

APPENDIX A

DEMENTIA CARE GUIDELINES
FOR FAMILIES

Third Edition

Division of Geriatric Psychiatry and Neuropsychiatry
The Johns Hopkins University

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THE JOHNS HOPKINS MODEL OF CARE FOR DEMENTIA

Most disorders causing dementia such as Alzheimer disease and vascular dementia are progressive and last for many years. This approach to care is grounded in four general areas.

1. Treat the Disease

Currently, the cause of dementia can often be identified with a high degree of certainty through a systematic evaluation. In addition, treatments are now available. So, the first step is to get an evaluation and diagnosis of what is likely causing the dementia and consider treatment.

2. Treat the Symptoms

Dementia is often accompanied by many troublesome symptoms. These include behavior problems such as resisting care, not sleeping at night, pacing and wandering and combativeness and many others. These symptoms can be addressed by a variety of methods including the use of medications to thoughtfully designing a schedule of activities to distract the patient. Different families will find different behaviors more troublesome. It is important to tell your doctor what you find most challenging so that a plan to help can be made.

3. Support the Patient

A person with dementia will need help to stay healthy by monitoring any chronic illnesses and recognizing and gaining prompt treatment for new ones. In most cases, the caregiver must also take responsibility for giving medications. A safe environment must be assured so [that] the patient cannot be harmed in the home. Enjoyable activities are also necessary. Legal protection is addressed by deciding who will make decisions for the patient[s] when they can no longer make them. Identification bracelets can help to identify a patient who has wandered away. Decisions such as when driving is no longer safe must be made.

4. Support the Caregiver

Care for those with dementia is often provided by one person or a small group. It is care that requires vigilance 24 hours per day every day. To help caregivers to do this, the clinical team must support them emotionally, give guidance in decision making, educate them about the disease their loved one has and assist in identifying resources in the community to help.

WHAT IS DEMENTIA?

In the past, terms like “senility,” “organic brain syndrome,” or “late life confusion” were used to describe the elderly person who had difficulty thinking and remembering. The understanding of what is normal aging and what is abnormal aging has progressed so that new terms are used.

The medical definition of dementia is the following:

A global decline in intellectual abilities of sufficient severity to interfere with occupational and/or social functioning. This occurs in clear consciousness.

What Does This Mean?

- *Global decline* means that more than one aspect of thinking is affected. So, a person who only has memory problems or who only has difficulty in speaking would not be described as demented. Persons who are demented often have difficulty in remembering, communicating, making decisions, and planning.
- *Sufficient severity* to impair functioning means that the problems the patient has are severe enough to produce problems in daily life. Common problems include not remembering to pay bills, not being able to plan, shop, and prepare meals, and getting lost in familiar places.
- *Clear consciousness* means that the person is awake and alert. This is in contrast to a person who is drowsy and not thinking properly due to an illness such as pneumonia and fever or who is impaired by medications, anesthesia, or alcohol.

What Causes Dementia?

Some conditions can mimic dementia and must be identified and treated. These include depression, intoxication from medications, both prescription and over the counter, and thyroid disease, among others.

There are many causes of dementia. Some get worse over time and some do not. Causes include strokes, Parkinson disease, Huntington disease and many others. Alzheimer disease (AD) is the most common cause. It can be diagnosed accurately and a variety of treatments are available.

WHAT IS ALZHEIMER DISEASE?

Alzheimer disease (AD) is the most common cause of dementia in later life. AD begins gradually and gets worse over a period of years. The common symptoms

of AD begin with the letter *A* and are known as the *4As* of *AD*. Each of the symptoms causes difficulty in daily life.

- **Amnesia:** (*Memory*) AD causes difficulty in registering new memories and recalling them. Common examples include asking the same question over and over and losing belongings. These problems occur because the part of the brain involved in registering new memories is damaged.
- **Aphasia:** (*Language*) AD affects the ability of the patients to communicate with others. Many patients develop difficulty in finding words and their speech becomes vague and empty. Second, patients will have difficulty in understanding what is being said to them. Language problems are frustrating for both the patient and caregiver.
- **Apraxia:** (*Doing things*) AD damages the parts of the brain that are involved in planning and directing the body to do things. Common problems are putting on clothing backwards and picking up food with the hands instead of using a knife and fork. Tasks must be simplified for the patient who has this symptom. Often, starting a task such as putting food on a fork and handing it to the patient can get a task started.
- **Agnosia:** (*Recognizing the world*) Though patients with AD can see the world, brain disease causes difficulty in recognizing what they see. Common examples of this are the person who stands in front of the refrigerator looking at the milk but being unable to recognize it. Some patients who may be unable to recognize their caregiver become uncooperative or run away.

TIPS FOR THE CAREGIVER

Eating

Many persons with AD develop difficulty with eating and weight loss. There are many causes of decreased eating including not remembering if they have eaten or not, inability to ask for food due to language problems, inability to open complicated packages and to prepare meals, and, lastly, inability to find or recognize food or drinks. Also, any source of pain, such as dental pain, can reduce eating and drinking. The following tips may help:

- Provide meals in a quiet and uncluttered place. TV and other noise can be too distracting for the person with AD.
- Serve one type of food at a time in small amounts. Too many choices can be overwhelming.
- Use simple place settings such as a contrasting plate and placemat and a single utensil.

- Provide meals on a routine schedule and have snacks and fluids readily visible for the person who needs to eat and drink more.
- Provide drinks every 2 hours instead of asking if he is thirsty.
- If the person can no longer cut up food, cut it in the kitchen before serving to preserve dignity.
- If the person chokes on thin liquids, add thickeners available at pharmacies.
- Maintain dental health by regular trips to the dentist or hygienist.
- If the patient eats very little, boost nutrition by adding calories to the regular diet.
- Sometimes, putting something sweet on the tip of the spoon will encourage eating.
- Finger foods will make eating easier for persons who can no longer use utensils.

Dressing

Getting a person with dementia dressed can be a challenge. The process of dressing can break down at many steps including inability to choose clothing, difficulty putting it on correctly, wearing the same clothes over and over and refusing to change clothes. As with other complicated tasks, one must determine where in the process the patient is having trouble and provide the help that is needed. The following tips may help:

- Limit the choices: clear out a closet and place an acceptable outfit in clear view.
- Allow ample time: schedule appointments in late morning or in the afternoon. Rushing can stall the process and upset everyone.
- Remove soiled clothing out of sight when the person is bathing. Replace it with clean clothing.
- Obtain clothing that is easy to put on and to take off. Jogging outfits, elastic waist pants, shoes with Velcro straps and clip on neckties can allow maximum independence.
- Purchasing sets of similar clothing from catalogues can help if the patient insists on wearing the same thing over and over.
- Be prepared for opportunities to change. If the person resists changing, keep spare underwear and clothing in the bathroom so that as he is sitting on the toilet and half undressed, clean clothing can quickly be put on.
- Be flexible: if arguments arise about changing clothes, drop the topic and try again later.
- Sometimes it is better to let people sleep in their clothes and attempt to change the next morning.

Bathing

Problems with bathing are very common in the care of those with dementia. Patients can become uncooperative with bathing for several reasons. They may have forgotten how to bathe, are frightened and cold, or don't recognize their caregiver. Many interpret attempts to bathe them as "someone trying to harm them." The following tips may help:

- Build on past routines. If the person always took showers, he may not resist that as much.
- Get organized: gather soap, towels, washcloths and clean clothes ahead of time.
- Fill the tub ahead of time to decrease frightening noise.
- Plan the bath at the time the patient is rested and most cooperative.
- Give instructions one step at a time.
- Ensure that the person is warm by covering him with a large towel or flannel sheet and washing one body part at a time. Purchase a terry cloth robe to put on as soon as the bath is finished. That will begin the drying process and ensure privacy and warmth.
- Give the person the soap and washcloth so that he can begin the process.
- A handheld showerhead on a flexible cable can allow the caregiver to wash the person easily.
- Obtain a shower or tub bench and install grab bars to avoid slipping. Put a towel on the bench to avoid slipping and to provide comfort.

Getting to the Bathroom

Losing control of the bladder and bowels is not expected in dementia until the late stages. Earlier on, patients can have accidents for many reasons. With good planning, accidents can usually be avoided. Patients can become easily distracted and not realize they need to go until it is too late. They may forget where the bathroom is. Complicated clothing may take too long to undo. They may not recognize the toilet and may use other things like trash cans instead. The following tips may help:

- Establish a routine: Asking the person if she needs to use the bathroom is insufficient to avoid accidents. One must take the person to the bathroom at least every two hours.
- Simplify clothing: eliminate complicated clothing such as panty hose, belts, and zippers. Replace fasteners with Velcro or eliminate them by using elastic waist pants.
- Limit fluids in the evening and avoid caffeine to reduce the risk of nighttime accidents

- Plan ahead: locate family bathrooms in shopping malls and airports. Always take a change of clothes just in case.
- If accidents begin suddenly, take the person to the doctor for a checkup. She may have an infection.
- When traveling, stop at least every two hours and take the person to the bathroom. Placing a sign on the door of the bathroom “Helping ill relative in the bathroom” can enhance privacy.

Structuring Activities

Persons with dementia gradually lose the ability to plan their day. Gradually, things they did in the past such as cooking, yardwork and participating in hobbies become too difficult and can become frustrating. As they lose a sense of time, they may get up during the night and try to go to work. A routine of activities during the day provides security to the patient and promotes rest and sleep at night. Without a routine, many persons with dementia follow their caregiver around all day. The following tips may help:

- Try to get the person up in the morning and in bed at the same times each day. Keeping him up and active during the day helps getting a good night’s sleep.
- Write down a schedule allowing ample time to complete tasks such as dressing and bathing. This will be helpful to other caregivers that provide help from time to time.
- Think of activities he liked to do when he was well. Break them down into short, achievable steps and give praise for completing each step.
- Doing the same thing over and over again is reassuring and not boring for many persons with dementia.
- Physical activities and time outside are useful. Even scheduling a walk in the yard or around a shopping mall can be enjoyable.
- Having a schedule also helps in asking for help from others. One can directly say, “Bob goes for a walk at 11 a.m. every day. Can you come over and take him?”
- If the patient becomes tired in the afternoons, allow him to sit and listen to music or look at magazines but avoid naps if possible.
- Planning an activity the person especially enjoys after dinner will encourage him to stay up so that he will sleep all night.

Communication

Communication difficulties are common in dementia and often frustrating for patients and caregivers. Examples of communication problems include: Difficulty

finding words, having words on the “tip of the tongue,” losing a train of thought, and not comprehending what is being said. The following tips may help:

- Make sure you have the person’s attention before speaking.
- Speak slowly in a calm, low tone of voice.
- Use hand gestures to demonstrate requests (“sit here,” patting the seat of the chair).
- Use simple, concrete words.
- Simplify the message into one or two parts.
- Give instructions one step at a time.
- Provide reassurance rather than try to reason or give an explanation. “I’ll wait for your return” provides much comfort to someone refusing to attend a day program.
- Respond to repeated questions with simple key words or phrases.
- Try to provide the word the patient is struggling to say.
- Observe facial and body language to better understand what the patient is saying.
- Listen carefully for key words.
- When trying to communicate, eliminate distractions such as radio and TV.

Medications

Taking medications properly is important. Memory loss and difficulty concentrating caused by dementia makes taking medications correctly a challenge. Taking extra doses can be just as harmful as forgetting doses. When dementia patients have more than one doctor prescribing medicine, the chance of mistakes is even greater. Supervision of medications is necessary even early on in the disease process. The following tips may help:

Take inventory:

- List all the medicines, including herbs, vitamins, and supplements, the doses, the frequency and the doctor’s name on one card.
- Gather and store all medications in one area.
- Check throughout the house to find medicines (including kitchen cupboards, dressers, purses, coats, bathroom cabinets).
- Take the list of medications to every doctor’s visit for review.
- Throw out any expired medicines or those no longer used.

Early in dementia, supervise medicine use:

- Use weekly pill organizers.
- Count the number of pills regularly to check for correct use.
- Make a simple schedule for patients to follow.

When mistakes are noticed:

- Remove all medicine from the person's possession.
- Keep medications stored in a secure place.
- Give the pills immediately when they are to be taken; pills left out may get lost.
- Make sure the person swallows the pill.

If a person with dementia refuses medicine, ask for liquid alternatives or check if the pill can be crushed and added to a favorite food like ice cream or pudding.

Be careful using "over the counter" medicines. Ask your doctor before giving cold and cough medicines or sleep preparations.

Hallucinations

Some people with AD or other dementias will develop hallucinations. These can be distressing symptoms for both the person and the caregiver. When they occur, the doctor should be informed so that treatment can be discussed. These are real experiences for the patient and can be frightening to her.

- Hallucinations are the experience of seeing things or hearing voices when nothing is there.
- Seeing things, animals or people are the most common hallucinations.
- Hallucinations may occur as a result of another illness, an infection, medication side effects or anesthesia.
- When patients hallucinate after surgery, they may be frightened and try to run away from the visions, creating safety risks.

If Hallucinations Develop

- Look for signs of an illness or infection. Examples include sudden onset of incontinence (wetting accidents), a cough, drowsiness, or unsteady walking.
- Let your doctor know this has happened.
- Provide reassurance. For example, you might say: "I don't see those people but I'll keep you safe."
- Provide distraction. Moving the patient to another room or changing the activity can sometimes distract her.
- Stay with the person when she is in the hospital, if possible, to avoid the use of restraints and unnecessary sedation.

Delusions

Many persons with dementia develop delusions. Delusions are fixed false beliefs. Such beliefs are strongly held, and patients cannot be convinced otherwise. Delu-

sions can result in aggression and put patients and their caregivers at risk of harm. *Common delusions* in dementia include believing that:

- Someone is stealing from them.
- People are in the house who are not there.
- Caregivers are not who they say they are.
- Their food or medicines are poisoned.
- Their spouse is unfaithful.

If Delusions Develop

- Avoid arguing or trying to reason. Provide reassurance. Try to find things they say are stolen.
- Inform the doctor of the delusions.
- Try to distract them. For example, if they are looking for their deceased mother, say, “I haven’t seen her lately, but let’s get a snack and you can tell me about your mother.”
- Make sure they are safe and cannot wander out.

Depression

Depression is a common complication of dementia causing needless suffering to patients and their caregivers. Once thought of as a natural consequence of dementia, depression occurs in 20-40% of patients and can be effectively treated. *No one can* “will” away depression by “being stronger.” Many patients won’t complain of feeling sad or depressed. It is most important to understand that this is a chemical illness much like diabetes and is not a normal reaction to the knowledge of having a dementing illness.

Symptoms of depression in dementia include changes in:

- *Mood*—tearfulness, anxiety, worry, loss of pleasure
- *Behavior*—irritability, uncooperativeness
- *Appetite*—eating less, eating more
- *Thoughts*—low self-esteem, fearfulness, guilt
- *Sleep*—difficulty falling asleep, awakening earlier than usual
- *Energy*—loss of energy, apathy, withdrawal

If Depression Develops

- Have the patient evaluated. Report symptoms to the doctor.
- Encourage small, frequent snacks and meals to ensure adequate nutrition.
- Encourage the patient to get out of bed and change her clothes despite refusals.

- Assist with the change of clothing to promote good hygiene.
- Inform physicians of side effects if taking an antidepressant.
- Offer reassurance and hope, since it may take time for medicine to be effective.

Driving

The issue of whether a patient with AD or other dementia should drive is important. The issue of independence makes driving a sensitive issue. Problems driving occur when something unusual happens, such as a child running into the street or a construction area. Problems in driving include:

- Getting lost
- Using poor judgment
- Driving in the middle of the road or on the wrong side
- Driving too fast or too slow
- Not obeying traffic signals

If There Are Driving Concerns

- If you feel uncomfortable driving with the patient or if you would not allow a grandchild to drive with him, begin steps to stop his driving.
- Enlist the help of your doctor in getting the person to stop driving.
- Disable the car if necessary.
- Provide alternate methods of transportation.
- Relocate or sell the car.
- Obtain a formal driving evaluation if necessary.

Task Breakdown

Task breakdown refers to simplifying the steps of activities in daily life. It can help to overcome frustrating problems like difficulty in remembering the steps of a task, becoming easily distracted, and having difficulty coordinating movements needed to complete a task.

Tips on How to Do Task Breakdown

- Write down all the steps of a task.
- Observe the patient trying to complete a task to identify parts that are difficult.
- Eliminate steps that are frustrating for the patient.
- Give instructions one step at a time.
- Give praise for the completion of each step.

- Begin tasks for patients by getting them started, such as holding a shirt and putting an arm through the armhole.
- Try putting your hand over theirs and guiding it during tasks like holding a fork to eat or brushing teeth. This is called “hand-over-hand” guidance.
- Encourage patients to participate as much as they can without frustration, such as allowing them to stir food when they cannot follow a recipe.
- Re-evaluate task performance regularly. Most patients will have more difficulty over time and will need more help.

Taking Inventory

By the time dementia is recognized, the personal affairs of the patient are often in disarray. Common problems include misplacing checks, forgetting to pay bills, hiding money, and/or repeatedly withdrawing money from the bank. Patients may be reluctant to allow someone to help in these matters. It is important to take inventory of the patient’s obligations and assets.

Go Through the House to Find the Following:

- All bills and obligations of the patient.
- The checkbook.
- Account numbers and location of all bank accounts.
- Stock and savings bond certificates.
- Social Security and insurance cards.
- Advance directives.
- Last will and testament.
- Discharge certificates from the armed forces.
- Pensions and other retirement benefits.
- Insurance policies.
- Completed power of attorney to manage finances.
- Jewelry of sentimental or monetary value.
- Costume jewelry to use as substitutes for valuable bracelets, rings, necklaces, and earrings.

Catastrophic Reactions

A catastrophic reaction is the sudden expression of a negative emotion or behavior such as yelling or running away. Such outbursts are often a reaction to something in the environment or to task failure. This term is useful, as it expresses the idea that the person is reacting to a seemingly minor event as if it were a catastrophe. Catastrophic reactions are associated with brain injury from any cause and are often seen in those who have had head trauma or developmental disabilities.

Example 1: A man with AD struggles to put his pants on and finally puts them on backwards. He then attempts to zip them up the back and can't do it. He then gets so frustrated by this that he takes them off and throws them on the floor, refusing to get dressed.

Example 2: A woman with AD is attending a holiday dinner at her daughter's home. Music is playing; small children are running about; holiday decorations are displayed. Previously, she would have enjoyed such an occasion. When her daughter asks her to carry a plate of food into another room, she suddenly starts crying.

How You Can Help

Know the functional limits of the person and do not expect her to do more than she can to prevent and avoid such reactions.

In *example 1*, simply assisting the man by holding out his pants in the correct presentation can allow him to continue to dress himself.

In *example 2*, limiting the size and complexity of the holiday dinner will help the woman to continue to enjoy it. Also, finding simple things that she can do will reinforce her meaningful contribution to the family.

In general, when you notice someone suddenly getting upset, stop what you are doing with them or move them to a different environment. Catastrophic reactions often stop by themselves. After the person is calm, think about how to avoid further reactions.

Rummaging and Hoarding

Rummaging and hoarding are two common behaviors in persons with more severe dementia. Rummaging is characterized by aimlessly moving objects about, looking through things and touching things. Persons who do this appear to be searching for something and may persist in this behavior for hours, often without accomplishing anything. Examples include going through closets, drawers, purses and briefcases.

Hoarding refers to the collecting of objects. Often the objects being hoarded have little value. They may include scraps of paper, styrofoam cups, and packets of sugar, junk mail or money. Once they are put away, the demented person forgets where they are and the rummaging begins again.

These behaviors can become a problem in several ways. If patients are rummaging in someone else's things, they could be accosted by the owner. If valuable things are being hoarded and lost, this can also be a problem. Examples are hoarding of money, mail, identification cards, and jewelry.

One solution to these problems is to create a small, safe area for rummaging and hoarding. A drawer could be set up with small objects that are not valuable. One closet door could be left unlocked for rummaging.

Another approach is to routinely check the person's room for hoarded items such as food or the possessions of others. This, of course, must be done when the person is not in the room.

Perhaps the most effective way to approach these problems is to provide structured activity programming such as that at a day care center.