

living with alzheimer's

for caregivers



tips for middle-stage caregivers

tip 1: enhance communication with simple changes

As people with Alzheimer's disease gradually lose their ability to find words, express thoughts and follow conversations, they may also have more trouble understanding others. The ability to exchange our ideas, wishes and feelings is a basic need, so the gradual loss of these abilities is difficult for everyone involved.

Other communication changes during the middle stage include word finding difficulty, repetition, the invention of new words, the tendency to lose train of thought, difficulty organizing words, reverting to a native language, lacking inhibitions (e.g., cursing), speaking less often, and relying on non-verbal communication. A number of physical conditions and medications can also affect a person's ability to communicate. Be sure to consult your family member's doctor if you notice sudden changes, in case they are curable or treatable.

Communicating with a person with Alzheimer's disease should always occur within the context of dignity and respect. Avoid talking down to the person or talking as if he or she isn't there. Try to speak slowly and distinctly, and use a gentle and relaxed tone of voice. Convey an easygoing, non-demanding manner. Be aware of your feelings and attitude as they are often communicated through your tone of voice, even when you are not aware of it.

When communicating with a person with dementia, it's especially important to choose your words carefully. Identify yourself and approach the person from the front and at eye level. Make sure to call the person by name and give the person a cue about your relationship. This will help orient the person and get his or her attention.

Please check below some of the techniques that you find helpful in communicating with the person with Alzheimer's disease.

- 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 expressions. For instance, say, "Please come here, your shower is ready," instead of, "Hop in!" Your family member may interpret it as a literal instruction.

- Avoid vague words. Try saying, "Here is your hat." instead of, "Here it is."
- Stress the words in a sentence you feel are most important. Say, "Here is your *coffee*," instead of, "Here you go."
- Always try to turn negatives into positives. Try saying, "Let's go here," instead of saying, "Don't go there."
- To help demonstrate a task, point to or touch the item you want the person to use. Or, begin the task for the person.
- Avoid quizzing or making the person feel like he or she should know something. Provide cues in your communications. Say, "It will be fun when we see Susan this weekend," rather than, "Aren't you looking forward to our plans this weekend?"

What other have you developed to communicate with the person?

New ideas to try:

tip 2: plan activities that provide meaning

Because visual cues such as labels on cabinets become less effective as the disease progresses in the middle stage, independent functioning can become more difficult. Structure and routine become more important.

Check those tips below that you are already using and finding helpful:

- ❑ Write a plan for each day. A planned day allows you to spend less time and energy trying to figure out what to do from moment to moment. In some instances, the plan for the day may include respite care, adult day programs or companions coming to the home. In general, the plan should include some time for preferred routines and some time for activities that provide meaning to the person.
- ❑ Think of “activities” as the things we do each day, rather than trying to invent new ideas. For example, making dinner for the family, gardening, going for a walk – these are all activities.
- ❑ Make sure to make time for yourself, or include the person with dementia in activities that you both enjoy. For example, if you typically take a daily walk, you can both walk together.
- ❑ Keep in mind that the goal is to help the person stay productive and independent rather than to accomplish a task thoroughly or perfectly. Focus on the process rather than the finished product.
- ❑ Break activities into simple tasks that can be approached step by step. For example, if a person enjoys gardening, you can break the activity into the following smaller steps:
 - Talk about your garden plan
 - Make a list of seeds to purchase
 - Buy the seeds
 - Help the person gather tools and put on gardening gloves
 - Help the person dig holes for seeds by providing hand-over-hand assistance

tip 3: assist with providing proper nutrition

Proper nutrition can keep the body strong and healthy, but regular nutritious meals may become a challenge for people with dementia. They may become overwhelmed with too many food choices, forget to eat or think they have already eaten.

Poor appetite, loss of interest in food, forgetting how to eat, or forgetting that one has eaten are other factors that can make mealtimes challenging. However, there are coping guidelines that often help caregivers adapt to eating transitions.

Check those tips below that you have tried and found helpful:

- Make mealtimes calm and comfortable.
- Serve meals in quiet surroundings, away from the television and other distractions.
- Keep the table setting simple and avoid plates, tablecloths and placemats that have lots of busy patterns that might confuse the person. Providing foods and plates in contrasting colors helps the meal look appealing and makes the food easy to find.
- For those who find using utensils difficult, consider offering “finger foods”. These may include sandwiches, fruit, bagels, muffins, chicken strips, fish sticks, raw vegetables, etc.
- Use only the utensils needed for the meal.
- Serve only one or two foods at a time. For example, serve mashed potatoes followed by cooked meat.
- Use simple, easy-to-understand instructions. For example, “Pick up your fork. Put some food on it. Raise it to your mouth.”
- Focus less on being sure that the person eats balanced meals at each sitting, and more on providing complete nutrition over the course of a day or a few days.

If you are having problems during mealtimes, consider the following:

- Is the problem physical? Sores in the mouth, poorly-fitting dentures, gum disease or dry mouth may make eating difficult.
- Does the person have other chronic diseases or is the person taking

medications that might lead to loss of appetite? Constipation or depression can also decrease appetite.

- Is the person agitated or distracted? If agitated, the person probably won't sit long enough to eat an entire meal. Think about how you can reduce distractions in the eating area. Frequent snacks can allow them to "eat as they walk".
- Have you recently changed eating styles or routines? Does the person have a preferred eating pattern? Some people who are not accustomed to sitting down at the table for three full meals may prefer to have several smaller meals or snacks.
- Remember that the person with dementia has long-standing personal preferences. Try to keep these likes and dislikes in mind when you are preparing food.
- People with Alzheimer's disease often prefer soft and sweet foods. Look for ways to make food appealing and nutritious. For example, offer mild shakes, bananas, apple sauce, and smoothies. Many such foods can be fortified with protein or fiber powders and vitamins.

What other ideas have you used successfully to help the person with Alzheimer's to maintain proper nutrition?:

Other ideas to try:

tip 4: help the person with dementia participate in self-care

Many people with dementia have loss of bladder or bowel control (incontinence). Possible causes include an inability to recognize natural urges due to changes in the brain, forgetting where the bathroom is located or side effects from medicine. Have the doctor rule out medical problems as the cause, especially if there are sudden changes in bladder and bowel patterns. Urinary tract infections are common and can cause dramatic behavior changes.

There are several ways to help the person you care for with using the bathroom. Check those that you are using with success:

- Removing obstacles from the path to the bathroom may prevent falls and make the room easier to access.
- Making sure the person's clothing is easy to remove can reduce accidents.
- Creating visible reminders such as a sign or picture of a toilet on the bathroom door may help the person find it more easily.
- At night, leaving the bathroom light on and the door open will aid the person in finding the bathroom.
- Using colored rugs on the bathroom floor and colored toilet lids may help the toilet stand out.
- Sometimes, offering reminders and encouraging the person with dementia to go to the bathroom regularly can reduce accidents.
- Watching for agitation, facial expressions, or pacing may provide you with indicators that the person needs to use the bathroom, especially later in the middle stage and early in the late stage.

Monitoring incontinence by identifying when accidents occur can help you develop a plan to avoid them, if possible. If accidents tend to occur every two hours, for example, you can suggest that the person go to the bathroom (or escort the person there) every hour and a half. You may also want to consider using incontinence products like rubber sheets or incontinence pads on the person's bed, padded undergarments or adult briefs, or a bedside commode. Needing help with toileting may embarrass the person, and your recognition and normalization of this feeling combined with a matter-of-fact approach can help the person with dementia accept your assistance.

Hygiene and bathing (or showering) can also become more challenging as the disease progresses. The person in the middle stage of the disease may need to be reminded about the need to bathe, and an increasing amount of assistance is often needed.

Once reminders are no longer adequate, think about the person's abilities, encourage the person to do as much as possible, and be ready to assist when needed. Assess his or her ability to:

- Find the bathroom
- See clearly
- Keep his or her balance without falling
- Reach and stretch his or her arms
- Remember steps in the bathing process and follow cues or examples
- Know how to use various products (soap, shampoo, washcloth, etc.)
- Sense water temperature

Helping the person with dementia maintain his or her appearance can help the person maintain dignity, and caregivers can help by providing the least amount of hands-on assistance needed. You can provide direction indirectly by laying out clothing in the order in which each item is put on. If you are providing additional assistance, you can hand the person one item at a time while giving short, simple instructions such as, "Put on your shirt," rather than, "Get dressed."

Other suggestions for helping the person participate in self-care include:

tip 5: plan ahead for trips to the hospital

A trip to the hospital with a person who has dementia can be stressful, particularly during the middle stage. The combination of unfamiliar surroundings and interaction with strangers can make a hospital stay frightening for the person with Alzheimer's disease. Here are tools and techniques that can make the process easier for everyone. The key is advance planning.

Check the items below that should be done ahead of time so that you will be ready should the need for hospitalization arise.

- Be sure that the following documents have been updated and have copies accessible:
 - Power of attorney documents
 - Advance directives
 - Insurance cards
- Have a list containing the following information prepared and accessible:
 - Current medications
 - Contact information for physicians

Check the items below as you do them when a hospitalization is necessary:

- Discuss hospitalization before it happens. Identify your support team and assign roles.
- Pack emergency bags for both the person with Alzheimer's and you. You may be called on to stay at the hospital for an extended time, and it will help to have the items with you that you would need for an overnight stay if necessary.

For the person with dementia, include:

 - Copies of insurance cards, power of attorney documents, advance directives, etc.
 - A change of clothing
 - Incontinence supplies (if used)
 - Comforting objects (e.g., music, pictures, etc.)
 - Games or activities that may help pass the time and distract the person if necessary

- A list that contains personal information for the individual, such as:
 - Current medications
 - Allergies
 - Preferred language
 - Contact information for other doctors, family and friends
 - Other illnesses/medical conditions/impairments
 - Routines, preferences, and information about any behavior triggers

For you:

- Notebook or journal and pens for recording questions or concerns to present to medical staff, as well as to note their recommendations
- A change of clothes and toiletries
- Snacks
- Cash
- A note to remind you to take your cell phone and charger
- If the person with dementia has begun to wander, research and enroll in one of the Association's safety services programs, Medic Alert® + Alzheimer's Association Safe Return® or Comfort Zone™, and look into other safety products that can protect against wandering.
- If insurance allows, it can help to ask for a private room.
- It is usually a good idea to only inform the person of the upcoming hospital stay shortly before it occurs. When and how you inform the person needs to be done in a way that you feel would lead to the best response from the person.

There are techniques that can help families proceed through the admission process, the hospital stay and discharge more smoothly. Inform staff about the person's typical state and abilities so that they can differentiate between dementia and confusion or delirium. You can also help staff by providing them with information about:

- The person's routine,
- Triggers for difficult behaviors,
- Your techniques to address the person's needs and reduce stress when the person is upset,
- How he or she prefers to be addressed,
- Personal habits and preferences, and
- Nonverbal signs of happiness, discomfort or pain.

Be sure to address the following:

- **Inform about wandering risk and manage together**
It is crucial that you inform staff if the person has any risk of wandering and determine together how to keep the person safe in this setting.
- **Avoid speaking as if the person with dementia were not present**
This can lead the person to feel left out or demeaned. If you receive confusing information, attempt to speak to the medical professional separately so as not to upset or confuse the person for whom you provide care.
- **Ask staff to explain**
Hospital staff may have a tendency to review processes, medications, treatment and discharge planning at a rapid pace and with medical jargon; be sure to speak up and ask the staff to slow down if necessary, repeat themselves, and answer any questions you may have. It will help if you keep notes each day about questions and responses from staff.
- **Caregivers as advocates**
Remember, hospital staff are there to provide care and comfort for many people. You are acting as an advocate for the person with dementia, so be patient and attempt to align yourself with the health care providers. You may not agree on every element of care, but if you can find some common ground, it will help open the door to positive communication.

tip 6: communicate effectively using ideas from others

Repetitive questions or behaviors are also common in the middle stage and are often the result of physiological changes from the disease itself or other medical conditions. They may also be reactions to environmental changes like being separated from you or being overwhelmed by the sights and sounds around them. Repetitive behaviors can also result from having difficulty with communication, either in self-expression or in comprehension of what is being said.

As you become more experienced as a middle-stage caregiver, you will develop techniques that work for you at a particular time. These techniques will need to be altered throughout the course of the disease as abilities diminish. This is when the experiences of other caregivers can be particularly helpful, and you can hear about a variety of techniques that have worked for others through support groups or message boards.

Check the ideas from other caregivers below that you have tried and found effective:

- Responding to the emotion instead of the specific question; the person may simply need reassurance.
- Reminding with brief, simple statements; do not remind the person that he or she has asked the question before as this may be upsetting.
- Using a gentle touch when a verbal response does not seem to help.
- Using a calm voice when responding to repeated questions.
- Using simple, written reminders with people who can still read (e.g., a large sign might say, "We will eat breakfast at 8:30 a.m.").
- Using pictures to replace written reminders when the ability to read is lost (e.g., a picture of a toilet might replace a sign that says "toilet" on the bathroom door).
- Not discussing plans with the person until just prior to an event.

- ❑ Checking in with the physician or other health professional to rule out physical or medication problems.
- ❑ Distracting the person with a favorite activity.
- ❑ Ignoring the behavior or question if doing so does not upset the person.
- ❑ Removing things in the environment that may trigger repetitive questions (e.g., a visible coat rack may trigger the person to ask repeatedly, "Is it time to go now?").

Repetitive behaviors and questions can be some of the most frustrating aspects of providing care in the middle stage of the disease. It will be important to learn to take time for yourself and to get some breathing room, even if it means just leaving the room for a moment. Take a bath, take a walk, do relaxation exercises, see a movie with a friend – these are the sorts of things that are important to build into your life as a caregiver in order to maintain your physical and emotional health. By doing this, you can often return in a state of mind in which you can better deal with these difficult aspects of caring for someone with Alzheimer’s disease or a related dementia.

Other ideas:

tip 7: be prepared to deal with aggressive behavior

There are a number of behavior changes that can arise during the middle stage of Alzheimer's disease that can present significant challenges for caregivers. There are ways to deal with the behavior changes, though, that can reduce the intensity of the behaviors and the impact on families.

There are several possible reasons that a person in the middle stage of dementia may be demonstrating agitation or aggression. It is up to caregivers to assess the situation to see what may be causing the behavior before attempting to intervene.

- **Explore pain first.**

Whenever there is a sudden shift in behavior, the first thing to explore is whether the person is in pain. Persons with dementia may demonstrate pain in indirect ways, so it is not always the first thing that comes to mind for someone who is not familiar with this aspect of the Alzheimer's disease. But it is the cause of behavior changes so frequently, and is so important to address immediately, that one of the prime caregiving tools is to look at the issue of pain first. Urinary tract infections are often the cause of behaviors that may appear to be unrelated, but are actually expressions of the pain associated with that condition.

- **Check for a medical cause second.**

If pain is not the immediate issue for the person, there may still be a medical concern that is responsible for the change in behavior. Check with the doctor to see if there is something happening medically that may be responsible for the agitation or aggression.

- **Explore environmental changes.**

The senses sometimes get overloaded by unfamiliar or sudden environmental changes like new furniture, loud noises, unfamiliar faces, or feelings of being lost or insecure.

- **Communication changes may be responsible.**

The person with dementia often begins to communicate differently due to the progressive nature of the disease and may become frustrated while trying to express him- or herself. Caregivers can learn to adapt their methods of communication to reduce anger and agitation.

Most of the time, the person can be soothed and the behavior can be brought under control by addressing these issues. However, instances of extreme agitation or aggression escalating into dangerous situations do exist.

When the person with dementia or those around the person are at risk for harm, sometimes, 911 will need to be called. Take the following steps to provide protection for everyone involved:

- Speak clearly to the dispatcher who takes the call about what is happening and the risk for harm involved in the situation.
- Inform the dispatcher that the person has a dementia and that you need medical assistance.

When the emergency team arrives, it will assess the situation and determine whether the person should be taken to the hospital for an evaluation by a medical team. The medical team can then evaluate and treat based on the assessment. They might administer medication to try to bring extremely aggressive behavior under control. They also will help determine the next steps needed to provide appropriate treatment for the immediate future.

Other important considerations for us:

tip 8: address the causes of hallucinations or delusions

Hallucinations, delusions or paranoia are thought disorders are symptoms of Alzheimer's disease that may begin or escalate in the middle stage. It is important to discover the source of these symptoms before deciding how to intervene.

These symptoms may be the result of either medical or environmental factors.

- **Medical causes** may include pain, changes in medication, brain damage due to the progression of the disease, physical trauma to the head, malnutrition, and physical illness.

Explore the medical aspects of these symptoms by:

- Checking in with the physician can allow you to rule out physical and/or medication problems as soon as possible. For example, sudden and drastic behavioral changes may be due to a urinary tract infection or medication side effect causing delirium. These problems are often treatable but should be attended to right away.
 - Although some families find medications to be helpful in reducing anxiety related to hallucinations, delusions or paranoia, there is a possibility that these medications may actually *worsen* dementia symptoms. Be careful to use medications only as ordered by the physician, and report any negative effects promptly.
- **Environmental causes** include unfamiliar surroundings, inability to recognize the environment or the caregiver, disruption in routines, removal of personal items, inadequate lighting, or an overly stimulating environment.

In addition to the medical aspects of delusions or hallucinations, there are some environmental components of these symptoms. You can minimize the risk of hallucinations, delusions or paranoia by:

- Assessing the environment and making changes when needed. For example, shadows can lead to visual hallucinations, so provide adequate lighting, night lights, etc.

- ❑ Explaining the potential or actual misinterpretation: “That loud noise is the train passing through the city.”
- ❑ Responding to general feelings that are behind specific statements. For example, a specific statement may be, “My father is at work,” when the person’s father is actually dead. The memory of the person may be stronger than the memory of his death. Instead of telling the person that his or her father is dead, try saying, “You must miss your father,” “It sounds like you loved your father very much,” or “Tell me about your father.”
- ❑ Memory loss and confusion may cause the person with Alzheimer’s to perceive things in new or unusual ways. Individuals may become suspicious of those around them, even accusing others of theft, infidelity or other improper behavior. Sometimes the person may also misinterpret what he or she sees and hears.

How to respond:

- ❑ Don't take offense. Listen to what is troubling the person, and try to understand that reality. Then be reassuring, and let the person know that you care.
- ❑ Don't argue or try to convince. Allow the individual to express ideas and acknowledge his or her opinions.
- ❑ Offer a simple answer. Share your thoughts with the individual, but keep it simple.
- ❑ Switch the focus to another activity. You can engage the individual in an activity or ask for help with a chore.
- ❑ Duplicate any lost item. If the person is often searching for a specific item, have several available. For example, if the individual is always looking for his or her wallet, purchase two of the same kind.

Other ideas:

tip 9: make changes to reduce sundowning

A person with Alzheimer's may experience increased confusion, anxiety, agitation, pacing, and disorientation beginning at dusk and continuing throughout the night. These late-day increases in behavioral problems are often called sundowning. Sundowning can disrupt the body's sleep-wake cycle, causing more behavioral problems.

Factors that may cause sundowning:

- **Mental and physical exhaustion** from a full day trying to keep up with an unfamiliar or confusing environment.
- **Increased noise and busyness at home** due to people returning home and attending to homework, having multiple conversations and preparing dinner.
- **Reduced lighting and increased shadows**, which may cause persons with Alzheimer's to misinterpret what they see — subsequently, becoming more agitated.

Tips for managing sundowning:

- ❑ **Reduce noise and activity levels**
Keep in mind that this is the time of day that is often busiest at home or in a facility. People returning home from work or professionals changing shifts can increase noise levels and upset the person with dementia. You might want to try having the person set up in a quiet area doing something that will occupy him or her prior to this time of day.
- ❑ **Monitor your exhaustion**
Be mindful of your own mental and physical exhaustion. If you are feeling stressed by the late afternoon, the person may pick up on that and become agitated or confused. Try to get plenty of rest at night so you have more energy during the day.
- ❑ **Plan ahead for calm evenings**
Plan more challenging activities (e.g., doctor appointments, trips, bathing) in the morning or early afternoon hours when the person is more alert.
- ❑ **Identify triggers**
Make notes about what happens before sundowning events and try to identify triggers.

- ❑ **Plan for light dinners**
Have a large meal at lunch and keep the evening meal simple.
- ❑ **Keep the home well lit** in the evening
Adequate lighting may reduce the person's confusion.
- ❑ **Don't physically restrain**
Trying to restrain the person makes agitation worse.
- ❑ **Channel restlessness**
If the person needs to pace back and forth, you might try allowing this to continue under your supervision. Take a walk outdoors if the weather permits or allow for other forms of exercise. as this may reduce restlessness.
- ❑ **Time taking medications**
Talk to the physician about **the best times of day for taking medication**.
- ❑ **Pharmaceutical intervention as last resort**
When behavioral interventions and environmental changes do not work, some people with Alzheimer's may need medication for their agitation during the late afternoon and evening hours. This should be discussed with the doctor.

Other suggestions to try:

tip 10: discover the cause of sleep problems before intervening

People with Alzheimer's disease can act in different and unpredictable ways that may be disturbing to you and others. It is important to remember that the person is not acting this way on purpose. All behavior is communication—it is a way of conveying information. Part of the responsibility of the caregiver is to try to identify the cause of the behavior and possible solutions.

Sleep problems

One behavior common in the middle stage and related to sundowning is difficulty sleeping. Sleep changes are often due to:

- Pain,
- Illness,
- Infection,
- Restless legs,
- Depression,
- Medication side effects,
- Sleep apnea,
- Inadequate exercise, and/or
- Excessive caffeine or alcohol.
- Feeling too hot or too cold,
- Too much light at night or too little during the day,
- Spending too much time in bed,
- Being awake during odd hours,
- Agitation, and
- Disorienting dreams.

Start by assessing for pain, which can be caused by medical conditions. Once you and the medical team have ruled these out as possible causes of the behavior, you can intervene with sleep problems by using behavioral interventions, and may consider using psychotropic medications if necessary.

Check those ideas below that have worked for you and consider trying the others as well:

- Get a good medical work-up to identify and treat medical problems. Have an

evaluation for depression performed if early morning awakening is a problem. Antidepressants given at bedtime may help with sleep. It is important that you use these types of medications only with very careful medical supervision. In some people with dementia, these medications have the opposite effect, making people *more* agitated or restless.

- ❑ Get the person up earlier or keep him or her up later until the person becomes tired. Make sure that the bed and bedroom are comfortable and familiar to the person; a favorite blanket, pillow or bed clothes may be helpful. Do not use bedrails, as they may lead to confusion and a feeling of being trapped. If the person tries to climb out of bed, the bedrails can make it more difficult and a fall can occur. Instead, consider lowering the mattress closer or on to the floor.
- ❑ Maintain a set bedtime and waking routine, and avoid daytime napping unless person seems very fatigued in the evening. An evening routine of a light snack with herbal tea or warm milk can help relax the person and promote sleep. Allow the person to sleep on a sofa or armchair if preferred. The person may enjoy having soft music playing on a radio beside the bed as well. Try to minimize noise, confusion and the numbers of people around. You might consider making all or a portion of the house safe for the person to wander in alone at night.
- ❑ Consider allowing the person to be up at night, if this can be accomplished safely and without destroying the caregiver's routine. When caregivers are unable to get adequate sleep themselves, night after night, they become high risk candidates for accidents or illness, and the person they care for becomes a more likely candidate for nursing home placement. Ask others to help supervise the person during some parts of the day or night, and consider hiring a companion for overnight coverage.

Additional behaviors that may arise include:

- **Forgetting that they are married and begin to flirt or make unwanted advances toward others.**

Try:

Distracting the person with another activity or lead him or her to another place.

- **Attempting to take clothes off at inappropriate times and in unusual settings.**

Try:

Assessing for pain, particularly for a urinary tract infection. This behavior is frequently an expression of discomfort and attempts to relieve pain. In general, clothing that is simple and comfortable for the person to wear is best. If the person can dress with assistance, you can choose the clothing for the day that is appropriate to the weather and lay it out in the order in which he or she should put it on.

- **Not understanding or remembering that merchandise must be paid for, and casually walking out of a store without paying for an item, unaware of any wrongdoing.**

Try:

Enroll the person in MedicAlert® + Alzheimer's Association Safe Return®, which will provide a bracelet that indicates that the person has Alzheimer's disease.

Other ideas:

tip 11: plan ahead to ensure home safety

In the middle stage, the person you care for is experiencing changes in judgment, sense of time and place, behaviors, physical abilities, and sensory functioning. Inevitably, these changes will create safety concerns that you will need to assess and manage.

Home environment:

It is essential to have a safe and supportive home environment, especially as your family member progresses through the middle stage. With these tips, you can adapt the home to ensure safety and support by using creativity, flexibility and general problem-solving skills.

Check any of the following tips for a safe home that you are currently using:

- Assess the home for appliances that could pose a risk for someone with dementia.
- Limit access to potentially dangerous chemicals and substances, such as cleaning products, medications, etc.
- Clear the home of loose rugs, wires, and other floor clutter to reduce the risk of falls.
- Create safety checklists for each area of the home, including closets, basements, attics, garages, and outdoor areas.

Activities:

Just as important as ensuring home safety is assuring that the person with Alzheimer's is not put in situations that could result in harmful consequences. Increased supervision will decrease the person's autonomy, which can be difficult for the individual and result in some resistance. When trying to balance safety and autonomy, keep in mind that some degree of autonomy can still be achieved by careful assessment of the person's current abilities. However, safety must come before autonomy in order to achieve the greater good of optimal care for the person with Alzheimer's.

The disease affects judgment in a more pronounced way during the middle stage. Therefore, people in this stage are less able to make sound decisions without assistance. This is important to note when assessing your family member's activities at home.

tip 12: take action regarding driving

It is in the middle stage of the disease when the person with Alzheimer's disease will need to stop driving. Once it is clear that the person with dementia can no longer drive safely, you should try to involve the person in the decision to stop driving. Explain your concerns by giving specific examples, and ask the person to voluntarily stop driving. Assure the person that you will do everything you can to make rides available.

Here are some other tips to help the person with Alzheimer's stop driving. Check those that you have used successfully.

- Let others do the driving**
- Reduce the person's need to drive.**
Have prescription medicines, groceries, or meals delivered.
- Be firm, yet positive, about driving.**
Avoid arguing or giving long explanations for why he or she cannot drive. Losing the independence that driving provides can be upsetting, and it may be hard to give up the car keys.
- Solicit the support of others.**
Ask the physician to write a letter stating that the person with Alzheimer's must not drive, or ask the physician to write a prescription that says, "No driving." You can then use the letter to remind your family member that the doctor said that they could no longer drive.
- Ask a respected family authority figure or your attorney to reinforce the message about not driving.**
- Experiment with ways to distract the person from driving.**
Mention that someone else should drive because you're taking a new route, because driving conditions are dangerous, or because he or she is tired and needs to rest. Tell the person he or she deserves a chance to sit back and enjoy the scenery. You may also want to arrange for another person to sit in the back seat as a distraction. If there is a history of anger and aggressiveness, it may be best not to drive alone with the person.

Enroll the person in MedicAlert® + Alzheimer's Association Safe Return and/or Comfort Zone™

It is possible for the person with dementia to wander or to get lost while driving. Be prepared for a wandering incident and enroll the person in one or both of these programs, both of which are available through the Alzheimer's Association. Visit the Safety Center at www.alz.org for more information.

Check any of the "last resort" ideas that you have used below:

Control access to the car keys.

Disable the car.

Remove the distributor cap, battery, or starter wire. Ask a mechanic to install a "kill wire" that prevents the car from starting unless the switch is thrown. Another option is to give the person a set of keys that looks like his or her old set but that will not start the car. These barriers to access to a working vehicle can help preserve the dignity of the person with dementia.

Consider selling the car.

Diffuse the situation by keeping the car out of sight.

In some states, it might be best to alert the Department of Motor Vehicles.

Write a letter directly to the authority and express your concerns, or request that the person's license be revoked. The letter should state that "(the person's full name) is a hazard on the road," and offer the reason (Alzheimer's disease). The state may require a statement from your physician that certifies the person is no longer able to drive.

Be prepared for the possibility that your family member may forget that he or she is not supposed to drive. In these instances, using the same strategy that worked the

tip 13: make arrangements for times when someone is alone

When the person with dementia lives alone, the options narrow for gradually transitioning to a supervised situation. But many people with Alzheimer's continue to live successfully on their own during the early stage of the disease, and some at the start of the middle stage. Making simple adjustments, taking safety precautions and having the support of others can make things easier.

Check those suggestions for living alone with Alzheimer's disease that have been helpful in your situation:

- Talk to staff** at the local Alzheimer's Association office or the doctor about where to get help for things like housekeeping, meals or transportation.
- Have someone take over paying the bills** for the person with dementia at this stage.
- Inform the bank** if the person has difficulty with record keeping and keeping track of accounts; the bank may provide special services for people who struggle with doing their own banking.
- Arrange for the direct deposit** of checks, such as retirement pensions or Social Security benefits.
- Plan for home-delivered meals**, if they are available in the community.
- Have a family member regularly **sort closets and dresser drawers** to make it easier to get dressed.
- Leave a set of house keys** with a neighbor.
- Schedule family, friends or a community service to make a **daily call or visit**; have the person keep a list of things they can discuss together.

At some point early in the middle stage, it will become too difficult or dangerous for the person to be left alone. The earlier that planning was done for where to live as the disease progresses, the simpler making the transition will be. It may help to assist the person in getting a helpful roommate, to live with relatives or to move to a residential care setting.

Other ideas to help someone living alone with Alzheimer's:

tip 14: reduce the risk of wandering

During the middle stage of Alzheimer's, preparing for and preventing wandering becomes a crucial part of care provision. Wandering affects a majority of individuals with dementia, and many individuals who have a tendency to wander will do so repeatedly.

Wandering often occurs as a result of a physiological, medical, or environmental changes or disruptions. These changes can include medication interactions or side effects, physical discomfort, stress, physiological changes within the brain, dehydration, sensory overload and/or deprivation, feeling lost, disorientation, a need to search for something, or an inability to negotiate unfamiliar surroundings.

Here are several tips to reduce wandering, prevent your family member from getting lost, and prepare for emergencies.

Check those tips to reduce wandering that you have used with success:

- Encourage movement and exercise to reduce anxiety, agitation and restlessness.
- Ensure all basic needs are met (toileting, nutrition, thirst).
- Involve the person in daily activities to provide him or her with a sense of structure, such as folding laundry or preparing dinner.
- Place color-matching cloth over doorknobs to camouflage them.
- Paint the door and the trim the same color as the walls to disguise them.
- Put a dark mat in front of the door. This may be interpreted as a hole and serve as a deterrent from approaching the door.
- Install door alarms.
- Redirect pacing or restless behavior.
- Reassure the person if he or she feels lost, abandoned or disoriented.

Check the following tips you have used to prevent the person with dementia from getting lost:

- Inform your neighbors and local emergency responders of the person's condition and keep a list of their names and telephone numbers.
- Keep your home safe and secure by installing deadbolt or slide-bolt locks on exterior doors and limiting access to potentially dangerous areas. Care

should be taken to only do this when the person is supervised so that he or she will have a way out in case of an emergency.

- ❑ Be aware that the person may not only wander by foot but also by car or by other modes of transportation.

To prepare for emergencies:

- ❑ Keep a list of emergency phone numbers and addresses for local police and fire departments, hospitals, and poison control centers as well as the MedicAlert + Safe Return emergency response number.
- ❑ Keep a list of physicians' phone numbers and current medications (with dosages).
- ❑ Keep copies of legal documents in a secure but close location (living will, power of attorney, etc.).
- ❑ Check fire extinguishers and smoke alarms to ensure they are working properly.

The Alzheimer's Association offers two support programs to help manage wandering behavior: **Medic Alert + Safe Return, and Comfort Zone**. To learn more about either of these programs, including costs and how to enroll, visit www.alz.org and click on the Safety Center..

Other ideas to keep the person from getting lost:

tip 15: get additional resources to reduce caregiver stress

If you are a caregiver, you will need a break from caregiving tasks. Additionally, someone with dementia may want a break from the daily routine and have the opportunity to meet others who share similar challenges. Respite care can help by providing a new environment or time to relax. It can be for a few hours or several days or weeks depending on your particular needs and interests.

In-home care services, such as companion services, personal care aides, homemakers, or skilled services can be accessed privately, through an agency, or as part of a government program. Paid professionals can come to your home and help as needed with various care and household needs.

Be sure the in-home services you choose are appropriate for your specific needs. Cost, level of training and specific services provided will vary among workers and agencies. For example, companions can help with supervision if the primary caregiver goes out to run errands or to a social gathering. Personal care aides can help with bathing, grooming, dressing, and similar tasks. Homemakers can help with meal preparation or household cleaning. Skilled services, such as home health care, can administer medical attention as needed.

Respite refers to a short time of rest or relief. Specifically, respite care provides a break from the typical care routine, allowing the caregiver some down time while the person with dementia continues to receive care from qualified individuals and has the opportunity to have different experiences. It can be provided for part of the day, evening or overnight, and can be offered on an occasional or on a regular basis

Check those from whom you have asked for help in order to get some respite from caregiving:

- Paid staff
- Volunteers
- Family or friends
- A community organization or
- A residential care center

Some caregivers work or have other responsibilities in addition to providing care. Respite care can give a caregiver the time and assistance required to meet those personal needs.

Respite care provides multiple benefits to the caregiver, including:

- A chance to spend time with other friends and family, or to just relax
- Time to take care of errands such as shopping, exercising, getting a haircut or going to the doctor
- Comfort or peace of mind knowing that the person with dementia is spending time with another caring individual

Additionally, respite care services can give the person with dementia an opportunity to:

- Interact with others having similar experiences
- Spend time in a safe, supportive environment
- Participate in enjoyable activities designed to match personal abilities and needs

Friends, family members, neighbors, and community volunteers have probably offered to help in some way – whether that means driving to a doctor’s appointment, bringing over a meal or visiting for a few hours. In the middle and later stages of Alzheimer’s, family and friends can take turns staying in the home with the person while you run errands or take time for yourself.

To help coordinate these plans for informal care, the Alzheimer’s Association offers **Lotsa Helping Hands** through its website at alz.org. This is a great online service specifically designed to help caregivers schedule respite care and other kinds of assistance with family, friends and colleagues. Using your computer and this service, you will be able to easily share a schedule with everyone who has offered to help. The password protected community calendar records dates and times indicating when people have offered to share caregiving duties. An online bulletin board allows you to share news about the person and provides a place for others to offer support or well wishes. It’s a great way to keep long distance family members and friends up-to-date on the person’s status.

Often, getting respite is a matter of asking. What do you think you could use help with in caregiving?

How might you divide those tasks up into smaller parts?

Who do you think you could ask to provide this kind of help to you as a caregiver, and how likely are those people to be able to help? If they are not able to help for whatever reason, who else could you ask?

tip 16: consider using adult day services

Adult day centers can vary greatly regarding services provided, cost, and quality. To choose the best setting for the individual with dementia, do the following:

- Consult a variety of sources to find an appropriate adult day center.
- Give the adult day center a chance. Consider using its services at least twice a week for one month before making a final decision
- Periodically reevaluate your need for adult day services. At some point, the person with Alzheimer's may need more care than the center can provide. The center's staff as well as support groups you attend can help evaluate your needs for future care.

Which of the following are important for you to explore before making a choice about adult day services for your family member?

- Does the center provide specific services for people with dementia?**
- Will the center address other medical or special needs?**
For example, some centers provide blood pressure checks and even physical, dental, foot, eye and ear examinations. Some also provide personal care, such as manicures and pedicures, shampoos and haircuts. Will the center's staff provide help with hairstyling, toileting, eating, showering and other personal care tasks?
- It is also important to know whether the center will dispense medication and/or offer medication reminders.**
Ask about any service restrictions before using the center to avoid surprises.
- How will the center evaluate your family member's needs?**
Will the evaluation cover medical needs, social and family history, cognitive functioning, and social skills? Some centers perform assessments in the person's home.
- How often are reevaluations performed?**
- Is the center in a convenient location?**
If not, getting to and from the center may consume a large part of your day and be stressful on your family member. However, some centers of-

fer pick-up and drop-off transportation services, while others provide transportation for outings and medical appointments.

- Does the center offer convenient hours?**
Most centers are open from early morning to early afternoon. Some have extended or weekend hours. People may attend the center as little as one day per week or as many as five. Be sure to ask about minimum attendance requirements and the notification policy for absences; also ask about the policy for late arrival or late pick-up.
- Is transportation provided to and from the center?**
Is it offered for field trips? What is the cost for that service?
- Is the service affordable?**
Many centers offer services on sliding scales, where caregivers pay according to ability or income. In some states, Medicaid covers this cost for people with very low income and few assets. Be sure to ask about basic fees, financial assistance, billing to insurance and additional charges for such services as crafts or field trips.
- Does the center have a clean, friendly environment?**
- Does the center provide nutritious meals and snacks?**
To make sure, you may want to sample one of the meals. In addition, can the center accommodate special diets or provide a culturally specific menu?
- Is the center adequately staffed with well-trained employees?**
Assess the qualifications of the staff as well as the number of staff per client. Do staff members have dementia-specific training? Does the center have a physician, nurse or health care professional on staff or on-call? If the center uses volunteers, are they adequately trained and supervised? Are staff members warm and friendly?

tip 17: screen carefully for in-home assistance

In-home care services, such as companion services, personal care aides, homemakers, or skilled services can be accessed privately, through an agency, or as part of a government program. Paid professionals can come to your home and help as needed with various care and household needs. Be sure the in-home services you choose are appropriate for your specific needs. Cost, level of training and specific services provided will vary among workers and agencies. For example, companions can help with supervision if the primary caregiver goes out to run errands or to a social gathering. Personal care aides can help with bathing, grooming, dressing, and similar tasks. Homemakers can help with meal preparation or household cleaning. Skilled services, such as home health care, can administer medical attention as needed.

Choosing an in-home care provider is a very personal decision, but before getting to the point of interviewing to determine who will fit well with the person and the needs of the household, there are some important pieces of information to gather.

Here are some quick tips to help find the right care provider:

- Good dementia care ensures safety, meets basic needs, and involves the person with dementia as much as possible.
- Providers should treat a whole person, not just a patient.
- Staff should be specially trained in dementia care. Ask about ongoing training for staff members as well.
- Care providers should have adequate supervision and be supported in their daily work.
- A good long-term care facility should feel comfortable and homelike.

When looking for in-home assistance, review the following, checking the information that you have already gathered. Be sure to cover any missing pieces before hiring someone to help.

☐ **References :**

If you are interested in contracting with an agency to provide and supervise staff, it is a good idea to ask for references from those who have used the agency in the past. Quality service agencies will be happy to offer you a number of references for you to contact. If you are consider-

ing employing someone who is not with an agency at the suggestion of someone you know, ask that person for personal references once he or she is being seriously considered for the role.

- ❑ **Bonding:**
Agencies often bond their employees, which means that the employees have undergone an extensive background check and that an external company is vouching for their honesty and integrity. If a claim is filed against the company for the activities of the bonded employee (e.g., stealing from the household while working there), the bonding company has money that is made available for any damages that may be awarded.

- ❑ **Licensure:**
In some states, there are roles performed by in-home care providers that require that the provider be licensed. That means that the person has been deemed qualified to perform that role by the state or local government.

- ❑ **Insurance:**
In-home workers may be insured through their agency to perform their roles, and if the worker is injured on the job, the claim is made against the agency rather than against the homeowner's insurance of the person who has hired the worker or agency to provide care.

Other important considerations for us:

tip 18: investigate senior living options

If the person with dementia prefers a community living environment or if living at home is no longer possible, there are several senior living options to consider.

Types of senior living:

- **Independent living**
This usually consists of a small, easy to maintain private apartment or house within a community of seniors. Services such as meals, housekeeping, transportation and social activities are often available.
- **Board and care homes**
These facilities provide meals, housekeeping, medication reminders and help with some daily activities. These residences may also be called adult foster care, elder care homes, adult homes, or residential care homes.
- **Assisted living residences**
Usually, 24-hour staff, recreational activities, meals, housekeeping, laundry, and transportation are provided here. Residents may choose which services they receive. Many also provide medication management and assist with daily living activities such as bathing. Regulations vary from state to state, but some assisted living residences allow residents to remain in their apartments after they need additional assistance if families engage a home health care provider.
- **Continuing care retirement communities (CCRCs)**
CCRCs provide different levels of care based on individual needs. A resident can move throughout the different levels of care within the community as needs change.
- **Skilled care**
This type of facility may provide a full range of medical and personal care needs, including acute care, rehabilitation and long term care. Check with your insurance provider to see whether nursing home care is covered under your plan.

- **Memory units**

Many facilities have special dementia care units designed to meet the needs of people with dementia; some are open units, while others are controlled to prevent wandering.

Here are some quick tips to help find the right care provider:

- Good dementia care ensures safety, meets basic needs, and involves the person with dementia as much as possible.
- Providers should treat a whole person, not just a patient.
- Staff should be specially trained in dementia care. Ask about ongoing training for staff members as well.
- Care providers should have adequate supervision and be supported in their daily work.
- A good long-term care facility should feel comfortable and homelike.

Check the following as you explore them when choosing a senior living option:

- Is the location convenient for you to visit?
- Are families involved with care planning?
- Are families informed of the resident's condition and changes in care ?
- Is transportation available if your family member wants or needs to go somewhere? Is there an additional cost for this service?
- How will staff provide the care needed by your family member?
- What is the environment like?

- ❑ Do residents look happy and engaged in activities? Visit unexpectedly to witness a typical day.
- ❑ Is the unit or facility secure? The indoor space should promote independence while still providing security to prevent wandering. Both indoor and outdoor areas should be safe and secure.

Be sure to visit a facility more than once before making a decision. If the facility is licensed, ask for recent state inspection survey results. Administrators are required to provide this information if asked. Another good resource is the Nursing Home Compare Web site, which can show you how the facility you are considering compares to the national average. The Web site can be found at www.medicare.gov/NHCompare/home.asp. In addition, the Alzheimer's Association's Senior Housing Finder, powered by SNAP for Seniors®, is a free Web-based service offering an easy way to search a current, nationwide list of licensed assisted living residences, nursing homes and other types of senior housing.

Other important considerations for us:

tip 19: plan ahead for payment

Paying for Alzheimer's care is a big concern as the disease progresses. Many different sources can help pay for dementia-related services.

Check the following sources of funding for paying for care that you have explored, and see whether the others might play a role as well.

- Government programs – these include Medicaid, Supplemental Security Income, Social Security Disability Insurance, and veterans' benefits.
- Insurance – may include Medicare, disability insurance, retiree coverage, life insurance, long-term care insurance, and employer-paid plans.
- Retirement benefits – these include individual retirement accounts, employee funded retirement accounts, and Social Security benefits.
- Personal savings and assets – may include stocks, bonds, savings accounts, and real estate holdings.
- Tax deductions – caregivers may qualify for tax deductions and credits if paying privately for care. The person with dementia must be certified by a physician as chronically ill in order to take federal tax deductions. Deductible expenses can include personal care items such as disposable briefs, home improvements such as grab bars, in-home care, physical therapy, nursing services, assisted living or other residential care, and nursing home care. If you plan to claim tax deductions for these items, be sure to keep receipts and consult with a tax advisor.

Plan a long-term care budget by listing the costs you might face in the future. Possible expenses include treatment for other medical problems, prescription drugs, personal care items, adult day programs, in-home care, and full-time residential care. After delin-

Other potential sources of funding for us:

tip 20: pay attention to your own feelings and get support

Caregiving can be a source of fulfillment and positive feelings about providing the best possible care for someone with Alzheimer's disease. At the same time, caregiving can be a source of stress, anger, frustration, resentment, guilt and even depression. It can help to keep in mind that the person with Alzheimer's cannot help the changes in his or her behavior. Try as much as possible to focus on the positive aspects of your relationship and remember to take time for yourself. If you are having feelings that are affecting both your physical and mental well-being, seek immediate help from your doctor.

It is very common to grieve the loss of a person when he or she is still alive. This is called anticipatory grief. As Alzheimer's progresses, the person with the disease is physically present yet emotionally and mentally slipping away. The person you once knew is changing, and he or she may not consistently remember shared experiences. You may get occasional glimpses of the person as he or she used to be, but you cannot rely on those moments.

Symptoms of grief include denial that the person is ill; periods of helplessness, despair and depression; changes in appetite or sleep patterns; feelings of anger or frustration with the person with Alzheimer's and with caregiver tasks; and withdrawal from social activities and relationships. If your grief is so intense that you feel your well-being is at risk, do not hesitate to ask for help from your doctor or a professional counselor.

You might feel as though you won't be able to say goodbye. Now is the time to connect with the person you care for, and to express your affection directly. Whether the person with dementia completely understands all of what you are feeling or comprehends very little of what you feel, there can be some knowledge and appreciation of your connection. You may want to get involved with a support group to connect with others who have been through these same feelings related to the process of dealing with dementia. These are people who truly understand the complex feelings associated with caregiving for a person with progressive cognitive impairment. Later, palliative care and hospice programs are available to support both the person with dementia and the family.

In order to cope with the difficult feelings that accompany caregiving, try to accept

your feelings of sadness, guilt, anger and frustration. You can expect to feel all of these emotions at various times throughout the course of caregiving. No two people experience grief the same way, and your way will be different from others'. Know that it is also common to feel conflicting emotions. People often feel love and anger at the same time.

It is also important to accept yourself and the things that are beyond your control. Focus your energy on making decisions about things within your control. Think about the fond memories you have of the person. Get involved in activities you enjoy.

Finally, finding support can do wonders to help you cope with difficult emotions. Be careful not to isolate yourself; call friends and family often, and find out what resources are available for you in the community. Talk with someone about your feelings by joining a support group or seeing a professional counselor. It helps to talk to others who are facing similar situations.

Other ideas:
