Family Care Guide

2012

The New Hampshire Family Care Guide
for Alzheimer's Disease and Related Disorders

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Family Care Guide

THE NH FAMILY CARE GUIDE FOR ALZHEIMER'S DISEASE AND RELATED DISORDERS

2012 EDITION

This edition of the New Hampshire Family Care Guide is adapted by NH Department of Health & Human Services, Bureau of Elderly and Adult Services, from the original version published by the Alzheimer's Association of Eastern Massachusetts in collaboration with the Alzheimer's Associations of Cape Cod and Islands of Eastern Massachusetts.

Copies of this Family Care Guide are available from: NH Department of Health & Human Services, Bureau of Elderly and Adult Services, 129 Pleasant Street, Concord, NH 03301 1-800-351-1888.

In addition to this Guide, a separate supplement is also available:

Legal Techniques for Medical and Personal Planning for Alzheimer's Families in New Hampshire

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DEDICATION

This guide is dedicated to all the family members and friends who are caring for a loved one diagnosed with Alzheimer's disease or other type of dementia. They are truly unsung heroes.

INTRODUCTION

Many questions arise in the course of caring for a family member with dementia. This guide has been prepared for those who are caring at home for individuals with Alzheimer's disease, dementia or other type of related disorders, offering concrete suggestions for daily management. Suggestions presented in this guide have been compiled from the existing body of literature on caring for persons with dementia, from professional service providers, and from family caregivers.

The most common of the dementias, Alzheimer's disease affects an estimated 5.4 million individuals nationally. (The Alzheimer's Association, 2011). This is a conservative estimate since it only takes into consideration those who have actually been diagnosed. There is no way to stop the steady, progressive deterioration that is an inevitable characteristic of Alzheimer's disease or dementia, however; there are medications that can delay the progression. A person may live with this disease for many years, requiring increasing assistance with all aspects of daily living. Caregiving is an ongoing responsibility, and caregivers are encouraged to seek help from community resources and to accept offers of assistance from neighbors, family and friends.

How to Use This Guide

This *Family Care Guide* is intended as a handy reference for busy individuals (family caregivers) who are caring for a family member at home. Family caregivers are encouraged to consult the *Guide* for ideas and suggestions as needed, and to use the blank spaces at the end of the guide to jot down notes on approaches that have worked for you.

Not all of these suggestions will be appropriate for every person with dementia or appropriate at every stage of a person's illness. It is hoped that this information will aid you in understanding the needs and capabilities of the individual you are caring for and help you to establish your own caregiving strategies.

Commonly Used Terms

In order to clarify some of the common terms throughout the guide definitions have been provided below.

Alzheimer's disease – References to "Alzheimer's disease" refers to that specific disease.

Caregiver – In this guide the term "caregiver" or "family caregiver" refers to family members, partners, or friends who are caring for an individual with Alzheimer's disease or dementia as opposed to a professional or individual paid to provide care.

Dementia – In this guide the term "dementia" applies to all related types of dementia including dementia of the Alzheimer's type.

Person – References to "person" or "individual you are caring for" refers to an individual diagnosed with dementia, or dementia of the Alzheimer's type.

General Guidelines

There are many approaches to caring for a person with dementia. There is no particular right or wrong way to provide care. Every person is a unique human being and patterns of behavior vary from person to person. No single caregiving technique always works with every individual. Approaches must be adjusted to each person's changing abilities.

Because the ability to communicate deteriorates as these diseases progress, the person with dementia cannot always tell you whether a certain approach is working. Trial and error and your own observations are usually the best guides.

Following are a few general guidelines that are common in approaching an individual with any type of dementia. These suggested approaches may help maintain the person at an optimal level of functioning and make life for persons with dementia and their family caregivers as comfortable as possible:

- When speaking with the person you are caring for, be calm and reassuring. Making a connection with the person is so important! Take time to establish a connection.
- 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 person 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. Take them up on their offers of help. 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 person. Attend a family caregiver support group. Explore options such as help in the home or a day program for the person.
- Plan ahead for your person's and family's financial future. Learn about legal and financial options that apply to your individual situation.

What Is Dementia?

Dementia is a medical term that refers to a group of symptoms exhibited by persons 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 an 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 type of dementia. Some of the other well-known diseases that produce dementia include: Huntington's disease, Multi-Infarct Dementia, Pick's Disease, Creutzfeldt - Jakob disease, and Amyotrophic Lateral Sclerosis (Lou Gehrig's disease).

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 (vascular dementia) occurs in 15 to 20 percent of persons with dementia.

Common Types of Dementia and Their Typical Characteristics

Type of Dementia	Characteristics
Alzheimer's disease	Most common type of dementia; accounts for an estimated 60–80 percent of cases. Difficulty remembering names and recent events is often an early clinical symptom; apathy and depression are also often early symptoms. Later symptoms include impaired judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking.
Vascular dementia (Also known as multi-infarct or post-stroke dementia or vascular cognitive impairment)	Considered the second most common type of dementia. Impairment is caused by decreased blood flow to parts of the brain, often due to a series of small strokes that block arteries. Symptoms often overlap with those of Alzheimer's, although memory may not be as seriously affected.
Mixed dementia	Characterized by the hallmark abnormalities of Alzheimer's and another type of dementia - most commonly vascular dementia, but also other types, such as dementia with Lewy bodies (see below).
Dementia with Lewy bodies, also known as Lewy body dementia	Pattern of decline may be similar to Alzheimer's, including problems with memory and judgment as well as behavior changes. Alertness and severity of cognitive symptoms may fluctuate daily. Visual hallucinations, muscle rigidity and tremors are common.

Type of Dementia	Characteristics
Parkinson's disease	Many people who have Parkinson's disease (a disorder that usually involves movement problems) also develop dementia in the later stages of the disease.
Frontotemporal dementia	Involves damage to brain cells, especially in the front and side regions of the brain. Typical symptoms include changes in personality and behavior and difficulty with language. Pick's disease, characterized by "Pick bodies," is one type of frontotemporal dementia.
Creutzfeldt-Jakob disease	Rapidly fatal disorder that impairs memory and coordination and causes behavior changes.
Normal pressure hydrocephalus	Caused by the buildup of fluid in the brain. Symptoms include difficulty walking, memory loss and inability to control urination. Can sometimes be corrected with surgical installation of a shunt in the brain to drain excess fluid.

(The Alzheimer's Association, 2010)

Medical Conditions that Mimic Alzheimer's or Dementia

Many older adults suffer memory loss, but never receive proper medical attention because of the belief that it is a normal part of the aging process.

There are more than 60 medical conditions that have symptoms that mimic Alzheimer's disease or dementia and may cause memory problems. Below are a few of the conditions, which are considered to be successfully treatable. Early diagnosis and treatment may improve memory.

Poor Nutrition - Body chemistry can become imbalanced from the "tea and toast" syndrome, eating meals lacking the full range of necessary nutrients.

Dehydration - Many people do not drink enough fluids, or they consume primarily caffeine beverages that flush fluids out of the body.

Fluctuation in Blood Sugar - People who develop diabetes late in life may go for years without realizing they should ask their physician to check their blood sugar.

Thyroid Deficiency - Possible thyroid deficiency can be checked by a physician and remedied with medication. Untreated thyroid or heart problems and some vitamin deficiencies can produce reversible confusion and memory loss.

Infection - Urinary tract or bladder infections are the most common infection, but any infection can potentially cause memory loss.

Medication Combinations - Taking multiple pills every day can result in mix-ups or medication interactions.

Medication Toxicity - Occasionally, too much medication accumulates in the blood. For example, digoxin (Lanoxin) is a heart medication, which can become toxic.

Depression - Some people lose interest in others and become confused when they get depressed. Antidepressant medication may help significantly.

Sensory Losses - Loss of hearing or sight may interfere with orientation to time and place.

Lung Disease - Memory loss may completely resolve when the person receives oxygen treatments.

Cancer - Tumors in the brain, liver, or other organs can lead to memory loss. Prompt diagnosis may mean that the tumor can be removed or reduced through treatment.

Toxic House - Furnaces sometimes malfunction and leave carbon monoxide in the air, producing confusion and sleepiness. Fixing the furnace may restore alertness.

What Is Alzheimer's disease?

Alzheimer's disease 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.

Alzheimer's disease can affect different people in different ways, but the most common symptom pattern begins with gradually worsening difficulty in remembering new information. This is because disruption of brain cells usually begins in regions involved in forming new memories. As damage spreads, individuals experience other difficulties.

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

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

The following are Warning Signs of Alzheimer's:

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing

- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality

Get a Complete Diagnostic Work-Up

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 person'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 the MA/NH Chapter of the Alzheimer's Association for a list of clinics that specialize in the diagnosis of Alzheimer's disease.

Mild Cognitive Impairment

Studies indicate that as many as 10–20 percent of people aged 65 and older have MCI.

MCI, is considered a transition stage between the cognitive changes of normal aging and the more serious problems caused by Alzheimer's.

With MCI cognitive impairment a person has problems with memory, language, or another cognitive functions that are severe enough that other people notice (such as: language, attention, reasoning, judgment, reading, and writing), but not serious enough to interfere with daily life. Because the problems do not interfere with a person's day to day activities, the person does not meet criteria for being diagnosed with dementia.

According to the Mayo Clinic individuals with MCI have an increased risk of developing Alzheimer's disease or dementia. But, not everyone diagnosed with MCI goes on to develop Alzheimer's, and may even get better.

The person may, or may not later develop Alzheimer's disease, although a significant number will.

Types of Alzheimer's disease

Younger Onset Alzheimer's

- Person diagnosed with disease before age 65
- Accounts for less than 10% of patients
- Affects many adults with Down syndrome because they experience premature aging. The symptoms first appear in their 30s or 40s.

Late Onset Alzheimer's

- Most common form of disease
- Usually appears after age 65
- One in 10 individuals over 65 have Alzheimer's
- Half of all individuals over the age 85 have Alzheimer's
- Approximately 95% of the time, Alzheimer's does not occur due to a genetic link; these cases are considered sporadic or caused by as of yet unknown reasons. Approximately 5% of the time, the cause is due to a genetic link.

Stages of Alzheimer's Disease

No cognitive impairment

Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

Very mild cognitive decline

Individuals at this stage feel as if they have memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses, or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family, or co-workers.

Mild cognitive decline

Early-stage Alzheimer's can be diagnosed in some, but not all, individuals have these symptoms. Friends, family, or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:

- Word- or name-finding problems noticeable to family or close associates

- Decreased ability to remember names when introduced to new people
- Performance issues in social or work settings noticeable to family, friends, or co-workers
- Reading a passage and retaining little material
- Losing or misplacing a valuable object
- Decline in ability to plan or organize

Moderate cognitive decline

(Mild or early-stage Alzheimer's disease) At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent occasions or current events
- Impaired ability to perform challenging mental arithmetic-for example, to count backward from 100 by 7s
- Decreased capacity to perform complex tasks, such as marketing, planning dinner for guests, or paying bills and managing finances
- Reduced memory of personal history
- The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations

Moderately severe cognitive decline

(Moderate or mid-stage Alzheimer's disease) Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- Be unable during a medical interview to recall such important details as their current address, their telephone number, or the name of the college or high school from which they graduated
- Become confused about where they are or about the date, day of the week, or season
- Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s
- Need help choosing proper clothing for the season or the occasion
- Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children
- Usually require no assistance with eating or using the toilet

Severe cognitive decline

(Moderately severe or mid-stage Alzheimer's disease) Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with customary daily activities. At this stage, individuals may:

- Lose most awareness of recent experiences and events as well as of their surroundings
- Recollect their personal history imperfectly, although they generally recall their own name
- Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces
- Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet
- Experience disruption of their normal sleep/waking cycle
- Need help with handling details of toileting (flushing toilet, wiping, and disposing of tissue properly)
- Have increasing episodes of urinary or fecal incontinence
- Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding
- Tend to wander and become lost

Very severe cognitive decline

(Severe or late-stage Alzheimer's disease) This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak, and, ultimately, the ability to control movement.

- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered.
- Individuals need help with eating and toileting and there is general incontinence of urine.
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired. (Stages of Alzheimer's)
- Consider utilizing hospice care.

Alzheimer's Disease and Dementia in Down Syndrome

According to the National Association of Down Syndrome an estimated twenty-five percent of individuals with Down syndrome over the age of 35 exhibit symptoms of Alzheimer's type

dementia. The percentage increases with age. The incidents of the disease are three to five times greater than that of the general population and begin at a younger age.

Early symptoms include:

- Loss of memory and logical thinking
- Loss of speech or change in language skills
- Personality changes, irritability, apathy
- Disorientation to time and place
- Decline in daily living and self care skills
- New onset of seizures
- Changes in coordination and gait
- Loss of continence when they had previously been independent in toileting

Often the person with Down syndrome lives with elderly parents (or siblings) who have cared for and advocated for them all of their lives. Now the parents (or siblings) are faced with new and multiple issues and concerns.

Seek Help Early after Diagnosis of Alzheimer's disease or Dementia

It is important to connect with community supports as early as possible once the diagnosis has been made. Educate yourself (both the family caregiver and the individual with dementia) about the disease and seek early treatment which can delay the progression of the disease. Advanced care directives and long term financial planning should be addressed while the individual with dementia can still be a part of the discussions (see Planning Ahead).

Connect with others in support groups. There are a number of different types of support groups available such as: telephone based support groups, support groups for family caregivers, support groups for both the caregiver and the individual with dementia as care partners, as well as early stage support groups. Take advantage of educational opportunities from the Alzheimer's Association and other groups.

Support Groups

It is sometimes difficult for family members 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 family members in managing the person with dementia and in understanding and coping with the daily challenges of caregiving. Mutual support and guidance, as well as educational information, are offered.

Since the list of support groups is ever changing it is best to call the local Alzheimer's Association office or the ServiceLink Resource Center in your area that keep current lists of disease specific groups.

Educational Series

Below are just two examples of the many excellent educational opportunities that are available in the community.

The "**Taking Control**" educational series offered by the Alzheimer's Association MA/NH for both the individual with early stage Alzheimer's disease or dementia, and their partnering family member gives people in the early stage of dementia the tools they need to make legal, financial, and medical decisions while they are still capable. This educational program and the subsequent support groups are tailored to the needs of those in the early stage, which differ greatly from later stage needs. The goal is to help people stay independent for as long as possible, plan ahead, and feel confident. Upcoming classes can be found on the Alzheimer's Association website under "Education" at http://www.alz.org/index.asp.

The "**Powerful Tools for Caregivers**" educational series take place at various times and locations around New Hampshire. In the six weekly classes, caregivers develop a wealth of self-care tools to: reduce personal stress; change negative self-talk; communicate their needs to family members and healthcare or service providers; communicate more effectively in challenging situations; recognize the messages in their emotions; deal with difficult feelings; and make tough caregiving decisions. Class participants also receive a copy of *The Caregiver Helpbook*, developed specifically for the class. *Upcoming classes* can be found on the ServiceLink website under "Caregiver Corner": http://www.nh.gov/servicelink/CaregiverCorner.htm.

Agencies that Provide Education on Alzheimer's disease and Dementia

Alzheimer's Association MA/NH, New Hampshire Office
www.alz.org/manh
(603) 606-6590
24/7 Helpline: (800) 272 -3900
5 Bedford Farms Drive, Suite 201
Bedford, NH 03110

alzheimer's association®
the compassion to care, the leadership to conquer®

New Hampshire's ServiceLink Aging and Disability Resource Centers
www.servicelink.org
Toll free number (866) 634-9412
The ServiceLink Resource Centers are trusted places in your community to get answers about healthcare and other services for older adults, persons with disabilities and family caregivers. The ServiceLink Resource Center team is one phone call away. They will listen to your needs, respect your privacy and help you find answers. There is never a fee or eligibility requirement.

Celebrating 10+ Years
ServiceLink
Aging & Disability Resource Center

Alzheimer's Foundation of America
www.alzfdn.org
(866) 232-8484
The Alzheimer's Foundation of America offers information about Alzheimer's as well as related illness. Also has information on Medicare and locations for memory screenings. Individuals can subscribe to receive a free copy for care Advantage, a quarterly publication for individuals caring for loved ones with Alzheimer's and related diseases.

Fisher Center for Alzheimer's Research Foundation
www.alzinfo.org
(800) 259-4636
The Fisher Center offers information on Alzheimer's disease, treatment options, and continuing care. The foundation has an Alzheimer's community, which has newsletters, chats, message boards, and an "Ask the Alzheimer's Experts" section.

The American Parkinson Disease Association - Massachusetts Chapter
www.apdama.org
Email: information@apdama.org
(800) 651-8466
The American Parkinson Disease Association offers locations of support groups in Massachusetts and New Hampshire, lists other resources, along with news, events, and research updates regarding Parkinson's disease.

National Parkinson Foundation
www.parkinson.org
Email: contact@parkinson.org
(800) 327-4545
The National Parkinson Foundation provides information, research, education, caregiver resources, and a searchable database of local chapters, physicians, and support groups.

Brain Injury Association of New Hampshire
www.bianh.org
Email: mail@bianh.org
(603) 225-8400
Helpline: (800) 773-8400
The Brain Injury Association offers services and supports, as well as a downloadable directory of resources for a variety of brain injuries and diseases.

National Alliance for Caregiving
www.caregiving.org
Email: info@caregiving.org

The National Alliance for Caregiving offers caregiving tips and guides, current legislation, publications, and reports on important caregiving issues.

National Family Caregivers Association
www.thefamilycaregiver.org
Email: info@thefamilycaregiver.org
(800) 896-3650
The National Family Caregivers Association offers resources, connections for caregivers, and advice for advocating for yourself and your loved ones.

Family Caregiver Alliance - National Center on Caregiving
www.caregiver.org
Email: info@caregiver.org
(800) 445-8106
The Family Caregiver Alliance offers caregiving advice, groups, and newsletters.

This Caring Home
www.thiscaringhome.org
This Caring Home website provides tips and tools to enhance home safety for persons with Alzheimer's and other types of dementia. This website is a project of Weill Cornell Medical College and winner of the 2010 National Alzheimer's Caregiver Award.

Well Spouse Association
www.wellspouse.org
Email: mainstay@wellspouse.org
The Well Spouse Association offers a resource directory, publications, support groups, online mentorship, and respite weekends for spouses who are caring for their loved one who has a terminal illness.

Remember that others can help

Help and advice are available from other family caregivers, from support groups, and from community and state resources. 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.

1. Make a point of contacting the local chapter of the ***Alzheimer's Association in MA/NH*** located in Bedford, New Hampshire. The local phone number is: (603) 606-6590. Learn as much as you can. Gaining knowledge will help in understanding the progression of the disease.
2. The ***National Alzheimer's Association toll free Helpline*: 1 (800) 272-3900.** The helpline is staffed by clinicians around the clock, seven days a week.
3. The ***ServiceLink Aging and Disability Resource Center*** in your area can assist you in finding local and state resources. The toll free number for ServiceLink is: 1 (866) 634-9412.
4. When you contact an agency by phone, here are some good tips to keep in mind:

- ☐ Take time to formulate your questions before making a call. Write them down.
- ☐ Be well organized, brief and to the point.
- ☐ Keep a note pad by the phone to take notes. It will help serve as a record of who you spoke with, and when.
  - 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!

USING COMMUNITY SERVICES AND RESOURCES

In New Hampshire, a number of community services and resources are available to individuals with Alzheimer's and/or dementia and their families. The availability of these services varies from area to area across the state.

On the next few pages you will find resources 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 individual's age, where he or she lives, and the individual'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 ServiceLink staff for help in "negotiating the system".

Some numbers to call for general information:

Alzheimer's Association MA/NH, New Hampshire Office
www.alz.org/manh 24/7 Helpline: (800) 272 -3900
5 Bedford Farms Drive, Suite 201
Bedford, NH 03110
(603) 606-6590

New Hampshire's ServiceLink Aging and Disability Resource Centers
www.servicelink.org
Toll free number (866) 634-9412

Tips to Introducing Services

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

- Expect that there will be a period of anxiety or resistance. Changes can naturally lead to anxiety for anyone; this is particularly true for someone with dementia.
- Consider introducing one service at a time. If this is not an option, introduce services slowly, or as they become available.
- Keep in mind that staff members of the various service agencies are accustomed to dealing with the challenge of reluctant individuals, so don't be afraid to ask them for help.
- Try leaving the individual alone with a familiar relative or friend a few times before introducing him/her to a companion who is a stranger. Have someone come over and visit. The caregiver should participate and be a part of the first visit.
- If the individual is upset by having a stranger come into the home, he/she may be more comfortable with a worker with a familiar ethnic or religious background.
- Once the professional caregiver begins to seem more familiar to the person with dementia, the anxiety will diminish.
- Sometimes families "give up" before the person with dementia has a chance to adjust.

Introducing an Adult Day Program to an individual with dementia:

Day programs can be very appropriate for individuals with dementia. In the beginning, persons with dementia may be resistant to going, but once they attend for a few days, some individuals look forward to it.

- Convince yourself first. Visit the center and see if it truly is a place your loved one would enjoy.
- Give a convincing reason as to why the individual should attend. Your doctor may be able to help you if you have trouble with this. You can also consult the Adult Day staff for ideas.
- Schedule a visit for the individual when there is an activity that they enjoy.
- For some individuals, it may be helpful to take one step at a time. Try a short visit the first time and remember not to push too hard.
- Start with a few short days and add more days as the individual becomes more comfortable going.
- For other individuals, it may be better to attend several days in a row to allow the environment and the people to become more familiar more quickly.

- Whichever method you choose, be firm but gentle. Your willingness to "give it the old college try" will maximize the individual's opportunity to adjust.
- Get the right person to take the individual the first few times. If you have the option, choose someone who is less emotional to take the individual until they begin to settle in.
- If the individual is not willing the first time, wait a little while and then approach them again.
- Reinforce any positive experiences that the individual may have while at the program.
- Be sure to consult the Adult Day program staff often. You may learn that the person is developing friendships and enjoying activities more than they are reporting. Remember, Adult Day programs would be empty if their clients couldn't adjust.

Tips on Hiring In-home Help

Many individuals with dementia are cared for at home. In-home help can provide families with the assistance and supports needed to continue to care for the person in familiar surroundings.

- Evaluate the help that is needed in your home.
- Write a job description based on the help that you need and include what level of training you want the caregiver to have.
- Develop a job contract. Write a contract based on the job description. Make sure the issues of wages, hours, job description, unacceptable behavior, and termination are included in this contract. Have it signed by both you and the worker.
- Prepare yourself for the interview. Write a list of questions that you want answered as well as references that you want to check.
- Interview the applicants. Inviting another family member or friend to sit in on the interview is a good way to obtain a second opinion.
- Check the applicant's references as well as obtain the following to ensure that you really know the person that will be caring for your loved one.
    - A criminal background check. The forms for the background check can be found at the NH Dept. of Safety, Division of State Police, Criminal Records Unit at: www.nh.gov/safety/divisions/nhsp/forms.html, or call (603) 223-3867.
    - NH Dept. of Health and Human Services, Bureau of Elderly and Adult Services state registry check. The forms can be found at: www.dhhs.nh.gov/dcbcs/beas/registry.htm, or call the registry at (800)

852-3345 ext. 8154, or via email at BEASStateRegistry@dhhs.state.nh.us.

- Monitor. Once the caregiver is hired have someone stop in unexpectedly to check on the care your loved one is receiving as well as any signs of abuse, neglect, or exploitation.
- Be sure to check the requirements of NH's Department of Labor laws. If that individual caregiver works for you, you may be responsible for employee tax withholding, workman's compensation insurance and other responsibilities of an employer. NH Dept. of Labor website: www.labor.state.nh.us , phone: (603) 271-3176.

Recommended Sources of Help

Where to get a Diagnosis	• Specialized memory loss clinics • Neurologists
Legal and Financial Advice	• Senior Citizen Law Project • Attorneys who specialize in elder law
Information About Available Resources and Services	• Alzheimer's Association • ServiceLink • Support groups • Bureau of Elderly and Adult Services • Books and Videos • Social Security Administration • Medicare • Medicaid • Veterans Administration
Care Management	• Geriatric care managers • Social workers
In Home Care	• Visiting Nurse Associations • Home health agencies • Home Care - Care is provided by either a hired caregiver or a family member or friend
Care in a Residential or Skilled Care Facility	• Assisted Living Facilities • Nursing Facility Care - This type of care is for individuals who may need round-the-clock care, wander away without supervision; and need more help than can be provided at home. • The Alzheimer's Association recommends that families consider Residential or Skilled Care Facilities with a Special Care Unit for those with dementia, or a program

	that is exclusively devoted to those with dementia whenever possible.
Adult Day Programs	• Programs where individuals can go for the day. Meals, activities, and some assistance with activities of daily living provided. The two types are: ○ Social day programs ○ Medical day programs.

Medicare Basics

Adult children of a parent (or parents) with dementia who is receiving healthcare benefits under Medicare may be confused about what is covered, and what is not. Often the task falls to family members to sort out an array of paperwork that includes bills, receipts and Medicare Summary Notices. Below are some basics about Medicare that are helpful for family caregivers to know.

Medicare is a health insurance that covers the following individuals:

- People age 65 and older
- People under 65 with certain disabilities
- People of any age with End-Stage Renal Disease (ESRD), (permanent kidney failure requiring dialysis or a kidney transplant)

There are different parts to Medicare and each part covers the following:

Medicare Part A (Hospital Insurance)
Helps cover inpatient care in hospitals Helps cover skilled nursing facility, hospice, and home health care
Medicare Part B (Medical Insurance)
Helps cover doctor's services, hospital outpatient care, and home health care Helps cover some preventive services to help maintain your health and to keep certain illnesses from getting worse
Medicare Part D (Medicare Prescription Drug Coverage)
A prescription drug option run by Medicare-approved private insurance companies Helps cover the cost of prescription drugs May help lower your prescription drug costs and help protect against higher costs in

the future
Medicare Advantage Plans (like an HMO or PPO) are health plans run by Medicare-approved private insurance companies. Medicare Advantage Plans, also called "Part C," include Part A, Part B, and usually other coverage like Part D, sometimes for an extra cost.

To find out more about Medicare benefits, eligibility, open enrollments and policies the Official U.S. Government website is: www.medicare.gov.

Locally, the ServiceLink Resource Centers have Medicare Specialists who can assist you.

Medicare Billing

More than likely you are assisting with paying bills, dealing with finances and sorting through medical claims on behalf of the individual you are caring for. It is a good practice to record dates of service on a calendar and save receipts and statements he or she gets from providers to check for mistakes or billing errors. Compare these with the claims that Medicare has processed to make sure that the person you are caring for and Medicare have not been billed for services not provided or items not received. Review the Medicare Summary Notices (MSN) to make sure that he or she wasn't billed for the same service more than once or the service was not ordered by the doctor.

It is perfectly acceptable to ask questions of the provider or plan if something does not make sense or may be incorrect. Contact the provider or plan if:

- You do not understand the charges billed
- You do not think the product or service was received that appears on the Medicare Summary Notice
- You feel the service or supply was medically unnecessary

If you have contacted the provider on behalf of the person with dementia and you suspect that Medicare is being charged for a service or supply that the individual did not receive, or if you don't recognize the provider on the Medicare statement, call 1-800-633-4227 (1-800-MEDICARE) or contact your local ServiceLink Resource Center and talk to the Medicare Specialist.

Beware of:

Telemarketers and unsolicited calls to offer ***free*** medical supplies and equipment.

People trying to sell unwanted, medically unnecessary supplies such as arthritis kits or orthotics (back, knee and wrist braces).

The largest growing area of health care fraud is in persons trying to sell unwanted and medically unnecessary supplies and equipment. By offering "free" medical services, these fraudulent callers are trying to steal credit card information, personal identification, and Medicare and Social Security numbers so they can access banking information.

Protect Medicare Cards

Never give out personal information to people you don't know. If you feel you have been a victim of health care fraud call your ServiceLink Resource Center.

Protecting Vulnerable Individuals

Adult Protection

Incapacitated adults such as persons with dementia could be vulnerable to abuse, neglect or exploitation. New Hampshire is a "mandatory reporting" state which means that if you suspect an incapacitated adult is being harmed you are required by law to call Adult Protective Services. The calls are anonymous, and in doing so you could be getting help to an individual who is incapable of advocating for himself. The role of Adult Protective Social Workers is to investigate reports and provide services to protect vulnerable individuals.

The Adult Protection Program is administered by New Hampshire's Bureau of Elderly and Adult Services (BEAS) and is intended to protect incapacitated adults who are unable to protect themselves or their own interests. Under the adult protection law, BEAS is responsible for receiving and investigating reports of abuse, neglect, self-neglect or exploitation, and when necessary, for providing protective services. To make a report, or for more information, call the Adult Protection Unit at the Bureau of Elderly and Adult Services' Central Office at 1-800-949-0470 (if calling within NH), or (603) 271-7014 (if calling from outside NH).

Office of the Long Term Care Ombudsman

The role of a family caregiver of an individual with dementia rarely ends when that individual is placed in a residential or skilled care facility. The caregiver may not be involved in the day to day personal care, but they find that they are managing some aspects of the care such providing some assistance to the staff at mealtimes, advocating for the individual and keeping a watchful eye on their care, among other things. The staff at the Office of the Long Term Care Ombudsman are available should you have complaints regarding the care at the facility. They are the advocates for the residents.

The Office of the Long Term Care Ombudsman receives, investigates and resolves complaints or problems concerning residents of long-term health care facilities. The program also provides advocacy services, and comments on existing and proposed legislation, regulations and policies affecting long-term care residents. Education is provided to residents, family members and facility staff concerning the legal rights of residents. To contact the Office of the Long Term Care Ombudsman, call 1-800-442-5640 (if calling within NH) or (603) 271-4375 (if calling from outside NH).

CARING FOR THE CAREGIVER

Caregivers are anyone who provides care for another individual. This guide addresses the needs and concerns of "informal" caregivers. An "informal" caregiver is a family member or friend who is providing the day to day care on a voluntary basis rather than an individual who is a professional who gets paid to provide care.

Taking care of a family member who has been diagnosed with dementia can be emotionally and physically challenging over a long period of time. Overwhelmed with the stress of caring for the individual, 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. It is important to find the balance between caring for another individual and yourself. Take a tip from those in the caring professions. They learn early on that it is as equally important to care for themselves in order to be at their optimum in caring for others. If a caregiver is exhausted and emotionally spent, he has little to give.

Steps to Taking Care of Yourself

- ☐ Become an educated caregiver. Learn what you can about the progression of the disease and how you need to adapt along the way. Learn what resources are available that can help you.
- ☐ Learn to recognize the signs of stress and what to do about it. Know yourself. Know when the stresses are becoming too much to bear and what you need to get your strength and objectivity back.
- ☐ It is okay to ask for help. Family members and friends may be able to provide some assistance and support. Find out what community resources are available. Ask for and accept help. Often friends and relatives need some direction from you on how they can help with household chores, or errands. Try not to rely on only one source of support.

> *"Each of us needs time for self, for friends, for fun, for recreation. Fulfilling these needs will not take away from our loved ones. Indeed, it will nourish and enrich us, and enable us to give more."*
>
> *~Juanita Tucker, Caregiver*

- ☐ Attend a support group. Call the Alzheimer's Association or the ServiceLink Aging and Disability Resource Centers 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. You may need to try different groups until you find one that meets your needs.
- ☐ Attend to your own health. Keep your appointments with your physician, dentist, counselor, etc.
- ☐ Try to maintain your outside interests and activities. Maintaining your own identity is vital to keeping who are intact. 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. Get help such as in-home care, or utilize adult day programs, so that you can take a break to go on outings or take part in activities you enjoy.

- ☐ Do something special for yourself such as meeting a friend for lunch, going shopping or taking in a movie.
- ☐ Exercise! Ask a friend, neighbor, or family member to stay with the individual you care for 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 the person you care for to ride it as well; this may reduce pacing or wandering.
- ☐ Rest when the individual you care for rests. Consider having someone sleep over occasionally who is willing to take over care so that you can get an uninterrupted night's sleep.
- ☐ Try to keep realistic expectations for yourself, the individual you are caring for, and others. Many of the behaviors that occur are beyond your control and the control of the person with Alzheimer's.
- ☐ Grieve your losses, but also focus on the positive moments. It is essential to set boundaries of what you can and cannot do. Giving the best care is important, but do not feel that you have to do everything yourself. You can promise to be the best caregiver possible, in whatever setting, including a nursing facility.
- ☐ As early as possible look at legal and financial planning. Consult an attorney to discuss legal, financial and care issues. If possible and appropriate, involve the person with Alzheimer's and other family members.
- ☐ Pace yourself. Do what is most important, and 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 allow myself to get upset one less time today").
- ☐ Take time occasionally to remind yourself of the value of what you are doing. Maintain your sense of humor. If you can laugh, even alone, do it.

Recognizing Caregiver Stress

If you experience some of these signs of stress on a regular basis, consult your doctor. Ignoring them can cause your physical and mental health to decline.

Symptoms of caregiver stress:

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness
- Irritability
- Lack of concentration
- Health problems

(Recognizing Caregiver Stress)

Helping Friends and Relatives Understand Alzheimer's Disease and Dementia

Friends and relatives can be excellent source of support if they understand what is involved in caring for an individual with Alzheimer's disease or dementia.

- Consider telling friends and family about the person's condition. You may choose to share a specific diagnosis such as Alzheimer's disease, or be more vague by stating the person has some cognitive problems. Either way, you can explain that as a result, the person may act unusual or out of character. Although outwardly the person may look fine; he or she has an issue with their brain; it is not contagious; and he or she is not crazy.

> *"I found out that I can't leave her [aunt] alone with stickers. I came home and found the cat with 150 stickers stuck all over him!"*
>
> *Joyce B., Derry, NH*

- 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 to learn about Alzheimer's disease and other types of dementia. Invite them to accompany you to a support meeting.
- Remind friends and relatives that the person is an adult. He or she may sometimes exhibit childlike behavior but still has feelings and needs. Like all human beings, they 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 person with dementia 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 person with dementia. Suggest that people visit one at a time to avoid over-stimulating and confusing the individual. Suggest that visitors stay for a short time; quality is always better than quantity or duration.
- 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.
- Family stresses have a way of surfacing during this time. For example, adult children may disagree about what is the best approach with the parent who has Alzheimer's; 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 meeting to air problems, divide tasks, and make decisions together.

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,

- Consider contacting the Alzheimer's Association to arrange a Care Consultation. These meetings are free of charge and are often successful in helping families to identify common ground issues on which they can focus.
- 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 the individual with Alzheimer's or dementia.

Dealing with Anger and Emotions

As caregivers there may be times that you feel your situation is unfair. You may feel like you are missing out on many things you used to do, or things you would have liked to have done if things were different. You may be angry that you are slowly losing the spouse, partner or parent that you care for so much. You may be tired from answering that same question for the umpteenth time. The feelings are there, but you keep them bottled up. Bottled up feelings

eventually simmer, then boil over and then erupt in anger or even rage. The anger can erupt over one small thing, exploding without warning.

> *"Caregivers are sometimes in danger of not recognizing their anger because they are trying to "care and please;" and they are too consumed with coping with the situation to recognize their own feelings." (Ballard, Gwyther, & Toal, 2000)*

According to psychologists there are three main ways of dealing with anger:

1. Expressing anger- the healthiest kind is when you don't harm yourself, others or things.
2. Suppressing anger- when you deny or refuse to acknowledge or confront the reason you are upset.
3. Maintaining control - when you know what is causing you to be angry, and you know how to respond in order to maintain control. You are able to clarify what your feelings are, and you have good solutions to deal with those feelings.

"Feelings are an important barometer of your needs and the needs of the dependent person. Do not neglect them. Solutions are not always available. The alternative is learning to respond in ways that do not increase or feed negative feelings." (Ballard, Gwyther, & Toal, 2000)

- Learn to set boundaries. Setting boundaries is essential in protecting your own health, needs and well-being. It is letting others know your expectations and where you draw the line.
- 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

Boundaries are Rights…

The right to get mad

The right to get help

The right to effective ways to respond to problems

The right to knowledge about what to expect in the care recipient

The right to empathy (not pity) and understanding from others

The right to respite and retreat

The right to respect: The buck stops with me. As caregiver, I am ultimately responsible for what goes wrong and what goes right.

The right for advocacy and competence from professionals: I understand that there are no absolutes in this disease; however, it is reasonable to expect…

The right to a life outside of caregiving, where "illness or disability is not always center stage."

The right to be free of guilt or feelings of selfishness when I weary of this job.

The right to be heard as an experienced, competent authority on my family member.

The right to expect that living will, health care power-of-attorney, etc. are honored. (Ballard, Gwyther, & Toal, 2000)

particular, the primary caregiver, can help make it easier to cope with the effects of dementia.

PLANNING AHEAD

As dementia progresses, the individual'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.

How will you know when to get involved? Some key indicators are when family members find they need to assist by taking over daily tasks, paying the bills and money management.

It is important that the individual is involved in the decision making while he or she still has the capacity and can make decisions about their future arrangements.

Plan ahead by learning about durable power of attorney for health care and financial conservatorship, guardianship, and other legal options. Consult a legal advisor who is experienced in the legal and financial affairs of older adults. Get a valid signature on legal documents while the person is still able and competent to sign.

A helpful resource is the "*Advance Care Planning Guide*" by New Hampshire's Foundation for Healthy Communities. This guide provides comprehensive information about advanced directives, defines terms, and answers many common questions. Included are basic forms for Durable Power of Attorney for Health Care (DPOA) and Living Wills. A copy of the guide can be obtained from:

Foundation for Healthy Communities
125 Airport Road
Concord, NH 03301
Phone (603) 225-0900
Website: www.healthynh.com

It is important to know the location and the specifics of the following:

- ☐ Life insurance policies
- ☐ Copy of the person's will and the contact of their attorney
- ☐ Bank books
- ☐ Automobile titles
- ☐ Tax records
- ☐ Safe deposit box keys and the name on the safe deposit box

☐ Cemetery plot deed, which funeral home they choose and their final wishes (you may want to distribute copies of end of life wishes to family members and other necessary parties)

Learn about benefit programs such as Medicare, Social Security Disability, Medicaid, or the Veterans Administration for which you or your loved one may be eligible.

- Medicare and most private health insurance programs do **not** pay for skilled care services provided in the home or in a nursing facility.
- 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 facility care.
- Medicaid regulations are complex and change often. Seek knowledgeable help and advice from the New Hampshire Bureau of Elderly and Adult Services, the local District Offices, ServiceLink Resource Centers, or an attorney 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.
- It is never too early to engage in legal and financial planning. Procrastinating can cause undue stress and create possible negative financial and legal consequences.

Talking About the Future

Planning ahead can help to ensure that the desires and needs of the person with dementia are met. Many caregivers find it difficult to start the conversation, however, due to fear, denial, or issues of privacy. The following are some suggestions for starting the conversation.

Decide who needs to be involved - The person with Alzheimer's should be involved in decision making and planning ahead if he or she has the capacity to make decisions and be involved in care.

Plan a time to talk - Make sure you have enough time set aside to discuss planning and paying for care now and in the future. A good time might be:
after a visit with the doctor
around the holidays
while you are drawing up your will or other estate planning

Think about what you want to say and then take advantage of openings that come up. Remember, this is a start to what can be an ongoing dialogue. Your conversation does not have to be perfect.

Among the areas you should talk about are:
living arrangements – care in the home or in another residence

how to pay for care – budget, cost of care, payment options, government assistance, tax deductions and credits
legal planning – advance directives; wills and estate planning

(Talking About the Future)

MAKING THE HOME "DEMENTIA-FRIENDLY"

Individuals with Alzheimer's disease or dementia are affected by their environment to a much greater degree than others. Factors such as light, noise, and other household activities that others take for granted can affect these individuals in such a way that they can become easily confused or agitated.

The good news is that there are things that can be done to modify the home environment to make it safer, more conducive to preserving as much independence as possible, and allow for greater quality of life for that individual.

The object is to provide a safe, secure home environment that allows for opportunities for meaningful activities to promote self worth and improve the quality of life for the individual with Alzheimer's or dementia. With early planning, preparation, and a bit of creativity, a home can be made "dementia friendly."

In the early stages of Alzheimer's disease and other types of dementia an individual's short term memory and ability to make decisions is gradually affected.

As the symptoms progress the loss of abilities, such as completing tasks, following instructions, and finding things becomes more pronounced. Routine tasks become more difficult, particularly ones that require a sequence of steps (many day-to-day activities require a sequence of steps). Often after starting a task, the person will get lost and lose track of what he or she was trying to accomplish.

- It becomes increasingly difficult for the person to effectively communicate with others and express him or herself. Sometimes the individual with dementia will find it hard to find the right words, and may mistakenly replace one word with another.
- Familiar places and things gradually become unfamiliar to the person with dementia, making it easy to become confused, disoriented or lost. Some individuals lose the ability to differentiate between day and night, and day of the week. The person's sense of time and place get all muddled up.
- Changes in visual-spatial perception make it difficult for the person to judge the height of a step or a curb, creating a greater risk of tripping or falling.
- Colors may be hard to distinguish.
- Vision, sense of smell, touch and taste can also be affected. Some things may look different or be hard to recognize.

- Changes in mood are common. The mood changes can be temporary reactions to particular situations or challenging events. Some individuals with dementia experience intense emotions, while others may actually have reduced emotional sensitivity.
- Individuals can become agitated, annoyed and irritable as they struggle to make sense of their surroundings. These changes, as frustrating as they are to the individual, also pose challenges for the family members and others who care for them.
- Persons with dementia may have a reduced tolerance for noise, activity and distractions in the home resulting in "sensory overload." This reduced ability to cope can result in behavioral issues that range from minor to severe.

Assessing the Home Environment

An individual with is at greater risk of falling or being injured. Factors such as poor judgment (for example: going out on a snowy day without a coat) and problems in judging distance (for example: the height of a step or how far something is from reach) can result in hazards. Assessing the home environment early with an eye for safety has benefits, not just for the person with dementia, but on the wear and tear of the family caregiver, as well. In addition to making the home safe it is important for the person with dementia to continue to do as much for him or herself as possible, for as long as possible. As the disease progresses and they can no longer initiate activities or follow through on their own, they may be able to assist someone else with guidance.

Following are some suggestions to make the home environment safe and dementia-friendly.

- A home environment from a lifetime of collecting and accumulating objects can appear cluttered and be a source of over-stimulation. Suggestion: Limit the amount of items collected (such as: five newspapers instead of 30), clear pathways and store items that can be removed without causing undue upset.
- If there are busy or loud patterns on carpeting, curtains or upholstery, or there are mirrored walls, consider installing solid colored curtains; upholstered chairs can be covered with a plain blanket or afghan; and mirrors can be covered or removed.
- A home that has little color contrast, or a monochromatic color scheme; hallways where all the doors and walls look the same, or are of the same color has the effect of being "under-stimulating." Consider adding color contrast to doors, door frames, or other areas or items to bring attention to them in order to make them easier to see and locate.
- Assess the noise levels in the home to determine what changes can be made. The object is to eliminate some of the stressors.

- Step back and listen to the sounds in the home. Is the radio or television on? Is anyone actually listening or watching, or is it background noise? What about the dishwasher, washer and dryer, vacuum cleaners, a fan, or a window air conditioner?

> *"People with dementia exposed to periods of continuous noise can experience increased alterations in memory and other cognitive functions, increased agitation, less tolerance for pain and feelings of isolation. This then affects the person's ability to understand and cope ….." (J. Schnell, 1999)*

- All these background noises can increase anxiety, sense of disorientation, confusion and frustration, as well as be disturbing to an individual trying to rest or sleep.
- Examine the different surfaces in the household. Are there many hard surfaces? Sounds tend to bounce off of hard surfaces such as countertops and many windows. Solid colored curtains or draperies and soft furnishings can help absorb some of the noise.

Visual Stimulation

By addressing and modifying the light levels in the home you are making it a more comfortable place for an individual with dementia and at the same time enabling him or her to stay below their stress threshold.

Windows are a wonderful source of natural light. In areas where there is little natural light, utilize clear, bright lights that create an even source of illumination adding to the brightness of a room.

Lights that are positioned well and light the center of the room are just as important as natural light.

Poor light, however, can result in shadows and glare.

- Glare is the effect of light bouncing off of high shine floors, shiny or glass tabletops, glossy walls and shiny surfaces.
- Glare can be distracting and even impair one's ability to move around.
- For example, glare on a high polished floor can make it appear slippery or dangerous. The individual may try to step around it, or avoid that area all together. They may even try to step over it (remember the impaired depth perception?) putting him or her at risk of falling.

- You can reduce glare on shiny furniture by covering it with a large doily or a tablecloth. Hang sheer curtains, blinds, or light filtering shades that maintain privacy but allow light through.

- As we age we generally require up to two or three times as much light as younger individuals. Good lighting and even levels of light throughout the household makes it easier to see pathways, objects in the way and changes in flooring such as raised thresholds.

- Sufficient lighting also helps to distinguish colors. This could be critical issue, particularly with medications. Without proper lighting it could be very easy to mistake one pill or capsule for another.

- A well-lit home is cheerful and contributes to minimizing depression. It has been suggested that good lighting can improve an individual's appearance, their self-image and their self-esteem.

- Low or insufficient lighting could result in a gloomy atmosphere with dark shadows. For example, consider the benign potted plant in the shadowy corner. An individual with dementia could misinterpret what he or she sees as something ominous or scary.

Importance of Color Contrast

Individuals with dementia have a decreased ability to perceive color contrast and have difficulty seeing clearly. By providing stronger color contrasts you are enabling the individual to function more effectively in the home environment. The good news is that these modifications are easy to do and are inexpensive.

- Provide a high color contrast between walls and doorways. You may even consider having doors different colors to make it easier to identify rooms, such as a bathroom.

- Use contrasting colors between walls and switch plate and outlet covers. If that is not possible, consider highlighting the edges of the switch plates with colored paint or tape.

- A contrasting color on a raised threshold between doorways helps reduce the risk of tripping or falling.

- Bright or contrasting edging on cushions, or furniture colors that contrast with the flooring makes seating much easier to see.

- Kitchenware: use dark dishtowels against light countertops, or light dishtowels against dark countertops. Cutting boards: use white or light colored cutting boards when cutting carrots, or other dark or brightly colored vegetables. Consider using a black or dark colored board for cutting things such as onions or garlic.

- Studies have found that providing a high color contrast between dinnerware and the table setting increases the individual's functional abilities at mealtimes and actually improves nutrition. By providing contrast you are making the meal more visually appealing. These small modifications do not need to be expensive. A little bit of resourcefulness goes a long way.

Visual Cliffs

Individuals with dementia have impaired depth perception and can misinterpret what they see in the environment. How does that translate into day to living? One issue would be for the individual stepping from one type of flooring surface to another. For example, the individual is moving from vinyl flooring in the kitchen to a hardwood floor in the living room. The change in flooring type may appear to that individual that he or she would need to take a step down to get onto the other flooring, in this case the hardwood floor. This is what is known as a "visual cliff." The perception is that there is a drop in floor height, though in reality, there is no drop.

- Consider the photo to right of light and dark tiles. This could pose a safety problem if he or she perceives the dark tiles as holes, particularly if he or she has problems with balance, or has difficulty walking.
- However, if the individual tends to wander, placing a rectangular black carpet or mat in front of the doorways and exits will discourage him or her from trying to leave the house.

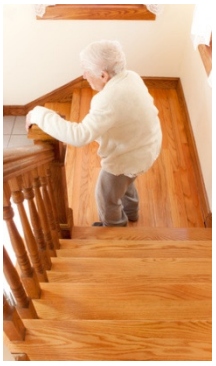
DARK TILES CAN APPEAR TO BE HOLES.

Reducing the Risk of Falling

Individuals with dementia are at a higher risk of falling due to impaired ability to avoid hazards and decreased visual-spatial perception. Knowing what can contribute to falling at home can help one make changes to reduce his or her chances of being hurt. There are practical things that can be done to prevent falls. Keep in mind that a lot of the changes that can make the most difference are easy to do, and are not expensive. Proper lighting, reducing clutter and putting electrical cords out of the way can all play a big part in reducing the risk of falling.

- The individual should have shoes that fit properly, with low heels and nonskid soles. Replace slippers that have stretched out of shape and are too loose. Avoid shoes with smooth, slick soles.
- Make sure the bed is easy to get into and out of.
- Install a night light along the route between the bedroom and the bathroom.
- Keep clutter off the bedroom floor and all pathways. Arrange furniture so that there is a clear pathway between rooms.

- Keep low-rise coffee tables, magazine racks, footrests and plants out of the path of traffic.
- Install easy-access light switches at entrances to rooms so you won't have to walk into a darkened room in order to turn on the light. Glow-in-the-dark switches may be helpful.
- Keep electric, appliance and telephone cords out of walkways, but don't put cords under a rug. Don't run extension cords across pathways; rearrange furniture.
- Secure loose area rugs with double-faced tape, tacks, or slip-resistant backing and remove throw rugs.
- Don't stand on chairs or boxes to reach upper cabinets.
- Keep stairs clear of packages, boxes or clutter. Light switches should be at the top and bottom of the stairs, or consider installing motion-detector lights which turn on automatically. Provide enough light to see each stair and the top and bottom landings.
- Put non-slip treads on each bare-wood step.
- Install handrails on both sides of the stairway. Each should be 30 inches above the stairs and extend the full length of the stairs.
- Place a slip-resistant rug adjacent to the bathtub for safe exit and entry.
- Install grab bars on the bathroom walls.
- Keep a night light in the bathroom.
- Use a rubber mat or place nonskid adhesive textured strips in the tub.
- Replace glass shower enclosures with non-shattering material.



Household Safety

Individuals with dementia 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.

- 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.
- Pad or cover the sharp corners on 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. Individuals may try to eat them.
- 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 person with dementia 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.
- Consider painting the top and bottom stairs a different color from the others.
- An intercom system or inexpensive baby monitor will allow you to hear the person 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.

COMMUNICATION

Alzheimer's disease or dementia eventually affects the individual'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. Words, gestures, eye contact, or other means can help you communicate with him or her.

- Remember that speech and language difficulties vary from person to person and may vary from day to day or even moment to moment.
- As the person's ability to use speech deteriorates, it may be difficult for the caregiver to adjust. Sometimes it is hard to accept the individual's limitations, especially when she continues to look like the same person she once was.
- Smile, nod, touch, and 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 individuals 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.

Often the patient will misuse … or alter familiar words altogether.

My husband, for example, used the word "smish" for sandwich. After a while, "smish" meant "food," and he would say "smish" whenever he was hungry.

Remember that in the person with Alzheimer's, the way the brain processes outside stimuli physically changes. Although you are clearly saying, for example, "I bought some lamb chops. Would you like one for dinner?" He may be hearing, "Wooden lamps are dimmer" – and wonder why you are repeating yourself and seem to be waiting for a reply.

If the person doesn't seem to understand you, break down your sentences into less complex patterns, establish eye contact when possible, and use simple, short statements to alleviate the stress related to failing communication. Remember that processing language will take longer than before – give the person time to think. (Koenig Coste, 2003)

- Provide reassurance and praise.
- 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 are specific and require only one choice at a time. Say, "Do you want coffee or tea"? Instead of, "What would you like to drink?"
  - 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 person with dementia still hear and may understand what is being said about them.
  - Do not talk to others about the person as if he or she weren't there.
  - Remember that the individual with dementia may be able to understand more than he or she is able to express and become frustrated with his or her inability to make himself or herself understood.
  - If the person 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 person is having trouble describing something, try asking, "Would you show me where it is?"
  - If the individual with dementia asks the same question over and over, remember that he or she probably cannot remember the answer. Repeat your answer once or twice and then reassure him or her that everything is fine, that you are there and that he or 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.
- If the individual frequently complains or makes insulting remarks:
  - Do not take such comments personally, attempt to contradict, or attempt to reason with the person with dementia.
  - 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 person with dementia does not necessarily have to understand **why** she needs to take a bath or change her clothes, as long as she does so.

PROBLEM AREAS

Memory Loss

Loss of memory has major implications for family members and care providers. Individuals with dementia may be unable to remember where they are or who the people around them are. Recent memory is the first to be affected. For example, the person 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.

Believe it or not, I do believe he still knows me. He stares at me when I walk in the door and keeps following me with his eyes. …when I say "kiss-kiss" he closes his mouth and kisses me. He only speaks gibberish with possibly one or two words we can understand but which don't make sense. A few weeks ago I said "Are you OK?" and he answered "home" a few times quite clearly. Also, I received a most precious Anniversary gift from him…when I said I loved him … he replied "I love you." Of course I say it many times all the time but this is the first reply in months and it happened on our anniversary.

Laurie L., Belknap County, NH

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 he or she 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.
- Provide the individual with a wristwatch if he or she is able to read one. Large easy to read numbers and calendar are helpful.
- Use a calendar with large print. Cross off each day. There are clocks now being sold that have not only the time, but the day of the week and the date on them.
- Display pictures of family and friends with names under the pictures.

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

Late Afternoon Confusion (Also known as "Sundowning")

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 person with dementia. Tell her the time, where she is, and what is going on.
- Reassure the person 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.

Clutter, Losing and Hiding Things

Older adults have spent a lifetime accumulating furniture, clothes, knick knacks, and memorabilia. The list is endless. Those who have downsized from a house to a smaller home or apartment struggle with having too much furniture, and items they have difficulty parting with. For an individual with dementia there are the additional issues of memory loss and impaired judgment.

- A memory-impaired person may not remember where to find an item, where he placed it last, or even that he had it. Some, as a coping mechanism to be able to find things may lay out items such as clothes, out in an open place like a dining room table. Others will put important items in a place that they feel is safe and where they will find it again. When the time comes to retrieve it, however, they have lost the thread of logic they used to place the item.
- 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.
  - Remove excess furniture.
  - Move furniture against the walls to leave a large section of uncluttered space in

"Imagine yourself in an Alzheimer's world. Your memory is going and you can't remember if you just did something. You turn to ingrained routines and clues for what to do. What happens if there are so many clues and things to look at that you get confused, uncertain, just lost in it all?" (Bakker, 2003)

the middle of the room.

- Reducing clutter makes it easier to find things if they are hidden or missing.
- If he or she is rummaging out of boredom consider redirecting them to activities that they enjoy doing.
- Reorganize their possessions. Throwing away items may be too upsetting. Consider offering to send items to a relative for safe keeping.
- Designate places for storing things such as glasses, jewelry, and things that can be easily lost.
- Organize clutter away from walkways and dangerous areas that could prove to be fire hazards such as stoves and radiators.
- Put away out of season clothing to simplify the closet and drawers, limiting the number of choices.
- Limit changes to only those that are necessary.

Clinging

Following the caregiver from room to room may give the person with dementia 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.

Pacing

For some individuals with dementia, 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.

Try to discover the reasons for pacing. Explanations may include:

Response to changes in the environment

- Boredom
- 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 it is thus unavoidable:

Make sure the individual 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 other forms of exercise, calories are burned during pacing.

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 the individual with a recent photograph to local police and fire departments.

Give the person with dementia a card with his or her address, telephone number, directions to their house, and instructions on what to do if he or she gets 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 individual 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.

- 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 person with dementia 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 he or she go? Do they take a consistent route? Can the route be incorporated into periodic walks?

Providing daily exercise for the individual 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.

MedicAlert + 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 in New Hampshire for more information on this program. MedicAlert provides live 24-hour emergency response for medical emergencies. To find out more call: 1-800-572-8566 or register online at www.medicalert.org/safereturn.

- Use bed rails unless the person attempts to climb over them.

Depression

Many individuals with dementia, 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

Things you can do:

- Encourage exercise.
- Alcohol, a chemical depressant, should be avoided.
- Avoid giving false hope or patronizing "pep talks".
- Encourage the person to talk about or otherwise express his or her feelings.
- Notice whether certain activities or people trigger moments of depression or an improvement in the person's mood.
- Do not force the individual to interact with others, but encourage him or her to be as socially active as is possible for that person. Encourage participation in simple activities that provided enjoyment in the past or in a non-demanding task or "job".
- For a period of time, counseling may be effective for some individuals. The person's memory and judgment problems may not be significant enough to 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.

Anger, Hostile and Demanding Behavior

Anger displayed toward you by the person with dementia is often not meant for you. It can reflect a misunderstanding of a situation or simply the person'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 person 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 person'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 person with dementia may be able to do it instead of demanding that you do it.
  - Regularly discuss concerns with anger and hostility with the person's physician(s). A clinician can assess if the anger may be caused by a medical condition and suggest possible treatment options. Often sudden changes in mood or behavior can be caused by acute conditions such as infections or other health related problems.
  - A doll or stuffed animal may be effective in calming or soothing the person with dementia.

Angry, Agitated Behavior

"It is important to recognize that angry or agitated behaviors are often symptoms of dementia and are not deliberate responses.

Sometimes keeping a log or a journal can be helpful in identifying why the person becomes angry or agitated. Try writing down everything that happened each time the person becomes agitated. What time of day was it? Who was present? What immediately preceded the outburst? Often a pattern emerges which can help the caregiver think about how to alter the situation.

The way which caregivers approach people with dementia is a critical part of avoiding angry behaviors. A gentle, supportive approach will almost always be more successful than commands or rationalizing. Dementia victims will often sense a caregiver's frustration or anger and become anxious or angry themselves." (Robinson, Spencer, & White, 1989)

- 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.

If the individual becomes violent:

- Call for assistance if necessary. Protect yourself and the individual.
- Isolate the person if he or she is in danger of harming himself or 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.

Catastrophic Reactions

A situation that overwhelms the person with dementia 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 person is resisting.
- Do not ask an upset individual to make decisions.

Identify and, if possible, avoid situations that have led to a 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 person with Alzheimer's disease or dementia.
- 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.
- Forgetfulness can be a benefit in these situations because the memory-impaired individual may quickly forget the episode.

Hallucinations and Delusions

Alzheimer's disease or dementia 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. Visual impairment easily leads to misinterpretation of the environment.
- Check the environment for adequate lighting and for noises that can be misinterpreted. Increase lighting and provide more even light throughout the environment. Shadows can lead to visual hallucinations.
- Whispering or laughing in front of the individual with Alzheimer's 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.

"Establish or reinforce a daily routine or pieces of a daily routine, such as meal rituals or bedtime rituals. Routines help give structure and a sense of the familiar to the individual who lives in an unfamiliar world. Even a few simple daily routines can help increase a sense of security." (Robinson, Spencer, & White, 1989)

Try these approaches for misplaced objects and suspiciousness:

- Remind individual where valuables are stored for safekeeping. Provide small amounts of money to individuals accustomed to having money on their person.
- Look for lost articles or assist in looking. Do not scold for losing items or hiding things.
- If feasible, keep a spare set of items that are frequently missed such as purse, keys or glasses.
- Learn where the individual's favorite "hiding places" are and let other caregivers know.
- Carefully choose your arguments with the suspicious person. Arguing or trying to reason with the person often makes the situation worse and can result in increased agitation or anger, creating more stress for everyone. State what you know to be true, and then attempt distraction, e.g., "Let's go for a walk."
- Anger and rage are often signs that the person is feeling loss of control of his/her life. Calmly acknowledge feelings even when you do not understand what is being said or why the person is angry. Saying something like "I know you are angry (or upset) about what is happening to you," can be helpful in reducing agitation.
- After episode has passed, try not to remind person of incident. He/she will probably soon forget. Caregivers should carefully consider what can be changed to avoid another reoccurrence. In addition, caregivers should work out an emergency procedure for themselves in the event of physical danger. (Robinson, Spencer, & White, 1989)

- False accusations, such as accusing a spouse of infidelity, may not be true delusions. In some cases, the person'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 by the person with dementia can be embarrassing and difficult to manage. In addition, the problem may be hard to discuss with friends and family.

- The person's indiscreet fondling of him or herself, touching others, and suggestive fidgeting should be discouraged gently and discreetly. Try redirecting the person's attention.
- If a person exposes himself or herself, they 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 person tries to disrobe, it may mean that he or she 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 individual with Alzheimer's.

Telephone

At some point 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.
- Most new phones have an option where you can turn the ringer off. For those that do not, a switch can be installed that turns the telephone ringer off while you are away.
- Telephone locks, available at office supply stores, can be installed to prevent outgoing calls while allowing incoming calls.

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 person's wallet or purse so that they will not be lost or misused. Fill the person'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 person with dementia wants to pay the cashier in a store, hand him the correct change.
- To avoid arguments, consider arrangements that reduce the person with dementia'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 deposit" of government benefit checks.

If you have not done so already, begin planning for the long-term financial needs of the individual and family.

Driving

The issue of whether or not an individual with dementia should be driving requires balancing the person's independence, and the safety of themselves, and others. Ideally, you want them to remain as independent as possible, for as long as possible. A single minor incident would not be a reason to take away the car keys. The caregiver, however, will want to be watchful of any changes over time. Dementia affects judgment and response rate; at some point, the person with dementia will be unable to drive safely. Caregivers often meet strong resistance when trying to prevent persons with dementia from driving.

Keep track incidents of by writing them down as they occur, and how often. The publication "*At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia and Driving*" (The Hartford Financial Services Group, Inc., 2010) is a helpful resource in knowing what to be aware of, and how to be sensitive in bringing up the subject. The entire guide can be obtained online at www.safedrivingforalifetime.com or can be ordered by writing to:

The Hartford
Publication Request
200 Hopmeadow Street
Simsbury, CT 06089

(Please be sure to indicate the title and quantity of the publications you are ordering.)

Below is a list of some of the warning signs to be aware of:

- Difficulty turning to see when backing up
- Riding the brake
- Easily distracted while driving
- Other drivers often honk horns
- Incorrect signaling
- Hitting curbs
- Failure to notice traffic signs
- Driving at inappropriate speeds
- Near misses
- Confusion at exits
- Getting lost in familiar places
- Car accident
- Confusing the gas and brake pedals (recommend they stop driving immediately)

Some strategies to consider:

Offer to drive.

Distract the individual by changing the subject or tell him or 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 him or her someone borrowed it
- Tell him or her the car is not working
- Tell him or her that her doctor said she should no longer drive, or ask the doctor to tell her directly
- Tell him or her that he/she is "getting older" and you are worried about his/her eyesight or reaction time
- Tell the individual that he/she has a memory impairment and that it is not safe for him/her to drive.

Smoking and Drinking

Drinking alcoholic beverages may increase confusion and may be dangerous for individuals who are taking medications. Smoking can be especially dangerous for persons with dementia 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 person'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.

Guns, Firearms and Weapons

An area of safety that should be taken into consideration is the existence of guns, firearms or weapons in the home, and their accessibility to the person with dementia.

If there are guns, firearms or weapons in the house:

- Remove all guns, firearms and weapons from the house.
- If guns or firearms remain in the house store them unloaded and keep ammunition locked in a separate place.
- Store unloaded guns, firearms or weapons in locked cabinets or drawers.
- Never let a person with Alzheimer's or dementia handle firearms or weapons.

Power Tools

Power tools stored in the garage, basement or shed is one area that is often overlooked by caregivers. Chainsaws, drills, power saws, and so on, can be very dangerous in the hands of an individual with dementia who can no longer safely use them. Consider storing them in a locked cabinet or closet.

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 the person's clothing so she can be seen more easily at night.
- Give the police a photograph so that they will recognize the individual with dementia if lost. Many 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 nationwide **MedicAlert + Safe Return** program through the National Alzheimer's Association for memory-impaired people. The phone number is 1-888-572-8566.
- Observe the person with dementia now and then to evaluate his or her ability to cross streets and follow other safety rules.
- Getting lost happens without warning. Believing you can predict when someone will get lost is not a realistic expectation.

Absence of Caregiver

Individuals in the early to middle stages of dementia 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 the individual with Alzheimer's or dementia has a regular time when he or she naps or watches television, use this time to do your errands if he or she can be left alone safely.
- It may be easier to leave the person 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 person with dementia 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 person may believe you are still there or be calmed by the sound of your voice.

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

- Using a temporal (ear) thermometer takes only five to ten seconds to read the temperature. Using digital thermometers 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 person with dementia.
- Arrange for the person with dementia to be seen by a physician regularly.
- Some individuals with Alzheimer's have seizures. If a seizure occurs, stay calm and let it run its course. Do not restrain the person 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. If the person with dementia has bed rails, there are seizure pads that cover the rails so that if individual's head hits the side of their bed, it will be soft and lessen the chance of head trauma.

Visiting the Doctor

An individual with Alzheimer's or dementia has a progressive disease which requires regular medical attention. Regular check-ups are also important because the person 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 person with dementia 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 person with dementia'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 person 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". Or, you can tell the individual that you are going for a ride and then wind up at the doctor's office.
- Explain that you are going to the doctor when you are almost at the office if this helps to reduce the person's anxiety.
- If the individual with dementia resists all attempts to go to the doctor, the doctor may make house calls.
- 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 the person with dementia'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 person, 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 person with dementia unsupervised in the waiting area.
- Take a walk or a short drive if the receptionist says that there will be a long wait.

Medication

Individuals with dementia are vulnerable to overmedication and to reactions from drug combinations. The person'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.
- Having an ongoing record of the person's medications can assist the caregiver and physician in reviewing the effects of medications on the individual's behavior.

- If he is capable of understanding, tell the person 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 the person with dementia and his or her 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. Try putting it in ice cream, pudding or custard.
- 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 individuals and caregivers.
- Many pharmacies are open on Sundays, off hours and some are open 24/7. Find out which ones keep these 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 and keep it in an easy place to find along with other emergency phone numbers.
- Keep Ipecac Syrup on hand in case you need to induce vomiting. However, do not automatically induce vomiting if overmedication is suspected. Call your doctor or poison control center for advice, or take the person to a hospital emergency room.

Sleep Problems

Changes frequently occur in the sleeping patterns of a person with dementia. 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 person 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 person's medication may be contributing to a problem with sleeping.

- Avoid fluids after dinner, particularly those with caffeine.
- Have the person with dementia 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 person'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 person with dementia to sleep wherever she is comfortable, perhaps a couch or comfortable chair.
- The individual may need to get up and pace or wander around the house until he or she finally lies down to sleep.
- If the person with dementia had always worked the night shift, he or she may be used to being up at that time.

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

frequent trips to the bathroom

headaches

straining

restlessness or increase in agitation

- Some medications can cause constipation. Talk with the person'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, but should not go more than three to four days without one. If this is a problem, you might need to use a suppository or fleet enema.

Pressure Sores

Pressure sores, also known as "bed sores" or decubitus ulcers 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 individual is very thin and either bedridden or uses a wheelchair.

- 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 person is bedridden and unable to turn herself, change her position every two hours.
  - Turn from side to side: two hours on the right side, two hours on the back, and two hours on the left side.
  - Use pillows for support. Place a pillow under the person's legs so the heels are off of the mattress.
- If the person 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 person's skin.
- Massage bony areas often with lubricating lotion.

DAILY LIVING

Toileting

As memory loss progresses, persons with dementia 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 person 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 person is no longer able to properly wipe himself, it must be done for him because of the risk of infection. Wipe from the front to the back to avoid urinary tract infections (UTI).
- 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.)

Incontinence

Incontinence refers to the loss of bladder or bowel control. The medical term for loss of bladder control is "enuresis." "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 person'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 person 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.

Oral Hygiene

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

- Demonstrate the steps of brushing; allow the person with dementia to imitate one step at a time.
- If you start the motion, the person's lifelong habit may take over. Try guiding the hand that is holding the toothbrush until the person takes over on his own.
- Brushing your teeth at the same time as the person may help him feel more comfortable.
- Dispense toothpaste as needed rather than leaving the tube out.
- If the person 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. Glycerin swabs help with keeping the mouth moist. Also, "toothettes" which are sticks with a little sponge material on the end that can be dipped in fluid and then rubbed in the person's mouth may be useful.

Bathing

Bathing can be one of the most difficult tasks for a caregiver to accomplish. Many individuals with Alzheimer's or dementia 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 (one to two times a week may be more appropriate) and may be damaging to fragile skin. Washing the person's face, hands, underarms, buttocks 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 person with dementia. 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 person 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 individual with dementia 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 person to be seen by a medical professional.

Grooming

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

- Encourage the person with dementia to groom himself for as long as he can.
- Guide and assist the person 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.

Dressing

With increased memory loss, the steps involved in getting dressed become more difficult for the person with dementia to handle on their own.

- Allow the person with dementia 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 person 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 person with dementia.
- You may find it helpful to describe to the person what you are doing as you do it. For instance, tell the individual, "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 with closed backs (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.
  - Dresses that can be pulled on over the head.
  - Velcro tape or large zipper pulls.
- Avoid a large selection 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 person insists on wearing the same clothing day after day, try buying several duplicate sets of the same clothes and rotating them. Try taking the clothes out of

the room while the individual is sleeping. If he or she doesn't see them in the morning, they may forget about 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 person 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 individual with dementia is on a low fat, low salt, diabetic, gluten-free, 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 person's level of exercise.
- If the person with dementia is losing weight, consult a medical professional. There may be problems with absorption of food, or other medical problems.
- If the person is eating poorly and is otherwise in good health, a nutritional supplement may be needed.

Mealtime

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

- Try to maintain a calm relaxing atmosphere at mealtime.
- A person 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 the memory-impaired person sit in the same place at the table.
- Utilize contrasting colors between the plate and the placemat to make it easier to see. Brightly colored plates also make it easier

for the individual with dementia to see what he or she is are eating. Wearing an apron helps protect clothes from spills.

- Buy a "collar" to fit over the edge of the plate. These can be found at some pharmacies or online stores that specialize in products to assist an individual with Alzheimer's disease or dementia. Having a collar attached to the plate makes it easier for the person to get food on his or her fork and 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 person 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).
- Modified utensils and dishes are available that can help the individual feed themselves such as: weighted utensils, scoop dishes, and sippy cups. Medical supply places and the Alzheimer's store sell these.
- Use foods the individual with dementia prefers and is accustomed to; new foods may confuse him.
- Colorful, aromatic, and flavorful food may enhance the person's appetite.
- It may be helpful to serve one food at a time. Choices are difficult for the memory-impaired person.
- For individuals who feel overwhelmed and you need to serve them one thing at a time start with the meat. When that is finished offer the vegetables, then dessert, and then their drink. This may help the person with dementia to feel not as overwhelmed as they would if they saw all the food at once.

Suggestions for Finger Foods (saves your energy and gives the person with dementia more independence):

- chicken nuggets
- fish sticks
- grilled cheese sandwiches (cut up)
- french fries
- raw vegetables sticks
- english muffins or toast
- hard boiled eggs (quartered)
- fried vegetable sticks
- cheese sticks
- pork or beef (cut in small pieces).

Always watch for a sign of choking.

- Encourage the person 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. If the person is having difficulty swallowing, he or she may need thickened liquids or a modified diet. A nutritionist can help with this.
- 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 person to stay seated for an entire meal, try smaller, more frequent meals, or serve finger foods that will allow the person to eat while moving around.
- Eating problems may stem from treatable causes such as poorly fitting dentures or a sensitive tooth.
- Keep the individual with dementia 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.

Exercise

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

- Consult a medical professional if the person has medical problems that may limit his ability to exercise.
- Continue as long as possible with the individual'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

rocking in a rocking chair

riding a stationary bicycle

- Exercises can be done sitting in a chair while listening to music.
- Remember to consult a doctor before starting an exercise routine for a person 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 individual with dementia.
- Ask the local Visiting Nurse Association, hospital social worker, or librarian to help you find books on exercises for people with physical limitations.

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 individual 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 person'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

  drawing or coloring

  singing

  painting

  playing a musical instrument

  working with non-toxic clay
- Do not ask the person with dementia 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).

- The following activities can be valuable if they are entertaining for the person with dementia:

  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.

- Other activities that work are:
  - folding linen
  - separating items
  - untangling a mess of ties knotted together
  - playing keyboard, even if they just use it to make noise
- Remember:
  - A person with dementia 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.
- Avoid letting the individual with dementia watch television if they become agitated and unable to discern what is real or fictional.

Shopping

Shopping can be a good activity for persons with dementia, 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 person 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 person'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 individual's pockets, or be sure he wears clothes without pockets.
- In a difficult situation, distract the person with dementia or move with him to another location to avoid embarrassment for everyone involved.

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 person'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 person with dementia 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.

HOSPICE AND PALLIATIVE CARE

There will come a time when decisions are made regarding the need for hospice and palliative care. It helps to know the difference between the two in order to make good decisions regarding which is most appropriate.

Hospice and palliative care have many similarities, and both are a model of compassionate care.

> "At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so." (The National Hospice and Palliative Care Organization)

Hospice

Hospice care can be for anyone with a serious illness whom doctors think has only a short time to live, often less than six months. The focus on hospice is on caring for the individual, not on curing them. Hospice services can be provided in the home, hospitals, nursing facilities, and in facilities known as "hospice homes." Hospice care utilizes an holistic approach that addresses medical care, pain management, emotional and spiritual support of the individual, as well as support of the family members.

Hospice care services are covered under Medicare, Medicaid, through the Veterans Administration and most private insurance plans.

Hospice care typically includes:

Regular visits by hospice staff

Hospice staff on call 24/7

Management of the individual's pain and symptoms

Assistance with the emotional and spiritual aspects of dying

Palliative Care

Palliative care extends the principles of hospice care to anyone with a serious illness that could benefit from receiving this type of care earlier in their illness or disease process. The care could also be helpful to any older person having general discomfort and disability later in life.

Under palliative care an individual can receive treatments to cure his or her illness. The care can be provided at home, in assisted living facilities, nursing facilities or hospitals. Palliative care would ideally segue into hospice care as the illness progresses.

HELPFUL WEBSITES

AARP: http://www.aarp.org/
AARP maintains the AARP Meeting Place, a support group for the caregivers available throughout America on line, provides information about AARP and its services.

Administration on Aging: http://www.aoa.gov/
Information designed for older Americans and their families.

Adult Day Services: http://www.adultdayservicesnh.org/
Adult Day Services are available in various locations throughout the State of New Hampshire. This site will assist you in locating these services in or near your local community.

Alzheimer's Association: http://www.alz.org/index.asp
The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

American Red Cross - NH Chapter: http://www.concord-redcross.org/index.asp?IDCapitulo=9635HCHPI3
The American Red Cross is a non-profit, community service organization dedicated to providing disaster relief and emergency aid to people living in central and northern New Hampshire.

Assisted Living Directory: http://www.assisted-living-directory.com/index.cfm
Assisted Living Directory strives to make quality online advertising accessible and affordable for assisted living facilities of any size.

Benefits CheckUp: http://www.benefitscheckup.org/
Provides individuals with a comprehensive list of federal and state programs for which they may qualify, including financial assistance, educational opportunities, employment programs, health care, home energy assistance, housing assistance, and volunteer opportunities.

Caring.Com: http://www.caring.com/
Created to help you care for your aging parents and other loved ones. Our mission is to give you the information and other resources you need to make better decisions, save time, and feel more supported.

Disability Resources: http://www.disabilityresources.org/
Has an extensive database of disability-related resources and an online guide to disability resources on the internet.

fiftypluscaregivers: http://www.fiftypluscaregivers.com/
This New England-based site provides caregiving programs, services, information, education and links to help family caregivers assist elderly loved ones. It also offers pertinent late breaking news.

Funeral Consumers Alliance: http://www.funerals.org/
Funeral Consumers Alliance is a nonprofit organization dedicated to protecting a consumer's right to choose a meaningful, dignified, affordable funeral. To accomplish that goal, FCA: Offer information via printed material and internet, monitors industry

trends, serves as a consumer advocate, provides guidance and advice, and refers individuals to funeral planning societies.

Granite State Independent Living: http://www.gsil.org/
A New Hampshire based advocacy group providing information to individuals and families.

Home Health Foundation: http://www.homehealthvna.org/
Provides Hospice, Home Health VNA, and Home Care services to the southern regions of New Hampshire. Home Health Foundation is the second largest home health agency in New England.

Home Health & Hospice Care: http://www.hhhc.org
A non-profit Visiting Nurse Association serving patients of all ages and all circumstances in southern New Hampshire and northern Massachusetts.

Language Line: http://www.languageline.com/page/welcome/
Interpreter services in over 170 languages.

Medicare Information:
http://www.medicare.gov/default.aspx?AspxAutoDetectCookieSupport=1
Information about Medicare for consumers or providers.

The Official U.S. Government site for Medicare:
http://www.medicare.gov/default.aspx
Medicare insurance is available in the US to those aged 65 years or older and is also made available to those with qualifying disabilities younger than 65 years of age.

National Family Caregivers Association: http://www.nfcacares.org/
The National Family Caregivers Association educates, supports, empowers and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age.

National Parkinson's Foundation, Inc.: http://www.parkinson.org/
The Mission of the National Parkinson Foundation is: To find the cause of and the cure for Parkinson disease through research. To improve the quality of life for persons with Parkinson and their caregivers. To educate persons with Parkinson, their caregivers, healthcare professionals, and the general public about Parkinson disease and its treatment.

National Senior Citizens Law Center: http://www.nsclc.org/
Covers the legal issues that "affect the security and welfare of older persons of limited income."

New Hampshire Association of Senior Centers: http://www.nhasc.org/
The New Hampshire Association of Senior Centers is a statewide, professional, non-profit organization dedicated to fostering the multipurpose nature of senior centers and professional development of senior center management.

New Hampshire Hospital Association: http://www.nhha.org/index-nhha.php?nhha
The Association's mission is to enhance the clinical and economic performance of hospitals, improve public confidence in hospitals, and expand access to coverage and care for the citizens of New Hampshire.

New Hampshire Housing: http://www.nhhfa.org/rent_vul.cfm
New Hampshire Housing provides a list of apartments for rent through landlords who are willing to participate in the Housing Choice Voucher Program. This list is updated periodically, but there is no guarantee that the unit will still be available even though they are on this listing. Please note: New Hampshire Housing does not endorse any particular landlords or owners. Contacting, and contracting with, landlords, owners, or apartment managers on this list is solely the responsibility of the prospective tenant.

New Hampshire Housing Authority: http://www.nhhfa.org/
Operating a broad range of programs designed to assist low and moderate income persons and families in obtaining decent, safe and affordable housing.

New Hampshire Legal Assistance (NHLA): http://www.nhla.org/
A non-profit law firm offering legal services in civil matters to seniors and eligible low-income persons. NHLA provides high quality legal services to vulnerable low-income people, ranging from simple legal information and advice to vigorous and thorough representation in all of New Hampshire's courts and before many of the local, state and federal agencies which play large roles in the lives of low-income people. In providing legal services to the poor, NHLA helps balance the scales of justice for all citizens.

PayingForSeniorCare.com: http://www.payingforseniorcare.com/
Provides a free, family/caregiver focused website and eldercare financial resource locator tool to help families find the financial resources they require to pay for long term care for their loved ones.

Social Security Administration: http://www.ssa.gov/
The Social Security Administration's mission is to advance the economic security of the nation's people through compassionate and vigilant leadership in shaping and managing America's Social Security programs.

The Alzheimer's Store: http://alzstore.com/
The Alzheimer's Store is dedicated to providing unique products and information for those caring for someone with Alzheimer's disease.

This Caring Home: http://www.thiscaringhome.org/
This Caring Home provides tips and tools to enhance home safety for person with Alzheimer's and other types of dementia. Includes: Virtual home, product guides, videos and animation.

Unused Medicine Disposal in New Hampshire:
http://des.nh.gov/organization/divisions/water/dwgb/dwspp/pharmaceuticals.htm
One pathway for pharmaceuticals entering water resources is via the manner in which people dispose of unused medicines. Developing medicine disposal practices that are legally and environmentally sound, and that prevent accidental drug poisonings or intentional drug abuse require the consideration of many issues and coordination of multiple stakeholders. DES is coordinating with interested stakeholders to address how to manage and dispose of unused medicine in New Hampshire.

Veterans Resources: http://www.nh.gov/nhes/veterans/index.htm
Veterans are given preference in each of our local offices in the referral to job orders. Our Veterans Representatives are available on a scheduled basis to assist veterans. They network with other veterans' social and supportive service agencies as well to get assistance for veterans.

Veterans Services: http://www.va.gov/
The official U.S. Department of Veterans Affairs website.

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