. In comparative tests, the Mini-Cog was at least twice as fast as the Mini-Mental State Examination. The Mini-Cog is less affected by subject ethnicity, language, and education, and can detect a variety of different dementias. Moreover, the Mini-Cog detects many people with mild cognitive impairment (cognitive impairment too mild to meet diagnostic criteria for dementia). This test is intended to be administered annually or as indicated by a clinician.

Scoring

- > 1 point for each recalled word
- Score clock drawing as Normal (the patient places the correct time and the clock appears grossly normal) or Abnormal
- > Score of:
 - 0 = Positive for cognitive impairment
 - 1-2 = Abnormal clock drawing test, then positive for cognitive impairment
 - 1-2 = Normal clock drawing test, then negative for cognitive impairment
 - 3 = Negative screen for dementia (no need to score clock drawing test)

Figure 1. The Mini-Cog scoring algorithm

The Mini-Cog uses a three-item recall test for memory and the intuitive clock-drawing test. The latter serves as an "informative distractor," helping to clarify scores when the memory recall score is intermediate.



Reference: Borson S. The mini-cog: a cognitive "vitals signs" measure for dementia screening in multi-lingual elderly Int J Geriatric Psychiatry 2000; 15(11):1021.

Anxiety and Agitation

A person with Alzheimer's may feel anxious or agitated. He or she may become restless, causing a need to move around or pace, or become upset in certain places or when focused on specific details.

Possible Causes of Agitation

Anxiety and agitation may be caused by a number of different medical conditions, medication interactions or by any circumstances that worsen the person's ability to think. Ultimately, the person with dementia is biologically experiencing a profound loss of their ability to negotiate new information and stimulus. It is a direct result of the disease. Situations that may lead to agitation include:

- > Moving to a new residence or nursing home
- > Changes in environment, such as travel, hospitalization or the presence of house guests
- Changes in caregiver arrangements
- > Misperceived threats
- > Fear and fatigue resulting from trying to make sense out of a confusing world

Tips to Help Prevent Agitation

To prevent or reduce agitation:

- > Create a calm environment. Remove stressors. This may involve moving the person to a safer or quieter place, or offering a security object, rest or privacy. Try soothing rituals and limiting caffeine use.
- > **Avoid environmental triggers.** Noise, glare and background distraction (such as having the television on) can act as triggers.
- > *Monitor personal comfort*. Check for pain, hunger, thirst, constipation, full bladder, fatigue, infections and skin irritation. Make sure the room is at a comfortable temperature. Be sensitive to fears, misperceived threats and frustration with expressing what is wanted.
- > Simplify tasks and routines.
- > *Provide an opportunity for exercise*. Go for a walk. Garden together. Put on music and dance.

TREATING BEHAVIORAL SYMPTOMS: Anyone experiencing behavioral symptoms should receive a thorough medical checkup, especially when symptoms appear suddenly. Treatment depends on a careful diagnosis, determining possible causes and the types of behavior the person is experiencing. With proper treatment and intervention, symptoms of agitation can be reduced.

Anxiety and Agitation

How to Respond

- > Listen to the frustration. Find out what may be causing the agitation, and try to understand.
- > **Provide reassurance.** Use calming phrases such as: "You're safe here;" "I'm sorry that you are upset;" and "I will stay until you feel better." Let the person know you are there.
- > *Involve the person in activities*. Try using art, music or other activities to help engage the person and divert attention away from the anxiety.
- > *Modify the environment*. Decrease noise and distractions, or relocate.
- > *Find outlets for the person's energy.* The person may be looking for something to do. Take a walk or go for a car ride.
- > *Check yourself.* Do not raise your voice, show alarm or offense, or corner, crowd, restrain, criticize, ignore or argue with the person. Take care not to make sudden movements out of the person's view.
- > **See the doctor.** See the person with dementia's primary care physician to rule out any physical causes or medication-related side effects.
- > Share your experience with others. Join ALZConnected, our online support community and message boards, and share what response strategies have worked for you and get more ideas from other caregivers. https://www.alzconnected.org

DO

Back off and ask permission; use calm, positive statements; reassure; slow down; add light; offer guided choices between two options; focus on pleasant events; offer simple exercise options, try to limit stimulation.

SAY

May I help you? Do you have time to help me? You're safe here. Everything is under control. I apologize. I'm sorry that you are upset. I know it's hard. I will stay with you until you feel better.

Behavior Calendar

For each time of the day, write in the number of times you or your loved one experience agitation/confusion (A/C).

For week beginning Sunday	and ending Saturday
Name	

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
MORNING	MORNING	MORNING	MORNING	MORNING	MORNING	MORNING
A/C: NOTES:	A/C: NOTES:	A/C: NOTES:	A/C: NOTES:	A/C: NOTES:	A/C: NOTES:	A/C: NOTES:
AFTERNOON A/C: NOTES:		AFTERNOON A/C: NOTES:	AFTERNOON A/C: NOTES:	AFTERNOON A/C: NOTES:	AFTERNOON A/C: NOTES:	AFTERNOON A/C: NOTES:
EVENING A/C: NOTES:	EVENING A/C: NOTES:	EVENING A/C: NOTES:	EVENING A/C: NOTES:	EVENING A/C: NOTES:	EVENING A/C: NOTES:	EVENING A/C: NOTES:
NIGHTTIME A/C:	NIGHTTIME A/C:	NIGHTTIME A/C:	NIGHTTIME A/C:	NIGHTTIME A/C:	NIGHTTIME A/C:	NIGHTTIME A/C:
NOTES:	NOTES:	NOTES:	NOTES:	NOTES:	NOTES:	NOTES:

Aggression and Anger

Aggressive behaviors may be verbal or physical. They can occur suddenly, with no apparent reason, or result from a frustrating situation. While aggression can be hard to cope with, understanding that the person with Alzheimer's or dementia is not acting this way on purpose can help.

Causes

Aggression can be caused by many factors including physical discomfort, environmental factors and poor communication. If the person with Alzheimer's is aggressive, consider what might be contributing to the change in behavior.

PHYSICAL DISCOMFORT

- > Is the person able to let you know that he or she is experiencing physical pain? It is not uncommon for persons with Alzheimer's or other dementias to have urinary tract or other infections. Due to their loss of cognitive function, they are unable to articulate or identify the cause of physical discomfort and, therefore, may express it through physical aggression.
- > Is the person tired because of inadequate rest or sleep?
- > Are medications causing side effects? Side effects are especially likely to occur when individuals are taking multiple medications for several health conditions?

THE MAIN CAUSE OF BEHAVIORAL SYMPTOMS associated with dementia is the progressive deterioration of brain cells, but other factors — such as pain — also can cause symptoms or make symptoms worse.

TREATING BEHAVIORAL SYMPTOMS: Anyone experiencing behavioral symptoms should receive a thorough medical checkup, especially when symptoms appear suddenly. Treatment depends on a careful diagnosis, determining possible causes and the types of behavior the person is experiencing.

ENVIRONMENTAL FACTORS

- > Is the person overstimulated by loud noises, an overactive environment or physical clutter? Large crowds or being surrounded by unfamiliar people — even within one's own home — can be over-stimulating for a person with dementia.
- > Does the person feel lost?
- > Most people function better during a certain time of day; typically mornings are best. Consider the time of day when making appointments or scheduling activities. Choose a time when you know the person is most alert and best able to process new information or surroundings.

POOR COMMUNICATION

- > Are your instructions simple and easy to understand?
- > Are you asking too many questions or making too many statements at once?
- > Is the person picking up on your own stress or irritability?

Aggression and Anger

How to Respond

- > *Try to identify the immediate cause.* Think about what happened right before the reaction that may have triggered the behavior.
- > Rule out pain as a source of stress. Pain can cause a person with dementia to act aggressively.
- > Focus on feelings, not the facts. Rather than focusing on specific details, consider the person's emotions. Look for the feelings behind the words or actions.
- > **Don't get upset.** Be positive and reassuring. Speak slowly in a soft tone.
- > Limit distractions. Examine the person's surroundings, and adapt them to avoid similar situations.
- > Try a relaxing activity. Use music, massage or exercise to help soothe the person.
- > **Shift the focus to another activity.** The immediate situation or activity may have unintentionally caused the aggressive response. Try something different.
- > **Decrease level of danger.** Assess the level of danger for yourself and the person with Alzheimer's. You can often avoid harm by simply stepping back and standing away from the person. If the person is headed out of the house and onto the street, be more assertive.
- > Avoid using restraint or force. Unless the situation is serious, avoid physically holding or restraining the person. He or she may become more frustrated and cause personal harm.
- > **Share your experience with others.** Join ALZConnected, our online support community and message boards, and share what response strategies have worked for you and get more ideas from other caregivers.

Hallucinations and Alzheimer's

When a person with Alzheimer's or other dementia hallucinates, he or she may see, hear, smell, taste or feel something that isn't there. Some hallucinations may be frightening, while others may involve ordinary visions of people, situations or objects from the past.

Understanding Hallucinations

Hallucinations are false perceptions of objects or events involving the senses. These false perceptions are caused by changes within the brain that result from Alzheimer's, usually in the later stages of the disease. The person may see the face of a former friend in a curtain or may see insects crawling on his or her hand. In other cases, a person may hear someone talking and may even engage in conversation with the imagined person. Alzheimer's and other dementias are not the only cause of hallucinations. Other causes include:

- > Schizophrenia
- > Physical problems, such as kidney or bladder infections, dehydration, intense pain, or alcohol or drug abuse
- > Eyesight or hearing problems
- > Medications

HALLUCINATIONS CAUSED BY PROGRESSIVE DEMENTIA USUALLY OCCUR DURING THE LATER STAGES OF THE DISEASE.

SEE THE DOCTOR If a person with Alzheimer's begins hallucinating, it's important to have a medical evaluation to rule out other possible causes and to determine if medication is needed. The first line of treatment for the behavioral symptoms of Alzheimer's is non-drug approaches, but if these strategies fail and symptoms are severe, medications may be appropriate. While antipsychotic medications can be effective in some situations, they are associated with an increased risk of stroke and death in older adults with dementia and must be used carefully. Work with the doctor to learn both the risks and benefits of medication before making a decision.

Coping Strategies

When responding to hallucinations, be cautious. First, assess the situation and determine whether the hallucination is a problem for the person or for you. Is the hallucination upsetting? Is it leading the person to do something dangerous? Is the sight of an unfamiliar face causing the person to become frightened? If so, react calmly and quickly with reassuring words and a comforting touch. Do not argue with the person about what he or she sees or hears. If the behavior is not dangerous, there may not be a need to intervene. For more coping strategies, join ALZConnected, our online support community where caregivers like you share tips on what has worked for them. You can also sign up for our e-newsletter to receive tips on a variety of caregiving topics.

OFFER REASSURANCE

- > Respond in a calm, supportive manner. You may want to respond with, "Don't worry. I'm here. I'll protect you. I'll take care of you."
- > Gentle patting may turn the person's attention toward you and reduce the hallucination.
- > Acknowledge the feelings behind the hallucination and try to find out what the hallucination means to the individual. You might want to say, "It sounds as if you're worried" or "I know this is frightening for you."

Hallucinations and Alzheimer's

Coping Strategies

USE DISTRACTIONS

- > Suggest a walk or move to another room. Frightening hallucinations often subside in well-lit areas where other people are present.
- > Try to turn the person's attention to music, conversation or activities you enjoy together.

MODIFY THE ENVIRONMENT

- > Check for sounds that might be misinterpreted, such as noise from a television or an air conditioner.
- > Look for lighting that casts shadows, reflections or distortions on the surfaces of floors, walls and furniture. Turn on lights to reduce shadows.
- > Cover mirrors with a cloth or remove them if the person thinks that he or she is looking at a stranger.

Depression and Alzheimer's

Depression is very common among people with Alzheimer's, especially during the early and middle stages. Treatment is available and can make a significant difference in quality of life.

Symptoms of Depression

Identifying depression in someone with Alzheimer's can be difficult, since dementia can cause some of the same symptoms. Examples of symptoms common to both depression and dementia include:

- Apathy
- > Loss of interest in activities and hobbies
- Social withdrawal
- > Isolation
- > Trouble concentrating
- > Impaired thinking

In addition, the cognitive impairment experienced by people with Alzheimer's often makes it difficult for them to articulate their sadness, hopelessness, guilt and other feelings associated with depression.

Depression in Alzheimer's doesn't always look like depression in people without Alzheimer's. Here are some ways that depression in a person with Alzheimer's may be different:

- > May be less severe
- > May not last as long and symptoms may come and go
- > The person with Alzheimer's may be less likely to talk about or attempt suicide

As a caregiver, if you see signs of depression, discuss them with the primary doctor of the person with dementia. Proper diagnosis and treatment can improve sense of well-being and function.

Experts estimate that up to 40 percent of people with Alzheimer's disease suffer from significant depression.

Depression and Alzheimer's

Diagnosing Depression with Alzheimer's Disease

There is no single test or questionnaire to detect depression. Diagnosis requires a thorough evaluation by a medical professional, especially since side effects of medications and some medical conditions can produce similar symptoms.

An evaluation for depression will include:

- > A review of the person's medical history
- > A physical and mental examination
- > Interviews with family members who know the person well

Because of the complexities involved in diagnosing depression in someone with Alzheimer's, it may be helpful to consult a geriatric psychiatrist who specializes in recognizing and treating depression in older adults. Ask your doctor for a referral.

The National Institute of Mental Health established a formal set of guidelines for diagnosing the depression in people with Alzheimer's. Although the criteria are similar to general diagnostic standards for major depression, they reduce emphasis on verbal expression and include irritability and social isolation.

For a person to be diagnosed with depression in Alzheimer's, he or she must have either depressed mood (sad, hopeless, discouraged or tearful) or decreased pleasure in usual activities, along with two or more of the following symptoms for two weeks or longer:

- > Social isolation or withdrawal
- > Disruption in appetite that is not related to another medical condition
- > Disruption in sleep
- > Agitation or slowed behavior
- > Irritability
- > Fatigue or loss of energy
- > Feelings of worthlessness or hopelessness, or inappropriate or excessive guilt
- > Recurrent thoughts of death, suicide plans or a suicide attempt

Depression and Alzheimer's

Treating Depression

Getting appropriate treatment for depression can significantly improve quality of life.

The most common treatment for depression in Alzheimer's involves a combination of medicine, counseling, and gradual reconnection to activities and people that bring happiness. Simply telling the person with Alzheimer's to "cheer up," "snap out of it" or "try harder" is seldom helpful. Depressed people with or without Alzheimer's are rarely able to make themselves better by sheer will, or without lots of support, reassurance and professional help.

NON-DRUG APPROACHES

- > Support groups can be very helpful, particularly an early-stage group for people with Alzheimer's who are aware of their diagnosis and prefer to take an active role in seeking help or helping others; counseling is also an option, especially for those who aren't comfortable in groups
- > Schedule a predictable daily routine, taking advantage of the person's best time of day to undertake difficult tasks, such as bathing
- > Make a list of activities, people or places that the person enjoys and schedule these things more frequently
- > Help the person exercise regularly, particularly in the morning
- > Acknowledge the person's frustration or sadness, while continuing to express hope that he or she will feel better soon
- > Celebrate small successes and occasions
- > Find ways that the person can contribute to family life and be sure to recognize his or her contributions
- > Provide reassurance that the person is loved, respected and appreciated as part of the family, and not just for what she or he can do now
- > Nurture the person with offers of favorite foods or soothing or inspirational activities
- > Reassure the person that he or she will not be abandoned

MEDICATION TO TREAT DEPRESSION IN ALZHEIMER'S

There are several types of antidepressants available to treat depression. Antidepressants called Selective Serotonin Reuptake Inhibitors (SSRIs) are often used for people with Alzheimer's and depression because they have a lower risk than some other antidepressants of causing interactions with other medications.

As with any medication, make sure to ask about risks and benefits, as well as what type of monitoring and follow-up will be needed.

Wandering and Getting Lost

Six in 10 people with dementia will wander. A person with Alzheimer's may not remember his or her name or address, and can become disoriented, even in familiar places. Wandering among people with dementia is dangerous, but there are strategies and services to help prevent it.

Wandering and getting lost is common among people with dementia and can happen during any stage of the disease.

Tips to Prevent Wandering

Wandering can happen, even if you are the most diligent of caregivers. Use the following strategies to help lower the chances:

- > Carry out daily activities. Having a routine can provide structure. Learn about creating a daily plan.
- > *Identify the most likely times of day that wandering may occur.* Plan activities at that time. Activities and exercise can reduce anxiety, agitation and restlessness.
- > Reassure the person if he or she feels lost, abandoned or disoriented. If the person with dementia wants to leave to "go home" or "go to work," use communication focused on exploration and validation. Refrain from correcting the person. For example, "We are staying here tonight. We are safe and I'll be with you. We can go home in the morning after a good night's rest."
- > Ensure all basic needs are met. Has the person gone to the bathroom? Is he or she thirsty or hungry?
- > Avoid busy places that are confusing and can cause disorientation. This could be a shopping malls, grocery stores or other busy venues.
- > *Place locks out of the line of sight.* Install either high or low on exterior doors, and consider placing slide bolts at the top or bottom.
- > *Camouflage doors and door knobs*. Camouflage doors by painting them the same color as the walls, or cover them with removable curtains or screens. Cover knobs with cloth the same color as the door or use childproof knobs.
- > *Use devices that signal when a door or window is opened.* This can be as simple as a bell placed above a door or as sophisticated as an electronic home alarm.
- > **Provide supervision.** Never lock the person with dementia in at home alone or leave him or her in a car without supervision.
- > *Keep car keys out of sight*. A person with dementia may drive off and be at risk of potential harm to themselves or others.
- > *If night wandering is a problem:* Make sure the person has restricted fluids two hours before bedtime and has gone to the bathroom just before bed. Also, use night lights throughout the home.

Wandering and Getting Lost

Make a Plan

The stress experienced by families and caregivers when a person with dementia wanders and becomes lost is significant. Have a plan in place beforehand, so you know what to do in case of an emergency.

- > Keep a list of people to call on for help. Have telephone numbers easily accessible.
- > Ask neighbors, friends and family to call if they see the person alone. Keep a recent, close-up photo and updated medical information on hand to give to police.
- > *Know your neighborhood*. Pinpoint dangerous areas near the home, such as bodies of water, open stairwells, dense foliage, tunnels, bus stops and roads with heavy traffic.
- > Is the individual right or left-handed? Wandering generally follows the direction of the dominant hand.
- > *Keep a list of places where the person may wander.* This could include past jobs, former homes, places of worship or a restaurant.
- > **Provide the person with ID jewelry.** Enroll the person in MedicAlert®+ Alzheimer's Association Safe Return®.
- > Consider having the person carry or wear an electronic tracking GPS device that helps manage location. Comfort Zone® and Comfort Zone Check-In®are two options.
- > If the person does wander, search the immediate area for no more than 15 minutes.

 Call "911" and report to the police that a person with Alzheimer's disease a "vulnerable adult" is missing. A Missing Report should be filed and the police will begin to search for the individual. In addition, a report should be filed with MedicAlert+ Alzheimer's Association Safe Return at 1.800.625.3780. First responders are trained to check with MedicAlert+ Alzheimer's Association Safe Return when they locate a missing person with dementia. You do not need to be enrolled in MedicAlert+ Alzheimer's Association Safe Return in order to file a missing report.

When someone with dementia is missing: Begin search-and-rescue efforts immediately. Ninety-four percent of people who wander are found within 1.5 miles of where they disappeared.

MedicAlert® + Alzheimer's Association Safe Return®

MedicAlert® + Alzheimer's Association Safe Return® is a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or have a medical emergency. We provide 24-hour assistance, no matter when or where the person is reported missing.

How it Works

If an individual with Alzheimer's or a related dementia wanders and becomes lost, caregivers can call the 24-hour emergency response line (1.800.625.3780) to report it.

A community support network will be activated, including local Alzheimer Association chapters and law enforcement agencies, to help reunite the person who wandered with the caregiver or a family member. With this service, critical medical information will be provided to emergency responders when needed.

If a citizen or emergency personnel finds the person with dementia, they can call the toll-free number listed on person's MedicAlert + Safe Return ID jewelry. MedicAlert + Safe Return will notify the listed contacts, making sure the person is returned home.

REPORT A WANDERING INCIDENT: CALL 911, THEN CALL 800.625.3780, MEDICALERT + SAFE RETURN'S EMERGENCY RESPONSE LINE

Cost and ID Jewelry

MedicAlert + Safe Return provide an ID bracelet or pendant to be worn by the individual with dementia.

\$55 + \$7 shipping and handling, you receive an enrollment package including:

- Member's ID jewelry with personalized information and MedicAlert + Safe Return's 24-hour emergency toll-free number
- > Personalized emergency wallet card
- > 24-hour emergency response service
- > Personal health record (PHR)
- > Six Steps to a Safe Return magnet

(Optional) Add \$35 for caregiver ID jewelry and membership

- > Membership includes everything listed above
- > The caregiver wears this worldwide-recognized ID jewelry to alert others that he or she provides care for a MedicAlert + Safe Return member, in case of an emergency

\$35 annual renewal fee

An annual fee of \$35 will be due after the first year for each membership.

Join

There are four easy ways to join MedicAlert + Safe Return:

- 1. ONLINE: www.medicalert.org/safereturn
- 2. CALL: 1.888.572.8566

- 3. MAIL: Completed enrollment form and photos can be mailed to: MedicAlert + Alzheimer's Association Safe Return 2323 Colorado Blvd. Turlock, CA 95380
- 4. FAX: Registration form to 1.800.863.3429



GPS Location
Management Service
The Alzheimer's Association
offers safety services that use
GPS and cellular technology.
Comfort Zone® and Comfort Zone
Check-In® can help you manage
a person's location. Comfort Zone
includes MedicAlert + Safe Return.

4. WHAT IS DELIRIUM?

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What is Delirium?

Delirium is a sudden, temporary onset of confusion that causes changes in the way people think and behave. Older people are most at risk. Knowing what to look for and treating the causes early can help save lives.

What causes delirium?

- > Infection
- > Medication side-effects
- > Not taking medications as prescribed
- > Recent surgery with anaesthetic
- > Worsening of a chronic illness
- > Dehydration
- > High or low blood sugar
- > Grief over a recent loss, for example death of a family member, friend, or pet

- Constipation or diarrhea
- > Pain
- > Alcohol use or withdrawal
- > Recent injury or fall
- > Recent move or hospital stay
- > Poor nutrition
- > Poor fitting hearing aids or glasses
- > Low blood levels of Vitamin B12

What puts someone at risk for getting delirium?

People are more likely to get delirium if they have:

- > Had delirium before
- > Memory or thinking problems
- > Severe illness resulting in hospital stays
- > Dehydration
- > Problems with seeing or hearing
- > Are taking 5 or more medications

The Difference Between Delirium, Depression, and Dementia

There are times when the same signs and symptoms can occur within different conditions. The chart below provides an overview of the differences between delirium, depression, and dementia. These conditions can mimic each other and even occur simultaneously.

Characteristics of delirium, depression, and dementia

	DELIRIUM	DEPRESSION	DEMENTIA
Onset	Hours to days	Weeks to months	Months to years
Mood	Fluctuates	Low/apathetic	Fluctuates
Course	Acute; responds to treatment	Chronic; responds to treatment	Chronic; with deterioration over time
Self-Awareness	May be unaware of change in cognition	Likely to be concerned about memory	Likely to hide or be unaware of cognitive deficits
Activities of Daily Living (ADLs) — examples include bathing, dressing, grooming, using the toilet, mobility	May be intact or impaired	May neglect basic self-care	May be intact early, impaired as disease progresses
Instrumental Activities of Daily Living (IADLs) — examples include transportation, food preparation, managing medications, finances, doing the laundry and household chores	May be intact or impaired	May be intact or impaired	May be intact early, impaired before ADLs as disease progresses

☐ I have spoken with my doctor about my symptoms and clarified which condition(s) I have.

Delirium Symptoms and Treatment

What are the signs and symptoms of delirium?

- > Confusion
- > Restlessness
- > Being easily upset or agitated
- > Slurred speech
- > Not making any sense
- > Seeing or hearing things that are not there > Trouble staying awake
- > Mixing up days and nights

- > Drifting between sleep and being awake
- > Forgetting things
- > Trouble concentrating
- > More or less alert than normal
- > Not knowing where they are

How is delirium diagnosed?

Delirium is diagnosed by:

- > Noticing signs and symptoms of delirium as described above
- > Learning the person's medical history
- > Learning the person's usual thinking ability, daily routines, communication style, moods, behaviors and sleep habits
- > Doing a physical examination
- > Doing blood, urine, and X-ray tests to find the cause

How is delirium treated?

Treating delirium means treating the underlying cause. It is very important to figure out the cause of delirium as soon as possible. This usually means doing tests and asking questions. Once the cause is known, the most effective treatment can be given. This may include medication as well as changing the person's surroundings.

For many people, delirium can clear in a few days or weeks. Others may not respond to treatment for many weeks. Some people never fully return to their normal selves. You may see some problems with memory and thinking that do not go away. Each person is different.

An individual's personal safety while delirious is very important because the delirium may cloud their judgment or cause confusion over simple, previously well-understood things. Delirium may contribute to someone getting lost. Be sure to talk with your healthcare provider about the need for temporary supervision/assistance with activities of daily living, driving, and the like. You may also want to investigate the use of a personal emergency response system.

Understand Your Delirium Medications

Your doctor will want to review your medications to understand if any of them may be causing contributing to your delirium.
☐ I will provide a list of all my medications including: > those I take regularly and occasionally > those for which I have a prescription > those that I buy or obtain without a prescription
□ I will include vitamins, minerals, herbal supplements and other things I take.
If your delirium is interfering with your safety or ability to function, your doctor may prescribe one of the following types of medications:
Anti-anxiety These drugs reduce your anxiety level. They may be regularly scheduled or taken as needed. These drugs can make you sleepy and should not be taken when you plan to consume alcohol. I will call my doctor while taking an anti-anxiety if I have: > dizziness > weakness/fatigue > increased confusion > excessive sedation > have fallen
Anti-psychotic: These drugs reduce the symptoms of hallucinations, delusions, paranoia, and extreme agitation. They may be regularly scheduled or taken as needed. These drugs can make you sleepy and should not be taken when you plan to consume alcohol.
, , , , , , , , , , , , , , , , , , , ,
> have fallen

Delirium – What can you do to help?

1. Learn about delirium

- > Know the signs and symptoms of delirium listed in this handout.
- > Tell the doctor or other health care team member if you notice any signs of delirium.
- > Understand that delirium is not dementia. Dementia is the gradual loss of memory and cognitive ability over time that results in decline of day-to-day thinking and function. Dementia cannot be cured.

2. Support healthy rest and sleep by:

- > Reducing noise and distractions.
- > Keeping light low or off when resting.
- > Improving comfort with a pillow, blanket, warm drink or back rub.
- > Not using sleeping pills if possible.

3. Support physical activity by:

- > Encouraging regular activity, assisting as necessary.
- > Talking with the health care team about safe exercise and activities.

4. Support healthy eating and drinking by:

- > Encouraging and helping with eating, as needed.
- > Offering fluids and healthy snacks often.

5. Support good hearing by:

- > Encouraging the wearing of hearing aids.
- > Making sure hearing aids are working and in the proper ear(s).

6. Support good seeing by:

- > Encouraging the wearing of glasses or use a magnifying glass.
- > Keeping glasses clean.
- > Using good lighting.

7. Support mental functions by:

- > Arranging for familiar people to visit.
- > Keeping sentences short and simple.
- > Gently reminding them where they are and what is happening. Please do not argue with them.
- > Talking about current events and what is going on around the person.
- > Reading out loud or using large print or talking books.
- > Bringing in a clock, calendar or pictures from home.

5. WEB RESOURCES

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Web Resources

Find trusted local and national resources for Alzheimer's, dementia, and delirium.

Alzheimer's, Dementia, and Delirium Health Information

> Alzheimer's Association Caregiver Center

www.alz.org/care

This section of the Alzheimer's Association website features tools to help care partners map out a caregiving action plan, tips for managing challenging behaviors, a caregiver stress check, training resources, links to local support groups, and more.

> U.S. National Library of Medicine

Delirium: www.ncbi.nlm.nih.gov/pubmedhealth/PMHoo32828

Alzheimer's: www.ncbi.nlm.nih.gov/pubmedhealth/PMHoo72544

Comprehensive site with detailed information on causes, incidence, risk factors, symptoms, signs and tests, treatment, drugs of interest, and more.

> Mayo Clinic

Alzheimer's: www.mayoclinic.org/diseases-conditions/alzheimers-disease/basics/definition/con-20023871

Dementia: www.mayoclinic.com/health/dementia/DSo1131
Delirium: www.mayoclinic.com/health/delirium/DSo1064

Easy-to-understand information on symptoms, causes, risk factors, complications, tests and diagnosis, and treatments and drugs. Also includes tips for preparing for a doctor's appointment, as well as lifestyle and home remedies and coping and support guidance.

> Dementia.org

www.dementia.org

This site offers lifestyle information like foods for dementia patients to eat, exercises to treat dementia, and interesting news from dementia research studies.

> MedlinePlus

Alzheimer's: www.nlm.nih.gov/medlineplus/alzheimersdisease.html

Dementia: www.nlm.nih.gov/medlineplus/dementia.html

Delirium: www.nlm.nih.gov/medlineplus/ency/article/ooo740.htm

Access to condition basics, multimedia tools, research information, handouts, and dementia news.

> Help Guide

www.helpguide.org/home-pages/alzheimers-dementia.htm

Gives tips on how to treat love ones with dementia, and tells you how to act around them. Also, it shows you a list of symptoms you may see if someone you know has dementia.

> CareTogether

www.caretogether.com

Free online resource that helps family and friends coordinate caregiving duties and provide updates on their loved one. Calendar syncs with BrightStar Care customer account so all member of the Care Team can see when a BrightStar caregiver is scheduled to visit.