NEW HAMPSHIRE'S

ALZHEIMER'S DISEASE AND RELATED DISORDERS

FAMILY CARE GUIDE

by
Alzheimer's Association of Eastern Massachusetts
in collaboration with
Alzheimer's Association of Cape Cod and Islands
and Western Massachusetts

for

New Hampshire Bureau of Elderly and Adult Services
Alzheimer's Program

NEW HAMPSHIRE FAMILY CARE GUIDE

June 2005 Edition

**By the Alzheimer's Association of Eastern Massachusetts
in collaboration with the Alzheimer's Associations of Cape Cod
and Islands of Western Massachusetts**

***The New Hampshire Alzheimer's Disease and Related Disorders Family Care Guide* is adapted from the *Family Care Guide* published in 1988 by the Alzheimer's Disease and Related Disorders Association of Eastern Massachusetts, Inc., which holds the copyright on this text. That Guide was revised and expanded from the Cape Cod and Islands' Alzheimer's Disease Family Care Guide, by Linnea H. Gordon (c. 1987 by the Health Resource Center of Cape Cod Community College and the Alzheimer's Disease and Related Disorders Association of Eastern Massachusetts, Inc.). The prior versions of this Guide were funded under a grant from the Administration on Aging, Office of Human Development Services, United States Department of Health and Human Services. Pages 13 through 17 of the original Massachusetts Guide have been altered here to reflect community resources available in New Hampshire; however, some references to Massachusetts' programs and agencies remain. Furthermore, the Supplement *Sources of Help* may not be inclusive of all current programs. Comments and suggestions on this Guide are welcome.**

Included with this Guide are two separately bound supplements:

Supplement I: *Sources of Help for Alzheimer's Families in New Hampshire*

Supplement II: *Legal Techniques for Financial, Medical and Personal Planning for Alzheimer's Families in New Hampshire*

Copies of this Family Care Guide and/or separate copies of Supplements I and II, are available from:

**Alzheimer's Program, NH Department of Health & Human Services
Bureau of Elderly and Adult Services
129 Pleasant Street, Concord, NH 03301 1-800-351-1888 Ext. 5554**

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Imagine finding yourself in a strange terminal. Dozens of people are moving about. You search in vain for a familiar face – a sign you can understand – a way out. Desperately you realize you don't know where you are or how you got there – or how to get out. Your heart pounds as you approach a young woman and ask her to help you call a cab or show you to the bus stop. But she merely smiles and reassures you that you're where you belong. How can that be? You don't know why you're here. You have no memory of this morning and who you were with. If only you could remember yesterday and what you were doing …where you live. Someone must be looking for you …wondering where you are. A husband. A mother! Mothers always want to know where their children are. There must be work you should be doing or bills to pay … a house to return to. Why can't you remember? You sit down and wait for the confusion to pass: Someone will have an answer …

Excerpted with permission from
…Once I Have Had My Tea; A Guide To Understanding and Caring For The Memory-Impaired Elderly
by Patricia Hladik

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I. INTRODUCTION

Many questions arise in the course of caring for a person with a dementing illness. This ***Guide*** has been prepared for those who are caring at home for people with Alzheimer's disease and related disorders, offering concrete suggestions for daily management. Personal experiences and "tips" from caregivers are included to provide readers with the benefit of others' experiences.

Alzheimer's disease is the most common of the dementing illnesses. To date, there is no cure for this disease, which affects an estimated 4.5 – 5 million American adults. There is no way to stop the steady, progressive deterioration that is an inevitable characteristic of Alzheimer's. A patient may live with this disease for many years, requiring increasing assistance with all aspects of daily living. Caregiving is an ongoing burden, and caregivers are encouraged to seek help from community resources and to accept offers of assistance from neighbors, family and friends.

There are no right or wrong ways of caring for a patient with dementia. Every patient is a unique human being; patterns of behavior vary from patient to patient. No single caregiving technique always works with an individual patient, and approaches must be adjusted to each person's changing abilities.

Following are a few general guidelines that may help maintain the patient at an optimal level of functioning and make life for patients and caregivers as comfortable as possible:

- *When speaking with the patient, be calm and reassuring. Speak slowly and distinctly, using simple words and short sentences.*
- *Establish a simple, consistent daily routine.*
- *Take care of yourself. Get enough sleep and exercise. Eat well. Keep your own medical and dental appointments. Be sure to give yourself time away from the patient on a regular basis.*
- *Try to maintain a positive outlook. Find ways to enjoy each day. Credit yourself for a job well done. Cultivate patience and good humor.*
- *Let family, friends, and others help you. Don't become isolated. Communicate your needs, fears, and problems as well as your gratitude.*

- *Make use of community supports that are available to you and your patient. Attend a family caregiver support group. Explore options such as help in the home or a day program for the patient.*

- *Plan ahead for your patient's and family's financial future. Learn about legal and financial options that apply to your individual situation.*

What Is Alzheimer's Disease?

Alzheimer's Disease, also called Alzheimer's Dementia or Senile Dementia of the Alzheimer's Type (SDAT), is a progressive, irreversible neurological disorder. The disease, first described by Alois Alzheimer in 1906, knows no social or economic boundaries and affects men and women almost equally.

Symptoms of Alzheimer's Disease may include a gradual loss of memory, a decline in the ability to perform routine tasks, impairment of judgment, disorientation, personality changes, difficulty in learning, and loss of language skills. The rate of change varies from person to person.

Problems of wandering, depression, belligerence and incontinence may develop. Ultimately, patients may be unable to recognize their loved ones.

A diagnosis of Alzheimer's Disease can only be made after a complete medical, neurological, and psychological examination to rule out other possible causes of the individual's symptoms. Some of these conditions may be treatable and reversible. **Do not accept a diagnosis without a complete medical work-up.**

A complete diagnostic work-up includes the following:

- **Detailed Patient History:** An evaluation of the patient's medications, behavior, and past medical problems helps in determining the diagnosis. Even the smallest detail can be very important.
- **Complete Physical and Neurological Examinations.**
- **Mental Status Exam and Neuropsychological Testing:** These tests assist in diagnosing depression, which can sometimes cause confusion and memory loss in older people.
- **Laboratory Tests – Chest X-Ray, Blood Tests, EKG:** These tests assist in ruling out other medical conditions that may be causing or contributing to the individual's problems. Untreated thyroid or heart problems and some vitamin deficiencies can produce reversible confusion and memory loss.
- **C. T. Scan, PET Scan, MRI Scan:** These tests **do not** diagnose Alzheimer's Disease. They assist in eliminating other treatable diseases.

Call your local chapter of the Alzheimer's Disease and Related Disorders Association (ADRDA) for a list of clinics that specialize in the diagnosis of Alzheimer's Disease.

What Is Dementia?

Dementia is a medical term that refers to a group of symptoms exhibited by patients with Alzheimer's Disease and the related disorders. These conditions are referred to as dementing illnesses (from the word "dementia").

Dementia is defined as the loss of intellectual functions (such as thinking, remembering, and reasoning) severe enough to interfere with and individual's daily functioning. Dementia is not a disease in itself but rather a group of symptoms that may appear in certain diseases or conditions. Symptoms may include changes in personality, mood, and behavior in addition to loss of intellectual functioning.

Alzheimer's Disease is the most common of the dementing illnesses. Some of the other well-known diseases that produce dementia includes: Huntington's Disease, Multi-Infarct Dementia, Pick's Disease, Creutzfeldt-Jakob Disease, and Amyothrophic Lateral Sclerosis (Lou Gehrig's Disease).

Other conditions that can cause or **mimic** dementia include hydrocephalus, depression, brain tumors, thyroid disorders, nutritional deficiencies, alcoholism, infections, (e.g., meningitis, syphilis, AIDS), head injuries, and drug reactions. Some of these conditions may be treatable or reversible.

Conditions that are very similar to Alzheimer's Disease are known as the related disorders. **Multi-Infarct Dementia** is one of the most common of the related disorders. This condition is caused by multiple small strokes (infarcts). Studies have shown that Alzheimer's Disease and Multi-Infarct Dementia occur in 15 to 20 percent of dementia patients.

A Note On Terminology

Throughout this ***Guide***, the following terms are used interchangeably:

- patient
- Alzheimer's patient
- dementia patient
- memory-impaired person
- person with a dementing illness
- person with Alzheimer's Disease or a related disorder

Note also that throughout the text, patients are referred to using male and female pronouns in alternate sections – "he," "him," and "his" in one section and "she" and "her" in the next.

How To Use This *Guide*

This ***Guide*** is intended as a handy reference for busy caregivers. Caregivers are encouraged to consult the ***Guide*** for ideas and suggestions as needed and to use the blank spaces at the end of each section to jot down notes on approaches that have worked for you.

Suggestions presented in this manual have been compiled from the existing body of literature on caring for persons with dementia, from professional service providers, and from family caregivers.

Not all of these suggestions will be appropriate for every patient, or appropriate at every stage of a patient's illness. It is hoped that this information will aid you in understanding your patient's needs and capabilities and help you to establish your own caregiving strategies. Because the ability to communicate deteriorates as these diseases progress, the patient cannot always tell you whether a certain approach is working. Trial and error and your own observations are usually the best guides.

A list of suggested readings follows for those who want more information about Alzheimer's Disease and other dementing illnesses.

Going to support group meetings, being with people who are experiencing basically the same problems, makes me feel more relaxed in coping with my situation. We are not only learning a lot regarding the patients themselves, but also about the legal, hospital, insurance, and nursing home aspects of the disease. You can get good information from the group; you don't have to go fetch for yourself.

T. S., Clinton

When I was leaving the house one day and putting on my coat, my mother (who had Alzheimer's disease) said, "Are you going to that family support group that you went to last week? You've been a much nicer person since you joined it."

C. K., Lunenburg

Selected References

Alzheimer's Disease and Related Disorders Association. *Understanding Alzheimer's Disease.* Miriam K. Aronson, Ed. New York: Charles Scribner's Sons, 1988.

Cohen, Donna, and Carl Eisdorfer. *The Loss of Self.* New York: W. W. Norton and Company, 1986.

Guthrie, Donna. *Grandpa Doesn't Know It's Me.* New York: Human Sciences Press, Inc., 1986.

Hladik, Patricia. *Once I Have Had My Tea; A Guide to Understanding and Caring for the Memory-Impaired Elderly.* P.O. Box 19261, Jacksonville, FL 32245, 1982.

Mace, Nancy L., and Peter V. Rabins. *The 36-Hour Day.* Baltimore: Johns Hopkins University Press, 1981.

Powell, Lenore S., and Katie Courtice. *Alzheimer's Disease: A Guide For Families.* Reading, MA.: Addison-Wesley, 1983.

Roach, Marion. *Another Name for Madness.* Boston: Houghton Mifflin, 1985.

Alzheimer's Disease Caregiver Support Groups

It is sometimes difficult for caregivers to believe that support groups can be of value to them. For someone who already feels too busy, attending a meeting can seem like just another burden. The benefits of joining a group, however, are often enormous.

The goal of support groups is to aid caregivers in managing the patient and in understanding and coping with the daily challenges of caregiving. Mutual support and guidance, as well as educational information, are offered. The Alzheimer's Disease and Related Disorders Association (ADRDA) is committed to the support and promotion of caregiver support groups, based on the belief, substantiated by research, that they can be of significant and continuing benefit to caregivers.

Remember that you are not alone and that help and advice are available from other caregivers, from support group leaders, and from agency personnel. Still, finding your way through the maze of government agencies and community services can be a complex and often frustrating experience. Following are some suggestions to make your quest easier.

- Take time to formulate your questions before making a call. Write them down.
- Be well organized, brief and to the point.
- Record the date of the call.
- Record the name of the person(s) with whom you speak.
- Record the responses to your questions.
- Be prepared to repeat your questions a number of times. You may have to talk to several people in the same agency.
- Do not be put off easily!
- Use each contact as a resource, asking what other services exist which might be of assistance to you.
- If you have not received satisfaction or your questions have not been fully answered, ask to speak to a supervisor.
- Save your notes to help avoid confusion later.
- Persevere. Do not let any obstacles keep you from seeking the help you need!

Minuteman Area Information and Community Resource Guide

II. USING COMMUNITY RESOURCES

In New Hampshire, a number of community services are available to dementia patients and their families. The availability and quality of these services varies from area to area across the state.

On the next page you will find a chart that will help you locate the best sources of help you may need at different stages of your loved one's illness and disability.

Some services have eligibility guidelines based on the patient's age, where he or she lives, and the patient's or caregiver's income. Eligibility requirements can be confusing, so it's a good idea to seek out experienced advisors, including other caregivers.

Don't hesitate to ask the Alzheimer's Association Chapter, social workers at community agencies, or the State Alzheimer's Program for help in "negotiating the system".

Some numbers to call for general information (see also the final page of *Sources of Help*):

Alzheimer's Association:

Vermont and New Hampshire Chapter…1-800-536-8864
National Office…….1-800-272-3900
Eastern Massachusetts Chapter……...1-800-548-2111

Caregiver support groups: Call ServiceLink toll free at 1-866-634-9412 for information about the group nearest you.

Type of help	Recommended Sources of Help (See Supplement I for more information)
Information about Alzheimer's Disease and related disorders	* Alzheimer's Association * support groups * books and videos * State Alzheimer's Program
Diagnosis	* specialized memory loss clinics * neurologists
Legal and financial advice	* Senior Citizen Law Project * support groups * attorneys who specialize in affairs of older people
Help with behavior management of the patients	* nurses, social workers and occupational therapists who specialize in working with dementia patients * State Alzheimer's Program
Information about available services	* Alzheimer's Association * support groups * State Alzheimer's Program *Bureau of Elderly & Adult Services District Offices
In-home help	* home health agencies (VNA's) * private help hired & trained by family * Community Action agencies

Type of help	Recommended Sources of Help
Day programs	* adult day care programs * respite care programs * nursing home day programs
Help with setting up a plan of services	* N.H.B.E.A.S. Alzheimer's Program * North Country Alzheimer's Partnerships * geriatric care managers * social workers
Therapy or counseling for caregiver, family unit	* community mental health centers * pastoral counselors * private practice psychologists, social workers, or psychiatrists
Benefits and entitlements	* Senior Citizen Law Project * Social Security Administration (Medicare and disability insurance) *NH Bureau of Human Services' District Offices (Medicaid) * Veterans' Administration * final page of Sources of Help
Help with nursing home placement	* NH Elderly & Adult Services District Offices * home health agencies * hospital and nursing home social workers
Autopsy planning & memorial gifts	* Alzheimer's Association * N.H.B.E.A.S.

I was worried about my mother eating properly, so I obtained Meals on Wheels for her. She was adamantly against this. On the first few days, we shared the lunches and I commented on how good the food was and how easy it was for her not to have to worry about cooking. After the first few days, she was quite content with getting her mealtime treat.

S.G., Billerica

During his initial visit to a day care program, the husband of one of our support group members told her, “I like it here. Nobody laughs at me here”.

W. N., Revere

Introducing Services to the Patient

Once the decision has been made to bring services into the home or involve your patient in a day program, it is important to think about how to introduce the change.

- Be persistent. Often Alzheimer's patients are resistant to change because it confuses and frightens them. Over time, the patient will become accustomed to a substitute caregiver, day program, or other services.

- Introduce only one service at a time.

- Staff members of the various service agencies are accustomed to dealing with the problem of resistant patients, so don't be afraid to ask them for help.

- Try leaving the patient alone with a familiar relative or friend a few times before introducing her or a companion who is a stranger.

- If the memory-impaired person is upset by having a stranger come into the home, she may be more comfortable with a worker with a familiar ethnic or religious background.

- Day programs can be very appropriate for dementia patients. In the beginning, patients may be resistant to going, but once they attend for a few days, they often look forward to it.

- In-home help:

    - Find out if the home care worker has training or experience in working with dementia patients. This will give you an idea of how much instruction you will have to give.

    - Be present when the worker arrives and be home before the worker is scheduled to leave.

    - Provide a written or verbal description of the daily schedule along with helpful tips to the worker when he or she arrives.

    - If the patient cannot be left alone, be sure that the worker understands this.

As soon as you decide to be a home caregiver of your Alzheimer's patient, try to line up one of two people you can depend on to sit with your patient once or twice a week so that you can get out to shop, visit friends, etc. You will find that you have to get out for some respite time to yourself. You cannot possibly take care of your patient by yourself 24 hours a day, and you should make arrangements for respite care as soon as possible.

K.S., Northampton

Laugh with the patient and at yourself. Keep your sense of humor.

Barbara Burns
Holyoke Alzheimer's Resource Center

As a caregiver, I'd like to say that coping with this slow deteriorating illness is overwhelming. It produces all kinds of stress, anger, sadness, frustration, depression, loneliness, and so much more. Sharing feelings and concerns with others in a support group environment can be helpful. Individual counseling may also be needed. The problems don't disappear, but it helps one to cope, one day at a time. Asking for help is a sign of strength, not weakness.

J.B.

III. CARING FOR THE CAREGIVER

Taking care of a family member who is suffering from dementia can be emotionally and physically exhausting. Overwhelmed with the stress of caring for the patient, caregivers can forget their own physical and emotional health. It is important for caregivers to pay attention to their own needs, or they risk becoming exhausted or ill.

- Attend an Alzheimer's Disease caregiver support group. Call 1-800-351-1888 extension 5554 for a list of groups in your area. There are many different kinds of support groups. Some are small and intimate; others are more formal, with speakers and presentations. Try different groups until you find one that meets your needs.

- Keep your appointments with your physician, dentist, counselor, etc.

- Taking care of someone with a chronic illness involves physical and emotional effort over a long period of time. Remember that caregiving is stressful and that it will take its toll on you if you don't care for yourself.

- Try to maintain your outside interests and activities.

- Exercise!

  - Ask a friend, neighbor, or family member to stay with the patient while you go for a walk.

  - Try to maintain your pre-caregiving exercise routine.

  - An exercise bike can provide you with a physical outlet. Try to encourage your patient to ride it as well; this may reduce pacing or wandering.

- Rest when the patient rests, or do something special for yourself.

- Get out of the house for a period of time each day.

- Have someone sleep over occasionally who is willing to take care of the patient so that you can get an uninterrupted night's sleep.

- Try to keep realistic expectations for yourself, the patient, and others.

- Try to avoid feeling guilty. Remember that you have nothing to do with your loved one's rate of deterioration.

There are times we all need to ask for help, but are afraid. When Mother was diagnosed as a dementia patient, I had a very difficult time emotionally, dealing with guilt, setting priorities, understanding the disease, dividing my time between my family and my mother. My doctor suggested I talk with a geriatric counseling service. I was skeptical, but agreed. The whole family, including Mother, benefited from one-on-one and family sessions with an experienced professional.

S.S., Lexington

Try to avoid any guilt feeling. You did not bring on this catastrophic nightmare. Watch your stress level. Try not to let stress control you.

T.S., Clinton

- Don't isolate yourself. Keep in touch with friends. You may have to call them. People may hesitate to call, not wanting to intrude or interrupt at a bad time.

- Ask for help. Often friends and relatives need some direction from you on how they can help with your patient's care, with household chores, or errands. Try not to rely on only one source of support.

- Don't feel that you have to do everything yourself. Being the best caregiver is not important; what is important is that your patient gets the best care.

- Make use of available community resources to help you provide the best care for the patient. *(see "Using Community Resources.")*

- Arrange to receive "Meals on Wheels" so you won't have to cook, or take the patient with you to a "meal site". Call your local Council on Aging, Area Agency on Aging, or Home Care Corporation for information. *(See Appendix 1.)*

- Look into the full range of benefit programs for which you and the patient may be eligible, such as fuel assistance, senior citizens discounts, and weatherization programs, in addition to health and disability insurance. Call your local Council on Aging, Area Agency on Aging, or Home Care Corporation for information. *(See Appendix 1.)*

- Pace yourself. Do what is most important, then do more if you have the energy. If not, **stop**.

- If you are trying out a new caregiving strategy, do not expect yourself to do it perfectly right away. Set realistic goals (e.g., "I'll try to yell one less time today").

- Know yourself. Know when the stresses are becoming too much to bear and what you need to get your strength and objectivity back.

- Allow yourself to grieve the losses that accompany Alzheimer's Disease.

- Take time occasionally to remind yourself of the value of what you are doing.

- Don't lose your sense of humor. If you can laugh, even alone, do it.

- It is common for family members and caregivers to experience feelings of isolation, anger, helplessness, embarrassment, grief, guilt, jealousy, frustration, fear, resentment, and panic. A support group is a place where you can share your concerns and express your grief with others who are experiencing the same feelings.

- Counseling for family members, including spouses, children, grandchildren, and in particular, the primary caregiver, can help make it easier to cope with the effects of dementia.

    - If your counselor, therapist, or pastoral counselor is not "tuned in" to caregiving issues, share this ***Guide*** with him or her.

My wife and I live alone. A telephone number I can call to bring a friend (or two) to guide me over a hump is a great help. Even if not used, having the number brings peace of mind. The need might likely be no more than doing errands like going to the drug store, to the market, to the bank or post office, or to the doctor. Nothing compares to human compassion.

M.S., Concord

When my husband saw our first brand-new grandchild for the first time, it gave him happiness, a real boost of morale, and a reconnection to his past and to his family.

E.H., Cotuit

A member of our support group told us that his wife's long-time friend could not believe his wife was really as confused and incompetent as he reported over the phone. The friend insisted that he bring his wife for a visit to her home while he went off for some time by himself. When he returned to pick up his wife, the friend was no longer a disbeliever.

E.H., Cotuit

My mother became a very solitary person. She had no more friends of her own. To see that she got some type of social stimulation, we would include her in activities with our own friends and with relatives, such as eating out, cookouts, and attending plays. My friends were aware of my Mom's disease and would be kind and understanding. She would enjoy the outings and it provided her some limited socializing.

S.G., Billerica

Helping Friends and Relatives Understand Alzheimer's Disease and Related Disorders

Friends and relatives can be excellent source of support if they understand what is involved in caring for a dementia patient.

- Tell friends and family about the patient's condition. Explain that a dementia patient may act in ways that are disturbing or annoying. Although outwardly the person may look fine, she has a brain disease. It is not contagious and she is not crazy.

- You and each family member should have a clear understanding of the disease and how caring for a person affects you and other family members.

- Recommend that friends and relatives read about Alzheimer's Disease and other dementing illnesses *(see "Selected References")*. Invite them to accompany you to a support meeting.

- Remind friends and relatives that the person is an adult. She may sometimes exhibit childlike behavior but still has feelings and needs. Dementia patients, like all human beings, need to be related to in a way that helps maintain their dignity and self-esteem.

- Some friends and relatives will handle visits with the patient better than others. For those who have difficulty, suggest other ways for them to assist you.

    - Suggest a specific task for them to do, such as grocery shopping or other errands.

    - Recommend that friends and relatives become involved in local, state or national advocacy efforts.

- Encourage children to visit. Remember that children will relate to who the person is **now**. They can often communicate well with someone who has a limited ability to express herself verbally.

- Prepare the visitor for problems with communication. Teach friends and relatives what you have learned about ways to communicate with the patient.

- Suggest that people visit one at a time to avoid overstimulating and confusing the patient. Suggest that visitors stay for only a short time.

Neighbors can be very supportive if they are aware of your problems. You might want to write them a general letter, explaining what is going on and what to expect of your patient. Here is a sample letter.

Dear Neighbor:

My wife/husband/mother/father has just been diagnosed as having Alzheimer's Disease. This is a progressive, irreversible brain disorder, which slowly destroys brain functions. As yet, there is no treatment or cure. We hope that _____ will be able to live at home for a few more years. As he/she becomes increasingly confused and forgetful, we hope we can count on your understanding and patience.

Familiar surroundings, activities, and people will help to stretch his/her capabilities. Your greeting, wave, handshake, or kindly smile will help. He/she needs your acceptance. As old inhibitions fade, he/she may act inappropriately. Please try to remember it is the disease and not your old friend who may be forgetful, rude, or inconsiderate.

If situations arise that you don't know how to handle, give me a call and we'll work out a solution. Together, we can hold back the darkness a little longer. Our family thanks you warmly for your cooperation and understanding.

Very Sincerely,

_____

- Plan activities for the visit such as having a snack, going for a walk, doing a simple project together, or looking at a photo album.

- Keep lines of communication open. Talk over problems as they arise to avoid misunderstandings.

- Accept the fact that some friends may drift away.

- Family stresses have a way of surfacing during this time. For example, adult children may disagree about what is the best approach with the Alzheimer's patient; a parent may worry everyone by refusing help with his spouse; one person may refuse to get involved at all.

    - Try setting up a family conference to air problems, divide tasks, and make decisions together.

Placement in a nursing home may be required in the later stages. Start looking into nursing homes well in advance of when it may be required. A year ahead is not too soon.

T.S., Clinton

IV. PLANNING AHEAD

As dementia progresses, the patient's ability to deal with financial and legal matters will be affected. At some point, a family member or other concerned individual will need to assume responsibility for decision-making.

- Plan ahead by learning about durable power of attorney, conservatorship, guardianship, and other legal options. Consult a legal advisor who is experienced in the legal and financial affairs of older people.

- Get a valid signature on legal documents while the person is still able and competent to sign.

- Locate insurance policies, wills, bank books, automobile titles, tax records, safe deposit box keys, etc.

- Learn about benefit programs (e.g., Social Security Disability, SSI Medicaid, etc.) for which you or your loved one may be eligible. *(See "Using Community Resources" and Appendix 1.)*

- Medicare and most private health insurance programs do **not** pay for services provided in the home or in a nursing home.

    - Planning ahead may save the family's resources from being exhausted. Consult a knowledgeable attorney or financial advisor for help.

    - Only Medicaid and a few private insurance policies pay for nursing home care.

    - Medicaid regulations are complex and change often. Seek knowledgeable help and advice from BEAS and District Offices, ServiceLink, a support group, or a lawyer or financial advisor who is familiar with Medicaid regulations.

- Support group members and other families who have faced issues such as estate planning and guardianship are excellent sources of information. Do not hesitate to ask other caregivers about their experiences.

Recently when we were having lunch in a restaurant, a song from the 1930's came over the piped-in music. My Dad began to sing along with it word for word. I sat there amazed. That gave me an idea, and I sent away for four tapes of hit songs from the 1930's and 1940's. He played them and sang along with them word for word. He cried; I cried. It was as if we were in a time machine.

National ADRDA *Newletter*

My husband seems to sense the anger in my voice. I have a hard time coping with him and by the end of the day, I'm at the end of my rope. At this point he usually senses my anger and says, "I love you. I'll go to bed now".

Holyoke Support Group

One caregiver would always bring his wife to support group meetings. During the meetings she would sit quietly and was never disruptive. One day she sat up very straight and asked, "May I say something?" The group was shocked because she had never uttered a word before. "Of course," the leader said. "I love my husband, but I cannot help it," she replied.

Natick Support Group

V. COMMUNICATION

Alzheimer's Disease affects the patient's ability to communicate. Problems with completing sentences, understanding others' words, repeating questions, and rambling make communication difficult. Much can be done to take advantage of the abilities that remain. It is important to maintain communication with your memory-impaired patient--with words, gestures, eye contact, or other means--and help her communicate with you.

- Remember that speech and language difficulties vary from patient to patient and may vary from day to day or even moment to moment.
- As the patient's ability to use speech deteriorates, it may be difficult for the caregiver to adjust. Sometimes it is hard to accept the patient's limitations, especially when she continues to look like the same person she once was.
- Smile, nod, touch, make eye contact. Feelings conveyed by your tone of voice or body language are as important as the words you use.
- It is helpful to just listen. Your interest conveys respect and concern.
- Using everyday courtesies such as "please" and "thank you" helps to maintain a warm, friendly atmosphere. Alzheimer's patients tend to adopt the moods of the people around them.
- Reducing distractions in the environment--such as radio and TV--may make communication easier.
- Use simple familiar words and avoid complex sentences. Speak slowly and distinctly without using a childish vocabulary or tone of voice.
- Try to speak in a lower pitched voice; it is easier to hear and understand than a higher pitched voice.
- Give one direction or ask one question at a time.
- Demonstrate what you mean by using pantomime or gestures.
- Allow ample time for the individual to respond or act.
- Provide reassurance and praise.

A welcome smile for no reason, a friendly touch on the shoulder or pat on the hand--these things take so little time and yet they mean so much. Maybe you and your patient can no longer discuss what's happening in the world news or even the plot of a TV situation comedy. But you can sit side by side or in the park, holding hands. You can pat his or her head as they fall asleep. It is wordless but it is communication. And it shows how very much you still care.

ADRDA of St. Louis

I have learned, and this lesson was easy, that there cannot be too many hugs and kisses. I say, "I love you" often. In addition to being true, it gives assurance and reduces fright. When we finish dressing in the mornings, it is easy for me to say, "Look in the mirror and see how beautiful you are". When we take walks, we hold hands. That way, neither one gets lost. And that's something in life, that you don't get lost.

M.S., Concord

One man whose wife has Alzheimer's found a little peace at last when he tried the afternoon "soaps" on TV. His wife is now devoted to them and watches then every afternoon. When another member of the support group offered to sit with the woman while the husband took a few hours off, the offer was accepted. The two got along fine in the morning, but when called for lunch, the woman's face puckered and tears seemed to come to her eyes. Her companion was puzzled until she learned that she had prepared lunch at exactly the time that the woman's favorite "soap" came on.

Falmouth Support Group

- Use humor, but do not laugh at inappropriate speech.
- Avoid slang or idioms that can give false cues or cause confusion if taken literally, such as, “Take a hike” or “You’re pulling my leg”.
- Ask questions that require only one choice at a time. Say, “Do you want coffee?” instead of, “Do you want coffee or tea”?.
- Positive statements convey a point more effectively than negative statements. Say, “Let’s go this way”, rather than “Don’t go that way”.
- Be sensitive to the fact that dementia patients still hear and may understand what is being said about them.
    - Do not talk to others about the patient as if she weren’t there.
- Remember that the dementia patient may be able to understand more than she is able to express and become frustrated with her inability to make herself understood.
- If the patient has difficulty finding words:
    - Try to be patient and noncritical.
    - Suggest a word, or provide a visual cue.
    - Ask the person to write it down if she can.
    - Ask a question that helps the person find a different way of communicating the same information. For example, if the patient is having trouble describing something, try asking, “Would you show me where it is?”
- If the memory-impaired person asks the same question over and over, remember that she probably cannot remember the answer. Repeat your answer once or twice and then reassure her that everything is fine, that you are there and she is not alone. Then try to change the subject.
- If the person makes up stories, don’t argue or disagree. It may be helpful to change the subject or respond to the part of the story that is accurate.
- Even if the individual mumbles or rambles, try to listen without comment. Do not discourage communication by criticizing her speech.
- If the person is upset or uncooperative, discontinue the activity or conversation. Try to distract her with another activity or thought, and, if necessary, try again, later.

No matter how out of character the person's statements are, don't disagree with them. Instead, pay close attention to what is being said and respond to the underlying meaning. For example if the person asks, "When is mother coming?" instead of answering. "Your mother died 20 years ago," say, "Your mother must have been a wonderful person, I'm sure you think of her often." He or she then may respond to your statement and begin telling you about his/her mother.

Barbara Burns
Holyoke Alzheimer's Resource Center

Look into the patient's eyes when discussing or suggesting something. Hold his or her hand or forearm, lightly. My wife seemed to be more co-operative when I did this; you could almost feel the tension leave her body.

T.S., Clinton

- If the patient frequently complains or makes insulting remarks:
  - Do not take such comments personally, attempt to contradict her, or attempt to reason with her.
  - Do not respond directly to insult; insults may stop if they don't arouse attention.
  - Respond sympathetically to the underlying feeling being expressed, e.g. "I'm sorry that you're upset".
- Maintaining a harmonious atmosphere can often be more important than communicating specific information. For example, the patient does not necessarily have to understand **why** she needs to take a bath or change her clothes, as long as she does so.

As we become aware that something was very wrong with mother, she too was aware of her memory loss. At times she became extremely upset and said things like: "My brain is dead". "Why can't people who are half-dead die?" "I must be losing my mind." This emotional pain was hard to ease. I hesitated to tell her she had Alzheimer's Disease, but felt that she needed some kind of explanation. I finally decided to use the doctor's term "SDAT" (Senile Dementia – Alzheimer's Type). I told her she had a disease called SDAT, that it was a disease just like measles or chicken pox were diseases and that it affected the memory and made you forget things. This seemed to satisfy her until she forgot and I would tell her again. Putting a name to what was a horror for her helped ease the emotional pain.

Concord Support Group

If a person repeatedly asks the same question, and if he or she can still read, write the answer down and read it out loud, e.g., "We will have lunch at 12 o'clock". This gives the person something tangible to hold on to and look at.

Barbara Burns
Holyoke Alzheimer's Resource Center

An example of total memory loss:
"Would you like chocolate pudding?"
"What is that like?'"

E.M., Carlisle

VI. PROBLEM AREAS

Memory Loss

Loss of memory has major implications for care providers. Patients may be unable to remember where they are or who the people around them are. Recent memory is first to be affected. For example, the patient may not recall what happened a few moments ago but may clearly remember childhood events. Learning something new becomes very difficult and, eventually, impossible.

- The individual's ability to remember will vary from day to day and will gradually decrease over time. Your expectations may need to change from day to day as well.

- A consistent daily routine helps minimize stress for the memory-impaired person.

- Keep regularly-used items in their usual place so that they can be easily located.

- Provide verbal cues:

  - Name the day's events; repeat as necessary.
  - Recognition is easier that recall, "Here is your granddaughter Mary," is more helpful that "Do you remember who this is?"

- As long as the patient continues to understand written words, signs and labels can be useful reminders of what things are and how they are used.

  - Label household items and rooms with words or pictures.
  - Use simple signs with large clear print to prompt memory, such as "Turn off the stove".
  - Prominently display a large easy-to-read clock. Digital Clocks may be easier to read than conventional ones.
  - Display a bulletin board or blackboard with the day, date, and season printed clearly.

Alzheimer's victims invariably deny or attempt to conceal lost abilities, but often are aware and afraid there's something wrong with their minds.

Caregivers must learn not to be shocked or surprised by anything the patient says or does. The most bizarre behavior is often an attempt to communicate what his or her brain cannot relate any other way. The key to understanding the patient's behavior is to know the patient.

T.S., Clinton

My father used to always watch the evening news. After a while, I noticed that during the news he was getting very restless and uptight, so I changed the channel to cartoons. He settled down right away and really enjoyed it. Maybe he was upset because he couldn't understand the news.

Athol Support Group

- Provide your patient with a wristwatch if he is able to read one.
- Use a calendar with large print. Cross off each day.
- Display pictures of family and friends with names under the pictures.

- When is it obvious that the patient's short-term memory loss is causing dismay, do not insist on orienting him to the present. Enjoy sharing old memories

I find a snack sometimes calms my husband down when he is getting restless and difficult in the early evening

E.H., Falmouth Support Group

We have experimented with various methods to reduce my aunt's level of agitation. One method that has had some success in quieting her at or near sundown (the most difficult time of day for her) is to play an audio tape of the entire rosary being recited in a slow monotone. Within a few minutes, the rhythm, the monotone voices, and perhaps the now dim association with the feelings surrounding the rosary, calm her and keep her in touch with her religious traditions.

P.R., Arlington

Late Afternoon Confusion

("Sundowning" or "Sundown Syndrome")

For unknown reasons, an increase in confusion in the late afternoon or early evening, sometimes coupled with restlessness, is a common symptom of Alzheimer's Disease.

- Encourage a nap or quiet time with soft music after lunch if it does not interfere with sleeping at night.
- An early dinner or late afternoon snack may help.
- Good lighting will sometimes assist in reducing confusion.
- Decrease your expectations of the person during this time of the day.
- It may be helpful to orient the patient. Tell her the time, where she is, and what is going on.
- Reassure the patient that you are with her, and perhaps involve her in a simple task near you
- Schedule daily routines that require cooperation, such as baths and medication, at another time of the day.

My wife was forever rummaging through her purse looking for her keys, so I bought her one of those clear plastic change purses and put her keys in it.

Fall River Support Group

Accusations only antagonize the patient, who does not realize he or she has taken something.

T.S., Clinton

My mother has never been wrong. When she could not find her watch, beads, etc. she would always say that they had been stolen. Once in a while they would be "returned" by the thief!

A psychiatrist explained to me that the constant preoccupation with the loss of one's jewels was a displaced concern for the loss of one's mind.

E.M., Carlisle

Like many others with Alzheimer's, Mom would hide things. Coffee and her pocketbook were her specialties. She was really quite ingenious in her hiding places. I would discreetly note where her hiding places were, but left the things hidden. When she called me to report that she was all out of coffee, or worst horror, that her pocketbook was missing, I would ask her if she had looked in this or that place and named some of her favorite spots. Most of the time she was able to locate what she needed.

Concord Support Group

Losing and Hiding Things

A memory-impaired person may not remember where to find an item, where he placed it last, or even that he had it.

- Drawers and cabinets with everyday articles can be labeled with large printed signs.

- Limit the number of hiding places by locking rooms, closets, and drawers that are not regularly used.

- If necessary, important or valuable items can be kept out of sight or locked up.

- Keep track of keys, eyeglasses, hearing aids and batteries, dentures, medications, and other essential items. Keep spares whenever practical.

- Learn the person's hiding places. Try to recall old favorite hiding places for gifts, etc.

- Check trash baskets before you empty them.

- If the memory-impaired person insists on searching for missing items, his anxiety may have more to do with a general sense that "something is missing" or lacking (his memory) than with a need to find a specific item. Reassurance or distraction may help.

On days when I would have to take my husband out, I used to tell him of our plans the first thing in the morning. Upon telling him he would get very anxious and follow me around the house saying. “We are going to be late,” over and over again. Now I no longer tell him of our plans until it is time to leave. I just say, “Let’s go”. He puts on his coat and we leave.

Fall River Support Group

Although my wife is unable to walk, speak, or feed herself, a stuffed bear seems to have made a difference in her life now. This new and constant companion is soft and cuddly and responds with grunts to voices or other sounds. My wife holds her soft new friend with one or both arms most of the time and sometimes strokes his “fur”. Judging from her facial expressions and her grasp of the bear, my wife seems to be more relaxed and contented now that she has this companion.

G.R., ADRDA of the Greater San Francisco Bay Area

A pet can provide Alzheimer’s patients with interaction without the fear of rejection. Dogs and cats need attention and affection and provide the same in return to their owners. For Alzheimer’s patients, this relationship with a pet can help ease isolation.

ADRDA of Orange County, California

Clinging

Following the caregiver from room to room may give the patient a needed sense of security, but can be difficult for family members to live with. Clinging may result from the anxiety caused by a scary or overwhelming situation or from simply not knowing what else to do.

- Reducing confusion, noise, and clutter in the household environment may lessen the need to stay with a caregiver.
- If clinging seems to be helped by physical contact, try substituting a pet, doll, or a stuffed animal.
- Provide a diverting activity while you are busy with something else.
- If constant attention is needed, regular “breaks” should be scheduled for the caregiver.

My friend's husband has Alzheimer's Disease and is in a Veterans hospital. One day another patient got dressed up and went walking up and down the hall nonstop. He stopped walking after a while and came over to sit down, undoing his coat. Then he leaned over and in a loud voice told my husband that he had just come back from a walk around the world and was tired! After about half an hour he put his coat back on and said, "Oh, dear. I now have to walk to Spain".

Mid-Cape Support Group

Pacing

For some people, pacing seems to be triggered by certain circumstances such as a noisy or confusing environment. For others, it becomes part of their everyday behavior and is related to changes in the brain.

- Always try to discover and, when possible, remove the reason for pacing. Reasons may include:

  response to changes in the environment
  bordom
  emotional reactions such as anger, anxiety, frustration, fear or confusion
  need for exercise
  constipation
  pain or discomfort
  too much sleep
  hunger or thirst
  need to use the bathroom.

- If pacing is related to changes in the brain and is thus unavoidable:
  - Make sure the patient has supportive, non-slip type shoes.
  - Set up a secure area in which he can pace without danger of tripping or getting lost.
  - Watch the feet and legs for swelling, blisters, bruises, and redness. Be sure to provide treatment for any problems that arise.
  - See that he is dressed in loose comfortable clothing.
  - Try to provide frequent rest periods.
  - Offer frequent snacks and fluids; as in forms of exercise, calories are burned during pacing.

An ID tag, if rejected on wrist or neck, may be worn on the ankle or attached to the handle of an omnipresent purse.

E.M., Carlisle

Wandering

Wandering can be dangerous. Wanderers may not realize when they are lost. They may wander into dangerous areas. They can become traffic or crime victims, and they are at risk of exposure and exhaustion.

- The memory--impaired person should carry some form of identification--such as a necklace, bracelet, or wallet card--containing the following information:

  - Name
  - Address
  - Phone number
  - An indication that the person is "memory impaired"
  - Pertinent medical information.

- Alert your neighbors; keep on hand a list of neighbors' phone numbers.

- Keep a recent clear photo on hand.

- Give the name and description of your patient with a recent photograph to local police and fire departments.

- **SAFE RETURN:** This nationwide identification registration program provides assistance in the safe return of individuals with Alzheimer's disease who wander or become lost. Safe Return provides assistance whether a person becomes lost locally or far from home. Call the Alzheimer's Association of Vermont and New Hampshire @ (603) 226-5868 or 1-800-750-3848 for more information on this program.

- Give the wandering patient a card with instructions on what to do if lost.

- If a person will not go out without a hat or pocketbook, hiding these items may prevent her from going out.

- To prevent the patient from leaving the house:

  - Use "child safe" doorknob covers that fit loosely over the knob so that only the cover turns, not the knob itself.

I remember when I awakened in the middle of the night on one occasion to find my husband opening the front door and on the point of going out. He had put on a pair of winter pajamas over his cotton ones, his baseball cap on his head, a pair of heavy gloves on his hands, and was wearing a pair of unlaced work boots on his bare feet. "Where do you plan on going at this time of night (2 AM)?" I asked. "Well, I have to put Joe Morrissey on the *Twentieth Century* for Albany," my husband said. "He will be starting his new job tomorrow and doesn't want to be late." "Oh dear," I said, "doesn't Joe know the *Twentieth Century* doesn't stop here any more?" He looked at me and said, "No, nobody told us," turned around just as he was and went back to bed all dressed up with nowhere to go.

D. O., Sandwich

- A simple change in the door latch may be enough to keep a wanderer in if she cannot work the new latch.
- Alarms that go off when you touch a doorknob can be bought from RV (recreational vehicle) dealers.
- Place bells on exit doors, so you will be alerted if the patient attempts to leave the house.
- Camouflage the exit door with a curtain or screen.
- Put a stop sign on the inside of the front and back doors.

- Evaluate the wandering. Where does she go? Does she take a consistent route? Can the route be incorporated into periodic walks?
- Providing daily exercise for the patient may help to control wandering that is caused by pent-up energy.
- To discourage nighttime wandering:
  - Set up a regular bedtime routine.
  - Experiment. Some people are soothed by having a night-light, while for others it is better to keep the room dark.
  - Use bed rails unless the patient climbs over them.

At one point a great change occurred in my mother's normally cheerful personality. Sadness, tears, withdrawal were a concern and depression was suspected. Her therapist confirmed our suspicions. With medication and therapy, mother recovered from her depression. Being able to express her feelings and her fears to a neutral person helped her through this stress, and helped us all to learn to cry together, laugh together, talk together, and face depression in a positive way.

S.B., Lexington

Give Your Alzheimer's Patient a "Job"

Occupying the Alzheimer's patient is one of the prime problems. My father could build anything--we called him "golden hands" for he would build the tools that he needed to do a job. Now he cannot plug a lamp cord into a socket. And, as everyone has experienced, he takes up every waking moment of my mother's time. I don't know where the idea came from, but trying to think of something that he could do with his hands, I got the idea of counting coins. I got $50 in pennies, nickels, and dimes and the wrappers for each. I told him that it was for my business, and my dad will sit for hours, sometimes late at night, counting and wrapping the money. The dimes are in penny wrappers, and nothing adds up to the correct amount that should be in the wrapper, but he counts and counts, and wraps and counts. When he is all done, I undo it and bring to him the same stack of coins and he starts all over again. My mother says that it has been a Godsend. I also give him about 15 packs of playing cards, and he spends most of this time "sorting" these--albeit into very weird combinations. But the important point is that this is his "job" and he gets tremendous satisfaction out of feeling like he is doing something useful for my business and my mother gets hours of peace.

ADRDA of New Orleans

Depression

Many Alzheimer's patients, especially in early stages, are understandably depressed and will respond well to reassurance and support. The depression that accompanies chronic illness is often treatable even if the illness is not.

- Loss of independence and feeling of failure can lead to depression or withdrawal. Reassurance will help.

- Some of the common signs of depression are:

  withdrawal
  reduced concentration
  hopelessness
  restlessness
  loss of appetite
  early rising
  poor sleeping or over-sleeping during the day

- Encourage exercise.
- Alcohol, a chemical depressant, should be avoided.
- Avoid giving false hope or patronizing "pep talks".
- Encourage the patient to talk about or otherwise express his feelings.
- Notice whether certain activities or people trigger moments of depression or an improvement in the patient's mood.

- Do not force the Alzheimer's patient to interact with others, but encourage him to be as socially active as is possible for him. Encourage participation in simple activities that provided enjoyment in the past or in a non-demanding task or "job".

- Counseling should be offered and encouraged. Memory and judgment problems do not prevent a person from benefiting from therapy if the therapist is skilled in working with memory-impaired people.

- Do not ignore references to suicide. Consult a mental health professional for advice on how to handle reference to or threats of suicide.

Having no interest in TV, newspapers, etc., my husband just wants to “go”. He loves to ride in the car. He’s very angry when I just sit and read. When I do, he always says. “What are we going to do now?” So we get in the car and go--anywhere, usually a one-stop shopping.

C.W., Falmouth Support Group

One caregiver accidentally tuned into a radio station that played light, smooth, non-classical (but not rock) popular music. Her husband, who had been particularly restless and miserable, calmed right down and was much happier.

Falmouth Support Group

A psychiatrist told me that the angry lashing out of a patient is displaced anger at the disease.

E.M., Carlisle

A sense of humor, music, and touching are all excellent tranquilizers.

When I am tired and getting impatient about all the demands my wife puts on me, I try to treat her as if it were our last day together.

T.S., Clinton

Hostile and Demanding Behavior

Anger displayed toward you is often not meant for you. It can reflect a misunderstanding of a situation or simply the patient's justifiable frustration with her disabilities.

- Irritability and belligerence can be signs of physical pain that the person is unable to express or describe. Ask her directly if she is in pain.

- Keep in mind that inappropriate or annoying behavior is usually not intentional. Often the patient simply doesn't remember what is expected of her.

- Try not to let your anger show. Remember that the memory-impaired person's anger can result from her frustration at her limitations or from misunderstanding a situation.

- A belligerent attitude may be a patient's defense against negative feelings about herself. A warm, accepting positive approach on your part and simple courtesies such as "please" and "thank you" indicate that you accept her as she is.

- Different approaches may work at different times:

    - Sometimes ignoring demands is the best approach.

    - If you simplify a task, the patient may be able to do it instead of demanding that you do it.

    - Saying "no" calmly and firmly, then redirecting the person's attention, may defuse a tense situation.

- If the patient becomes violent:
    - Call for assistance if necessary. Protect yourself and the patient.
    - Isolate the patient if she is in danger of harming herself or others.
    - Remove anything that might be used as a weapon.
    - Keep emergency telephone numbers easily accessible.

- If you are in danger, protect yourself until help arrives.

- A doll or stuffed animal may be effective in calming or soothing the dementia patient.

- Pets seem to have a calming and soothing effect on people with dementia. If keeping a dog or cat is not feasible, try animals that don't require as much care, such as birds or goldfish.

Try not to overload the victim's brain system with compound sentences, complex directions, or shouting. This may cause a blow-out of those "faulty wires" in the brain. The victim will be overwhelmed! Confusion will increase and he or she will become either more agitated or forget what he or she has been told.

T.S. Clinton

Distraction is the best way to diffuse the violent behavior of the Alzheimer's person. You cannot reason with him as you would a rational person. One wife said her husband held a hammer above her head and said, "I'm going to kill you!"…and she responded by saying, "Why don't we have lunch first?" and he said "Okay", and put the hammer down. One support group member said her husband wanted to sleep in his shoes and, being tired, she said, "Nobody sleeps in shoes, so take them off!"… and he came at her to hit her with one of the shoes. She hid her face and did not "feed" the reaction, and the outburst died instantly. However, if the catastrophic reaction is "fed" either verbally or physically, there could be danger to those involved.

ADRDA of Orange County, California

Catastrophic Reactions

A situation that overwhelms the dementia patient can lead to a reaction that is out of proportion to the situation. New places, loud noises, new people and large groups, or uncertainty about a task, may lead to an excessive emotional reaction such as weeping, shouting, or striking out.

- Try to avoid stressful situations that may trigger catastrophic reactions.
    - If a task is becoming too difficult, simplify it or redirect the person to another activity.
    - Do not force participation in an activity if the patient is resisting.
    - Do not ask an upset individual to make decisions.
- Identify and, if possible, avoid situations that have led to catastrophic reaction in the past.
- When a catastrophic reaction occurs, stay calm. Do not overreact; your nervousness or anxiety can heighten the tension in an already tense situation.
- Try to avoid sudden moves to avoid frightening the Alzheimer's patient.
- Reduce confusion around him.
- Remove him from the distressing situation if possible.
- Cautiously distract his attention with an activity that he can easily do and enjoys.
- Even very angry people can respond to reassurance. A calm statement like, "I know that you are upset and I want to help you", may defuse the situation. Hold and touch when appropriate.
- Restrain only if absolutely necessary.
- Forgetfulness can be a benefit in these situations because the memory-impaired individual may quickly forget the episode.

My mother spent several days pouring through the phone book, looking for the name of the “man with the gun” who stole her jewels.

E.M., Carlisle

The delusions and suspiciousness of Alzheimer’s victims can easily be trying! You may feel hurt, embarrassed and bewildered by the patient’s unjust accusations. They are related distortions of a failing brain and the frightening world the victim is in.

When my wife would tell me that she wanted to go home (while we were in our own home), I would take her for a short walk around the block. When we returned to our front or back door, she was back home.

T.S., Clinton

After many disturbed nights when my husband would wander, I was awakened early one morning by him shaking my shoulder and telling me I had to wake up. “What’s the matter?” I asked. “Well, my wife will be coming home very soon, and she had better not find you here,” he said. “But I am your wife,” I said. “Oh, no you are not,” he replied. “You only think you are!”

Mid-Cape Support Group

Hallucinations and Delusions

Alzheimer's Disease sometimes causes a person to see or hear things that are not there (hallucinations) or believe things that are not true (delusions).

- Have the individual's hearing and eyesight checked. Be sure she wears her glasses or hearing aid, if needed.

- Check the environment for adequate lighting and for noises that can be misinterpreted.

- Whispering or laughing in front of the Alzheimer's patient may be misinterpreted.

- If a person appears to be hallucinating, leave her alone or approach her slowly to avoid scaring her.

- If a delusion/hallucination does not seem to frighten or bother her, ignoring it may be the best approach.

- Avoid arguing or trying to explain that what she is thinking, seeing, or hearing is not real. Reassure her but do not argue with her. Remember that hallucinations look or sound very real to the person who is experiencing them.

- Try to interpret what the delusion/hallucination may mean for the individual, or respond to the emotion being expressed. For example, say, "It sounds as if you are frightened.

- False accusations, such as accusing a spouse of infidelity, may not be true delusions. In some cases, the patient's accusations may be her way of looking for reassurance, for example, that her husband won't leave her for someone else.

- Do not assume that hallucinations or delusions are an inevitable consequence of Alzheimer's Disease. A physician must make this decision. Medications and other illnesses can cause hallucinations or delusions.

Sexuality

Inappropriate sexually-oriented behavior can be embarrassing and difficult to manage. In addition, the problem may be hard to discuss with friends and family.

- Indiscreet fondling of himself, touching others, and suggestive fidgeting should be discouraged gently and discreetly. Try redirecting the person's attention.
- If a patient exposes himself, he may need to use the bathroom.
- Have a plan for various toileting situations while traveling or attending social activities outside the home.
- Loosely fitting clothing with elastic waistbands are more comfortable and less likely to encourage fidgeting.
- If the patient tries to disrobe, it may mean that he is tired and wants to go to bed.
- Sexual desire may increase or decrease after the onset of Alzheimer's disease. At some point, a spouse or partner will need to adjust her expectations in a sexual relationship with an Alzheimer's patient.

Telephone

A memory-impaired person will have difficulty making and receiving phone calls. She may become upset or irritated at calls. She may not understand the message or remember who the caller is. She may make phone calls and not remember who she is calling.

- Use a telephone answering machine.
  - Leaving the machine on when you are home will give you the option of not answering the telephone when you are busy.
- Changing the locations of telephones might make it difficult for the memory-impaired person to find and use them.
- Cordless portable phones can be placed out reach.
- A switch can be installed that turns the telephone bell off while you are away.
- Telephone locks, available at office supply stores, can be installed to prevent outgoing calls while allowing incoming calls.

If a patient feels slighted in not being asked to sign a document, **find** a place for him or her to sign – in addition to an official signature.

E.M., Carlisle

My husband wanted to have his wallet with him all the time, even in his pajama pocket. I took everything of value out of it except his expired license and a dollar or two. The license was a form of I.D. should he have wandered.

R.H., Cape Cod

Money

People with Alzheimer's Disease and other dementias generally lose their ability to handle money or a checkbook before they lose the feeling that they need money.

- Remove all credit cards from the patient's wallet or purse so that they will not be lost or misused.

- Fill the patient's wallet with photographs, a small amount of money, identification cards, and other items. This will allow the memory-impaired person to feel as though he still has his "valuables".

- If the Alzheimer's patient wants to pay the cashier in a store, hand him the correct change.

- To avoid arguments, consider arrangements that reduce the patient's direct involvement in handling checks or money.

    - Look into joint bank accounts, conservatorship, durable power of attorney, and other legal options.

    - Arrange for "direct depositing" of government benefit checks.

- See page 28 for suggestions on how to begin planning for the long-term financial needs of the patient and family.

Time to stop driving!
"What are those yellow streaks in the road? We never had those where we used to live."

E.M., Carlisle

My husband still wishes to drive a car and insists that he will go to the Registry to renew his license. He went a few months ago and was told that he did not pass the eye test. Unfortunately, he still insists that he can pass the eye test and driver's test, too. Usually I have diverted him by saying, "The Registry is not open today", and changing the subject.

L.S., Brewster

Patients may quietly, and sadly, stop driving, but for some – especially men, for whom driving is part of their self-image and independence – this loss is the most difficult of all to accept and can provoke anger.

If the patient ignores the physician's orders not to drive, the caregiver may "lose" the keys, file them down, or replace the keys on the familiar key ring with others – or disable or dispose of the car. Sometimes the difficulty with convincing the patient not to drive is a brief phase and the caregiver may resort to parking the car elsewhere and carrying the keys for a time. If all else fails, the caregiver or physician can write to the **Registry of Motor Vehicles, Medical Affairs Branch, 100 Nashua Street, Boston, MA 02114** and the patient will be required to undergo a competency examination and road test. In **New Hampshire you can write to Director, Department of Safety, 33 Hazen Drive, Concord, NH 03305 or call (603) 271-2484.**

In December, a Springfield patient left home against his wife's wishes for a short drive. He was located 36 hours later, 250 miles away. Don't let this, or worse, happen to you!

Visiting Nurse Association of Springfield

Driving

Alzheimer's Disease affects judgment and response rate; at some point, patients will be unable to drive safely. Caregivers often meet strong resistance when trying to prevent patients from driving.

- Offer to drive.
- Distract the patient by changing the subject or tell her you are not ready to go yet, thus avoiding the issue.
- Suggestions for preventing a person from driving who is not capable of driving safely:
    - Disconnect the battery
    - Lock the car and hide the car keys
    - Leave the car with a neighbor or friend
    - Remove the distributor cap
    - Have a mechanic install a "kill switch" that will prevent the car from starting unless the switch is thrown.
- It is important that all family/household members agree on one way of approaching this issue. Different approaches may work for different individuals. One of the following explanations may work if used consistently by everyone involved:
    - Remove the car and tell her someone borrowed it
    - Tell her the car is not working
    - Tell her that her doctor said she should no longer drive, or ask the doctor to tell her directly
    - Tell her that she is "getting older" and you are worried about her eyesight or reaction time
    - Tell the patient that she has a memory impairment and that it is not safe for her to drive.

Smoking and Drinking

Drinking alcoholic beverages may increase confusion and may be dangerous for patients who are taking medications. Smoking can be especially dangerous for patients who may forget that a cigarette or pipe is lit and may leave it unattended or hide it where it could start a fire.

- Alcohol interacts with certain medications. Consult your pharmacist or physician.

- Consider substituting non-alcoholic beverages such as “near beer” or sparkling grape juice.

- If the patient’s physician or other medical professional is comfortable with moderate drinking and smoking, maintain control by mixing the drink yourself and giving out cigarettes one at a time.

    - Avoid potential hazards by keeping matches, lighters, and cigarettes in your possession.

Going Out Alone

Before allowing the memory-impaired person to venture out alone, consider her safety. Ask yourself if she can reach her destination and return safely. Awareness of her surroundings will decline over time, so her abilities should be constantly reevaluated.

- Make sure the memory-impaired person carries identification.

- Give her a card with her address, telephone number, directions to her house, and instructions on what to do if she gets lost.

- Try sewing bicycle reflectors on your patient's clothing so she can be seen more easily at night.

- Give the police a photograph so that they will recognize the Alzheimer's patient if lost. Many Massachusetts communities have "Alzheimer's Alert" programs that allow a memory-impaired person's description and photograph to be "registered" with local police departments. There is also a nation wide "Safe Return" program for memory-impaired people. The phone number is 1-888-572-8566.

- Observe the patient now and then to evaluate her ability to cross streets and follow other safety rules.

Absence of Caregiver

Patients in the early to middle stages of a dementing illness can sometimes be safely left alone. Appropriate precautions can minimize the anxiety caused by a brief or extended absence of a familiar caregiver.

- If you are away from home:
  - Leave a note in sight indicating where you are going and when you will return.
  - Notify neighbors or police if necessary.
- If a patient has a regular time when he naps or watches television, use this time to do your errands if he can be left alone safely.
- It may be easier to leave the patient in his own home and have someone remain with him if the regular caregiver is absent. It is often difficult for the memory-impaired person to adjust to a new and unfamiliar place.
- Encourage familiar people to visit while you are away.
- Even if you are leaving for only a short period, say good-bye and tell the patient when you will return.
  - Try setting a cooking timer and explaining that you will be back when it goes off.
  - Prominently displaying a large photograph of yourself may help reduce anxiety about your absence.
  - Try recording your voice or other familiar sounds on cassette tapes. When the tape is played, the patient may believe you are still there or be calmed by the sound of your voice.

My husband was obsessed with security. It was so bad that he insisted on sleeping with his shotgun. One day I took his gun to a gunsmith and had the pins removed. This was safer than hiding the bullets.

Fall River Support Group

My wife tries to eat anything that is attractive to her, like flowers, waxed or fresh. Whatever looks pretty she thinks is edible.

We have to be careful of boiling water, stove burners, and matches or anything else that can cause any danger or accidents around the house. While food is cooking, she is very apt to put her fingers in to see that it's cooking right – especially with soup, to see if it's hot enough. I know this can happen, so I'm careful to watch her closely when I'm cooking.

T.S., Clinton

My mother refuses to eat her lunch without a cup of tea to go with it. She cannot operate the stove safely, so the knobs have been removed. I bought her a thermos and I fill it up with tea and leave it next to her sandwiches.

Fall River Support Group

Masking tape can be used to cover the knobs on the stove and keep them out of mind.

F.O., Wellesley

VII HOUSEHOLD SAFETY

Dementia patients are vulnerable to a number of dangers in and around the house. Taking the time to make your home as safe as possible is important to prevent accidents.

- It is essential that the caregiver have knowledge of first aid procedures, cardio-pulmonary resuscitation (CPR), and the Heimlich maneuver (a technique for dislodging food caught in the throat). Literature and courses are usually available from your local library, Red Cross, or hospital.

- Be sure to have fire extinguishers and working smoke detectors in the house, and have them checked regularly.

- Keep a list of emergency numbers by every telephone.

- Maintain an uncluttered home. Limit the number of small items within reach, and put knick-knacks away.

- Remember that a person with Alzheimer's Disease may be prone to falling because of stooped posture, shuffling gait, stiffness, loss of motor coordination, or misjudging distance.

- Keep furniture in its usual place.

- Pad or cover the sharp corners on furniture.

- Keep walkways clear. Avoid scatter rugs and exposed extension cords. Consider removing coffee tables and other small pieces of furniture.

- Don't wax floors to the point that they are slippery. Falls on non-cushioned floors can inflict serious injuries.

- Poisons, medications, and hazardous substances, such as bleach and furniture polish, should be kept out of reach or in a locked cabinet.

- Remove all poisonous plants. Common examples include coleus, philodendron, and poinsettia.

- Remove firearms from the house, or keep them locked up.

- Removing the knobs from the stove, disconnecting appliances, or restricting access to the kitchen when it is not in use can prevent kitchen fires. Try shutting off the circuit or loosening a fuse.
- Avoid use of look-alike objects such as fruit-shaped magnets on the refrigerator.
- Good lighting increases visibility and helps reduce the risk of accidents.
- Use non-locking doors inside the house, or remove existing locks. Be sure that you have keys for doors that are locked.
- Hide a spare key outside the house in case the patient locks you out.
- Give a set of keys to one or more trusted neighbors, friends, or family members for emergencies. Keep on hand an emergency reference list of medications, physicians, daily routines, and phone numbers of back-up people.
- Use safety locks on windows.
- Use a gate to prevent access to stairs.
- Keep attic and basement doors locked.
- Place sturdy grab bars or handrails near the bed, toilet, bath, and on stairways and hallway walls.
- Use reflector tape on walls or floor to help guide the patient.
- Consider painting the top and bottom stairs a different color from the others.
- Put non-skid strips on steps.
- Use bed rails or place the mattress on the floor if the patient tends to fall out of bed.
- An intercom system will allow you to hear the patient when you are not in the same room.
- Evaluate the outside of the house and surrounding areas; you may need rails on porches and steps, and a fence around the yard.

When dealing with an Alzheimer's patient you need to become an investigative lay doctor. No matter what, my mother was always "just fine". My sister was staying with her when she noticed that Mom was having difficulty holding down any food. She also seemed very weak. I went over to investigate and found her extremely despondent, but when questioned about how she felt, she was "just fine". We took her to the hospital and discovered that she'd had a severe heart attack. Diagnosing an illness is a scary and difficult ordeal with Alzheimer's victims. You need to be suspicious, doubting, persistent and very observant.

S.G., Billerica

VIII. MEDICAL ISSUES

ILLNESS

Alleviation of health problems may improve the person's level of functioning. It is important to be sensitive to signs of illness. A person with Alzheimer's disease or a related disorder may not be able to tell you that he is experiencing discomfort or pain.

- An abrupt behavior change, such as increased restlessness, refusal to perform routine tasks, shouting or moaning, withdrawal, sudden increase in confusion, or a change in personality could signal a health problem.

- Symptoms of illness may be obvious or subtle. The following may be symptoms of illness. Seek medical care if a condition worsens or persists over time.

coughing	drowsiness	diarrhea
sneezing	headache	fever
refusal to eat	chills	flushing
irritability	dry skin	difficulty breathing
increased confusion	falling	nausea and vomiting
thirst	rapid pulse	hallucinations
incontinence	calling out	convulsions
swollen ankles, legs or hands		bluish lips and fingernails

- Using a paper thermometer and using the underarm for temperature measurement are preferable to taking the temperature with a glass thermometer by mouth.

- Contact your doctor or other health professional if a condition worsens, persists, reoccurs, or changes suddenly.

- Discuss with a health professional whether flu and pneumonia vaccines would be appropriate for the patient.

- Arrange for the patient to be seen by a physician regularly.

- Some Alzheimer's patients have seizures. If a seizure occurs, stay calm and let it run its course. Do not restrain the patient or force his mouth open, but be sure he has an airway through which to breathe. If he is seated, ease him on to the floor. Protect him from injury by removing any sharp objects from around him, but do not attempt to restrict his movement. Let him sleep after the seizure is over.

Don’t talk about the individual in front of him or her. When I explained the types of problems my mother was experiencing, the doctor, who was a kind and caring person, rarely spoke to my mother directly. Most of the conversation was directed to me. My mother knew what was being said, but wouldn’t ask questions until we left the physician’s office.

S.G., Billerica

I always carry my own notebook. It is impossible for me to remember for two people. When I realize that I have forgotten something, I write it down so that I will not forget it again.

Brockton Support Group

One thing I did which turned out to be very helpful to my family and doctors was to keep notes on my wife’s behavior. This practice helped the physician to understand the progression of the disease.

E.C., Orange

Visiting the Doctor

An Alzheimer's patient has a progressive disease for which she needs regular medical attention. Regular check-ups are also important because the patient may have medical problems in addition to the dementing illness.

- Be sure to communicate all pertinent information and concerns to the doctor. Preparing a list in advance will help ensure that all of your concerns are addressed. If necessary, speak privately with the doctor so that the patient does not overhear information that will upset her.

- Keeping a daily diary, although another chore in the caregiver's busy day, makes it easy to document changes in the patient's behavior or physical condition. Note any changes that seem to be associated with a new medication.

- To avoid getting involved in an argument, ignore or downplay objections to visiting the doctor. For example, if the patient says, "I will not go to the doctor", instead of saying, "Yes, you will", try saying, "We'll stop for a snack after seeing the doctor".

- Explain that you are going to the doctor when you are almost at the office if this helps to reduce the patient's anxiety.

- If the patient resists all attempts to go to the doctor, the doctor may make house calls or prescribe a tranquilizing medication.

- Plan ahead to minimize the stress of an office visit:

    - Consult the office staff and schedule an appointment for the office's least busy time or during your patient's best time of day.

    - Allow plenty of time for getting ready, getting out of the house, traveling, and parking.

    - Bring something that will distract or comfort the patient, such as a book, magazine, or stuffed animal.

    - Bring a snack in case there is a long wait.

- Take someone with you to help if needed.

- Do not leave the patient unsupervised in the waiting area.
- Take a walk or a short drive if the receptionist says that there will be a long wait.

My pharmacy keeps a computerized record of each customer's purchases. Whenever I ask for it, they give me a printout of all of my wife's medications, which I can review with her doctor, and keep for my financial records.

G.D., Lexington

Medication

Dementia patients are vulnerable to overmedication and to reactions from drug combinations. The patient's behavior should be closely monitored for any changes that may indicate negative effects of medication.

- Consult a doctor or other medical professional before giving over-the-counter medication. Pharmacists are a good source of information about medications and their effects.

- Keep a written record of all current medications. Note the name of the medication, dosage, and starting date.

    - Keeping an ongoing record of the patient's medications can assist the caregiver and physician in reviewing the effects of medications on the patient's behavior.

- If he is capable of understanding, tell the patient what the medication is and why it is being given. Use language that can be understood and accepted.

- Establishing a routine for taking medications may reduce resistance and arguments.

- Medication boxes that separate pills by the day and time to be taken can be a useful memory aid for both patient and caregiver.

- If necessary, put a lock on the medicine cabinet or use a locked drawer.

- Be certain that pills have been swallowed. Pills can be hidden in the cheek and under the tongue.

- If the person is unable to swallow pills, crush and mix them with a small amount of food or liquid.

    - Some medications come in liquid form; ask your doctor or pharmacist.

- If you are not able to get out of the house, use a pharmacy that delivers. Some pharmacies may provide this service even if they do not advertise it.

- Taxi services can deliver medications to housebound patients and caregivers.

- Find out which pharmacies are open on Sundays and off hours. In an emergency, your local police department or hospital emergency room may be able to provide this information.

- Know the poison control center telephone number. Keep Ipecac Syrup on hand in case you need to induce vomiting. Do not automatically induce vomiting if overmedication is suspected. Call your doctor or poison control center for advice, or take the patient to a hospital emergency room.

My husband is unable to get out of bed. Late one night he kept calling me, insisting that I call our son and have him take care of the deer that he had just killed. “Okay, I’ll do that”, I said and left the room. A few minutes later I returned and said, “I called him and he said he will be here in a few minutes, but he asked you to go to sleep until he arrives”.

Athol Support Group

When it was time for us to go to bed, my wife would refuse to sleep with me because she did not know who I was. I solved the problem by sitting on the bed with her for about a half hour prior to bedtime and going through old albums.

Athol Support Group

Sleep Problems

Changes frequently occur in the sleeping patterns of a person with dementing illness. Sleeplessness at night is a common feature of Alzheimer's Disease; this and other changes can be very stressful for the caregiver.

- Maintain a consistent and soothing bedtime routine and a regular wakeup time.
- Avoid daytime naps if the patient has trouble sleeping at night.
- Encourage daily exercise.
- Evaluate any physical or emotional problems that may be contributing to sleep difficulties, such as pain or depression.
    - Medications, including over-the-counter drugs, may affect, the sleep-wake cycle. Consult a doctor of pharmacist if you suspect the patient's medication may be contributing to a problem with sleeping.
- Avoid fluids after dinner, particularly those with caffeine.
- Have the patient use the toilet before going to bed.
- Use a night-light if helpful.
- The use of a sleep medication or tranquilizer can be considered if other approaches are not effective. However, these drugs may cause extreme drowsiness during the day and must be used with caution.
    - Consult the patient's doctor before giving the over-the-counter sleep medication.
- Keep to as normal a routine as possible for as long as possible. Eventually it may become necessary to allow the patient to sleep wherever she is comfortable, perhaps a couch or comfortable chair.

Constipation

Forgetfulness, poor diet, inadequate fluids, lack of exercise, and certain medicines may contribute to constipation.

- Watch for the following signs of constipation:

  abdominal pain or bloating
  headaches
  restlessness or increase in agitation
  frequent trips to the bathroom
  straining.

- Some medications can cause constipation. Talk with the patient's doctor if you suspect medication may be causing or contributing to this problem.

- In order to prevent constipation, each person's daily diet should include exercise, plenty of liquids, and foods containing fiber and roughage (prunes, figs, and prune juice; whole grain breads, cereals, and pasta; fresh fruit and vegetables).

- To avoid impaction, discuss with a health professional the use of a stool softener or agents that add bulk to the stool.

- Remember that it is not necessary to have a bowel movement every day.

Incontinence is a symptom which is invariably part of the Alzheimer's Disease progression and has enormous implications for the caregiver. For patient and caregiver alike, incontinence can evoke feelings of anger, shame, and helplessness.

Sometimes urinary incontinence can be caused by factors other than problems in the brain – notably urinary tract infections and constipation. Prostatic enlargement in elderly male patients can cause obstruction to bladder emptying, with resulting "overflow". Some medication may predispose the patient to problems. The patient with brain damage may be unable to express discomfort appropriately, which adds to the general distress.

Never withhold fluids to lessen output! Inadequate intake leads to constipation and concentrated urine irritates the bladder, especially when medications are being used.

If the onset of incontinence is sudden or is accompanied by a change in behavior, fever, chills, or a strong odor to the urine, consult your physician.

Wenda Restall
Visiting Nurse Association of Springfield

Disposable diapers can be resealed with masking tape.

F.O., Wellesley

Incontinence

Incontinence refers to the loss of bladder or bowel control. The medical term for loss of bladder control is eneuresis. Encopresis means loss of bowel control. Stress incontinence may follow laughter, coughing, lifting, or any sudden exertion.

- Incontinence may be a correctable problem; a medical evaluation is the first step in dealing with this problem.

- Sometimes incontinence results from the person's inability to find the bathroom or undress quickly enough (see "Toileting").

- Keep track of bowel movements in order to learn the patient's patterns, if there is one. This will help to avoid accidents.

- Do not cause dehydration by restricting daytime fluids in an attempt to prevent incontinence.

- If there is no medical cause for frequent urination, establish a regular toileting routine every 2-3 hours (upon rising, before and after meals, and at bedtime). If necessary, distract the patient from toileting at other times.

- Praise successful performance; do not punish mistakes.

- Keep the genital area clean and dry to avoid infections and discomfort. "Baby wipes" are effective for this purpose.

- Use adult sanitary briefs, adult "diapers", or other incontinence products if needed.

    - Baby diaper doublers – available in some drug stores and supermarkets – can extend the "life" of more expensive adult diapers.

    - Don't forget to request a senior citizens discount (if eligible) when purchasing incontinence supplies.

- For the bed, use plastic sheets or disposable bed pads.

- On chairs, use washable chair cushions or towels over plastic cushions.

Pressure Sores
(“Bed Sores” or Decubitus Ulcers)

Pressure sores first appear as reddened spots over bony areas and develop into open sores. They occur when a person stays in the same position too long and are more difficult to cure than to prevent. The most common areas for pressure sores are the base of the spine, shoulder blades, and heels. The problem is more likely to occur if the patient is very thin and either bedridden or chair-bound.

- Good nutrition and exercise promote circulation and reduce the likelihood of developing bed sores.

- Use of protective aids such as soft cushions, water beds, lambskin, or an “egg-crate” foam mattress pad, help to prevent pressure sores.

- If the patient is bedridden and unable to turn herself, change her position every two hours.

    - Turn from side to side.

    - Use pillows for support.

- If the patient is confined to a chair for long periods, help her stand and, if possible, walk at least every two hours.

- Use loose clothing made of soft fabric to reduce friction and pressure on the patient’s skin.

- Massage bony areas often with lubricating lotion.

A picture of a toilet might provide a helpful visual cue if displayed on the bathroom door.

Joanne Koenig-Coste
Newton and Wellesley Nursing Home

When my father started to lose control of his bladder, I would always have a hand-held urinal nearby, especially in the car or bathroom.

W.N., Revere

One caregiver always makes sure that when he puts out a new roll of toilet paper, he gets the paper started, leaving a little hanging down. Otherwise his wife won't remember how to use it.

S.S., Greenfield

IX. DAILY LIVING

Toileting

As memory loss progresses, patients lose their ability to use the toilet without assistance.

- If the person needs to use the bathroom, remind him where it is verbally or by pointing; lead him there if necessary.
- Restlessness or pulling at clothes may indicate a need to use the toilet.
- Learn the terminology that the patient uses to state his need to use the bathroom.
- Make a "trail" to the bathroom with thick tape or carpeting, clearly mark the bathroom with a sign or a picture of a toilet, or paint the bathroom door a bright color.
- If necessary, bring the toilet closer to the individual; use a portable commode or urinal.
- For safety's sake, remove the lock from the bathroom door.
- An elevated toilet seat and grab bars may be helpful to prevent falls.
- Toileting will be easier if clothing is easy to manage.
    - Avoid belts.
    - Use pants with elastic waists such as sweat pants, which are comfortable, non-binding, and easy to take on and off.
- Encourage independent toileting. If assistance is needed, do not provide more help than is necessary. Start with verbal cues and gestures before helping with clothing, positioning, wiping, and readjusting clothing.
- If necessary, stimulate urination by running water or giving fluids to drink.

- If the patient is no longer able to properly wipe himself, it must be done for him because of the risk of infection.

- Limiting fluids in the evening can reduce the need to use the bathroom at night. (Encourage fluids during the day; they are necessary for good health.)

A caregiver bought one of those new kinds of toothpaste with the pump, figuring that it would be easier for his wife to use. He gave it to her and she just kept insisting that it wasn't toothpaste.

S.S., Greenfield

My wife has dentures. I didn't know how to remove them from her mouth, so I asked the dentist to show me.

T.S., Clinton

Oral Hygiene

Poor oral hygiene can lead to infection, gum disease, or toothaches.

- Demonstrate the steps of brushing; allow the patient to imitate one step at a time.

- If you start the motion, the patient's lifelong habit may take over. Try guiding the hand that is holding the toothbrush until the patient takes over on his own.

- Brushing your teeth at the same time as the patient may help him feel more comfortable.

- Dispense toothpaste as needed rather than leaving the tube out.

- If the patient wears dentures, you may need to supervise the cleaning process, and see that they fit properly. Poorly fitting dentures make it difficult to eat and digest food.

- Try using a long handled or angled brush or electric toothbrush if you are doing the brushing.

- Be aware of medications that cause dryness of the mouth. Frequent mouth rinses can help a dry mouth, but avoid commercial rinses that contain alcohol, which contributes to dryness.

Try to find a retired nurse, nurse's aide, or practical nurse that would be willing to come in and help with bathing, fingernails and toenails, haircuts, and shaving, etc.

K.S., Northampton

My husband refuses to take a bath. After I tell him, "It's time to take a bath", he would inevitably say, "I took one yesterday", or "I just had one this morning". After a few months I was getting desperate. My husband has always been a sound sleeper, so one night I tried to give him a sponge bath while he was in bed asleep. I got about one third of him washed before he started to wake up. Now every night I get one third of him washed.

Wellesley Support Group

Bathing

Bathing can be one of the most difficult tasks for a caregiver to accomplish. Many Alzheimer's patients have a fear of water. A bath can be scary and confusing for a person who does not fully comprehend what is happening.

- Remember that bathing may be accomplished by a bath, shower, or sponge bath.

- Daily bathing is not always necessary and may be damaging to fragile skin. Washing the patient's face, hands, and genital area may be all that is essential.

- Think about the best time and routine for bathing; it may reduce stress if you follow the same pattern each time.

- Avoid discussion of the need for a bath or shower. Be matter-of-fact: "It is time to take a bath now".

- Do not schedule a bath or shower at times that are already stressful for you or the patient. Pick a time when you are least likely to be interrupted. Leaving a confused or frail person alone in the tub or shower can be frightening and dangerous.

- Make sure you organize all the bath items you need (in order of use) before starting the bath.

- Use plastic containers rather than glass.

- Use a rubber bath mat and install grab bars in the tub. (Make sure they are installed properly.)

- A sturdy chair or stool in the bath or shower will eliminate some of the problems of getting the patient in and out of the tub or shower and help prevent falls. Special bath chairs are available from drug stores and hospital supply stores.

- Allow the patient to do as much for herself as possible.

- If she is frightened, distract her with conversation.

- Use moisturizing soap. Avoid bubble bath and bath oil because they can make the tub or shower slippery and contribute to urinary tract infections.

- Be certain the genital area is clean to avoid infections. If the person needs assistance, be matter-of-fact and calm.

- Dry the skin thoroughly. Use a lotion for dry skin after the bath (when pores are open), and check the condition of the skin for any changes, including bruises, discolorations, or breaks in the skin. If you note any changes, be sure to arrange for the patient to be seen by a medical professional.

Keep a woman's hair style simple, manageable with a quick whisk of a comb or brush.

E.M., Carlisle

My husband refused to let me wash his hair. A barber suggested brushing aftershave lotion into his hair and then drying his hair with a towel. He explained that the alcohol in the aftershave breaks down the oil in the hair.

A.V., Lexington

Grooming

Good grooming helps to maintain the patient's sense of self-worth.

- Encourage the dementia patient to groom himself for as long as he can.
- Guide and assist the patient as needed. Give step-by-step instructions, allowing him to finish one step at a time.
- Keep finger and toenails clean and cut short.
- For men, encourage daily shaving with an electric razor. Use a pre-shave softener to help reduce pulling and razor burn.
- For women, continue a normal makeup routine if practical.
- Short hair is usually easier to manage than long hair.
- Continue to visit the barber shop/beauty salon regularly.
    - Some hairdressers will make home visits.
    - To reduce waiting and confusion, ask for the first or last appointment of the day.

When garters are too difficult to put on, try “thigh-hi’s”. They are stockings with a wide elastic band that comes above the knee, so they can be worn with a skirt.

Bras with front closures are easier for the patient to manage.

E.M., Carlisle

When right and left, and which is first, confused my wife when dressing, I would hand her things to her one at a time, in the proper order.

M.S., Concord

My husband refuses to change his clothes. He will take off his clothes to change into pajamas, but will not let me touch them. My solution is to wash the clothes while he is sleeping. I remove his belt and wallet, wash and dry the clothes, and then put everything back exactly as he left them.

Holyoke Support Group

My wife tried to sleep in her clothes or wear two or three sets at a time. This problem, I learned, was the fear of her clothes being stolen. After finding out the problem, I bought her three pairs of slacks, blouses, sweaters, and shoes (the same type and color). I had no big problem after that. She had a fresh outfit every day.

T.S., Clinton

In the winter, hypothermia is a danger, especially to older people. Your loved one may not communicate that he or she is cold, so you need to make decisions for both of you about what to wear. Bundle up and wear hats.

Visiting Nurse Association of Springfield

Dressing

With increased memory loss, the steps involved in getting dressed become more difficult for the patient to handle by herself.

- Allow the dementia patient to dress herself as long as she is able to do so regardless of how long the process takes.

- Give step-by-step instructions, allowing the patient to finish one step before continuing on to the next.

- Lay out clothes in the order they will be put on. If necessary, hand each item of clothing one at a time to the patient.

- You may find it helpful to describe to the patient what you are doing as you do it. For instance, tell the patient, "It's time to get dressed now. Here is your shirt".

- Clothing should be comfortable and loose fitting.

- If shoelaces, zippers, buttons, and buckles are difficult, consider using:

    - Slip-on shoes (ones that won't slip off easily)
    - Elastic shoe laces
    - Sneakers with velcro closings
    - Pants with elastic waist bands
    - Clothing that closes in the front.
    - Velcro tape or large zipper pulls.

- Avoid a large section of clothes or accessories. Keep only seasonal clothes in the closet or keep the closet locked and put out one outfit at a time.

- If the patient insists on wearing the same clothing day after day, try buying several duplicate sets of the same clothes and rotating them.

Nutrition

A balanced diet is essential for good health. It helps avoid dehydration, constipation, malnutrition, or other illnesses, and promotes a sense of well-being.

- Be sure the patient eats a balanced diet and drinks at least six cups of liquid daily. It is important that the foods offered meet any medical requirements, especially if the patient is on a low fat, low salt, diabetic, or other restricted diet.

- Rather than argue with a memory-impaired individual about foods that she should avoid for health reasons, it is better not to have tempting but unhealthy foods in the house, or to store them in an inaccessible place so that you can control how often they're eaten.

- If weight gain is a problem, try serving smaller portions or small frequent meals, substituting nutritious snacks for high calorie "junk food", or increasing the patient's level of exercise.

- If the patient is losing weight, consult a medical professional. There may be problems with absorption of food, or other medical problems.

- If the patient is eating poorly and is otherwise in good health, a nutritional supplement may be needed.

I make chicken stew instead of soup, because it is easier for my wife to eat with her fingers.

My wife eats with her fingers probably half the time. Sometimes she can use a fork and sometimes she uses her spoon. I let her use whatever method she finds easiest.

T.S., Clinton

On looking back over the last five years, I can see the mistakes I made when I really did not know what was happening to my husband, such as the day I lost my temper at the dinner table and shouted, "Why can't you use your fork? You know perfectly well what a fork and knife are for". It was very soon afterwards that he forgot how to use a teaspoon as well.

D.O., Sandwich

Remember that you are dealing with an adult. There are many things that the Alzheimer's patient can do for him or herself. For example, if drooling, give the patient the opportunity to wipe his or her face.

Barbara Burns,
Holyoke Alzheimer's Resource Center

Mealtime

Although most dementia patients do not need special diets, the patient may develop eating problems that make it difficult to see that she is receiving proper nutrition. Dehydration is also a danger for the dementia patient who loses her sense of thirst or simply forgets to drink.

- Try to maintain a calm relaxing atmosphere at mealtime.
- A patient who has been accustomed to cooking for herself or others may enjoy helping with meal preparation. Depending on her level of functioning, appropriate tasks may include: stirring food, setting the table, folding napkins, wiping the table, and washing the dishes.
- Serve meals at a regular time at the same table. Have a memory-impaired person sit in the same place at the table.
- Use a plastic tablecloth. Wearing an apron helps protect clothes from spills.
- Buy a "collar" at the drugstore to fit over the edge of the plate. This makes it easier for the patient to put food on the fork and keeps the food from falling off the plate.
- It may be easier to use a bowl instead of a plate.
- To avoid spills, do not fill glasses or cups to the top. Clear glass or plastic may be difficult to see. Try using a spill-proof cup or a mug with a large handle.
- Allow the patient enough time to eat.
- You may need to demonstrate how to use utensils.
    - A spoon may be easier to use than a fork or knife.
    - Serving finger foods (e.g., sandwiches or cut-up vegetables) avoids the need for utensils (see next page).
- Use foods the patient prefers and is accustomed to; new foods may confuse him.
- Colorful, aromatic, and flavorful food may enhance the patient's appetite.

Suggestions for Finger Foods (saves your energy and gives the patient more independence): Chicken nuggets, fish sticks, grilled cheese sandwiches (cut up), french fries, raw vegetables sticks (let the patient peel them), english muffins/toast, hard boiled eggs (quartered), fried vegetable sticks, cheese sticks, pork or beef (cut in small pieces). Always watch for a sign of choking.

Wash-up: After eating, fill a small plastic basin/wash pan with warm sudsy water and have the Alzheimer's person soak their hands (this can be very relaxing). After massaging and washing their hands, clean and clip nails and pat dry. A calm environment can make a mealtime relaxing for both of you!

Hot Weather Precautions: Always make sure your family member has enough water to drink. Many persons with Alzheimer's Disease will not know they are thirsty, or may drink very little. During the summer heat (and even during the rest of the year), we all need enough fluids in our body!

Barbara Burns
Holyoke Alzheimer's Resource Center

- It may be helpful to serve one food at a time. Choices are difficult for the memory-impaired person.

- Encourage the patient to eat slowly and chew one mouthful at a time.

- For easy swallowing, the person should be sitting with her head slightly forward – not backward.

- Soft, thick food is less likely to cause choking than pieces of food that are slippery or require a lot of chewing.

- Do not feed a person who is drowsy or agitated.

- Do not feed a person who is lying down.

- If restlessness makes it difficult for the patient to stay seated for an entire meal, try smaller, more frequent meals, or serve finger foods that will allow the patient to eat while moving around.

- Eating problems may stem from treatable causes such as poorly fitting dentures or a sensitive tooth.

- Keep your patient sitting up for twenty minutes after eating. If a person lies down too quickly, food just swallowed may come back into the throat, causing choking and possibly death.

I take my wife for walks – a lot of walks. We walk through shopping malls. She may be mumbling to herself, but I hold her hand and she enjoys herself. She looks at the clothing in the store windows. If she smells pizza, I buy her a pizza.

My wife gets home from day care around 3:00 PM. TV has no interest for her whatsoever, but music has been great. When I put on an Artie Shaw record, she'll try to do the jitterbug with me. But it's not as good as the Oriental (Greek, Syrian, Armenian) music. I put the Oriental music on starting at about 4:00 PM before dinner. She gets up and dances. I dance with her for an hour and a half or two hours after dinner. We do the two-step. Her body still remembers the steps. Every so often, she'll push me away and do the individual step. She puts her hands in the air, turns around, and laughs, and cries.

B.D., Cambridge

Exercise

Exercise aids sleep, relieves tension and restlessness, regulates appetite, helps digestion, and improves strength, coordination, and flexibility.

- Consult a medical professional if the patient has medical problems that may limit his ability to exercise.

- Continue as long as possible with the patient's usual exercise routine, if he has one. If he does not have a routine, attempt some type of daily exercise.

- Encourage exercises that are enjoyable and that the person can do well enough to give him a feeling of satisfaction.

- Walking is easy and safe. It also provides a change of pace and a chance to get out of the house. Grocery shopping and window shopping involve walking and provide exercise.

- Dancing is good exercise and can be relaxing and fun.

- Playing with pets and children can be a pleasurable way to get some exercise.

- Any type of movement can provide exercise:

  sweeping the floor
  raking leaves
  tossing a ball
  riding a stationary bicycle
  rocking in a rocking chair

- Exercises can be done sitting in a chair while listening to music.

- Remember to consult a doctor before starting an exercise routine for a patient with any medical problems or physical limitations.

- Ask your doctor to write a prescription for a physical therapist to come to your home to set up an exercise program for the patient.

- Ask your local Visiting Nurse Association, hospital social worker, or librarian to help you find books on exercises for people with physical limitations.

One day I came out into the kitchen to find every pan out of the cupboards, flour, sugar, shortening spread all around and many baking dishes covering the tops of the counters. "What's going on here?" I had to ask. "Oh, I just thought I would make a blueberry pie," said the baker. I resisted the impulse to say "**Oh no!**" and went away and left him to it, thinking he was doing something he always loved to do. He had won blue ribbons for his baking. When I came back about fifteen minutes later, it was to find a very frustrated and unhappy man, struggling to mix his pie crust and finally just pouring blueberries into a pie dish, and dropping handfuls of questionable batter on top, putting it into the oven. He finally ended up, after the concoction was taken out of the oven, by sitting and eating his baked blueberries with spots of dough on top – and enjoying it!

D.O., Sandwich

When matching dishes puzzled her while putting them away, I would ask my wife to hand them to me, one at a time.

M.S., Concord

Take your cue from the patient. If he doesn't **want** to "get out the dishes", "make the coffee", or "put this away", it is likely he knows he **can't** do it.

E.M., Carlisle

My mother enjoyed rearranging her jewelry and would spend a great deal of time at it. Just make sure that anything of value is removed.

Milford/Northbridge Support Group

My wife attends day care regularly. She was unable to go for several days, so the day care center gave us a large box of buttons to have her sort. She was extremely content to work for hours at "her job".

Holyoke Support Group

Activities

Creating an atmosphere of quiet activity in the home promotes the feeling that the memory-impaired person continues to be an important member of the household. Restlessness decreases, and life is more enjoyable for everyone.

- Some activities, such as cooking, may help the patient feel a part of what is happening around her. Other examples include gardening, raking leaves, and simple household chores.

- Helping with chores gives a memory-impaired person the feeling that she has something to contribute to the household.

- Tasks that do not require much supervision give the caregiver a break.

- Simple chores might include drying dishes, setting the table (plates and utensils may have to be stacked on the table), wiping countertops, folding napkins, sweeping the floor or outside walkways, folding laundry, or emptying wastebaskets.

- Remember that the patient's ability to perform a certain task may vary from day to day or moment to moment.

- Activities that provide an opportunity for self-expression include:

  dancing
  singing
  playing a musical instrument
  drawing or coloring
  painting
  working with non-toxic clay.

- Do not ask the patient to do a simplified version of an activity or craft in which she once excelled. Her awareness of her loss of skills may be painful.

- Try to include some form of exercise in each day's activities. Walking, throwing a ball, or playing with a pet are simple activities that provide exercise (see previous section).

As an activity, trace an outline – perhaps of a pumpkin or a Christmas tree – on a piece of paper and have the person cut it out, following lines. Even people in advanced stages seem to be able to do this. Use a good pair of scissors and provide supervision.

Barbara Burns
Holyoke Alzheimer's Resource Center

I plan to rent a VCR machine and old 1930 – 1940's movies for my husband for his 75th birthday, and will continue to rent old-time movies for once-a-week viewing if he appreciates his birthday movies.

He loves birds, so I have a suction-cup bird feeder on our long sliding-door windows so he can watch the chickadees, titmice, and cardinals "up close and personal".

L.S., Brewster

When the task of writing notes at Christmas time brought on complete bewilderment, help was needed. This I could supply by asking my wife what she would like to say. I would type it, and she would copy the typing. In this manner the message was hers, and so was the handwriting.

M.S., Concord

- The following activities can be valuable if they are entertaining to the patient:

  car rides
  excursions to zoo/garden/pet shop/art museum
  listening to music
  playing cards/table games/simple puzzles
  watching sports.

- Certain activities that involve reminiscence help promote a feeling of well-being. These include sorting or looking at old photographs, looking at picture books, or playing records from earlier years.

- Remember:

  - A person with a dementing illness is likely to have a short attention span.

  - She may have little creative capacity and may not be able to initiate activities. You may need to provide things for her to do.

  - Activities that call for making choices or decisions may cause stress.

  - Be creative; experiment with new approaches.

Taking my wife shopping was a very hard experience. We had to watch her very closely. She would put things in her pockets, thinking that she could just walk out of the store with them, that they were hers.

T.S., Clinton

Have cards made up explaining the nature of the illness and hand one out to save explanations in an awkward situation.

N.N., Natick

When taking patients shopping or traveling, be sure they are dressed in bright colors, so that they will be easy to spot in a crowd if you should get separated.

Barbara Burns
Holyoke Alzheimer's Resource Center

Shopping

Shopping can be a good activity of dementia patients, if care is taken to anticipate and avoid potential mishaps.

- Window-shopping is a form of exercise and can be a good leisure activity.
- Grocery shopping involves exercise and helps the dementia patient feel useful.
- If necessary, explain to others privately the nature of the memory-impaired person's illness.
- Shop when stores are least busy.
- Explain the patient's illness to regular merchants.
- Keep the memory-impaired person busy by giving him things to hold, asking him to push the cart, asking him to check off a list of items.
- Before leaving the store, check for items in the patient's pockets, or be sure he wears clothes without pockets.
- In a difficult situation, distract the patient or move with him to another location to avoid embarrassment for everyone involved.

One caregiver often traveled with her husband while he was in the middle stages of his Alzheimer's illness. Often people traveling at the same time would ask them to dinner. She would unobtrusively lean over and say softly, "My husband has Alzheimer's, so I'm not sure it's a good idea". Invariably people would respond positively and supportively, and they would all go out. The dinner companions rose to the occasion and made a point of being really nice to her husband.

Falmouth Support Group

On a trip with my husband, an Alzheimer's victim, he had to use the men's' room. I permitted him to go in alone. When he did not return, I asked another man to look for him. My husband had locked himself in a broom closet. The experience was terrifying for him – as well as for myself. After that horrible experience, I would ask a man to check if anyone was using the bathroom and then to stand guard outside for me while I took him to the john.

A.K., Brookline

Dining Out

Planning ahead is important so that eating out becomes a pleasant experience.

- Dine when restaurants are least busy.
- Avoid very noisy restaurants.
- Make reservations to avoid waiting in line.
- Sit near the restroom.
- You may want to talk with the restaurant manager about the patient's illness, explain her need for assistance in the bathroom, and establish who is paying the bill.
- Dine with a few people rather than a large group.
- Allow the patient to sit quietly if it is more comfortable for her than joining the conversation.
- Spending some time talking about familiar past events will allow the memory-impaired person to feel that she has something worthwhile to contribute to the conversation.

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