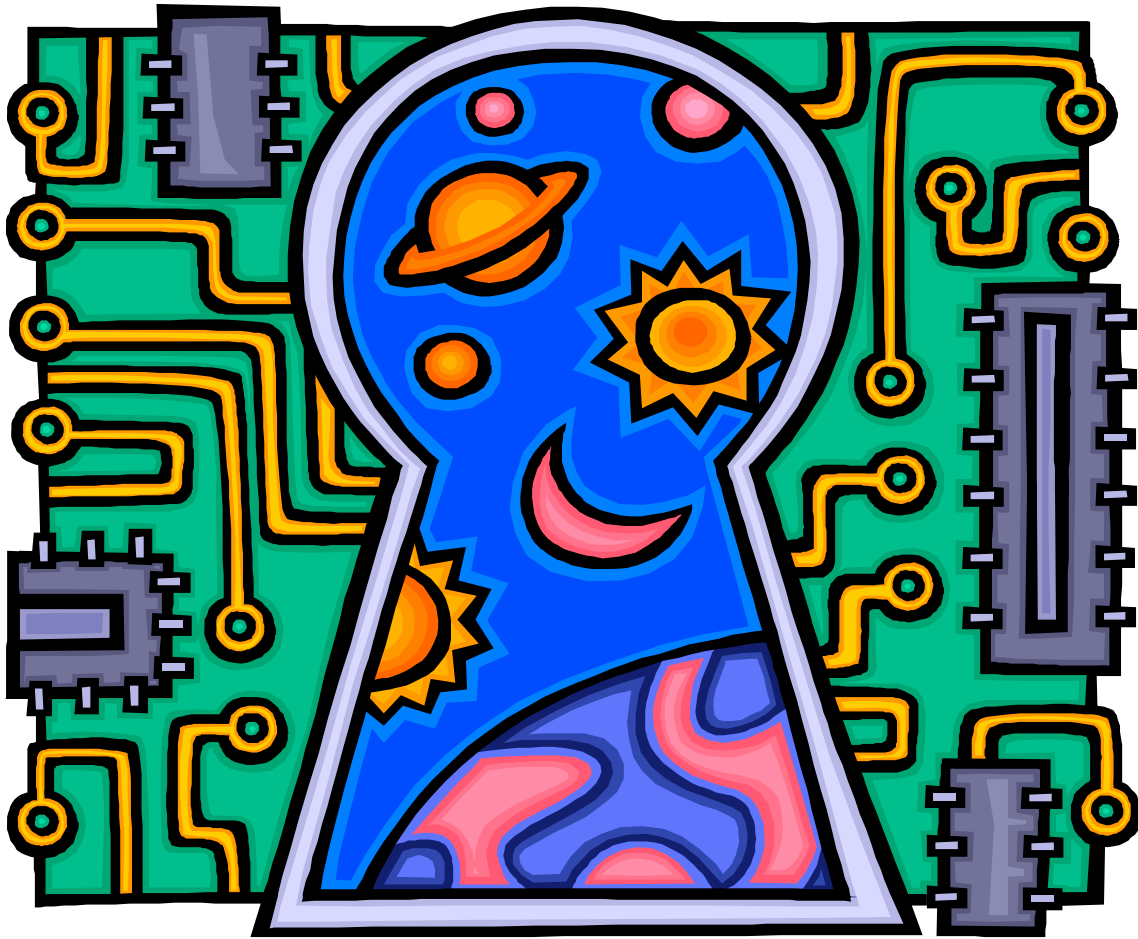


# Things to Know and Do: AFTER THE DIAGNOSIS OF ALZHEIMER'S DISEASE OR A RELATED DEMENTIA



For more information, please contact Alzheimer's & Dementia  
Services of Northern Indiana:

922 E. Colfax  
South Bend, IN 46617  
(888) 303-0180, toll-free, or  
(574) 232-4121

[www.alzni.org](http://www.alzni.org)  
[info@alzni.org](mailto:info@alzni.org)

## After the Alzheimer's Diagnosis ...

### A CHECKLIST TO HELP

# T

- Be sure you have an accurate diagnosis** and that other treatable conditions that cause dementia have been ruled out.
- Find a physician familiar with dementia** with whom you will be comfortable asking questions and dealing with over the long haul.
- Learn as much as you can about dementia** so that you can respond to your loved one's changing needs and abilities in the most supportive and empowering way possible.
- Contact organizations that can help** such as Alzheimer's & Dementia Services of Northern Indiana (888/303-0180) and your Area Agency on Aging. (Some financial assistance services have long waiting lists, so it's important to call as soon as possible.)
- Consider having a family conference** to help everyone understand the disease, the changes it may cause, give everyone a helping role, and plan for both short-term and long-term needs of the person with dementia and the primary caregiver. Have ongoing family meetings -- whenever a major change occurs.
- Plan a daily routine** to make things go more smoothly. Persons with dementia function best in a calm, routine, structured, supportive environment. If there are times of day when the person with dementia is less confused, make the most of these moments. Keep in mind that this routine may have to be modified as interests change or impairment increases.
- Consider and monitor safety issues**, such as ability to drive, smoke, run power tools, or the potential to wander and get lost (both walking and driving). These issues will need to be re-assessed frequently. Also consider home safety issues.

- **Consult an elder law attorney** who has experience in working in the areas of durable power of attorney, guardianship, end-of-life decisions, and trusts. Legal problems are complex and should be addressed as soon as possible after the diagnosis. Working with an attorney who specializes in elder law can help prevent unanticipated legal/financial problems down the road.
  
- **Plan ahead for services** by finding out what resources are available to you -- both formal (e.g., home-delivered meals, home health, adult day services, volunteer companions, etc.) -- and informal (e.g., church groups, next-door neighbors, etc.) You may not need these services now, but knowing what your options are is easier than searching for them under pressure. Many caregivers feel that using these services has enabled them to provide better and longer care for their loved ones. **Check out other potential resources**, including all organizations of which the person with dementia is a member, to see if they provide any type of assistance. **Make sure to contact the Veteran's Administration** if the person is a veteran or a spouse of a veteran.
  
- **Find support, including someone to talk with who understands.** This might be a family member, friend, clergy, or a support group. Talking through feelings provides a healthy outlet to manage stress. Online support is also available.
  
- **If signs of wandering or confusion about location arise**, enroll your loved one in the Project Lifesaver program and learn how to manage wandering behaviors.
  
- **Monitor your own stress, especially if you are the primary caregiver.** Make sure to maintain your own health (both physical and emotional), plan ahead (including for emergencies), talk with others in the same situation, and arrange for ongoing relief, or respite, to give yourself habitual breaks. Taking care of yourself will help you be the best caregiver you can possibly be for your loved one.

**PROGRAMS AND SERVICES OF ALZHEIMER'S & DEMENTIA**  
**SERVICES OF NORTHERN INDIANA**

Serving the counties of Elkhart, Jasper, Kosciusko, Lake, La Porte, Marshall, Newton,  
Porter, Pulaski, Saint Joseph and Starke

**(With the exception of Milton Adult Day Services, all programs provided without  
cost to families)**

**TOLL-FREE TELEPHONE SUPPORT LINE:**

Confidential telephone service that offers emotional support, disease information, caregiving tips and support, and referral to local community services. (888) 303-0180 or (574) 232-4121

**SUPPORT GROUPS:**

For both caregivers and persons in early stages of dementia, focusing on support and education.

**MONTHLY DEMENTIA CLASSES:**

Free monthly classes that provides information and education regarding various aspects of Alzheimer's disease/dementia. Available in both St. Joseph and Lake Counties. Call us for details on time, date, and location!

**CARE CONSULTATION:**

Meets one-on-one with families to provide assessment, education, help with problem-solving and linkage to appropriate community services.

**SPECIALIZED EDUCATIONAL WORKSHOPS AND SEMINARS:**

Provides disease orientation, caregiving skills, and coping strategies.

**SPEAKERS' BUREAU:**

Available to community groups, churches, etc. -- regarding Alzheimer's-related issues.

**CARE CONNECTION WEEKLY SUPPORT GROUP BY TELEPHONE:**

Sponsored by our national affiliate, Alzheimer's Foundation of America (AFA), **free, weekly** telephone support network offering caregivers disease coaching, support, and national speakers. To access each Thursday at 1 p.m. EST, call toll-free 1-877-AFA-2992, then enter guest ID 271004#.

**AFA RESPITE SCHOLARSHIP FUND and SADIE MAGER EMERGENCY RESPITE GRANT:**

Sponsored by the Alzheimer's Foundation of America (and available only via member organizations such as Alzheimer's Services), the AFA scholarship provides grants of up to \$1,000 to families who are in need of respite services. May be renewed annually. The Sadie Mager Emergency grant, available to lower-income families, provides a one-time grant of \$500 for respite services.

**WEB SITES:**

Alzheimer's Services: [www.alz-nic.org](http://www.alz-nic.org) Alzheimer's Foundation of America: [www.alzfdn.org](http://www.alzfdn.org)

**NEWSLETTER:**

Features information on caregiving tips, disease information, upcoming educational conferences/workshops, advances about Alzheimer's.

**CAREADVANTAGE QUARTERLY MAGAZINE:**

Free magazine produced by the Alzheimer's Foundation of America, for caregivers of persons with Alzheimer's disease/related illnesses.

**LENDING LIBRARY:**

Contains books, videos, and pamphlets regarding various aspects of dementia and the caregiving process.

**MILTON ADULT DAY SERVICES:**

Not-for-profit, full-service day center in St. Joseph County offering structured activities, socialization, health monitoring, and safe and secure surroundings for physically or cognitively-impaired older adults during the daytime. Various financial assistance programs available, including Veteran's Administrations. Website: [www.MiltonADS.org](http://www.MiltonADS.org) Call (574) 232-2666

## **THE FIVE STAGES OF ALZHEIMER'S DISEASE**

*(Adapted from the model developed by Barry Reisberg, M.D.)*

As infants mature into adults, their stages of growth progress from simple to complex. This pattern of expanding competency is reversed by the stages that characterize Alzheimer's disease. The following stages of deterioration should be considered a general guide. All persons do not exhibit all symptoms, and symptoms may occur in a different order from those listed.

### **NORMAL OLDER ADULTS:**

**These are normal changes for any person over age 40**

**Symptoms:** Harder to remember names or where things are put  
Takes longer to learn new things  
Ability to retrieve information slows down

**Responses:** May complain of memory problems

### **STAGE 1 - EARLY STAGE OF DEMENTIA:**

**Loss of memory primarily affects work and social situations; memory problems become apparent to others, however, some persons are able to mask problems better than others**

**Symptoms:** Impaired short-term memory, i.e. forgets recent events  
Forgets what he/she was just told to do  
Forgets phone numbers and names  
Trouble handling money or paying bills  
Often loses things  
Takes longer to do familiar/routine tasks  
Impaired ability to use abstract reasoning  
Impaired judgement, makes bad decisions  
Changes in personality, e.g., less tolerant, less energy, or starts to withdraw from usual activities

**Responses:** Irritated/angry, or anxious regarding memory problems  
May try to cover-up or deny memory problems  
May withdraw socially to avoid attention  
May avoid familiar/complex tasks

**Care Needs:** Emotional support  
Organize and simplify daily routines  
Structure home environment for safety  
Assist with finances

### **STAGE 2 - EARLY MIDDLE STAGE OF DEMENTIA:**

**Functional ability range: early adolescence to eight years of age**

**Symptoms:** May forget address  
Repeats the same stories, information, or questions

Forgets how to do familiar/routine tasks  
May get lost or disoriented, even in familiar places  
Difficulty sequencing tasks  
Forgets recent personal/news events  
Needs assistance to manage affairs  
Shorter attention span  
May have delusions due to misunderstanding of reality (e.g., thinks adult child is stealing from them)  
Difficulty making decisions/choices  
Increasing safety concerns, e.g., driving, cooking

**Responses:** May deny memory/functioning problems  
May blame others for problems  
May begin to withdraw emotionally

**Care Needs:** Supervision; monitor safety concerns  
Take over complex tasks, e.g., shopping, managing finances, taking medications, driving  
Limit choices and set routines  
Remind and repeat gently  
Encourage strengths  
Break down tasks into steps  
Provide help but always treat as an adult

### **STAGE 3 - MIDDLE STAGE OF DEMENTIA**

**Functional ability range: from seven to five years of age**

**SYMPTOMS:** Forgets day of week/date/season  
Forgets names/faces of younger family members or those not seen often  
Says or does things repetitively  
Forgets major aspects of current life  
Often doesn't know where they are  
Needs help with choosing proper clothing  
Needs reminders to bathe or assistance with bathing  
Increased difficulty recognizing familiar objects, sounds, etc. because of perceptual impairment

**Responses:** Extreme, changeable emotional reactions  
Anger/suspicion/tears due to misunderstanding reality of situation  
Impaired ability to do personal hygiene

**Care Needs:** Full-time supervision  
Behavioral/emotional management  
Assistance with activities of daily living

**STAGE 4 - LATE MIDDLE STAGE OF DEMENTIA:**

**Functional ability range: from five to two years of age**

**Symptoms:** Forgets minute-to-minute experiences  
Can only do simple, one-step tasks  
Disturbed sleep patterns  
Unable to care for personal needs  
Becomes incontinent; first bladder, then bowel  
Strongly identifies with earlier life (e.g., does not recognize spouse at present age)  
May have hallucinations (sees/hears what others don't)  
No longer recognizes members of the family  
Inappropriate behavior problems

**Responses:** Personality changes  
Does not understand current life/time frame and identifies with past  
Behaviors due to lack of understanding of present reality

**Care Needs:** Constant supervision  
Increased use of non-verbal cues/communication  
Increased use of sensory stimulation  
Full-time care (bathing/dressing/toileting/eating)

**STAGE 5 - LATE STAGE OF DEMENTIA:**

**Functional ability range: from 15 months to newborn**

**Symptoms:** Completely incontinent and bedridden  
Cannot talk, smile, or hold up head  
Inability to feed self  
Seizures/skin breakdown  
Weight loss

**Responses:** Can no longer respond except via sensory connections (e.g., touch, sound, visual) similar to infant

**Care needs:** Total care

## TIPS FOR CARING FOR A PERSON WITH DEMENTIA

- Adapted from Geriatric Assessment Program, University Geriatric Center, Omaha, Nebraska

1. Because Alzheimer's begins in the part of the brain that stores short-term memories (new information), much of what you say to the person may soon be forgotten. That is why they repeat the same stories, why they cannot remember what they had for breakfast, or ask you the same question over and over again. Be prepared to repeat yourself often and try not to lose your patience.
2. Your body language (i.e., what you are showing the person through your facial expression, gestures, tone of voice) is the most powerful tool for communicating with a person with dementia, as the person will pick up on and magnify your mood. **The way** you are saying something is much more important than the words you're using. Calm, supportive, positive body language is very important, and a smile can work wonders.
3. Avoid presenting the person with more than one thought at a time and limit choice options to no more than two, e.g., "Either (this) or (that)."
4. Distraction is another powerful tool, unless the person is already upset or agitated. Try distracting the person from an irritating or repetitive topic by using a word from the conversation to change the subject. Try pleasant distractions, such as taking them for a walk or drive, looking through family photos, playing music that they enjoy, or giving the person a simple, repetitive task to perform, such as folding towels.
5. If distractions fail, try validating the person's feelings if they are sad, angry, or experiencing a negative emotion. Reassure them that whatever they are worrying about is going to be okay, e.g., "I understand how upsetting it feels to lose your purse. I'd be upset too. But I'll help you look for it. Please try not to worry; I know it must be in the house someplace and I'm sure we'll find it."
6. Use a calm voice, and respond to repeated questions with brief, simple statements. Try using touch and direct eye contact when responding in order to emphasize what you are saying.
7. Memory aids, such as clocks, calendars, and simply-worded notes, may help a person in earlier stages remain oriented.
8. Most memory-impaired persons function best when they follow a familiar routine in familiar surroundings. Avoid abrupt and frequent changes of routine. Avoid discussing plans for activities or appointments until just prior to the event so the person does not worry and ask repeated questions ahead of time.



9. Allow the person to do as much for themselves as they possibly can, even if they are slower and less efficient. Positive reinforcement and praise helps them maintain skills and promotes self esteem.
10. Avoid correcting them, arguing with them, and using negative commands (e.g., “no, we can’t do it now;” “don’t do that ...”) Instead, use a positive focus (e.g., “yes, that’s a great idea; we’ll do that as soon as I’m finished,” “let’s do ..”)
11. Closely monitor their performance of tasks and be prepared to break things down into smaller steps and to lower your expectations for their performance. Tasks that involve complex reasoning or present safety problems (such as driving, using the stove, managing financial affairs) need special scrutiny and may have to be assumed by others sooner rather than later.
12. Depending on the person’s ability/desire to learn more about their diagnosis, give them only information that they can handle and remember. Minimize the impact in losses of their abilities. Confronting the person with their loss of ability may lessen their sense of dignity and self esteem. Give them frequent, reassuring messages of how important they are to you, how much you love them. Try to remind them how much they can still do for themselves.
13. As dementia progresses, it will affect the parts of the brain that control the person’s ability to remember, use language, and use reason and judgment. Parts of the brain that remain intact include their ability to feel emotions, enjoy music, their spirituality, their ability to remember things from long ago, their desire to communicate, and their ability to “chit chat”.
14. At some stage of the disease, reality orientation (e.g., “your mother died 20 years ago, don’t you remember?”) is not only ineffective but can be very agitating/upsetting to persons with dementia. As the disease progresses, a person will get younger and younger in their mind, as dementia causes them to lose their layers of memories in reverse order as they acquired them (ie., their earliest memories will be retained the longest and their newest memories will be lost first). Instead of fighting the useless battle to try to bring them into the present, enter their world and give them an answer that makes sense in their reality (“your mother is working now; she asked me to stay here with you until she gets back home.”) It is **not** lying to the person; it is therapeutic communication that builds your relationship with that person, rather than impairs it.
15. If they become agitated with you, try to get out of their field of vision as soon as possible! They can form new emotional memories, and the longer they look at you when they are agitated, the more likely they are to form a negative emotional memory. As soon as an argument or negative encounter begins, excuse yourself from the room (e.g., “I’ll be right back; I just remembered I left something on the stove.”) When you return, make sure that you are acting different (calm, positive,

body language) and maybe bringing something that evokes their pleasure (e.g., their favorite drink, a dessert, a flower, a favorite object). This is like hitting the “reset” button and will not only de-escalate their agitation (and your own), but will help keep your relationship positive and on track.

16. Prevention is the most effective approach to reduce behavior problems. Anticipate and avoid activities and discussion that provoke anger or agitation.
17. All behavior is a form of communication. Try to determine a reason for troublesome behavior. Is the person trying to communicate feelings of fear, pain, hunger, the need to toilet? Respond to the need or emotion you feel the person is trying to express.
18. Make note of when a catastrophic reaction occurs. Is there a pattern – ie, time of day, type of activity, specific person – that can be identified? Once you identify possible “triggers,” try eliminating them one by one.
19. Simplify the environment by reducing extra clutter, noise, and activity.
20. If the person becomes extremely agitated, remove him/her from the stressful situation or place. Use a calm voice and slow movements. Do not try to reason with the person as their ability to understand logic and reason is impaired because of damage to their brain.
21. Emotional support and taking a break from caregiving duties are essential to helping you cope. Arrange for someone to help for several hours at a time on a regular basis so that you can “recharge your batteries.” Neglect of your own needs and trying to do it all by yourself will ultimately impact your caregiving (and possibly your own health) in a negative way.
22. Consider joining a support group or taking classes to understand better ways to help your loved one. These offer an excellent, safe setting in which to express your feelings and learn creative approaches to care.
23. Be kind and patient with yourself. Recognize that you will make mistakes and will become angry and impatient at times. Know your own limits and try to eliminate guilt, which only drains you of energy. Remember, you are only human!

# COMPASSIONATE COMMUNICATION WITH THE MEMORY IMPAIRED

## DON'T

**Don't reason.  
Don't argue.  
Don't confront.  
Don't remind them they forget.  
Don't question recent memory.  
Don't take it personally!**

## Do

**Do give short, one-sentence explanations.  
Do repeat instructions or sentences exactly the same way.  
Do allow plenty of time for comprehension.  
Do eliminate "but" from your vocabulary; substitute "nevertheless."  
Do agree with them or distract them to a different subject or activity.  
Do accept the blame when something's wrong (even if it's fantasy).  
Do leave the room, if necessary, to avoid confrontation.  
Do respond to the feelings rather than the words.  
Do be patient and cheerful and reassuring. Do go with the flow.  
Please DO elevate your level of generosity and graciousness.**

## REMEMBER

**He is not crazy or lazy. He is saying and doing normal things for an Alzheimer's patient. If he were doing or saying things to deliberately aggravate you, he would have a different diagnosis.**

**Some days he'll seem normal, but he's not. His reality is now different than yours and you cannot change it. You can't control the disease. You can only control your reaction to it.**

**His disability is memory loss. He cannot remember and can't remember that he cannot remember. He'll ask the same question over and over, believing it's the first time each time.**

**He is scared all the time. Each patient reacts differently to fear. They may become passive, uncooperative, hostile, angry, agitated, verbally abusive or physically combative. They can't remember your reassurances. Keep repeating them.**

**Once dementia is diagnosed, the patient is excused 100% of the time.**

*Excerpted from an article by Liz Ayres, former caregiver and Alzheimer's Association volunteer.*

# Helping Persons with Alzheimer's & Dementia: *A Problem-Solving Guide*



Caregivers can do a great deal to help persons with Alzheimer's disease/dementia compensate for the many changes they are experiencing as the disease progresses. The first step is to try to understand the changes the disease is causing from the diagnosed person's perspective.

T-E-A-C-H is a problem-solving guide, each letter in the acronym representing the five basic areas that present difficulties for persons with dementia or the ways that persons can be empowered to maximize function, independence, and quality of life.

<p><b>T = TASK or ACTIVITY</b></p>
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- Breaking tasks down into simple steps, given one at a time (and never rushing the person)
- Making sure persons are still able to do the task you are asking them to do and adjusting tasks to make them easier as the person's function declines
- Don't try teaching the person new or unfamiliar things; use existing abilities

A task that may seem simple to us can be overwhelming for someone with dementia.

- Using visual and verbal cues in combination with instructions
- Simplifying (and sticking to) routines
- Making sure the task/activity is one that the person enjoys doing
- NEVER forcing participation in a task when a person is resisting. If it's something that *must* be done (like bathing) and the person is refusing, try again later

Suggestions to help the person include:

- rather than pushing the issue
- Using the person's "best" (most alert/oriented) time of day for most complex tasks
- Minimizing choices – (offer no more than two at a time)

<p><b>E = ENVIRONMENT</b></p>
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The proper environment goes a long way toward supporting persons with

dementia. As impairment increases, persons may have more problems negotiating the environment. Steps that can help the person include:

- Making sure the environment is not too large and confusing. Smaller spaces are quieter and easier to negotiate
- Keeping changes to an absolute minimum
- Environment should be calm, predictable, and structured
- Using good lighting and keeping walkways free of clutter
- Minimizing noise and distractions to avoid “over stimulating” the person
- Avoiding “under stimulation” so the person does not withdraw
- Using orientation cues, like clocks, calendars, labels, pictures, etc.
- Using contrasting colors to emphasize; monochrome colors to camouflage
- Using cues at the person’s eye level

- Screening television if it is upsetting to the person
- Using music (the kind that they enjoy) to calm, soothe, stimulate
- Avoiding unfamiliar environments

**A = ATTITUDE OF CAREGIVER**

The caregiver’s attitude/body language is the single most important tool for communication; persons with dementia will mirror what they are being shown. More important than *what* you are saying, is the *way you are saying it* through your body language, facial expression, and tone of voice. An important rule of thumb for caregivers to remember is: Let power struggles go! -- Once persons are diagnosed with Alzheimer’s disease, they are right 100% of the time!

Other things to remember are:

- Stay calm, even if the person you are caring for becomes upset/frustrated
- DO provide frequent verbal reassurances that the person is safe, loved and valued

- DO expect repetition and be patient
- DO NOT remind the person that they forget (e.g., never say things like, “don’t you remember, we talked about this yesterday? ... )
- DO NOT try to reason with, argue or correct persons, even when you know they’re wrong
- DO minimize failures and praise successes
- DO NOT talk down to the person or talk about them as if they’re not there
- DO NOT ask questions that require factual information
- DO NOT take personally any negative comments they might make
- DO encourage independence as much as possible, unless it’s causing the person frustration
- You can’t change their reaction or behavior, so change YOURS.

**C = COMMUNICATION CHANGES**

Many times people with dementia become angry or anxious because they don't understand what is happening or what is expected of them. Or, they may be frustrated with their inability to make themselves understood. Caregivers can help them compensate for these changes by utilizing the suggestions offered above and by validating their feelings and being a good listener. Let them know that what they have to say is important and give them frequent reassurance that they are loved, safe, & valued.

to tell you in words that they are hurting.

<b>H = HEALTH CONCERNS</b>
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Other medical problems, besides dementia, can also cause problems. Any time a change in behavior is sudden and consistent, call their doctor and/or look for a possible health concern such as effects of medications, impaired vision/hearing, acute illness (e.g., stomach or head ache, urinary tract infection, etc.), dehydration, constipation, depression, fatigue, physical discomfort (e.g., hunger), or another chronic medical illness. Remember, persons with dementia may not be able