Alzheimer’s and Dementia

Caregiver Information Booklet

Support for those who care for others

Northwest Regional Council Family Caregiver Support Program
An Area Agency on Aging
Alzheimer’s and Dementia

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Caring Tips for Alzheimer’s

There are specialized techniques that can be utilized in caring for a person with Alzheimer’s. Some of these are contrary to the way we have learned to treat others. The participant is an individual, who in spite of memory loss and confusion often retains some social graces and who is sometimes aware of their condition. The lack of confidence and loss of a sense of personal dignity can be devastating. When everyone and everything is unfamiliar and you can’t remember things one minute to the next the world can be a frightening place. Therefore, PATIENCE, UNDERSTANDING, ACCEPTANCE, RESPECT, CALMNESS are essential.

- Use relaxed body language. Be calm, smiling, and sincere.
- Use touch if the participant is responsive to it. A simple pat on the arm, holding hands, or a hug, will often convey feelings of caring and acceptance. However, some participants will not respond to touching in a positive manner. Most will.
- Maintain eye contact and speak slowly and calmly using short sentences without choices. Choices are difficult to make for a person with memory loss. Use suggestions rather than asking questions (“Let's have some juice,” instead of, “would you like juice or coffee?”).
- Using distraction by changing the subject will often solve an undesirable situation. They will forget in moments what went on before.
- Identify yourself and use their name to 'tune' them in to you. They will forget who you are from session to session. Trying to get them to remember people or events previous even within the same day can often be frustrating to them.
- Join in a participant’s make believe world or in the past. They are often not able to live in the present and feel more comfortable in the past. If you have trouble understanding them, try to focus on a word or phrase that you can repeat back to them for recognition of their effort. Even understanding their feelings rather than their thoughts is recognition. They may repeat the story or thoughts or questions over and over. Stay calm and patient.
- Their attention spans are very short. Repeating directions in a calm and matter of fact manner will reassure them. Remember to encourage them to take activities one step at a time and to talk them through it rather than doing it for them. Praise them for their efforts.
- The confused person often misjudges situations and becomes suspicious and accusing. They may make unkind remarks and are not tactful. You can not take it
personally because they are reacting to a situation which is threatening to them. They will not remember treating you this way. Use humor or distraction to change the situation. Participants can not be taught to remember recent events or moral lessons.

- Feeling deserted after only a few minutes can cause anxiety. Reassure them and be truthful about what time it is and when their family/caregiver will return. This anxiousness may be repeated numerous times. You must repeat your reassurances patiently since they will not remember they or you have had the conversation before.

- Creativity and flexibility are necessary in your approach to the participant. If one approach doesn't work, try another one.
Compassionate Communication with Alzheimer’s Patients

by Liz Ayres, a volunteer of the Alzheimer’s Association and former caregiver

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

- Give short, one sentence explanations
- Repeat instructions or sentences exactly the same way
- Allow plenty of time for comprehension
- Eliminate “but” from your vocabulary; substitute “nevertheless”
- Agree with them or distract them to a different subject or activity
- Accept the blame when something’s wrong (even if it’s fantasy)
- Leave the room, if necessary, to avoid confrontation
- Respond to the feelings rather than the words
- Be patient and cheerful and reassuring – go with the flow
- Please elevate your level of generosity and graciousness

Remember

- They are not crazy or lazy. They are saying normal things, and doing normal things, for an AD patient. If they were doing things, or saying things, to deliberately aggravate you, they would have a different diagnosis.
- Some days they’ll seem normal, but they’re not. Their reality is now different than yours and you cannot change them. You can’t control the disease. You can only control your reaction to it.
Their disability is memory loss. They cannot remember and *can’t remember that they cannot remember*. They’ll ask the same question over and over believing it’s the first time they’ve asked.

They do not hide things; they protect things by putting them in a safe place and then forgetting they’ve done so. Do not take ‘stealing’ accusations personally.

*They are scared all the time.* Each patient reacts differently to fear. They may become passive, uncooperative, hostile, angry, agitated, verbally abusive, or physically combative. They may even do them all at different times, or alternate between them. Anxiety may compel them to follow you everywhere. They can’t remember your reassurances. Keep saying them.

**Examples**

**Don’t Reason**

**Patient:** “What doctor’s appointment? There’s nothing wrong with me.”

**Don’t:** (reason) “You’ve been seeing the doctor every three months for the last two years. It’s written on the calendar and I told you about it yesterday and this morning.”

**DO:** (short explanation) “It’s just a regular check-up.”
(accept blame) “I’m sorry if I forgot to tell you.”

**Don’t Argue**

**Patient:** “I didn’t write this check for $500. Someone at the bank is forging my signature.”

**Don’t:** (argue) “What? Don’t be silly! The bank wouldn’t be forging your signature.”

**DO:** (respond to feelings) “That’s a scary thought.”
(reassure) “I’ll make sure they don’t do that.”
(distract) “Would you like to help me fold the towels?”
Don't Confront

Patient:  “Nobody’s going to make decisions for me. You can go now… and don’t come back!”

Don’t: (confront) ”I’m not going anywhere and you can’t remember enough to make your own decisions.”

DO: (accept blame or respond to feelings) “I’m sorry this is a tough time.”
(reassure) “I love you and we’re going to get through this together.”
(distract) “You know what? Don has a new job. He’s really excited about it.”

Don’t Remind them they Forgot

Patient:  “Joe hasn’t called for a long time. I hope he’s okay.”

Don’t: (remind) ”Joe called yesterday and you talked to him for 15 minutes.”

DO: (reassure) “You really like talking to Joe, don’t you?”
(distract) “Let’s call him when we get back from our walk.”

Don’t Ask Questions of Recent Memory

Patient:  “Hello, Susie. I see you’ve brought a friend with you.”

Don’t: (question memory) ”Hi Mom. You remember Eric, don’t you?” …What did you do today?

DO: (short explanation) “Hi Mom. You look wonderful! This is Eric. We work together.”

Don’t Take it Personally

Patient:  “Who are you? Where’s my husband?”

Don’t: (take it personally) ”What do you mean who’s your husband? I am!”

DO: (go with the flow, reassure) “He’ll be here for dinner.”
(distract) “How about some milk and cookies? Would you like chocolate chip or oatmeal?”
Do Repeat Exactly

**Patient:** "I’m going to the store for a newspaper."

**Don’t:** (repeat differently) "Please put your shoes on." “You need to put your shoes on.”

**DO:** (repeat exactly) “Please put your shoes on.” “Please put your shoes on.”

Do Eliminate “But” – Substitute “Nevertheless”

**Patient:** “I’m not eating this. I hate chicken.”

**Don’t:** (say ‘but’) "I know chicken’s not your favorite food, but it’s what we’re having for dinner.”

**DO:** (say ‘nevertheless’) “I know chicken’s not your favorite food, (smile) nevertheless I’d appreciate it if you’d eat a little bit.”
Dementia Education and Training Program

from the University of Alabama

Definition of Dementia

- Permanent, progressive loss of multiple intellectual functions
- In 1906 Alois Alzheimer first described this disease by studying a brain specimen from an autopsy
- Alzheimer’s disease is one type of dementia, although the term is often used synonymously with dementia

Epidemiology of Dementia

- Approximately four million Americans are afflicted with Alzheimer’s disease
- Alzheimer’s disease is the fourth leading cause of death among individuals over the age of 65.
- Approximately 10% of the population over 65 have Alzheimer’s. Forty seven percent of those over the age of 85 are demented, which is the fastest growing segment of the US population. With the aging of America, it is estimated that by the year 2050 the US will have 67.5 million people over the age of 65 compared with 25.5 million today.
- Dementia afflicts both men and women in all racial, religious, and socioeconomic groups.

Clinical Symptoms

- Intellectual
  - Amnesia: Loss of memory function
  - Aphasia: Loss of ability to understand the spoken or written word (receptive) or inability to speak (expressive)
  - Apraxia: Loss of the ability to perform remembered motor tasks, for example, buttoning a shirt or turning a door knob
  - Agnosia: Loss of the ability to remember what things look like (visual agnosia), for example, the face of a close relative
Psychiatric
- Depression: 25%
- Psychosis (hallucinations and delusions): 30-40%
- Poor judgment, irritability, inappropriate behavior
- Major personality changes

Non-neurological systems
- Only the brain is damaged by Alzheimer's disease. Other organ systems are not damaged.

Causes of Dementia

Dementia is caused by the death of nerve cells. Once a nerve cell dies, it cannot be replaced and its function may be lost. Nerve cell death is caused by:

- Alzheimer's disease: 60-70%
- Multiple small strokes: 15-30%
- Multiple other causes: 10-15%

Reversible Causes of Intellectual Decline

- Five to 20 percent of the elderly patients who appear demented have treatable diseases such as depression, hormone imbalance (i.e. hypothyroidism) or medication induced confusion.

Causes of Alzheimer's Disease

There is no clear reason why nerve cells die. Inheritance plays some role:
- 5% of cases are clearly inherited (autosomal dominant)
- 20-60 percent may have a genetic predisposition
- There is no specific genetic test for Alzheimer's disease
- Diet and lifestyle do not contribute to Alzheimer’s’ disease
Treatment for Dementia

- Current:
  - No known treatment stops nerve cell death in Alzheimer’s disease
  - Current medications may slow progression in early states
  - Psychiatric symptoms can be treated with medication

- Future
  - Future therapies will try to prevent the death of nerve cells and maximize the function of surviving nerve cells
  - Adequate preventive measures are probably 10 years into the future
  - Brain cell implants offer little promise

Stages of Dementia

- Dementia is a relentless, progressive disease
- No patient’s course is ever predictable
- Patients have long survival because other organ systems are not damaged

- Early Years (3-5) of Disease
  - Mild amnesia (memory loss), good function at home, few psychiatric symptoms

- Middle Years (3-10) of Disease
  - Many intellectual impairments, poor function at home, many psychiatric/behavioral problems

- Late Years (5-20) of Disease
  - Multiple, severe intellectual impairments
  - No function at home
  - Total care patient to include feeding tubes
  - Loss of bowel and bladder functions

Continuum of Care

- Essential components for a complete continuum of care include:
  - Inpatient/outpatient clinical evaluation and treatment
  - Domiciliary care
  - Nursing home dementia units
  - Adult day care for demented clients
  - Respite care
  - Home health services
– Family support groups

**Financing Care**

- 50-60 percent of all nursing home patients are demented. The annual cost of nursing home care ranged between $36,000 and $40,000. Most expenses are ultimately borne by patients’ families.

- Approximately 70% of the care given Alzheimer’s patients is provided by the families. The cost of the family caring for the patient at home averages $18,000 per year.

- Paying for Alzheimer’s disease—including the cost of diagnosis, treatment, nursing home care, and lost wages—is estimated to be more than $80 billion each year in the U.S.
Friends: Here’s How You Can Help with Alzheimer’s

The ways in which friends and family are able to help the person with Alzheimer’s disease and their caregiver have no limit. Use your unique abilities and gifts to really make a difference in someone’s life!

The following suggestions are written from a spouse’s point of view, but could well apply to the parent/child caregiving relationship as well:

1. Offer to sit with my husband/wife even if I do not leave the house. This will give me the time to do other things around the house and garden.

2. Come for a visit when you can, but call first to confirm that it will be convenient. We both get lonely and bored. Don’t assume that the Alzheimer’s patient needs rest at the expense of communication or that communication must be a two-way street.

3. Talk to my spouse, who can understand some things even though he/she cannot respond. Even if there is no understanding, it is comforting to have a friend there to pretend that my spouse does understand. We do not know what gets through.

4. Be patient and understanding. Put yourself in my spouse’s place and imagine what you would feel like when memory fades and you become more and more helpless. Hold his/her hands. Give praise but no scolding or corrections.

5. Make a specific offer of help—say, “I want to come over Monday at 3:00 to bake, clean house, do laundry, or whatever.” If you say, “Call me anytime for anything,” I won’t know what you want to do or when you are free…so I probably won’t ask.

6. Offer to watch TV with my spouse some afternoon when an old movie is on. Bring a book or magazine in case he/she falls asleep. This will give the feeling that his/her company is still enjoyable without either having to entertain the other.

7. Suggest coming over to take my spouse for a walk. Exercise is terribly important, but I sometimes cannot find time for a walk, and my husband/wife enjoys it; be ready to hold his/her hand.

8. Encourage your wife/husband to come over to visit us in the evening. My spouse enjoys company and it gives me a chance to have a normal, sensible conversation, when my spouse cannot do so.
9. Cook a dinner or other meal entrée and stay to eat with us if you can. Familiar company helps both of us. Be prepared to eat slowly and don’t be surprised if food gets spilled.

10. Bake cookies, brownies, bread, etc., or something special that my spouse likes—a favorite recipe. If possible make enough so some can be frozen.

11. Run errands. Find out what needs to be done. Take my spouse along while you do some shopping or do an errand.

12. Once in awhile, when I can get a sitter, join me for an evening meal at a restaurant and/or some evening entertainment such as the theater, a concert, or a movie. I need to have some stimulating and enjoyable time.

13. Offer to help at holiday and birthday times. Assist in buying gifts, wrapping presents, trimming the Christmas tree, or anything else you can think of.

14. Even if the joke is terrible, tell it! Bring Reader’s Digest or other material and read aloud. Describe what is funny out there. It may not tickle my spouse’s ribs but it won’t hurt. Speak to that part of my spouse that is alive, for that is the real person.

15. Touch or hug my spouse if you feel like it. The isolation of being “mentally” out of it is pretty devastating.

16. Bring some music—cassette tapes or records. If you play an instrument, bring it along, even for practice. Sing some old-time songs with my spouse (“Let Me Call You Sweetheart,” etc.). Music brings pleasure and even memories, when non-musical memories are gone.

17. Tell my loved one how great he/she looks, even if you have to stretch the truth a bit. Self-esteem is terribly important when the power to do things has weakened or gone.

18. Tell us about the real life you are living. This will help my spouse to feel less like an untouchable and may give the sense that he/she is still involved in the world. One of the hardest things about Alzheimer’s disease for both of us is the problem of conversation. If you don’t talk to us about the real world, we are left with meals, birds, flowers, weather, and TV to talk about, and gradually most of those are disappearing from my spouse’s world.

19. Go to a meeting with my spouse—most any kind. You may meet friends who will enliven his/her life for a moment, even if forgotten two minutes later. Take him/her to lunch so I can get away by myself or have time to catch up on correspondence, house cleaning, or even a nap.
## Functional States in Normal Human Development and Alzheimer’s Disease

<table>
<thead>
<tr>
<th>Approximate Age</th>
<th>Acquired Abilities</th>
<th>Lost Abilities</th>
<th>Alzheimer’s Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>12+ years</td>
<td>Hold a job</td>
<td>Hold a job</td>
<td>INCIPIENT</td>
</tr>
<tr>
<td>8-12 years</td>
<td>Handle simple finances</td>
<td>Handle simple finances</td>
<td>MILD</td>
</tr>
<tr>
<td>5-7 years</td>
<td>Select proper clothing</td>
<td>Select proper clothing</td>
<td>MODERATE</td>
</tr>
<tr>
<td>5 years</td>
<td>Put on clothes unaided</td>
<td>Put on clothes unaided</td>
<td>MODERATELY SEVERE</td>
</tr>
<tr>
<td>4 years</td>
<td>Shower unaided</td>
<td>Shower unaided</td>
<td></td>
</tr>
<tr>
<td>4 years</td>
<td>Toilet unaided</td>
<td>Toilet unaided</td>
<td></td>
</tr>
<tr>
<td>3-4.5 years</td>
<td>Control urine</td>
<td>Control urine</td>
<td></td>
</tr>
<tr>
<td>2-3 years</td>
<td>Control bowels</td>
<td>Control bowels</td>
<td></td>
</tr>
<tr>
<td>15 months</td>
<td>Speak 5-6 words</td>
<td>Speak 5-6 words</td>
<td>SEVERE</td>
</tr>
<tr>
<td>1 year</td>
<td>Speak 1 word</td>
<td>Speak 1 word</td>
<td></td>
</tr>
<tr>
<td>1 year</td>
<td>Walk</td>
<td>Walk</td>
<td></td>
</tr>
<tr>
<td>6-10 months</td>
<td>Sit up</td>
<td>Sit up</td>
<td></td>
</tr>
<tr>
<td>2-4 months</td>
<td>Smile</td>
<td>Smile</td>
<td></td>
</tr>
<tr>
<td>1-3 months</td>
<td>Hold up head</td>
<td>Hold up head</td>
<td></td>
</tr>
</tbody>
</table>
Knowing What to Expect for Alzheimer’s

The following is a reprint of an information sheet that a caregiver wrote for the friends and other family members of her loved one, whom we'll call “Jane.” The caregiver would like us to share it with you, too. Family caregivers can be the best sources of information about dementia behaviors and caregiving tips.

What to Expect

By knowing a little more about Jane’s illness and the way it is affecting her, we hope you will be less likely to be caught off-guard when her behavior, or the way she responds to a particular situation, is not quite what you might have expected. Instead, we hope you will recognize that her behavior, although perplexing at times, is quite normal for someone with Alzheimer’s.

Communication Changes

- When you explain something to Jane, she often is still able to understand what you are telling her. The problem is that she quickly forgets what she understood. Don’t be surprised if you need to explain again later.

- She often repeats stories, sometimes within minutes, forgetting that she has already told you. This is a typical and sometimes disconcerting symptom of the disease. Just be patient, and subtly redirect her to a new subject.

- “Creating” details is a very common cover-up for Alzheimer's victims when they come up against a gap in memory; they’re not trying to be dishonest. Also, it’s not unusual for Jane to tell you a perfectly reliable story, but use the wrong names. Therefore, be forewarned not to pass her stories on to anyone else unless you verify the accuracy.

- Jane’s ability to initiate or follow conversations, and to “stay on track,” is becoming more limited, particularly in groups. She seems more successful in one-on-one conversations.
Memory Losses

- Names and relationships, even of very close friends and relatives, are escaping her. She may quickly recognize you as someone familiar, but still not remember who you are, or what your name is. This is a result of the disease and is not intentional. Don’t feel slighted; merely supply your name upon greeting her, and if necessary, give her a verbal clue or two.

- As the disease progresses, she is having more and more trouble remembering recent events, and some days she remembers better than others. There’s no way to predict. However, she is more successful at reminiscing about events from the past, and has many interesting and fun stories to tell. Don’t be surprised if some of the details aren’t quite as you remember them.

Behavior Changes

- Sometimes Jane is unaware of her deficiencies, while at other times she seems quite aware but is unable to do anything about it…except attempt to “cover up.” Allow her the dignity of doing so.

- As is typical of Alzheimer’s disease and related dementias, Jane will sometimes exhibit childlike behaviors. However, try to remind yourself that she is still an adult with adult feelings, and relate to her accordingly.

- She sometimes tends to doze off quite easily, particularly if she is unable to participate in the conversation. If this happens, just gently wake her up and get her talking or moving around a bit. At such times, it is best to keep the visit short.

- Have patience. If Jane does exhibit a behavior that you think is not quite appropriate, remind yourself that, due to her memory loss, she does not always remember what is expected and acceptable. She is doing the best she can.

Phone Calls

- When you call Jane on the phone, immediately identify yourself even through she may sound like she knows who it is. She often recognizes a voice as sounding “familiar,” but that doesn’t mean she remembers who you are, or the name that goes with the voice.

  - If you make any plans with her on the phone, before you hang up ask to talk with me to confirm the arrangements. Even though Jane may sound like she understood what you were telling her, by the time she hangs up she is generally unable to remember who she was talking with, much less the specifics of the conversation. She can really fool you on this.
Social Activities

- Don’t make any plans or arrangements with Jane without telling me. I will make sure all necessary details are noted, see that there aren’t conflicts, and, most importantly, will see that Jane doesn’t forget.

- As her disease progresses, because of memory lapses and declining manual dexterity, her table manners can be expected to deteriorate somewhat. She is gradually needing more guidance and assistance. You might offer to help her put her sandwich together, or to cut things up a bit if you see she needs help. Move unnecessary items out of the way. If necessary, help her “scoot” up to the table. She will often sit back too far, and doesn’t remember how to solve the problem.

- At a restaurant, provide some helpful suggestions on ordering. Some days she does fine in making appropriate choices; other days “choices” are terribly confusing. You’ll know. If she needs to go to the women’s room, please accompany her. She likely would not be able to find her way back to the table alone, or to tell anyone the name of the person she is with. Suggest she not lock the bathroom door…that you will hold it for her. (If she manages to lock the door, she may not be able to unlock it.)

- If all this worries you a bit, don’t hesitate to ask me to accompany you. As the disease progresses, this may become a necessity.

Suggested Social Activities

- Call me to arrange a time to drop by for a half hour visit with Jane. Bring along something to show her such as photos of family or postcards from a recent or planned trip…or sit and look at a photo album with her (she has lots of them) and reminisce…or plan to watch a specific television program you think she might like (realizing that she might doze off through part of it)…or take her for a short drive to see the flowers or the Christmas lights.

- As you are heading for the door after a visit, or about to hang up the phone, it is not unusual for Jane to suddenly, and sometimes very inappropriately, suggest doing something “tomorrow.” This is merely her way of letting you know that she wants to see or talk with you again soon; that she wants to stay in contact. Just thank her, and tell her you can’t make any plans right now, but that you will call her, or drop by, again very soon. If there is any question, call me later.

Neighbors

- Please, if you see Jane walking down the street by herself, or if she drops by for an unexpected “visit,” call me immediately…or walk her back home. Jane can easily and quickly become lost, even in familiar surroundings, and may not be able to find her way back.
Ten Tips for Adult Children of People with Dementia

1. **Make sure you understand the legal and medical powers process.** If a competent adult does not yet have the powers, do this today.

2. **Become informed about Medicare and Medicaid.** Consult with a lawyer who specializes in Elder Law regarding legal and financial questions.

3. **Be involved with your parent’s physician** while educating yourself about the disease. Be aware of the later stages.

4. **Appreciate your Alzheimer’s parent the way he or she is now.** The patient is declining. Allow for recurring periods of grieving for yourself and the caregiver as each new level evolves.

5. **Unless you’ve been trained as a nurse, you cannot expect to be one simply because the needs is there.**

6. **Be nice to the caregiver.** If you are the caregiver, do nice things for yourself.

7. **Conduct a family meeting with the immediate family,** either in person or by telephone. Include a frank discussion of finances. Do not be afraid to assign jobs to your siblings.

8. **Remember that each of us reacts differently to a person with Dementia.** Some people take longer to recognize the diagnosis. Denial is part of our coping mechanism.

9. **Contact your local Alzheimer’s chapter and the AD association closest to your parents.** (Your chapter can help you find the number.) Attend support group meetings and encourage other family members to do so also.

10. **Research and investigate adult day care centers and nursing homes as early as possible.** They may become part of the solution.
"This Long Disease"

An essay by Roger Rosenblatt

My mother stares at me with a bottomless fury. “It’s not a laughing matter,” she says, her voice as dry as cracked wood. I have just attempted, unsuccessfully, to kid her out of her adamancy, but she only repeats what she has been demanding for the past hour: “Put me in my bed!” Yet the nurses have told her over and over that she must sit up part of the day to prevent bedsores and worse.

“Put me in my bed!”

“In an hour, Mom. They’ll put you back in an hour.”

Her mood is so black I wonder if it goes beyond the bed issue, down to some remembered anger with me for bad-son behavior that occurred 30 or 40 years ago. I wonder if she is thinking, “I carried you to bed often enough!” I wonder if she still resents my putting her in this nursing home. I can wonder my head off.

In a way, the disease demonstrates the essential incomprehensibility of the human mind by reducing it to pure puzzle. It represents all that is impenetrable about who people are and what they think. Alexander Pope referred to “this long disease, my life.” That’s Alzheimer’s, especially in my mother’s case.

In the 15th year of her affliction, her 90th of living, she has become an exhibit in Ripley’s Believe It or Not! Come see the former junior high school English teacher, wit, storyteller, and singer to children transformed before your very eyes into a sphinx. Yet she is still a great beauty, ladies and gentlemen. The silver hair, the smooth pink skin. Go ahead and touch her. She won’t bite. (Then again, she might.)

The little lady was electrocuted 14 years ago, yet her body goes on forever. This is how fate has treated her. It doesn’t do much for one’s opinion of fate.

Given no choice, I tell myself that within her rejiggered brain cells, in the reconstructed network of 10 trillion nerves inside the hippocampus, the temporal lobe and the parietal lobe, she may discover different kinds of happiness. Perhaps it is oddly fulfilling—the complete use of a brain—to know only that you want to be moved from a wheelchair to a
bed. Life consists of small, discrete goals that become the entire universe. Why would she not be furious with me for thwarting her vast ambition?

Yet she is not always like this. Sometimes she does not recognize me and thinks I am a doctor. She complains of an ailment, which she expects me to treat. Sometimes she does not speak at all. Sometimes, when she manufactures a new narrative of our family history, she can be very funny.

“Did you know that Aunt Regina used to work as a prostitute?”

“No, Mom, I did not.” The woman she names (long dead) was in her 80s when we knew her and looked as much like a prostitute as Margaret Thatcher.

“She charged her customers $10 an hour.”

“Hard to believe, Mom.”

“Did you bring ice cream?”

Against the nurses’ orders I bring her vanilla ice cream from time to time in a small cardboard cup, and I feed her with a flat wooden spoon. She takes her regular food through a tube in her stomach, so the taste of the sweet, cold substance makes her salivate and smile. She will exclaim, “This is delicious!” after every taste, with exactly the same intonation, as if she feared that if she used any other formula to express her appreciation, I would not reward her with another spoonful.

Language, which used to be the source of her pleasure, is now mainly a tool, but it is impossible to know if she says what she intends or even if she hears what she says. I read that damaged minds lose the storytelling capability and leap over chasms of logical sequence. They lose words too, of course.

I wonder if my mother is losing all her words one by one, until she eventually will be down to her last word, the only word left her in the world. What word would that be?

I wonder if I ever understood her, and if she acquired Alzheimer’s deliberately to make that point. I wonder if she thinks that I have Alzheimer’s because she cannot understand me.

“Put me in my bed!”

People always used to say nice things about my mother’s blue eyes, which I inherited. We use our blue eyes to stare at each other now. Hers are full of rage, and mine are searching for a way to relieve the pain, which I pray is mine alone.
Admitting Your Loved One to a Nursing Home

by Carly R. Hellen, OTR/L, Nursing Home Services Director

Admitting a loved one into a nursing home is a stressful event for all involved. It is only natural for such a decision to make family members feel upset, sad, and apprehensive. But with good planning, admission day can be an open door to new and positive opportunities for persons with Alzheimer’s disease and their loved ones.

Admission Guidelines

- The best days for admission are Monday through Thursday, when the home is fully staffed. Friday is too close to the weekend.
- Plan a morning admission, 10-10:30 is preferable. This usually is the best time for the patient, and allows you to observe morning activities taking place at the home. Also, lunch time provides a good excuse for leaving.

Making An Easy Move

The day before admission to the home, follow this checklist:

- Mark all clothing and belongings with a laundry pen.
- Sign as much of the paperwork as possible so you are available for the patient during admission.
- Bring family pictures to hang and a favorite chair.
- Bring a familiar bedspread or afghan to help the patient find her or her room.
- Make a scrapbook for the patient. Fill it with past and present pictures of the patient; places visited, statements about the past, or perhaps favorite scripture verses. This gives the patient a sense of security and helps staff get to know him or her.
On Admission Day

- Have confidence in your decision and realize that the home will give you and your loved one caring support.
- Bring another family member or a good friend.
- When it’s time to say goodbye, the family knows the best way. A simple “Goodbye, John. I have some errands to do. I’ll come back soon,” is usually best. Giving the patient a personal item, like a scarf or cap “to keep for me until I come back” may also help.

Visits

- Visits should be planned by the staff and family together. The patient needs time to get used to the home.
- When you visit, expect changes in your loved one. A home is a new environment. It is natural for a person with dementia to have difficulty getting used to a new place. With time, patients almost always adjust to the nursing home.
- Some patients’ spirits appear to “improve” because of the group activity and socialization in the home. Do not take this to mean the person is “getting better.”
- Realize that the patient usually cannot remember how often you visit or for how long.

Admission day is a time for saying goodbye, and a time for new beginnings. Be open to opportunities this positive move will provide. It is a time for you and your loved one to share a new journey together.